



GUIDELINES FOR COUNSELLING IN INFERTILITY

SPECIAL INTEREST GROUP
'PSYCHOLOGY AND COUNSELLING'



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<ST>1. INTRODUCTION

Heribert Kentenich

The desire for a child is a result of individual development. It does not exist from birth but usually increases as time passes.

The wish for a child is not only a deeply felt need originating from individual instincts. It also depends on:

- the development of individual personality,
- sociocultural processes,
- economic factors,
- individual biographical changes,
- fate,
- interpersonal processes between partners and
- family dynamics.

These psychosocial factors moderate the wish for a child. If the wish is not fulfilled and an infertility problem becomes apparent, this may result in a narcissistic wound that diminishes self-confidence. Hopelessness may arise. The patients may express feelings of guilt. There may be desperation and grief. The problem of infertility becomes a problem within the relationship of the partners (Menning, 1980; Golombok, 1992; Möller & Fallström, 1991).

During the last two decades great advances have been made in the field of assisted reproductive technology (ART). Treatments such as in-vitro fertilisation (IVF) and microinjection (ICSI) have given new hope to many infertile patients.

There is a danger that the emotional impact of infertility is neglected and that the problem is reduced to a biological or medical one.

However, in addition to the necessary medical procedures, one should also focus on the patients' psychosocial and emotional needs by

- understanding childlessness,
- giving information and ensuring it is processed,
- implications counselling,
- support counselling and/or
- therapeutic counselling.

Caring for the emotional needs of the patient demands continuity and should not be treated as a single event.

The information-giving and counselling of the patient takes place both in the general practice and in the fertility clinic. The teams consist of more medically orientated members such as nurses, doctors, biologists, embryologists and lab technicians, and of more psychosocially orientated members such as counsellors, psychologists or psychiatrists. The individual processes and interpersonal dynamics within the different groups in the team should be recognised.

These Guidelines have been set up in order to provide a framework for counselling in infertility. We are aware that counselling is dependent upon the legal, ethical and cultural background of every country. Therefore these Guidelines are not strict rules or fixed regulations. They are based on the current best practice and are a proposal for a counselling framework as an official paper of the European Society of Human Reproduction and Embryology (ESHRE).

<A>The specific characteristics of infertility consultations

The infertility consultation differs from other symptom- or disease-orientated consultations in obstetrics and gynaecology through the following characteristics:

- (a) The central focus of the consultation is an unfulfilled wish or goal in life. The result is that counsellors are not dealing so much with the objective of finding a diagnosis but far more with subjectively defined suffering determined by various personal and psychosocial features.
- (b) The wish for a child aims to create a not-yet-existing third person who cannot be included in the decision-making process and into the treatment. There are specific ethical issues resulting from the absence of the third person. Some of the essential issues that must be considered include the best interests of the child, the family environment into which the child conceived by the use of assisted reproduction will be born and any possible contradictions and conflicts between the wishes of the patients and the presumed interests of the child.
- (c) The treatment of the unfulfilled wish for a child very frequently consists in a cycle of repeated interventions which can be successful, but often are not. This long-lasting process creates specific emotional stresses accompanied by disappointment and possible desperation.
- (d) Diagnostic procedures and medical treatment in infertility have an important impact on the intimate life of the patients. Therefore, the couple's relationship dynamics, sexuality, ability to cope with the psychological and emotional effects caused by this process must be considered in addition to the course of treatment and future treatment options.

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<ST>2.1 COUNSELLING WITHIN INFERTILITY

Bernhard Strauss and Jacky Boivin

<A>Introduction

A person suffering from infertility will face complex issues which span biological, psychological, social and ethical domains. Discussion of these issues in a counselling context is often beneficial for patients.

Definition of counselling

Counselling is a notoriously imprecise term, used to describe a wide range of functions and performed by an equally wide range of individuals (Blyth, 1995). A formal definition of counselling would be that it was “an interpersonal process, based on a theoretical framework, which [was] used to bring about change in a skilled and systematic way” (K.R. Daniels, personal communication). However, counselling with infertile individuals is often also about support and the clarification of life goals. Thus counselling definitions which focus on counselling as a context for support, advice and guidance rather than as a vehicle for change (Applegarth, 1999, p. 89) or as a place where individuals can be given an “opportunity to explore, discover and clarify ways of living more satisfyingly and resourcefully” (British Association of Infertility Counsellors, 1999) also describe the type of counselling used with infertile people. Regardless of the precise definition the term ‘counselling’ as used in these Guidelines is considered to be an entity which requires professional qualification and which differs from patient-centered care.

Differentiating counselling from patient-centered care

Patient-centered care is the psychosocial care provided as part of routine services in the clinic. It is an approach to care which is expected from all members of the medical team at all times.

Patient-centered care aims to facilitate communication processes between staff and patients and aims to ensure that the people being treated are understood as individuals and not only as biological entities. Patient-centered care is desirable and may provide a good basic relationship

from which the patient may then feel comfortable seeking support and/or initiating counselling. In many countries (e.g., Germany, Switzerland) 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 (see for example, Bundesärztekammer, 1998). Such models propose further that professionals involved in primary medical treatment be qualified to provide not only basic patient-centered care but also counselling and psychotherapeutic interventions (e.g. Kemeter, 1988). Whilst individuals qualified to provide counselling can also provide patient-centered care, the reverse is not necessarily true and professionals need to be mindful of the limitations on their competence (see Section 2.2). The information in these Guidelines discusses the psychological issues faced by infertile individuals and will be of use for both patient-centered care and counselling.

<A>Purpose

The aims of counselling are to explore, understand and resolve issues arising from infertility and infertility treatment and to clarify ways of dealing with the problem more effectively. The counselling process should consider the needs of the patient and any other person who might be affected by the treatment process and the decisions that have to be made. Counselling may have different functions and/or goals depending on the life situation of the patient (e.g. married, single or lesbian woman) and the treatment desired (e.g. embryo donation, surrogacy) (see specific sections in Guidelines). Individuals may also seek counselling to help make decisions regarding the continuation or termination of treatment. However, counselling will frequently address issues outside of the treatment context. It may be used to discuss alternatives to parenthood such as adoption (see section 5.5) or fostering and/or it may be used to identify ways of living a meaningful and fulfilling life without children.

In the context of infertility medical procedures, the following tasks of counselling are commonly distinguished (see for example Human Fertilisation and Embryology Authority, Code of Practice, 1998, part 6) although in practice these tasks will normally overlap:

- information gathering and analysis,
- implications and decision-making counselling,
- support counselling and
- therapeutic counselling.

Information gathering and analysis and implications and decision-making counselling

Providing sufficient information about the medical aspects of the treatment is primarily the responsibility of the medical doctor. However, patients consult counsellors (directly or as part of a mandatory referral process) to obtain more information concerning the social and emotional implications of the infertility treatment. It is often the task of the counsellor to help the individual collate and make sense of all the information to be considered when making a decision related to treatment and parenting options. Implications counselling aims to enable the person or people concerned to understand the implications of the proposed course of action for themselves, for their family and for any children born as a result. Whilst medical information is the domain of the physician mental health professionals should also have a good grasp of the medical issues involved.

Counselling which focuses on information and implications should assist the patient in making decisions about the most appropriate course of action. It should be distinct from the more legal concept of informed consent (see National Bioethics Consultative Committee, 1991). Implications counselling should focus on the specific meaning of any information to the individual and highlight the consequences of treatment decisions – including termination – for every person who is involved in the process. Implications counselling may be especially important in the context of sperm and egg donation and surrogacy, but should be part of any other type of counselling as well.

Support counselling

Support counselling aims to give emotional support to patients experiencing distress. Distress can be caused by the frustration of the desire for a child, social and family pressure as well as by the reproductive technology employed and its limited success rate. Such distress motivates the need for emotional support from many sources (such as family members, partner, support groups). The treatment process will also provoke periods of particular distress that might increase the need for support counselling. For example, during phases of intensive assessment, waiting periods, failure to achieve pregnancy, decision conflicts with respect to treatment termination, the end of treatment and so on. While the provision of emotional support should be part of any patient-centered care and treatment, support counselling should specifically focus on the resources patients themselves have in coping with emotional (and physical) distress and on working out new strategies of coping that might help in managing stressful situations. It is often the case that patients need support once treatment has ended. That is, when the couple are no longer patients at the clinic. Counselling services within clinics should therefore be developed in such a way that couples continue to have access to professional help for issues which may arise and/or persist after treatment has ended.

Therapeutic counselling

Within infertility, there is often a natural progression from support counselling to therapeutic counselling. Several models of therapeutic counselling have been developed over recent years (e.g. Hammer Burns & Covington, 1999; Strauss, 2001) providing a wide variety of counselling modalities (e.g. individual, couple or group) and intervention strategies.

Therapeutic counselling can focus on

- reflection of individual problems and (family) history,
- the acceptance of the situation,
- the meaning and impact of infertility, including grief work,
- work on alternative life and self-concepts for the future,
- the development of coping strategies and strategies to minimise distress,

- problem and conflict solving, and/or
- specific issues such as sexual, marital and other interpersonal problems.

More general therapeutic counselling can comprise supportive, coping-orientated and problem-solving strategies (Strauss, 2001). The theoretical framework of the counselling models described in the literature to date varies, including psychodynamic psychotherapy, cognitive-behavioural techniques, solution-focused psychotherapy, crisis intervention and process-experiential grief counselling (see Applegarth, 1999). Interventions based on these models can be designed and applied wherever appropriate whether it be before, during or after treatment has ended.

<A>Typical issues

Some of the main issues affecting the counselling process have been discussed. These were defining counselling and differentiating patient-care from professional counselling. Issues concerned with qualifications and who should offer counselling will be covered in the next section (see section 2.2). Another issue is related to whether counselling should be mandatory or voluntary. In most clinics patients are offered counselling without the obligation to attend. Occasionally clinics use a mandatory process with patients being offered treatment only after having had at least one counselling session. There are advantages and disadvantages to both approaches. Mandatory counselling ensures that all patients have access to a professional service with the opportunity to discuss their own personal circumstances and issues. However, the fact that the service is mandatory may mean that patients are unwilling to discuss any issue openly and/or that they feel suspicious about the true purpose of the session (i.e., support or screening? see section 2.2). As a result the main topics discussed in mandatory counselling may primarily relate to the processing of medical information and treatment implications rather than emotional issues. Voluntary counselling may also give rise to worries concerning screening but because the patient is the one to initiate counselling there is usually a greater willingness to overcome these fears. Thus counselling with self-referred patients tends to focus more on the emotional aspects of infertility and its treatment, especially issues causing current distress, then on the medical aspects of treatment. However, it is noteworthy that patients rate the experience

of counselling as positive regardless of whether it is mandatory (Connolly et al., 1993) or voluntary (Stewart et al., 1992). It is the task of the counsellor to ensure that patients feel comfortable during either type of counselling.

A related issue is the finding that few patients attend counselling when it is offered on a voluntary basis. Patients have many reasons for not taking up offers of counselling and these reasons differ as function of whether they are experiencing high distress or not. For example many patients feel they can cope with the strains of infertility using the coping resources available to them (e.g., helpful family and friends) while others, especially those who experience distress, may not use counselling because they feel unsure about how to get such help (e.g., who to contact) (Boivin et al., 1999). Clinic staff need to recognise and respect patients' strengths in coping with this life event but also need to ensure that information concerning counselling is easily and clearly available.

A final issue is the theoretical perspective which the counsellor adopts and its compatibility with the patient's needs. As noted previously, counsellors can adopt a variety of perspectives (e.g., psychodynamic, cognitive-behavioural) to guide their work with infertile people. Difficulties can arise when the counselling approach adopted by the counsellor is incompatible with the needs or personality of the patient. This problem is of greater importance in medical settings because patients tend to use the counsellors recommended by the clinics rather than find a counsellor themselves. The clinic counsellor must therefore assess whether their approach is compatible with the needs of the patient and if not, be able to refer patients to more a suitable alternative.

<A>Communication skills

Counselling according to the principles described above needs specific skills and qualifications. These qualifications will be described in the following section (see Section 2.2).

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<ST>2.2 WHO SHOULD COUNSEL?

Elizabeth Corrigan, Ken D. Daniels and Petra Thorn

<A>Introduction

To be in a position to provide counselling in a planned and skilled way, mental health professionals require training in therapy or counselling as well as an in-depth understanding of the psychosocial and physical aspects of infertility. The qualifications needed in order to provide counselling to infertility patients vary from country to country in the European Union.

<A>Qualifications needed to offer counselling in infertility clinics

In some countries governmental recommendations describe who can act as a counsellor in fertility clinics. In the United Kingdom for example the Human Fertilisation and Embryology Authority (1991) have taken a qualification-based approach. The Act recommended the minimum qualifications required for a counsellor to be:

- a certificate of qualification of Social Work or
- an equivalent qualification recognised by the Central Council of Education and Training in Social Work or
- an accreditation by the British Association of Counsellors or
- Chartered Psychologist status.

In other countries governmental regulations do not exist but professional societies which provide guidelines for medical professionals in infertility clinics also provide guidance on the most appropriate qualifications for counsellors working with infertile people. For example, the American Society for Reproductive Medicine, through its Mental Health Professional Group (Hammer Burns & Covington, 1999, appendix 2), recommends that the mental health professional should have:

- a graduate degree in a mental health profession (e.g., psychology, social work)
- a license to practice (i.e., registration, certification, chartered status)
- training in the medical and psychological aspects of infertility
- a minimum of one year of clinical experience
- regular attendance at certified continuing education programmes

In other countries qualifications are determined by the working models adopted by medical departments and thus describe qualifications for counsellors working in any field of medicine and not just infertility. As described in the previous chapter countries which adhere to integrated psychosomatic (or psychosocial) models for their approach to medical care (e.g., Germany) incorporate psychological training in the curriculum of medical practitioners and/or ensure that mental health professionals are integral to the multidisciplinary team treating the patient (see for example, Bundesärztekammer, 1998).

A perusal of the infertility literature makes it clear that 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 the medical and psychosocial aspects of infertility.

<A>Typical issues concerning counselling in infertility clinics

<C>Should the counsellor be part of the medical infertility team or should s/he have an independent position?

Being part of the team ensures that patients have easier access to counselling services as well as facilitating interdisciplinary exchange. However, it must be decided within the team to what extent information gained during counselling is disclosed to others within the team. Also, for the sake of confidentiality, patients must be informed about this and be in agreement with it. Being an independent counsellor – working apart from the team – makes it easier to see counselling as a separate entity in coming to terms with infertility and makes it easier to convey confidentiality

to patients. It may limit what other staff can offer as patient centered care because they will have less personal information about the patient available to them (see section 2.1).

<C>Should counsellors carry out assessment?

In some countries, assessment of suitability prior to treatment, especially prior to treatment with donated gametes, is carried out. This assessment aims to ensure that the welfare of all parties involved, especially the child to be born, is taken into account. There are controversies as to whether the counsellor is the appropriate person to carry out this assessment. On the one hand, the counsellor has the professional skills to perform such assessments; on the other hand, counselling is considered a voluntary, open-ended process and patients tend to be less open if an assessment is carried out.

Patients making use of counselling provided inside or outside an infertility clinic often have concerns about the use of information disclosed within the entire treatment process. Even when counselling and screening are clearly distinguished the expectation persists that the counsellor might be involved in the selection process. If this is the case, the counselling process and the establishment of a trusting relationship can be impaired; sometimes patients may even be prevented from seeking help. However, it can also be the case that counsellors may be hindered in fostering the patients' autonomy and advocating the patients' interests when assessment is distinguished from counselling.

Even if there is clear demarcation between sessions involving assessment/counselling and those involving counselling, it might still be useful to focus on the dilemma and ask the patients to express their concerns, fears and fantasies related to the consequences of counselling. If these concerns can be assuaged, the patients should be encouraged to use the counselling session(s) by openly discussing all relevant issues.

<C>Should other staff offer counselling?

There are medical and psychosocial issues to be considered in almost all options considered by infertility patients. Medical implications must be considered with suitably trained medical, nursing and scientific personnel. The psychosocial implications are best considered by those providing counselling services (as described in the introduction to this section). While such a distinction is helpful for the staff, patients frequently do not make such a distinction and all staff may find themselves being asked to discuss both medical and psychosocial implications. This practical reality is likely to require all staff to have a basic understanding of the psychosocial issues related to infertility as well as basic communication skills with which they can help support the patient through the medical process (see section 2.1). It is vital, however, that all staff recognise their limitations and seek to avoid discussing areas that are outside their competence: for example, when implications counselling reveals psychological problems, patients should be referred to the counsellor.

<C>Who should refer patients?

The question is whether all patients are referred to a counsellor, whether a specific group should be referred or whether patients refer themselves. A minimum consensus would be to provide access to counselling services to everybody, independent of the type of treatment and potential or presenting psychological complaint (see Section 2.3). However, not all patients who might benefit from counselling are willing to take up the offer presented to them. Consequently, medical personnel may sometimes need to play a more active role in presenting counselling as a useful adjunct to the patient's medical therapy.

<C>Should supervision be a requirement?

Many therapists and counsellors consider supervision helpful in order to avoid transference and counter-transference issues, to provide for their professional development and to evaluate the counselling process. Proof of regular supervision is also required by some professional bodies. Some counsellors choose to work with infertility because of their personal experience of fertility problems. These counsellors need to decide if and to what degree self-disclosure is appropriate and helpful.

<C>How should counsellors be paid?

There are various methods of incorporating counselling into medical treatment and this also affects payment for the counselling service. If the counselling service is included in the treatment fee, it is most likely to facilitate access for a high number of patients. On the other hand, it makes treatment more expensive for those patients who do not take advantage of the counselling service. Independent counsellors usually charge a fee and this determines to some extent who can access counselling, but it also guarantees high motivation on the part of the patients.

<C>Can the staff team benefit from consultation provided by counsellors?

It is not uncommon for professionals who deal with people in distress to benefit from consultative and support services. Counsellors can provide the opportunity for any individual staff member in dealing with patients or difficult decisions to reflect on issues arising.

<A>Communication skills

Counsellors with professional training have a wide range of communication skills in planning, carrying out and evaluating counselling processes. Other team staff will find it useful to have basic communication skills in order to provide patient-centered care, to understand the psychosocial aspect of infertility and to refer patients appropriately.

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<ST>2.3 WHO IS LIKELY TO NEED COUNSELLING?

Jacky Boivin

<A>Introduction

Any patient can use professional counselling and all patients should be assisted in obtaining the help they feel they need. However, the literature identifies several groups of patients as needing specialised psychosocial care. They include:

- (a) Patients who use donated gametes, surrogacy and/or adoption to achieve parenthood. So-called third-party reproduction raises psychological reactions and issues which can be more fully discussed and/or addressed in counselling (see section 5, Special Fields).
- (b) Patients who experience great distress. Distress most commonly shows itself as depression or anxiety, but it can be manifested as any negative affective reaction. Patients often consult the counsellor because distress reaches a level at which it interferes with daily activities. About 15–20% of infertile patients are expected to experience this level of distress at some point in their infertility experience (Boivin, 1999).
- (c) Patients considered to be at risk because of their psychological history or presenting profile. Leiblum and William (1993) found that most clinics refused to treat patients and/or required pre-treatment counselling for patients who showed evidence of substance abuse, had a history of psychiatric (e.g. schizophrenia) or cognitive (e.g. profound intellectual impairment) disorder, or who presented with either a severely disturbed marital relationship and/or irresolvable discord between spouses on treatment issues. Patients whose history showed any indication of child maltreatment were refused treatment.
- (d) Patients who require some form of genetic counselling as part of their fertility treatment (i.e. pre-implantation genetic diagnosis). 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 (see Hammer Burns & Covington, 1999 for a full discussion).

Patients experiencing high distress will be the topic of the present section.

<A>Purpose

The purpose of counselling with highly distressed patients will be determined partly by the theoretical framework in which the counsellor works. Psychodynamic approaches might examine how feelings of loss provoked by infertility reawaken past losses, whereas cognitive behavioural approaches might want to focus on modifying maladaptive thinking patterns. Despite theoretical and methodological differences, most counsellors would agree that the ultimate goal of counselling is to help the patient achieve a better quality of life. The type of counselling offered to patients (e.g. individual, couple, group) will depend on the patient and the cause(s) of their distress as well as the resources of the clinic.

<A>Objectives

The objectives of counselling highly distressed patients are to:

- enable the expression of emotions,
- identify the cause(s) of distress and
- provide intervention(s) to minimise distress and help patients better manage distress.

Depending on the theoretical framework, different methodologies will be used to meet these objectives. Ultimately the patient should feel understood and better able to cope with the challenges infertility and its treatment present.

Risk factors for high distress

Much research has been carried out on the factors which predict poor adjustment among infertile patients. These risk factors fall into several categories.

<C>Personal

Personal risk factors include:

- pre-existing psychopathology (e.g. personality disorder, depression),
- primary infertility,
- being a woman,
- viewing parenting as a central adult life goal and
- general use of avoidant coping strategies (e.g. wishful thinking, fantasy).

<C>Situational or social

Situational or social risk factors include:

- poor marital relationship,
- impoverished social network and
- situations or people which remind the person of their infertility (e.g. family reunions, pregnant women).

<C>Treatment-linked

Risks associated with treatment include:

- side effects associated with medication (e.g. mood fluctuations),
- situations which threaten the goal of pregnancy (e.g. miscarriage, treatment failure) and
- decision-making times (e.g. start and end of treatment, foetal reduction).

It is often a combination of factors which make distress overwhelming. Some risk factors are actually the cause of distress (e.g. miscarriage) and when combined with personal risk factors make the experience of infertility unmanageable. For example, ending treatment will be distressing for most patients but it may be especially so for individuals with a history of depression or those whose central goal in adulthood was parenting. It is important to keep in mind that the risk posed by some factors may be mitigated by the presence of buffers such as a strong marital relationship and/or good social support.

<A>Typical issues

Identifying patients experiencing high distress

Different strategies have been used to identify patients experiencing high distress. Some research identifies highly distressed patients through ‘clinical caseness’ which identifies people scoring above a certain cut-off point on standardised measures of psychiatric and psychological adjustment (e.g. Minnesota Multiphasic Personality (Inventory MMPI)). Other research uses psychiatric diagnostic criteria (e.g. Diagnostic and Statistical Manual (DSM) –IV)) assessed during clinical interview, while self-report of subjective distress is the basis of identification in other studies. Interestingly, the incidence of ‘caseness’ is the same regardless of the method used (e.g. about 20%) which would suggest the sensitivity of all these methods to be more or less equivalent. However, few clinics use formal pre-treatment assessments. This is not as alarming as one might think, because the number of patients taking up counselling is also 20%, suggesting that those who need help manage to obtain it through self-referral or referral by clinic staff.

Patients who refuse help

Despite the best efforts of counsellors some highly distressed patients will refuse to attend counselling. There may be a variety of reasons for this refusal but one study found that a principal barrier for such patients was the practical aspect of getting help (Boivin *et al.*, 1999). It was shown that more patients would use counselling if they were contacted personally and if the

steps by which they could obtain such help were clearly outlined. Other patients refuse help because they do not recognise the need for such help. For example, patients may direct their anger at clinic staff venting feelings of disappointment and anger without recognising that such emotions more frequently stem from the infertility than from poor care by clinic staff. In such cases it is important to acknowledge the triggers of emotions but also to help patients acknowledge the deeper reasons for their reactions.

<A>Communication skills

All skills involved in professional counselling are required.

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<ST>2.4 THE ROLE OF PHYSICIANS IN COUNSELLING

Heribert Kentenich

<A>Introduction

Infertility involves suffering. To be infertile means to suffer from childlessness and it is the psychological trauma of childlessness and its 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. Only in rare cases is psychotherapy a primary necessity. Thus, despite the psychological issues involved the problem of infertility leads to an almost exclusive focus on medical aspects for which physicians are responsible.

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. However, there are also psychological issues which are unique to the physician which arise from the special nature of the physician-patient relationship. Whilst couples are trying to achieve their intensely desired goal of pregnancy the physician will become a person of central significance in their lives. Physicians must be prepared to deal with the emotional and psychological issues provoked by the important role they now play (Lalos , 1999). Initially patients may react to the physician in ways consistent with the relationship they have developed together. However, patient reactions, thoughts and feelings may also be determined by early childhood and past life experiences which occurred outside the physician-patient relationship (Kentenich, 1992).

The physician too will react to the patient or couple and may also be confronted with their own psychological issues when considering their feelings about these patients. Reactions to patients will vary: The physician may feel his/her contact with the patient is “pleasant” and “easy” or may find it “unpleasant” and “difficult”. This will depend on his/her personal history and personality traits as well as on those of the patient or couple.

Psychologists call patients’ reactions to physicians ‘transference’ whereas the physician’s reactions to the patient are called ‘countertransference’.

While most of the psychological work the physician does will be confined to what we have termed ‘patient-centered care’, it may also extend, depending on qualifications, to professional counselling.

The issues which confront the physician may also be experienced by the entire team involved in the care of the infertile patient and couple. Various professional groups are involved in medical diagnosis and therapy, each with special tasks according to their skills. The medical side is made up of physicians, biologists, embryologists, nurses and lab technicians whereas the psychological side is composed of counselors, nurses, psychologists, psychotherapists and psychiatrists.

<A>Purpose

From the physician's first meeting with the patient/couple, an atmosphere should be created that nurtures a trusting physician-patient or physician-couple relationship. Such an atmosphere is one based on openness and mutual respect. Couples should be given the opportunity to ask questions at any time. Above all, they should be given an opportunity to voice their own ideas about diagnosis and therapy.

The physician can achieve this goal by regarding the patient/couple as a medical *and* psychological unit. Infertility involves suffering, anxiety and insecurity and it is the physician's task to ensure that such distress is minimised during the diagnostic and treatment phase (Golombok, 1992). For example, about one third of all couples report sexual dysfunction during the diagnostic investigation and treatment. Since couples often have difficulties discussing matters of sexuality, it is important that consultations take place in an atmosphere that makes it easier for couples to talk about such intimate matters. Physicians should therefore be prepared to 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).

The physician is also responsible for ensuring that patients receive the care they need. The physician is the patient's principal partner in medical treatment. Once a diagnosis has been made, s/he has a decisive role in choosing – along with the couple – the course of (medical) therapy. His/her advice is of particular importance with regard to the question of whether medical treatment is indicated and, if so, what kind of treatment, what treatment intervals should be, and when it would be advisable to terminate therapy. The physician should also assess whether psychological counseling will be necessary and be prepared to either provide and/or refer patients to appropriate sources of psychological help.

<A>Objectives

One of the primary tasks of the physician is to provide information. Many couples have only an inadequate understanding of how their bodies work. They know little of the causes of infertility,

the diagnostic possibilities and/or options for treatment. Here, it is up to the physician to ensure that information is available, whether provided by himself or herself or whether provided through the team. This information can be given in person or in booklets, videos, CD-ROMs or by other means. Immigrant couples may have additional communication or language problems which may compound the problem of understanding diagnostic and therapeutic information. It is therefore essential that information is available – and, preferably, can be given – in the patient's mother tongue.

In order to best help patients and couples the physician should know not only the medical problem at hand but also the *person* and *couple* s/he is treating. Key questions which might be useful in gathering information to achieve this goal would include:

- The patient's or couple's personal experience of infertility
- The effects of infertility on their partnership and sexuality
- How the couple deals with childlessness inside and outside the partnership (e.g. in professional/ working life).

Other questions which might also be useful for a psychological understanding are presented in the appendix to this chapter.

Another important objective for the physician is to ensure that the medical procedures and treatments used do not prevent [further] deterioration in reproductive *and* psychological health. Physicians should talk openly to patients about unhealthy lifestyles (e.g., smoking, alcohol, drugs), negative effects and/or side-effects of medication, and the pros and cons of different operations as they affect the person's health. During these discussions the psychological effects which may occur must also be discussed. For example, mood and cognitive changes caused by some fertility drugs or surgeries which are unlikely to yield any meaningful increase in fertility potential.

<A>**Typical issues**

One problem for the physician and patient is the almost exclusive focus on the medical aspects of infertility. Progress in the treatment of infertility has been almost exclusively in the medical field. Treatments such as IVF and ICSI mean greatly improved chances for patients to become pregnant and have a child. Because of this, it is understandable that the medical aspects of treatment are given considerably more weight than psychological counseling. Both patients and physicians focus on medical success and the birth of a healthy child. It is also understandable that both sides are interested in active medical treatment, that both have difficulties with temporary pauses in treatment and that both tend to advocate invasive forms of therapy which

may have a higher success rate. As a result, a subconscious preference for and focus on active medical treatment may occur on the part of both patient and physician.

Couples use different strategies to cope with infertility and these may interfere with the work of the physician. Patients overestimate their chances of success with treatment and idealise both a potential pregnancy and the longed-for child. They also idealise the physician and his/her team as well as new techniques/technology. Another frequent way of coping with infertility is denial, where either the poor chances of success or the causes of infertility may be denied. However, it should be noted that an early phase of idealisation may then be followed by phases in which negative aspects are focused on. The physician's abilities may be viewed with contempt, particularly if s/he or his/her team have been unsuccessful or if mistakes have occurred in therapy. Behaviors involving unrealistic optimism, idealisation and denial are coping mechanisms. It is important for the physician to be aware of them so that s/he can better understand the patient's or couple's reactions (Edelmann et al. 1994).

Another problem is that physicians can come to feel omnipotent. The advantage of paying attention to both psyche and soma (i.e., adopting patient-centered care) is that the person and/or couple is seen as a whole. This can be a great help in establishing a trusting physician-patient relationship. On the other hand, providing both medical and psychological care can also cause physicians (and patients) to overestimate the impact of the physician and what they can do. It is imperative therefore that physicians recognise their limitations in the psychological domain and draw upon the expertise of counselors, psychologists, psychotherapists and other mental health professionals in the team.

However referral to a counsellor may cause problems for some patients. Patients may interpret referral as rejection on the part of the physician and may feel they have been "passed on". Such a referral may hurt a patient's feelings, especially if medical treatment has been unsuccessful. Because of this, involvement of counselors should always be integrated into the patient care from first consultations and presented to couples in a positive light (Boivin et al., 1999).

One issue which has caused some debate and difficulty for physicians is the criterion by which success in infertility care can be decided. Physicians and couples generally consider successful treatment of infertility to mean achieving pregnancy and the birth of a child. However success can also mean that not having children is accepted and/or that couples are enabled to see their childlessness from another perspective which allows them to reshape their lives and achieve life satisfaction (de Parsevale, 1992; Kemeter, 1998).

Finally, when patients are being treated in infertility clinics the clinic ethos or culture is important in making couples feel helped in a caring way. Infertility clinics are normally run by physicians and because of this have a strong medical orientation. However, teamwork means not

only that individuals have their own particular tasks but also that they should be respected as members of the team whether they attend to the medical or psychological needs of the patient. If either aspect of care is devalued or if domains within the medical (e.g., embryology, nursing) or psychological spheres are devalued then tensions may arise which can easily be transmitted to patients. The goal of patient-centered care is more likely to be met if those who manage infertility clinics ensure that their teams can function to the best of their abilities in as positive an environment as can be created.

<A>Communication skills

Physicians play a central role in dealing with the problem of infertility. They must not only be competent medical specialists but also have a basic understanding of the psychological problems involved in childlessness, the stress of therapy, coping mechanisms and the importance of the physician-patient relationship. As these issues will only rarely have been part of their medical studies, physicians need to try to gain the relevant knowledge elsewhere. In the long term, medical training needs to be changed so that training in counselling is an integral part of every physician's preparation for his professional task.

An ability to guide conversations with different interviewing techniques facilitates contact between the patient and physician. Moreover appropriate training in psychological interview techniques can help physicians identify symptoms of psychological distress which may signal the need for more in-depth counselling. Physicians should therefore make an effort to master these techniques.

During infertility treatment, there are always situations in which dealing with a couple proves exceedingly "difficult". Both the patient or couple and the physician may become aware of their dissatisfaction, which may even involve aggression and anger. Peer supervision groups allow physicians to discuss such difficult cases and to look for solutions in a supportive environment with other physicians and under the supervision of a group leader. Attending such groups is recommended, either on a regular basis or at regular intervals.

Finally, as mentioned, fertility clinics operate as teams. Within these teams, people may have much in common, but there is also the possibility of friction, aggression and dispute. Team meetings should not only cover the discussion of organisational matters but also concern themselves with the "culture within the team". Emotion, friction and disagreement are normal in a team. Outside team supervision may be advisable.

<A> Appendix: Additional questions for patient interviews

- How long have you wanted a child/children?
- How long have you been under treatment?
- How many physicians have you seen?
- What do you think is the cause of your infertility (i.e., subjective theory)?
- Who is more upset by your infertility, the man or the woman?
- What has changed in your life since becoming aware of infertility?
- How satisfied are you with love and sexuality (e.g., frequency, lack of orgasm, difficult coitus, sexual desire)?
- Has anything in your life as a result of the infertility (e.g., social, sexual, etc.)?
- What treatment do you think should be used?
- How do you view the alternatives (e.g., adoption, fostering, remaining childless)?
- What are your personal limits for treatment? How long can it last?
- What will the person or couple do if treatment is not “successful”?

Additional questions which may help the physician prepare for reactions to diagnostic and/or treatment events:

- Does the patient suffer from an ulcer, asthma, abdominal pain or skin conditions which are triggered or worsened by stress?
- Is there a history of psychiatric symptoms or psychotherapeutic treatment in response to life crises, partnership issues and/or infertility?

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<ST>3. COUNSELLING IN INFERTILITY TREATMENT

Johannes Bitzer

The following chapter presents a framework for integrating patient counselling within the medical environment.

The infertility diagnostic process (i.e., work-up) and treatment can be described as a 10-step circular process:

- Step 1: Introduction and initiation of a working alliance
- Step 2: Problem assessment and monitoring
- Step 3: Clarification about problem definition and negotiation about objectives and priorities
- Step 4: Exchange of hypotheses and decision-making concerning diagnostic procedures
- Step 5: Investigations, diagnostic procedures
- Step 6: Information giving about results
- Step 7: Elaboration of options to resolve infertility problem
- Step 8: Decision-making about specific options
- Step 9: Treatment procedures
- Step 10: Evaluation of outcome

The 10-step cycle may restart at different points or may terminate at any point. Patient-centered care and counselling can be integrated at each step in this process. Moreover, the psychosocial process at each step can be further described in terms of purpose, objective(s), typical issue(s) and required communication skills.

‘Purpose’ defines why psychosocial care is necessary at each step in terms of cognitive, emotional, relational, motivational, decision-making and behavioural domains.

‘Objectives’ define normative entities or specific goals to be realised by psychosocial care and may include (1) emotional support of the patient, (2) enhancement of patient’s sense of autonomy and self-determination, (3) empowerment for the patient through increased knowledge and competence, and (4) comprehensive person-orientated, individual care for the patient.

‘Typical issues’ refer to negative experiences of the patient and team that pose specific challenges to interactions and communication efforts and which may endanger, disrupt or completely block the problem assessment and problem-solution process.

‘Communication skills’ describe specific attitudes and knowledge as well as verbal and non-verbal techniques necessary to provide the basis for a successful completion of the step concerned.

For each of the 10 steps, the specific purposes, objectives, typical issues and communication skills are presented below.

<A+>STEP 1: INTRODUCTION AND INITIATION OF A WORKING ALLIANCE

<A>Purpose

This is the first cognitive and emotional contact, and provides the basis for a helpful relationship.

<A>Objectives

Emotional support

The patient should experience emotional relief from the infertility crisis.

Autonomy

The patient should feel understood, accepted and respected.

<A>Typical issues

There is no emotional contact between the infertility team and the patients. The team is occupied by charts, writing down the history, etc. The patients feel like an anonymous number in an anonymous institution and they have the impression that they, with their specific individual problems, are not understood.

<A>Communication skills

Emotional and relational skills are used to build up a relationship. The team builds up personal contact by introducing everybody and by taking care to perceive the patients as individuals with unique needs and characteristics. Their names, professions and nationalities should be remembered, and the team should give the patients reassurance that these aspects of their identity are important.

An important part of this step is perception of underlying reactions in patients' emotions and behaviour. Shame, anger, frustration, aggression, feelings of inferiority and rejection are frequently encountered during the first visit. The team should register and note these emotions to foresee possible difficulties in the relationship between the team and the patients. Occasionally these emotions should be verbalised by the team to indicate to the patients that emotions are permitted and that they have found the time and the place to express their desires and fears regarding their unfulfilled wish for a child.

<A+>STEP 2: PROBLEM ASSESSMENT AND MONITORING

<A>Purpose

Cognitive

The team can obtain and gather information about all the patient's problems related to the unfulfilled desire for a child. The team should obtain information about the background, the history and the consequences of the problem as well as the subjective theories of the patients about what is causing the problem. The team should obtain information about previous attempts at problem solution.

Emotional

The patients can express themselves and the team can respond to patients disclosures emotionally and with support.

Relational

The team and patients get closer; a process of bonding begins.

<A>Objectives

Emotional support

The patients should have the opportunity and the time to tell their infertility story and to express all the emotional and social problems related to their infertility.

Autonomy and participation

The patients should have the opportunity to express their ideas about possible causes of their infertility and possibly gain some insight into lifestyle factors that influence their fertility.

Comprehensive person-orientated care

The team should obtain a comprehensive picture of the infertility of the patients with its psychosocial background and consequences.

Comprehensive problem assessment

This is the step during which screening for psychosocial risk factors can be made.

<A>Typical issues

The patients do not have the time to tell their story. They are frequently interrupted by the team with closed questions and pressed into a specific response by scheme of suggestive and leading questions. The team does not address psychosocial issues of infertility: patient communication and behaviour, conflicts, sexuality, etc. The patients' perception of the problems and those of the team are incongruent and contradictory.

<A>Communication skills

Listening

The most important skill in this phase of the process is actively listening and observing. Who tells whom which type of story? What is the emotional impact? How do the patients interact? What are the reactions of the team?

There are very different types of information that can be obtained at this step, including reported information about facts of the patients' lives, and about their feelings and reactions to certain life events, as well as direct information by observing their behaviour and by perceiving and interpreting the emotional reactions.

Questions

The team should ask important open-ended questions, such as: When did you realise for the first time that you couldn't get pregnant although you wanted to? How did you react? What were your feelings? How did you first handle the situation? How did this infertility experience affect your life? What are your feelings and ideas about possible causes of this fertility problem? How do you perceive and handle the problem as a couple? What were the influences on your partnership and your sexuality?

A questionnaire can also help to screen for psychosocial risks such as depression, severe conflicts of the patients, social isolation, personality disorders, etc. If these factors are diagnosed, referral to an appropriate resource – e.g. a psychotherapist or other mental health professional – is indicated and helpful.

<A+>STEP 3: CLARIFICATION ABOUT PROBLEM DEFINITION AND NEGOTIATION ABOUT OBJECTIVES AND PRIORITIES

<A>Purpose

Cognitive

The patients' problems are summarised and verified. The objectives of the patients can be clarified and priorities defined. The patients obtain information about the possibilities and limitations of the work-up and treatment.

Emotional and relational

There is deepening of rapport or working alliance between the patients and the team. A common concept of problems and objectives is established.

<A>Objectives

Respect and support

The patients should feel assured that all important problems are noted and should understand that their agenda is accepted.

Autonomy and participation

The patients should be involved in the definition of objectives and understand their own participation and responsibilities.

Increase knowledge and empower patients

The patients should get comprehensible information about the possibilities and limits of medical help.

<A>Typical issues

The patients and the team do not reach or formulate a common agenda of problems, priorities and objectives. Each side's views remain fixed; there is no exchange, but increasing mistrust.

The patients have unrealistic, idealistic expectations and projections regarding [unlimited] treatment opportunities. The team is idealised to be later devalued. The patients' priorities and concepts differ from those of the team. The patients want immediate direct help, while the team wants to focus first on a diagnostic work-up. The partners have divergent and even opposing priorities and objectives: for example, one partner may want intensive treatment, while the other is hesitant, and the wish for a child is therefore asymmetric. A central issue is how to deal with gender differences in this context.

<A>Communication skills

General verbal and cognitive

There is a summary of the problems and verification to ensure that all relevant information has been included. The patients are encouraged to ask questions and give additional information. It might be helpful to create a problem list.

Educational

At this stage it is important for the team to give information about the general knowledge regarding infertility, about the scope of the intervention and about the possibilities and limitations of infertility treatment. There are some basic rules to facilitate patient education. First, the counselor has to be sure that the patients' agenda is addressed. Second, the patients should take an active role in the learning process, by demonstrating their understanding. Third, the amount of take-home information should be limited. 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.

The principles of information giving are: establish rapport with the patient; use lay terms and avoid professional jargon; highlight the message; present each category of information separately; give small units of information; summarise the major points; provide supplemental material; put information in writing; check for patient comprehension.

Negotiation

The team and the patients negotiate about priorities and related objectives of co-operation. Each party proposes issues and exchanges views to build up a common working objective. Negotiation means exchange of information, opinions, wishes and fears to create a common platform for decision-making.

Verbal techniques and major issues

The questions are mainly open; there is much verification and information giving. The content of the communication should include discussion of the following questions: What are the expectations of the patients with respect to work-up and treatment? What do they know about it, what are their questions? What are the priorities of the patients? Do they primarily wish to know about the causes, or do they want 'care or cure'? Do they want the fastest way to a child, or do they want to be as natural as possible? What are the limits for the patients, and what are their fears and doubts? What amount of money and time do they want to invest? What do they think about the future development of the treatment? What are they going to do if treatment fails?

<A+>STEP 4: EXCHANGE OF HYPOTHESES AND DECISION-MAKING CONCERNING DIAGNOSTIC PROCEDURES

<A>Purpose

Cognitive

The physician generates hypotheses about the causes of the infertility problem and elaborates a diagnostic plan. The team gives information to the patients about possible causes of the infertility and about possible diagnostic procedures referring to these causes. The patients express their concepts, ideas and comments on the propositions.

Motivational decision-making

The team and the patients enter into a decision-making process concerning the diagnostic procedures.

<A>Objectives

Comprehensive approach to infertility

There should be comprehensive hypothesis generation by the physician or the team.

Increase knowledge and competence

The patients should receive adequate information about diagnostic measures.

Enhance autonomy and participation

There should be mutual decision-making about which diagnostic procedures to apply.

Empower the patients

The patients should be enabled to give (or withhold) informed consent regarding diagnostic interventions.

<A>Typical issues

There is a limited and narrow scope of hypotheses, very often either purely somatic or purely psychosocial. The patients cannot contribute and integrate their concept into the diagnostic work-up and the decision-making. The team's decision is imposed on the patients, preventing them from understanding and participating. The patients and team have different views and opinions about certain diagnostic measures and cannot find a compromise. The partners have different views and opinions about certain diagnostic measures.

<A>Communication skills

Educational

Information is given in a comprehensible way adapted to the language of the patients. Information should be given in small units with continuous checking back with the patients. Important points should be announced and summarised. The range of possible causes of infertility is explained by demonstrating the large spectrum of biological, psychological and social factors involved (broad hypothesis-generation and explanation).

Negotiation

The patients are encouraged to make their beliefs and views clear, and these are compared to the hypotheses of the team and discussed. The advantages and disadvantages of the different diagnostic procedures are discussed and evaluated to come to a common decision about which tests to apply.

<A+>STEP 5: INVESTIGATIONS, DIAGNOSTIC PROCEDURES

<A>Purpose

Cognitive

Investigations provide specific information for the team about causes or contributing factors to the infertility problem (biological, psychological, social factors). Investigations enable the team to elaborate a problem-solution plan. Diagnostic procedures allow the patients to become experts in infertility procedures and to know more about their infertility problem.

Emotional

There should be decreased anxiety and increased reassurance.

Relational

The patient–team relationship should be strengthened.

<A>Objectives

Comprehensive care

The causes of the infertility should be recognised, to enable the team to come to a comprehensive diagnosis.

Increase of knowledge and competence

The patients are helped to understand better their infertility problem through personal experience.

<A>Typical issues

The patients suffer pain and frustration during the diagnostic procedures. They experience feelings of helplessness, of being abandoned or being insufficient. They feel fear about possible negative results. Stress reactions may include depressive mood and bodily symptoms. The patients may have difficulty in coping.

<A>Communication skills

Educational

The team should explain exactly and in a way that the patient can understand what is going to be done, as well as the possible outcomes. Supplemental charts and diagrams and other written material can be helpful.

Emotional

The team should react to and verbalise the emotions the patient(s) display during the procedures.

The team should be able to perceive and pick up negative emotions. A possible query might be

‘You look very tense and anxious to me. Can I help you?’

<A+>STEP 6: INFORMATION GIVING ABOUT RESULTS

<A>Purpose

Cognitive

The team informs the patients about the results. The patients receive and understand the implication of the information about the results.

Emotional

The patients can express and handle the emotional reactions to the results. The team supports their emotional reactions.

Relational

There is deepening of rapport.

<A>Objectives

Competence and knowledge

The patients should better understand the causes and factors contributing to their problem.

Increase emotional and social competence

The patients should be enabled to cope with this information emotionally.

Support and care

The team should help the patients with coping.

<A>Typical issues

The patients do not understand the results or misunderstand certain parts of the results. The language used by the team is not appropriate. There are too many professional words. The information giving about the results lacks empathy, so that the patients are traumatised by receiving negative results they cannot cope with. A special issue is unexplained infertility. In these cases the patients may suffer the difficulties of coping with uncertainty.

<A>Communication skills

Educational

Use appropriate language. Give small pieces of information. Check back. Allow questions, etc.

Emotional

Provide emotional support for coping with negative or stressful results. The team has to learn how to transmit or transfer these results. The team should help coping.

<A+>STEP 7: ELABORATION OF OPTIONS TO RESOLVE INFERTILITY PROBLEM

<A>Purpose

Cognitive

The team elaborates different options to resolve the problem of infertility based on the diagnosis (e.g., treatment, temporary pause in trying to conceive, child-free living, adoption). The patients

receive and reprocess this information and have time to consider it.

Emotional

There is relief and hope for resolution.

<A>Objectives

Increase of competence

The team should aim to increase the knowledge of the patients about possible problem solutions.

Autonomy and self-determination

Options should be created for the patients.

Comprehensive care

Treatment should be individualised.

<A>Typical issues

The patients do not understand the options. The patients have misconceptions about the options.

There are no options for the patients. Only one option is proposed by the team. None of the options is acceptable.

<A>Communication skills

Educational

Demonstrate and explain options. Give as broad a spectrum of options and possible decisions.

Verify. Encourage questions.

<A+>STEP 8: DECISION-MAKING ABOUT SPECIFIC OPTIONS

<A>Purpose

Cognitive

The team and the patients discuss the advantages and disadvantages of the different options.

Possible outcomes are anticipated and worked through.

Emotional

Possible emotional reactions to different outcomes are discussed.

Relational

The patients participate in the decision. The team and the patients are partners.

<A>Objectives

Participation and self determination

The patients participate in the decision-making process.

Patient-centered care

Decisions regarding treatment are highly individualised.

Informed consent

The patients can make decisions on an informed basis, knowing about advantages and disadvantages of the different procedures, etc.

<A>Typical issues

The patients cannot make decisions on their own. There is much external pressure and sometimes pressure from the team. The partners do not agree and there are conflicts about the method each prefers. Possible outcomes of procedures are not discussed and the advantages and disadvantages are not worked through. The patients cannot give truly informed consent, having balanced the advantages and disadvantages of their decision. There are undetected differences and conflicts.

<A>Communication skills

Educational

The procedures should be explained repeatedly until the message is understood.

Decision-making and negotiation

Work through the advantages and disadvantages of the different procedures with the patients. Point out possible outcomes and anticipate emotional reactions.

Relational

Create an atmosphere of partnership.

<A+>STEP 9: TREATMENT PROCEDURES

<A>Purpose

Motivational

The patients are motivated to follow the treatment instructions.

Behavioural

There is a practical realisation of the treatment plan with physical interventions. The patient takes the necessary steps to have the diagnostic tests/treatments.

<A>Objectives

Problem solution

The infertility problem should be resolved. A pregnancy and later a healthy baby should be attained.

Comprehensive care

The patients should not be harmed or traumatised.

Autonomy and participation

The individual partner should be able to cope with the treatment and be actively involved.

The team should help to deal with uncertainty.

<A>Typical issues

The patients suffer intensive physical, sexual and/or psychological distress and anxiety through side effects of the treatment. In case of failure, the patients experience frustration, anger, feelings of inferiority and insufficiency and/or depression, which have to be understood by the team.

There are stressful waiting periods. Uncertainty must be dealt with.

<A>Communication skills

Emotional

The patients should have the opportunity to have intermittent talks and counselling to explore the emotional reaction or experience.

Cognitive

All steps in the treatment process should be anticipated and the patients encouraged to ask questions.

Educational

It is important to teach skills for coping with stress and for handling failure.

Behavioural

To decrease vegetative reactions, the patients should be offered relaxation techniques.

<A+>STEP 10: EVALUATION OF OUTCOME

<A>Purpose

Cognitive

The team receives important information. The patients receive information, comments and explanations from the team.

Emotional

The results evoke emotional reactions, which the patients have to cope with.

Motivational and decision-making

Eventually the cycle is re-entered at one of the steps.

<A>Objectives

Comprehensive care

There should be emotional support and understanding for the patients.

Empowerment

The patients should be empowered to make sense of their own experiences and increase their knowledge and their competence for decision-making.

Enhance self-competence

The patients should be enabled to make choices and to cope with difficulties and losses. The patients should be helped to deal with positive and negative reactions in the context of pregnancy. Facilitate and accompany the mourning process related to the repetitive experience of non-fulfilment of the wish for a child.

<A>Typical issues

There may be disappointment and frustration about failure experienced by the patients. Emotions such as depression, anger and other negative affect must be dealt with. There may be aggression towards the treatment team. There may be anxiety and/or rigid, repetitive obsessive-compulsive behaviour by the patients.

<A>Communication skills

General

The team should listen, reflect emotions, verify and encourage questions.

Emotional

The team should tolerate negative emotions, respond positively and show empathy, perceive and verbalise unexpressed patients may be experiencing. The team should understand the different phases of shock and grief.

Educational

The team should teach coping techniques, as well as create awareness about the individual coping mechanisms and show the different possibilities of coping.

Decision-making

The team and the patients can re-enter a decision-making process about stopping or re-entering the cycle.

<A+>Remarks

The principles of care for infertile patients are based mainly on knowledge about the biology of human reproduction and the technologies derived from this knowledge. Advances in the subcellular and molecular dimension of the fertilisation process have been a very successful way of increasing the medical potential of gamete manipulation and have thus broadened therapeutic possibilities for infertile patients. This is the unquestioned progress of reproductive medicine.

As they look beyond the biology of reproduction and focus on the psychosocial dimension of human procreation, doctors continue to be confronted with the emotional impact of the unfulfilled wish for a child and the human dimension of the creation of a life.

Compared to the medical dimension, this human dimension is much less spectacular and, with respect to emotions, thoughts, behaviour, conflicts and other psychosocial factors, there is much less progress because the people involved in creating a new life will always be subject to the limitations, weaknesses and inheritances of human nature. Only by including the psychosocial dimension into the infertility consultation, however, will we be able to make biological reproduction human reproduction.

Until now the psychosocial aspects of involuntary childlessness, the emotional needs of the patients and the interpersonal encounter during infertility work-up and treatment have either been largely neglected by purely technically based services, or a division has been established between the biotechnical part of the infertility cure provided by reproductive endocrinologists, embryologists, surgeons, etc. on the one hand and the infertility care provided by psychologists, counsellors and other mental health professionals.

This division has certain advantages, the most important being the high degree of professional competence through specialisation. Reproductive technologies, diagnostic procedures and above all therapeutic interventions have become so complicated that highly specialised training is an absolute precondition. At the other end of the multidisciplinary spectrum there is a long tradition of counselling by psychologists, which has led to an accumulation of an enormous amount of knowledge about the emotions, cognitions, behaviour, stresses and coping mechanisms of infertile patients.

The second advantage is that the infertile patients may have several people (a multidisciplinary team) as partners, choosing the ones they need the most for the moment; finally, it can be an advantage that the patients may have independent counselling and advice.

What are the disadvantages of this dualism? Patients may have difficulties establishing a stable therapeutic relationship; they may feel themselves subdivided into bodies and minds, and lack the feeling of being treated as a whole person or as an individual couple with an individual

fertility problem. Furthermore, patients may feel misunderstood and even ashamed to be considered or looked upon as in need of a 'psychospecialist' as if they were neurotic or psychiatrically ill. This reluctance to accept, or the frank rejection of, professional psychological help may mean that those patients who would in fact need and want help the most remain untreated. Unmet psychosocial needs could be one of the factors contributing to unsuccessful treatment.

It therefore seems useful to elaborate a concept of the infertility consultation itself, in which biotechnical standards and achievements are combined with valuable standards of psychosocial care and competence with the service providers.

This integrative approach to the consultation is based on two grounds. One is the ethical work to define objectives of care that go beyond the 'baby take-home rate': qualities of the doctor-patient relationship, communication, comprehensive care, emotional response, empowerment of patients through participation, respect for autonomy and involvement in decision-making all help to cope with stress and other negative consequences of infertility.

The second is an integrative model of the consultation which has been developed over years and applied to different fields of medicine. The integrated 10-step model described is the application of this interactive paradigm to the infertility diagnostic and treatment process. It attempts to microanalyse the process taking place in the consultation in order to better focus on the different critical dynamic points at which the collaborative process between the patient and treatment team can be enhanced or blocked.

Some of the steps may seem to be artificially separated from others. Some other steps may seem to consist of two different phases instead of one. It may also be difficult in the beginning to differentiate between purposes, objectives, problems and skills, but the theoretical definitions are given and these concepts have proven their usefulness in different clinical research projects and practice. It is still a preliminary model that can be adapted and modified according to new research results and conceptual work. We believe, however, that reproductive medicine needs an integrated model of infertility consultations and this model can be defined through systematic

description and operationalisation of the key features of psychosocial care in infertility consultations (purpose, objectives, typical issues and communications skills). Such a model is needed for three reasons. First, to evaluate the combined biotechnical and psychosocial interventions with respect to defined quality standards; second, to serve as a basis for empirical research on patient satisfaction and treatment outcome; and, third, to provide reproductive special units with a tool for training residents and specialists to enhance and improve their psychosocial competence.

<ST>4.1 PREGNANCY AFTER INFERTILITY TREATMENT

Patricia Baetens

<A>Introduction

Patients' infertility history has an impact on the way they live through pregnancy and child rearing. Infertility creates a crisis at the individual, relational and social levels. The transition from infertile patient to pregnant patient may be influenced by the individual fertility history of each patient, the way they have dealt with the infertility problem in the past, their sociocultural environment and the kind of treatment they have had.

<A>Purpose

Infertile patients have had to go through tremendous efforts in order to have a child. The pregnancy represents an enormous investment of time, emotions, energy and often money. During the treatment patients focus on becoming pregnant. Patients have many fantasies about how extremely happy they will be once pregnant. However, when pregnant they have to deal with the possibility of complications and the risk of losing the pregnancy. This is especially problematic if they already have experience with reproductive loss. Clinical experience shows that anxiety and stress are increased during the pregnancy after infertility treatment. Two extreme reactions in relation to the pregnancy might appear in some patients. Denial might occur in women who are not capable of developing an attachment to the foetus because of the anticipation or fear of negative events during pregnancy (e.g., miscarriage). Others may develop an exaggerated worry about each 'normal' physical event in the pregnancy (Covington & Hammer-Burns, 1999). The fact that pregnant patients do not feel extremely happy about their pregnancy, as they feel they should, produces feelings of guilt and shame, which further reinforce feelings that may have developed when the infertility problem was first discovered.

Being pregnant introduces issues concerning the welfare and especially the health of the baby to be born. The patients' inability to conceive may have already produced a lack of confidence in their bodies and therefore might decrease the belief in their bodies' competence during pregnancy and delivery. Higher anxiety levels during the pregnancy are related to the in-vitro fertilisation (IVF) mother's concern for the well-being of the baby and her fear of being separated from her baby after it is born (McMahon *et al.* 1997). Moreover, infertility patients have to deal with a lot of uncertainty about the quality of the future parent-child relationship and child-rearing practice. Becoming a parent has lost its naturalness. Patients often have the feeling that they have to prove that they will be worthy parents. Sometimes they even feel that they are not competent to be parents.

Patients who used donor gametes have a lot of worries and anxiety about the consequences of the use of donor material for the future father-child and mother-child relationship. Although most of them are counselled about matters such as anonymity of the donor and about whether to tell the child about its conception, this discussion was mainly theoretical before the treatment started. Moreover, during pregnancy, anonymous material can introduce curiosity about the donor, anxiety about the donor's health and genetic background, anxiety about the physical characteristics of the baby and sometimes even a sense of alienation from the child to be born.

In all cases counselling should also deal with the side effects of assisted reproductive techniques such as multiple gestation, multifoetal reduction and pregnancy risks due to a higher maternal age.

<A>Objectives

The team should:

- Facilitate the transition from infertility patient to pregnant patient. The patients must set themselves free from the infertility treatments and invest in the pregnancy. The patients must adjust to the pregnancy. They need to normalise the pregnancy and to develop an attachment

to the foetus. Furthermore, they need to start an important role transition, i.e. the transition to parenthood. In clinics where obstetric and infertility teams differ, patients need to separate themselves psychologically from the infertility team and trust the obstetric team that will support them through the pregnancy and delivery.

- Reduce stress and anxiety levels, help patients to deal with their feelings of guilt and restore feelings of self-efficacy in order to help them to feel in control over their pregnancy.
- Reassure patients about the impact of the treatment on the health of their baby without underestimating the chance of having a baby with a congenital or genetic problem. Help them to deal with their fear of having a baby with a health problem.
- Compare their anxieties and stress with those of patients who become pregnant by natural means: show the similarities and explain the differences resulting from the infertile situation. For every pregnant woman, pregnancy is a period of profound physical and emotional changes influencing the body image, the relationships with others and the identity of the pregnant mother. Moreover, the woman must share her body with another and develop an attachment with the baby. Some ambivalent feelings may occur during pregnancy. On the one hand, pregnant women develop a sense of accomplishment and a higher sense of self-esteem. Nevertheless, anxiety, self-doubt, lower self-confidence and distress about body competence can also occur in pregnant women complicating adjustment to the pregnancy (Covington & Hammer-Burns, 1999)
- Patients should be informed that some ambiguous feelings may exist towards the child. These feelings are often provoked by the idea that they have to be 'perfect' parents and that they may not meet this self-imposed standard. Moreover, transition to parenthood can be more difficult than they expected. Patients can also question the 'correctness' of their decision to have a child through IVF. Parents may worry that their child will be affected negatively if s/he is informed about her/his conception in a non-natural way. Continued counselling after the birth of the child should be available.

- Cope with ambiguous feelings towards the foetus in third-party reproduction.
- Counsel on matters such as secrecy and anonymity in third-party reproduction.

<A>Typical issues

The main problem encountered is that after the first ultrasound, performed at 7–8 weeks, pregnant patients and partners are often followed by a obstetricians outside the infertility centre.

Form this point on patients are considered by these teams to have normal pregnancy. However, the majority of patients will differently in respect of their pregnancy than other people who have never been infertile. In this context, previously infertile people do not allow themselves to have negative feelings and, therefore, deny any they experience. Only in interviews years after the child is born will patients recognise these feelings to some extent.

Moreover, the fertility team is often enthusiastic about the success of the treatment, forcing patients to react happily. Teams might show a lack of understanding for the doubts and the uncertainty about the pregnancy of former infertile patients. Especially if patients have undergone multiple cycles of treatment before becoming pregnant, some physicians might become overprotective and overcautious.

IVF parents are more likely to have a multiple pregnancy. They should be counselled about the physical consequences and medical risks of multiple pregnancies and the stress involved in taking care of multiples.

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attachment after in-vitro fertilisation conception. Hum. Reprod., **12**, 176–182.

<ST>4.2 MULTIPLE PREGNANCIES

Alexina McWhinnie

<A>Introduction

Statistics about the incidence of multiple births show a steep increase over the last 20 years. Most countries report an incidence of multiple births of 20-30% following assisted conception. The medical risks both to the mothers and the babies are well documented. The social consequences also cause concern, but the realities of these consequences are not generally addressed in the medical literature (Fisk & True, 1999; Templeton & Morris, 1998).

There is a contemporary debate about the advisability of reducing the number of embryos transferred while maintaining approximately the same chances of achieving a pregnancy. There is, however, less discussion of the fact that a proportion of the increase in multiple births arises from the use of drug stimulation.

Twins and their upbringing have been studied and researched extensively (Bryan 1992). This has shown that they are frequently slower learners in language and in other school subjects, that they develop their own unique social relationship and that parents find it difficult to give them the individual attention and personal contact that is possible with singletons. Their presence in a family can cause difficulties for older singleton siblings because of the immediate appeal of twins to adult outsiders.

Triplets and higher order birth children present the same problems as twins, but to a more extensive and intensive degree. Bryan has called them “super-twins”. But to date their particular relationships and specific emotional problems have not been studied in the same depth as have twins.

<A>Purpose

Decision-making and informed consent are part of medical counselling in relation to the above double scenario of risk assessment. Also very relevant are the social and financial consequences

of creating multiple birth families. These relate both to the provision of hospital care for several premature babies and to the burden of lifelong parenting of such children. Hospital care for premature babies is both expensive and limited in each medical centre. The likelihood of disabling conditions in premature babies and the resulting long-term medical care and social provision for these children falls on personal resources and/or hospital and community budgets.

Aspects of the parenting of these children which have been studied are practical, financial and housing provision, as well as psychosocial aspects and mental health consequences for the parents (Botting *et al.*, 1990; Bryan 1992). The practical issues are spelt out by Botting:

- Feeding premature babies - smaller and slower than full term babies.
- Changing clothes/nappies/washing/drying facilities.
- Lack of sleep can become a major problem - one baby crying wakes the other.
- Social isolation of mother - problem of going anywhere with three small children; loss of friends and social contacts.
- Financial outlays - house extension; all costs of clothing, etc occur at the same time; loss of mother's potential earnings.

Mothers recognise they need regular practical help from outside but are reluctant to ask for it. To do so implies they are not coping.

Relations, immediate and wider kinship, and social networks in the vicinity can play a crucial role in the family's ability to cope in the early years of these children's lives. Many grandparents, however, feel overwhelmed. Not all community and social service providers recognise the potential needs of these families.

<A>Objectives

Couples need to be provided with a realistic picture of what it would be like to parent three, four or more children of identical age. The relevant aspect of this is that they are all at exactly the same developmental stage and all requiring the appropriate degree of individual adult attention

and concern for that developmental stage. Where there is prematurity, the babies are likely to be slower and so need more adult care.

A study from the Australian Multiple Births Association (1984) found that simply caring for three babies aged 6 months and doing some household chores took 197.5 hours per week, clearly a task well beyond one adult.

Typical reaction of infertile partnerships when they learn of a multiple pregnancy is either that they are euphoric and make the comment, "That would be a ready-made family". Murdoch (1997) in a survey of patients' attitudes about the number of embryos to transfer found that 69% felt a multiple pregnancy would be the ideal outcome of IVF. They certainly did not see it as a problem. A similar study from the USA offered a similar conclusion, but on the basis of an extremely low response rate to the questionnaire (Gleicher *et al.*, 1995).

<A>Typical Issues

The work of the counsellor in this respect is made more difficult by the fact that the public as a whole are intrigued by the sight of three or more small children, a picture reinforced by the media, and because it is generally assumed it is the same as caring for several young children in any family.

Risks to the stability of the partnership and the mental health and the social well-being of the parents is high in the case of triplets and quadruplets. The reasons for this have already been spelt out. There is little time for the parents to spend time together and there is constant strain on financial and personal resources of all kinds. That such situations produce depression, stress and related conditions of varying degrees of severity and/or marital problems is not surprising. Studies to date suggest that such problems may occur in one in three to four families. There is also some evidence that children from such families may be more likely to be received into public care and/or be subjected to non-accidental injury however more systematic inquiry of these issues is required (McWhinnie, 2000).

Foetal reduction, i.e. reduction of a multiple pregnancy to twins or a singleton, is now available. Although clearly controversial in nature, it is offered in some units as a routine option. It is also controversial regarding the outcome for the family. Follow-up studies to date are limited and confined to one year after reduction (McKinney, et al., 1995, Schreiner-Engel et al., 1995). Schreiner-Engel reports that acute feelings of emotional pain, stress and fear are experienced during this procedure and that mourning for the loss of the foetus or foetuses was reported to occur in 70%, but that most grieve for only a month. However, moderately severe sadness and guilt can persist for some “especially for an identifiable sub-group who were younger, more religious and who had viewed the multi-foetal pregnancy on ultrasonography more often”. (Schreiner-Engel et al., 1995). This study concluded that the majority were reconciled to a termination of some foetuses to preserve the lives of the remaining few.

Counselling needs to recognise this and also to discuss with the partnership how they will deal with telling the surviving child or children about the foetal reduction (McWhinnie 2000).

<A>Communication skills

Counselling dilemmas for medical and non-medical counsellors relate to all the uncertainties involved - the desired outcome versus the possible consequences.

Written and discussion material would be helpful to allow decision-making to take account not just of the medical problem of childlessness but the long-term medical and psychosocial consequences of a multiple pregnancy and birth for a particular partnership. Also to be considered are the financial resources and hospital care and community provisions that may be available to them.

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<ST>4.3 FACING THE END OF MEDICAL TREATMENT

Tewes Wischmann

<A>Introduction

Infertility can be seen as a critical life event. For some patients, unsuccessful medical treatment can lead to an existential life crisis with severe emotional reactions (Atwood & Dobkin, 1992; Dunkel – Schetter and Lobel, 1991; Wischmann et al., in preparation). Patients, especially those with unexplained infertility, often believe that their infertility is of psychological origin when medical treatment fails.

<A>Purpose

The perspective of living without a child (by birth) should be acknowledged from the beginning of medical treatment to prevent depression after unsuccessful treatment. The counsellor should be aware that mourning after unsuccessful infertility treatment is rarely finished. The patients should not feel deficient if they cannot make the pain disappear (Meyers et al., 1995). Patients should be encouraged to look for support either from the team's counsellor or from a specially trained counsellor at home.

<A>Objectives

With the diversity of medical treatment options available today, deciding to stop treatment can be more difficult than continuing. At each new step of treatment, the patients should ascertain their own personal limits of endurance. At the end of each unsuccessful stage of medical treatment, counselling should facilitate consideration of new perspectives and/or options for the future. This could mean pausing infertility treatment, considering alternative medical treatment methods or intensifying medical treatment. The patients should be encouraged to actively participate in this decision-making process. The patients should be prepared for the emotional reactions accompa-

nying unsuccessful treatment. At the end of treatment, the team and the patient(s) should discuss the personal meaning of the loss of an important life goal (Sewell, 1999), but also the advantages to the individual of a 'child-free' life. The patients should be encouraged to find out what kind of resources they themselves already have to cope with unsuccessful infertility treatment. This could mean involving relatives or friends, or contacting self-help groups. One possibility is to ask the patients whether it would be worthwhile for them to create their own bereavement ritual to prevent a state of chronic, unresolved loss (Meyers *et al.*, 1995), especially when miscarriages and/or stillbirths have occurred (Lothrop, 1997). The decision to end treatment can be seen as a way of regaining choices, independence and privacy in the patient(s)' life (Anton, 1992). There is no empirical evidence that 'child-free' partnerships are more unhappy or more unstable in the long term than the partnerships of patients with children.

<A>Typical issues

After unsuccessful medical treatment (e.g. in-vitro fertilisation or microinjection) patients may press for continuing treatment. New techniques can provide new hope but also result in new disappointment. The chances and the risks of new techniques should be discussed openly.

Patients quitting infertility treatment or going to another centre may disparage and/or devalue some or all members of the team, so that psychological support offered by the team will not be accepted.

Patients may fall get into a communication trap in which the decision about ending treatment is based on perceived or assumed feelings instead of their real feelings.

<A>Communication skills

Skills

Each member of the team should keep in mind the end of treatment at any stage. Each member of the team should know the typical emotional reactions towards unsuccessful treatment (e.g.

depression, anxiety, poor self-image, feelings of unfulfilment) and should be open for discussions about these feelings with the patients. Counsellors should point out that unexplained infertility is not in most cases equivalent to psychogenic infertility. The counsellors should ensure that the patients are fully aware of the success rate of the next step in medical treatment. A formal ending is a helpful ritual to mark the patients' ordeal, to discuss the changes that have taken place and to discuss the future (Atwood & Dobkin, 1992; Meyers *et al.*, 1995; Sewall, 1999). Interviewing patients about their experiences in infertility treatment can be helpful to gain information for better understanding future patients and can give the patients a positive appreciation. Patients should be given the feeling that they have resolved their infertility to the best of their ability, regardless of the point at which they ceased medical treatment. The counsellor should be as neutral as possible towards the motivation to continue or abandon medical treatment. Not using assisted reproduction technologies because of ethical or religious reasons should be accepted. Accurate information about the 'artificiality' of ART should be given. The counsellor has to explore whether the patients are under pressure from relatives or friends either to stop treatment ('you have to reduce this stress to get pregnant!') or to intensify treatment (e.g. for cultural reasons, see Section 4.8). The counsellor should also accept and put forward for discussion the different opinions partners may have concerning the end of medical treatment. The partner who wants to stop treatment might wait for the other one who has not decided yet.

Content

Typical questions at the beginning of the medical treatment include: What are you willing to do to fulfil your wish for a child? How would you recognise that you have reached your limit in the medical treatment? If medical treatment fails, how would your life look five years later? What perspectives of living without a child of your own could you imagine?

Typical questions at the end of the medical treatment include: How has infertility shaped the way you see life and yourself? In a positive and a negative way? How can you develop a ritual or ceremony to say goodbye to your dream child? Now that you are at the end of treatment, what are your recommendations for your doctors? What recommendations would you make to other

patients? What helped you in coping with infertility?

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<ST>4.4 SEXUALITY

Joëlle Darwish

<A>Introduction

Sexuality and infertility are associated in different ways. First, as is well described in the literature (e.g. Hammer Burns, 1999; Greil *et al.*, 1989) and obvious from clinical practice, sexual functioning is a key aspect of individual experience and is particularly sensitive to infertility crises. Second, sexual dysfunction may pre-date the diagnosis of infertility, be reinforced by investigations and treatments or even cause infertility. Finally, sexual problems may be incidental to infertility and due to a variety of reasons, as would be the case for fertile people. It is important to note that the definition of sexual problems is subjective and culturally determined. Investigation should therefore carefully consider the ways in which the individuals perceive sexual issues the team consider a problem.

Sexual problems causing infertility

For a small percentage of infertile patients, sexual problems are the primary cause of infertility and can be masquerading as cases of infertility: e.g. infrequent intercourse, vaginismus, dyspareunia, lack of sexual desire, erectile dysfunctions. These sexual problems may be of organic and/or psychological origin.

Sexual problems secondary to infertility

For a larger percentage of patients (10–60%; see Möller, 1999), infertility may have various repercussions on sexual functioning (e.g. lack of sexual desire, orgasmic dysfunctions), ranging from episodic problems necessitating education and support, to sexual dysfunctions requiring specialised treatment. Studies on this subject do not show homogeneous results: some find evidence suggesting alteration of sexual functioning due to fertility problems, whereas others do

not.

Sexual problems are often caused by the pressure associated with scheduled sex, by the psychological presence of the medical team in the patients' intimacy and by the fact that intercourse becomes goal-oriented and is itself a reminder of infertility (Greil et al., 1989; Hammer Burns, 1999). Some procedures such as the post-coital test are particularly involved in the impairment of sexual functioning (Boivin et al., 1992).

In addition, the crisis of infertility alters self-esteem and body image, resulting in feelings such as inferiority, depression and anxiety. These psychological repercussions may also have an effect on sexuality.

<A>Purpose

The purpose of counselling is to bring aspects of sexuality into the consultation. On the one hand, patients are encouraged to express their feelings and thoughts about sexuality and to share their difficulties. The counsellor is thus able to identify these difficulties, to assist the patients to work through them or to define adequate treatment. On the other hand, preventatively, the patients are informed that their sexuality is challenged during investigation and treatment. Helping patients become aware of the common sexual problems associated with infertility can be therapeutic in itself and can allow for better coping.

<A>Objectives

The team should:

- Open the discussion systematically on questions linked to sexuality, taking into account gender differences.
- Consider the significance and the severity of the sexual dysfunction for the individuals

themselves. Establish whether the sexual problems are pre-date and/or are secondary to infertility. Take note of whether the sexual problems are induced by specific treatment procedures. Evaluate if it is a transitory and reversible problem or a more long-lasting dysfunction. In the first case, the counsellor can offer education and support. In the second, the counsellor must, in addition, verify if there is a possible organic origin and propose adequate treatment.

- Evaluate the psychological aspects associated with the infertility crisis having an effect on sexuality (e.g. depression). When sexual problems are signs of long-standing individual or relational disturbances, it is necessary to work through them or to refer patients further to a psychologist, couple or sex therapist, preferably before the beginning of any infertility treatment.
- Help the patients rebuild their sexuality as a source of pleasure in the cases where sexuality has become goal-orientated and very much based on performance (Tuschen-Caffier *et al.*, 1999).

<A>Typical issues

Opening the discussion about sexuality may be difficult both for the patients and for the counsellor. If a trusting relationship is not yet established, the counsellor's questions may be perceived as too intrusive. One partner may want to discuss this theme while the other does not. Such a difficulty can also be due to a variety of reasons, including social and cultural variables.

In the case of acknowledged sexual dysfunction, it may be hard for the counsellor to refer the patients to a sex therapist, as there is frequently a lot of ambivalence. For example, couples want to seek professional help for their sexual difficulties but at the same time they are fearful of the possible consequences on their relationship as a couple.

An ethical dilemma emerges when sexual problems causing infertility are highlighted but when the patients want to begin treatments without first trying to resolve their difficulties. In these cases, the team must decide whether to treat or not.

<A>Communication skills

The counsellor, if not qualified to provide sex therapy, should nevertheless have acquired specialised knowledge in the field of sexuality linked to infertility. S/he should also be able to ask the relevant questions about sexual behaviour sensitively.

The counsellor should be able to refer patients to appropriate specialists in case of acknowledged sexual problems requiring treatment (sex therapy, medical investigation, etc.).

Typical questions may include: How would you describe your sexuality as it was at the beginning of your relationship? Have you noted any changes since your fertility problem has been defined? If you have noted changes, what do they signify for you? How do you evaluate the influence of the procedures and/or treatment on your sexuality? How satisfied are you with your sexual life?

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<ST> 4.5 PATIENTS IN MIGRATION

Heribert Kantenich

<A>Introduction

At present, the countries of the European Union are home to around 17 million people of foreign origin, of whom two-thirds originate from countries outside the EU. The proportion of immigrants in the individual EU states in the mid-1990s varied between 1% (e.g. Portugal) and 29% (Luxembourg) (Council of Europe, 1994; Salt *et al.*, 1994).

It can therefore be expected, especially in large urban clinics, that a proportion of fertility patients will be immigrants. Indeed, in some gynaecological hospitals in major cities or industrial regions almost half the patients are of migrant backgrounds. Physicians and counsellors are frequently overtaxed when having to take into consideration the individual desires of patients-in-migration and the possible influences of a 'foreign' religion, culture and ethnicity on their wish for a child. Particular sociocultural conditions (migration, social isolation, ghetto-like living conditions, the particular importance of having offspring, the stigma associated with lack of children) make involuntary childlessness among patients in migration more challenging and complicated than for other patients.

In many cultures infertility leads to social isolation for the patients and especially for women as in some cultures women are seen to be responsible for childlessness regardless of the actual cause of the fertility problem.

<A>Purpose

The purpose of counselling include:

- Explaining very carefully the necessary diagnostic and therapeutic procedures to the patients

and to accompany and support them in every step;

- Creating an atmosphere open to and respecting of ethnic, sociocultural and religious particularities; and
- Assisting in translating and interpreting, for which written and supplementary visual materials aiding in the doctor–patient dialogue are helpful.

<A>Objectives

Possible objectives are:

- Understanding the meaning of infertility in the cultural setting, and encouraging the patients to talk about the cultural background of infertility;
- Making diagnosis and therapy both accessible and respectful of the patients' sociocultural background;
- Providing fertility clinics with a network of translators/interpreters, who should be either professional translators/interpreters or members of the team who are native speakers; and
- Providing female gynaecologists and female counsellors for some patients for whom a male gynaecologist would not be allowed to examine female patients.

<A>Typical issues

Often the infertility problem is even more pressing abroad than in the native country because of ghetto-like living conditions. When the patients are abroad, the wish for a child has greater individual importance (David *et al.*, 2000). Migrants are often threatened by unemployment and the majority have lower-class backgrounds. For them the fulfilment of the wish for a child may be a more important life goal than for their fellow citizens.

Because of the lower educational level of many migrants, there is often little understanding of bodily functions, the causes of the fertility problem or of the treatment options available. Educating and information-giving are therefore important components of counselling with migrant patients. This lack of understanding can manifest itself in different ways for example the cause

of infertility may be ignored or it may be kept secret from one of the partners (e.g., in the use of donor gametes). Health care providers must evaluate patient's understanding of the information provided and ensure it is inline with the information given.

It should also be noted that patients from the same foreign country may also differ among themselves with regard to class and ethnic or cultural traditions. Health care providers must therefore ensure that patients from the same country are not treated as a homogeneous group. Patients with mixed national or ethnic backgrounds (about 50% of all patients in migration) can experience the acculturation process in a different way.

In patients who feel a high intrapsychic pressure to become pregnant, there is a tendency to demand and persist with invasive methods. There is a great responsibility on the part of the physician to prevent over-treatment in such cases.

Gender differences must be taken into account. In many cultures the question of conception and infertility is not regarded as a joint problem affecting the couple, as it is in Western cultural circles; rather it is considered almost completely a woman's problem. This can lead to feelings of shame in women and men. In some cultures, questions of sexuality cannot be discussed between men and women. The patients should be asked whether they would prefer a male or a female counsellor to discuss these issues.

Masturbation is not socially acceptable in some cultures. This must be taken into account when dealing with difficulties regarding producing the semen sample.

The professional capacities and medical knowledge of the translators/interpreters in the clinical environment is highly significant. The use of children for translating/interpreting is particularly problematic, due the issues of privacy and shame involved with infertility.

Migrating patients are often younger than other infertile patients (David *et al.*, 2000). Among such patients both the rate of spontaneous pregnancies and the rate of multiples following treat-

ment is higher, despite the existing infertility problems. This should be taken into consideration in every ovarian stimulation treatment.

<A>Communication skills

An open atmosphere should be created to allow for addressing cultural issues in the clinical setting. Training native speakers in the team in counselling for infertility is vital.

The production and availability of information brochures/videos/internet in the different languages is also important. Videos and pictures are of major importance, as 10–20% of the patients are illiterate.

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<ST>5.1 DONOR INSEMINATION

Ken R. Daniels

<A>Introduction

Donor insemination (DI) is the oldest of the medical interventions designed as a response to infertility. It is not so much a ‘treatment’ for infertility as a means of circumventing infertility; that is, the male partner remains infertile despite the birth of a child. The fact that it is the female who is inseminated with sperm from a man other than her partner means that the medical attention is focused on her – she is, in effect, receiving ‘treatment’ for her partner’s condition. For the infertile partner, DI represents significant challenges to his role as a male. The involvement of another male – usually identified as a ‘donor’ – raises issues concerning how the three parties view themselves, their roles and their relationships and this, in turn, will have an impact on any offspring that result from the treatment.

Traditionally the relationships have been mediated by the medical professionals who have required, advised or encouraged secrecy and anonymity between the patients, the donor and the resultant child. This culture of secrecy extended to the offspring with most not being told of the nature of their conception. The culture surrounding DI has changed dramatically over the past 20 years. The examination of the relationships between the various parties involved – infertile patients, provider of semen, offspring and medical professionals – has led to changed policies and practices in some countries. These changes have major implications for the provision of counselling services.

<A>Purpose

Counselling in DI focuses on two different parties – the couple or single person who is seeking DI and the man who provides his semen. While the general purpose of counselling – providing support, considering implications and being available for therapeutic work – will apply to both parties, the issues that give rise to the counselling will be very different.

For those seeking to use DI, the emphasis is on family creation. This point has been reached only after acknowledgement that a ‘third party’ will be necessary to assist them in achieving their aim. There are normally feelings of loss associated with not being able to accomplish this without assistance. The purpose of counselling includes exploring the meanings of this loss along with the implications of using DI as an alternative means of family creation.

For the donor, the purpose of counselling will include consideration of the meanings associated with providing his gametes to and for someone else. A particular consideration will be the implications of this action for his present, or any future, family. Exploration of the expectations/ requirements regarding the sharing of information between the involved parties will also be part of the purpose of counselling.

At a more specific level, Klock and Maier (1991) have suggested that the purpose of counselling includes a consideration of:

- legal issues,
- risk of sexually transmitted diseases and HIV infection,
- parenting roles,
- informing others and
- religious and cultural considerations.

Given the advent of patients using identified donors (sometimes known as personal donors), they suggested that the following matters also needed to be considered as part of counselling for this latter group:

- effects on family dynamics,
- informing others,
- donor coercion and
- donor interview.

Anderson and Alesi (1998) have also given consideration to this area and have divided their suggestions into those applying to anonymous donations and those to known donations. They work in Victoria, Australia, where legislation requires counselling for patients and for the donor and his spouse or partner (if applicable). In addition to the points made by Klock and Maier (1991), they suggest that psychological screening for anonymous donors should include assessment of

- motivations,
- realistic expectations,
- psychiatric illness and
- drug use.

For known donors the additional points that should be considered are:

- future relationships with participants,
- future relationships with child,
- emotional aspects of relationship to child,
- telling child,
- confidentiality with other parties,
- number of planned donations and
- implications of negative outcome of treatment.

<A>Objectives

The primary objective of counselling is to try to ensure that all parties benefit from the use of DI. Recognition of the psychosocial dimensions of family building using DI, as well as the factors that lead to the need to use DI, is an essential element in achieving this goal.

Clinic policies vary considerably on the issue of when and if counselling should be recommended or mandatory. In some situations all couples or single applicants are expected to be seen, while in others a decision will be made by staff, either singly or jointly, as to who should be referred to the counsellor. The latter policy is likely to be applied when a clinic views the function of counselling to be primarily therapeutic. This means that only those who are deemed (by those not trained in psychological assessment) to be psychologically in need of assistance will see a counsellor.

An alternative model, proposed by Mahlstedt and Greenfeld (1989) argues that all applicants should be seen by a counsellor with the focus being on preparation for parenthood involving third-party reproduction. If implications counselling is to receive attention, this will include psychosocial considerations and this should be handled by an appropriately qualified person.

In some clinics, all providers of semen are expected to see a counsellor, again with the objective of fully informed consent and consideration of the impact of donating. This may well include seeing those who are significant to the donor, e.g. his spouse/partner. Consideration in such counselling will also extend to any current children or future children of the donor.

<A>Typical issues

At the clinic level, there may be reluctance from staff to acknowledge this; they may prefer to see DI as a straightforward medical treatment.

There may also be reluctance on the part of those seeking DI and by the donor to recognise the psychosocial issues. This may arise partly from their desire to see the procedure as a 'medical fix' for their problem. They may also equate psychosocial considerations and counsellors with therapeutic work and be fearful of this. They may also fear that they are being assessed for their suitability to parent. Assessment is felt to be an unjustified intrusion into the marital relationship by some patients, and they are therefore reluctant to take part in it.

This is an area of serious tension in the field of DI. Those who argue for assessment cite their concern for the welfare of the future child. They argue that such assessment takes place in the field of adoption and should be used in DI as well. Those who argue against assessment suggest that this will compromise any therapeutic work and will certainly lead participants to be 'less open' in counselling.

Discussion of future family relationships, and particularly the issue of talking to children about the nature of their conception, can also present challenges. An infertile couple, for example, may not be able to consider issues arising appropriately if they do not know if they will have a child.

It is suggested that the counselling should be provided at pre-intervention, intervention and post-intervention stages. The provision of post-intervention counselling raises issues for counsellors and clinics in that most counselling has tended to be offered while participants are involved with a clinic.

Underlying a number of the issues raised above are the questions of the offspring being told of the method of their conception and if they are, having access to information concerning their conception. The functioning of a family that is based on the deliberate decision to withhold information (which many would argue offspring have a right to) and to practise secrecy must be a matter of concern for any person with an awareness of the psychosocial impact of secrets.

There can be little doubt that this is an important issue facing clinics, recipient patients, donors

and, of course, counsellors.

Another issue for consideration is the counselling focus that should apply when the recipient is single or a lesbian couple. This also has implications for the donor, especially given that a growing number of clinics allow donors to choose which categories of recipients may receive their sperm.

<A>Communication skills

All skills involved in professional counselling are required. Given that counselling is likely to involve working with more than one person, skills in couple and family work are essential.

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<ST>5.2 OOCYTE DONATION

Patricia Baetens

<A>Introduction

Oocyte donation provides a solution for infertile women with ovarian problems, such as primary or premature ovarian failure. In addition, women with normal ovarian function may require oocyte donation, for instance, in the case of recurrent failure of in-vitro fertilisation (IVF) treatment. Some of these problems are age-related.

The main problem is shortage of donor oocytes. The donation of oocytes, as opposed to sperm donation, involves invasive medical treatment of the donor. As a consequence, not many women are willing to donate anonymously. In order to avoid a long waiting period, different procedures to recruit oocyte donors are proposed, such as egg-sharing and the recruitment of a donor by the patients themselves.

<A>Purpose

Voluntary oocyte donors

According to Englert (1996), 'occasional' donors are psychologically fragile women, looking for recognition or massive self-repair. Similar features were found in other research where voluntary oocyte donors reported histories of family trauma or reproductive trauma. The trauma is often the reason why women are able to identify with the loss experienced by the woman who is in need of donor oocytes.

Englert (1996) fears the risk of disrupting an unstable psychological balance and would, therefore, exclude some 'occasional' donors. On the other hand, Schover *et al.* (1991) believe that, when issues of loss are examined and when the expectations of the donor are realistic, the proc-

ess of helping another women can be reparative. Counsellors have to be very cautious because traumas may cause psychological distress and extra support may be necessary in this stressful medical procedure. In some cases where the distress caused by trauma is considerable, it might be in the donor's interest to postpone or even cancel the treatment.

Oocyte donation with a donor recruited by the patients

In some centres the recipient patients can choose between two types of donation: known donation (i.e. treatment with the oocytes of the donor recruited by the patients) or anonymous donation (i.e. exchange of the oocytes of the donor recruited by the patients with those of a donor recruited by another patient(s) in order to ensure anonymity between donors and recipients). The aim of the counselling is not to enforce certain decisions but to guide the decision-making process regarding the kind of donation to be used (Baetens et al. 2000). Attention should also be paid to possible psychological consequences of this decision.

Egg-sharing

Ahuja et al. (1996) introduced egg-sharing using IVF patients. IVF patients seem ideal donors since there is no supplementary medical risk. In this system, donors share their oocytes with an anonymous recipient. In return, recipients share the costs of the treatment of the donor. Nevertheless, some believe that an ethical problem might arise in cases where the recipient woman conceives and gives birth to a child while the donor herself does not conceive. According to Ahuja et al. (1996), an unsuccessful IVF treatment cycle will always cause distress and there is no indication that this is more upsetting for the patient who has been a donor. This procedure is often the only solution for women over 40 who are unable to recruit a donor because the members of their peer group are not suitable as donors.

<A>Objectives

Voluntary oocyte donors

The counsellor(s) should:

- Inform oocyte donor extensively about the treatment procedure, the consequences for her personal life during the treatment and the risks;
- Evaluate the motivation of the oocyte donor, her ability to cope with the uncertainties and stress in a donor cycle and the expectations she has about the donation and whether these are realistic;
- Inform the donor about the use of oocytes in general and the importance of sustaining her commitment without putting pressure on her; and
- Evaluate consent and support of the donor's partner.

Oocyte donation with a donor recruited by the patients

The counsellor should: (Baetens **et al.** 2000)

- Guide the decision-making process for known or anonymous donation and discuss the consequences of this choice for the recipients, the donor and the child;
- Evaluate the motivation of the donor, and verify whether the donor understands the boundaries of her role and whether she is fully capable and free of any kind of coercion in giving informed consent;
- Evaluate the motivation of the recipients for known or anonymous donation, and check whether this choice is not made due to pressure from the donor and whether they understand the boundaries of the donor's role;
- Counsel on secrecy/openness towards the social environment and the consequences of this decision; and
- Counsel on secrecy/openness towards the child and the consequences of both.

Egg-sharing

The counsellor should:

- Evaluate with the donor the consequences of the donation on their own treatment. Counsel donors on the consequences of an anonymous gift. Special attention should be paid to patients who donate because of financial need. Their freedom to consent is restricted by this need.
- Recipients of egg-sharing should be counselled on the consequences of anonymous donation. Furthermore, they should be counselled on the possibility that donor cannot be matched except for ethnicity and should be prepared for a waiting period. Recipients should also be informed that if the donor does not have the required number of oocytes needed in this procedure the treatment will be postponed.

<A>Typical issues

Voluntary donors

The risk of drop-out just before or even during the treatment is considerable. The recipient patients need to be prepared for the possibility that no oocytes will be available.

Oocyte donation with a donor recruited by the patients

Criticism of known donation focuses mainly upon the role of the donor towards the child to be born after oocyte donation. Donors are often presented as a kind of ‘third’ parent. Nevertheless, donors did not make a decision to have a child themselves; they only provided the infertile patients with the means to fulfil their wish for a child. Considering the donor to be a parent conflicts with the boundaries of her role in this project.

In the anonymous procedure, recipients and donors can often not be matched except for ethnicity. Knowing that sometimes donors cannot be matched might influence the mother’s relationship to the child. Mothers might search for differences and similarities between their child and them-

selves and be afraid that the social environment might see that the child is not genetically related to her. Anonymity has an influence: first, during pregnancy, when the image of the baby to be born is not complete; and, second, after the child is born, when parents and children can be confronted with questions about the donor that cannot be answered. The question of whether secrecy is harmful or beneficial has not really been studied. Many of the patients' questions remain unanswered.

In cases of known donation, openness towards the child can have consequences for the donor and her family. Children might seek information on the donor and her family and this might affect the relationships and dynamics in the family of the donor.

Counsellors should also decide on the desirability of counselling donors and recipients together or separately. A joint session reinforces in some cases the view of donors and recipient on oocyte donation as a common project of two women in order to help one woman to become pregnant. In these cases donors are confronted with a multiple-patient situation requiring a systemic and dynamic approach of the counsellor. It is sometimes preferable to consider donors and recipients as two separate entities, especially if donors and recipients wish to reduce the dependency of the recipients. In these cases counsellors can focus on the specific contribution of each woman involved in the treatment and evaluate whether the expectations of each participant are concordant.

Egg-sharing

A minimum number of oocytes is required in an egg-sharing cycle. If this number is not reached, patients who agreed to donate to finance their treatment are confronted with financial problems.

The peer group of woman over 40 is not suitable for finding an oocyte donor. Egg-sharing is often the last solution for them, but at the same time they also have the feeling that there is not much time left to become a parent. Being put on a waiting list may be very difficult for them.

In some countries, law prohibits oocyte donation. Counsellors in neighbouring countries frequently receive patients who have travelled abroad. They should respect cultural differences and help patients to deal with their feelings of doing something 'illegal' and with their fear for the consequences for themselves as (pregnant) parents and for the child.

Oocyte donation is a treatment that is often suggested because of age-related fertility problems, forcing fertility centres to decide on difficult issues such as a reasonable age limit for the treatment of the woman who wishes to become pregnant.

In families where more children are born after oocyte donation with different oocyte donors, counsellors should help patients to cope with this multigenetic origin of the children.

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<ST>5.3 EMBRYO DONATION

Timothy C. Appleton

<A> Introduction

Embryo donation is indicated where there are severe male factor problems (azoospermia or aspermia) which are not amenable to treatment. It is also indicated when there are no existing oocytes, existing oocytes are of poor quality or when there has been repeated failure of in vitro fertilisation (IVF) treatment. In embryo donation the recipients are unlikely to have a genetic relationship to any children who might result from embryo donation. Embryo donation can be achieved in two ways:

1. Using a combination of egg and sperm donation - such donors should already have been properly counselled.
2. Using spare cryopreserved embryos from patients who have already been successful and have consented to the donation of their remaining embryos

<A> Purpose

The implications for counselling are similar to egg and sperm donation in (1) - where both partners have no genetic relationship to the embryo - but require additional care in (2), where counselling is necessary for both donors and recipients. Counselling should be available to help all the parties concerned understand the implications of embryo donation for themselves and for the future children, be comfortable with what they are undertaking and have the strengths and resources to move forward.

There must be sufficient space and time for them to explore their own feelings on the treatment proposed.

<A> Objective

Counselling should provide sufficient background information for all concerned to make their own choices and to be able to make informed consent.

** Donors**

Those patients who decide that they wish to donate their embryos to another couple rather than allow them to die or be used for research will need to consider:

- whether they are quite sure they will not want the embryos for future siblings for any existing children?
- how they feel about the real possibility that there may be other children alive sometime in the future who are the result of their own genetic material;
- what sorts of people need embryo donation;
- not knowing (perhaps) whether the donation has been successful or not;
- confidentiality
- fully informed consent must be obtained from both donors and recipients.

** Recipients**

Recipients of donor embryos may have specific concerns such as

- Has adequate health screening (e.g., HIV, hepatitis, karyotyping for chromosomes abnormalities) of donors been carried out? Is there any incidence of physical, mental and/or genetic disorders within the family?
- What is the intelligence, social background of the donors etc?
- What are the motives of the donors? Were they paid?
- Will any children born seem out of character with the recipients and other members of the family?

- Must they, or should they, tell the child, born as a result of embryo donation the facts?
- Confidentiality – will they be able to know the identity of donors? In most countries complete confidentiality is observed; in others (e.g. Sweden), the child has the right to know the identity of the donors.

<A>Typical issues

Embryo donation is a comparatively new possibility. Donations have been forthcoming only after some time has elapsed after the creation of embryos stored by Cryopreservation. Patients will be asked at the time of freezing embryos what their preferences, are should they die within the storage interval: i.e. allow the embryos to die, donate them to another couple or donate them for research. In some countries these options may not be available in law. Couples who choose to allow their 'spare' embryos to die often ask for some form of disposal ceremony, which may or may not be in a religious form. Whilst the patients may not consider their embryos as persons they frequently do see them as living entities which have some potential, therefore there is often a need for a sensitive end to that potentiality.

Four problems have emerged, however:

1. Some donating couples have found it difficult to accept that there may be children alive (resulting from their embryo donation) who might show similar characteristics to their own children: some have expressed the fear of looking at children almost expecting to recognise such similarities. Some potential donors have not been able to feel comfortable with donating their embryos and have opted for their destruction. Others have felt more confident when it has been possible for the donated embryos to be used at a well separated geographical location. Pre-donation counselling is essential

2. Most clinics would feel that they couldn't offer embryo donation if the numbers of cryopreserved embryos is less than three since this gives the recipients a poor chance of success. For those patients who have strong feelings that they wish to give their spare embryos every chance of life, this can be very distressing.
3. The ability to accept embryo donation is not always equal on both sides of the gender divide. It is often the male partner who has the most difficulty in accepting the possibility of embryo donation - The woman has the compensation of carrying the child and giving birth.
4. Recipients are often concerned about how they should tell their child about his/her conception if they decide to do so? Children's storybooks are available to help them in that task (e.g., Appleton, 1999).

<A>Communication Skills

Counsellors will need the same skills as in any fertility counselling. In order to maintain confidentiality they will need to take particular care; a wise precaution may be to keep the matching of donors and recipients separate from the counselling process.

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<ST>5.4 SURROGACY

Timothy C. Appleton

INTRODUCTION

Surrogacy has been described as an emotional and ethical minefield, that is putting human nature under pressure. In most countries in Europe it is banned, in many others it is not practised, and only the United Kingdom(UK) and Israel openly allow for surrogacy. In the United States it is practised more frequently in the Western part of the country.

It can be undertaken in two ways:

1. By artificial insemination of the surrogate - so that she will be carrying a child, derived from her eggs. Very often no clinic or doctor is involved and a 'do it yourself' surrogacy comes about - often without any counselling.
2. By in vitro fertilisation (IVF), in which the embryos are transferred to the uterus of the surrogate; she is therefore carrying a child with no genetic relationship to her. Clinics will usually provide extensive counselling and support. Many will refer each case to an ethics committee for approval before proceeding

<A>Purpose

Counsellors often find it difficult to provide assessments about their patients. Yet in surrogacy there will always be some element of assessment involved in the work of the counsellor; to some extent this can be mitigated by separating the counsellor's role from that of the person(s) who must make the decision on whether a particular case of surrogacy should proceed.

The objectives are therefore directed in two directions:

1. To help all those involved understand all the implications involved (see the Typical issues subsection below), to draw upon their own resources and to cope with the uncertainties involved. This will include:
 - the commissioning couple,
 - the surrogate, her partner/husband if applicable and any existing children of the commissioning couple or of the surrogate,
 - the wider circle of families, friends and work colleagues, and
 - the health care professionals, particularly those involved in the handing over of the child at birth.

2. To relay to those who must make the decision as to whether the case can proceed - with the consent of all involved:
 - that there is sufficient confidence that the case is built upon a sound and trusting relationship between the commissioning couple and the surrogate;
 - that there is an adequate support structure to help them through the difficult times ahead, and for as long as is needed or is possible;
 - that the welfare of any existing children, or prospective child, has been taken into account;
 - that an adoption procedure or a change in parentage can take place;
 - and
 - that the aggregate of foreseeable hazards is not too great for any of the parties including existing or future child/children.

<A>Typical issues

There are several areas which will need to be explored and which may raise problems in the future. Counsellors may be needed for many years to help all the parties through the issues involved including:

- The relationship between commissioning couple and surrogate – in the UK about 50% of the cases are between relatives and friends; the remainder between people who did not originally know each other but who have spent some time together, so that there is understanding and trust.
- Marital status – most commissioning couples are either married or are in a stable relationship, while some surrogates are single, divorced or separated. Care is needed to establish that there is sufficient family support in all surrogacy undertakings.
- Indications for surrogacy include hysterectomy either as a result of complications in a previous pregnancy/labour (often with the loss of a baby) or as a result of cancer diagnosis and surgery/therapy, genetic absence of the uterus, repeated failed infertility treatment, repeated miscarriages or ectopic pregnancies. The reasons for needing surrogacy are distressing. Social reasons for surrogacy (e.g. busy life-style, etc.) are not usually acceptable to clinics.
- Motives of surrogate – most surrogates have seen the distress which childlessness causes in their friend, are grateful for their own experiences of parenting and want to help others less fortunate. Sometimes the motives may be financial and counsellors must be sensitive to those possibilities.
- The effect of surrogacy on any existing or future children must be considered – the welfare of children must be taken into account whether they are in the family of the surrogate or the commissioning couple. The arrangement for surrogacy should not proceed if a child in the surrogate's family finds the idea of surrogacy offensive.
- The legal situation must be taken into account. In those countries where the

initiation of surrogacy is illegal, it may not be illegal to 'have' a child born as a result of surrogacy. Many patients will seek help in countries such as the United Kingdom or USA. Counsellors will need to help patients establish a proper legal framework for the future of any children born through surrogacy before a surrogacy pregnancy is initiated.

- Surrogate mothers are initially clear in their own minds that the child they are carrying is either wholly genetically that of the commissioning couple or partly so.
- Surrogacy which involves donor gametes may present additional problems for commissioning parents and the children – parenthood then becomes difficult to define and may involve: genetic mother, social mother, birth mother and her partner, genetic father, social father).
- Handing over the child and bonding. Surrogate mothers expect that the child will be handed over at birth so that there is minimal physical contact leading to bonding. A surrogate will never be able to forget that they have given birth to another child who they have 'given' to the commissioning couple. Any regrets should be compensated by the knowledge of happiness they have given the commissioning couple.
- Registration of the child – there will need to be some form of parental change in law or adoption procedures which may involve inter-country boundaries.
- Complication in pregnancy and postnatal depression. No pregnancy is immune from complications and with surrogacy there is no child as 'compensation'.
- Abnormalities with possibilities of termination of pregnancy can occur and cause distress to all the parties concerned.
- Failure of treatment (a miscarriage) is particularly distressing. Surrogacy arrangements between friends or relatives can cause particular emotional problems. In surrogacy arrangements where there is no such tie the distress may be mitigated by being able to 'walk away from the situation'; this is not possible between friends and relatives.

- Future access/contact to the child by the surrogate must be considered. Within families and friends there will inevitably be further contact between birth mother and child. Surrogate mothers will need sensitivity and often help in handling this situation.
- Expense v. payment. In Europe payment for adoption/surrogacy presents legal problems in changing parentage. It is often difficult to distinguish between genuine expenses paid and what is effectively a payment for services. Courts may need some evidence of what payments have been made.
- Telling the child? The complications of family relationships in surrogacy are such that the child will have to be told about their conception and birth. In most countries the adoption and parental change arrangements will mean that the child has the right to their original birth certificate on reaching 18 years of age.

<A>Communication skills

In addition to the usual skills of infertility counselling, the counsellor in surrogacy must have a detailed knowledge of all the issues in surrogacy and the legal situation which exists in the country in question. Legal knowledge is necessary because there will be procedures which may involve adoption after the birth of the child. In many cases successful parents are so delighted with the outcome that they may forget what those procedures are and they may well need further contact with the counsellor to remind themselves of the proper steps forward. Counsellors may need a couple's permission to divulge to the courts the fact that they were counselled.

Good information in the form of booklets often provides a reference which parent can refer to at a later stage. There should be the opportunity for good follow up counselling and an awareness for all the parties concerned that further counselling support will be available for commissioning couples, the children and the-surrogates for as long as they may need it.

Counsellors must be aware themselves of their role in surrogacy and be clear that the couples understand that role.

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<ST>5.5 ADOPTION

Judith Baron

<A>Introduction

The adoption of children is one route to achieving full legal parenthood. However this relationship with the child may not be an exclusive one because in some European countries there are systems of open adoption where the natural parents still have rights of access to their child. For example in the United Kingdom an adoption order will transfer all legal rights of parenthood to adoptive parents including inheritance but the natural parents may have rights of contact by letter or in person. Obviously this would not satisfy those people for example, searching for a tight nuclear family or a close exclusive relationship with their child.

Adoption is also available to those who are not infertile and who have no medical problems; this means that any person with infertility problems has competition and faces additional assessment for the smaller number of children requiring a permanent home. Such applicants are at further disadvantage as they may not be able to demonstrate successful parenting skills. These are particularly important as the children available nowadays are likely to be older or have special needs.

Prior to the 1980's adoption, along with surrogacy and artificial insemination with donor or husband sperm were the major route to achieving parenthood for those with infertility problems. Since that time, scientific advance in the field of reproduction, along with changing social attitudes and greater state support for parents, has meant that those people who would previously have placed a child for adoption now keep the child instead. Thus adoption is no longer an easily available route to parenthood for most people in Europe. Some choose to adopt from countries that are still dealing with considerable social problems and cultural change. However, these routes too are becoming more difficult to use. This is either because the receiving country is aware of the difficulties the deprived children face and the extra parenting skills the adopters need, or because the countries in which the children were born have developed the services and cultural awareness to wish to keep their own citizens.

<A>Purpose

The purpose of counselling when adoption is under consideration is to provide a confidential and secure environment in which the loss and adjustment reaction to medical problems can take place. Through counselling the patient(s) can assess whether or not they wish to pursue adoption as a course of action, and in particular address the change of focus from their own needs, biological and emotional, to the needs of an existing child with no physical or genetic link to them. They can also be directed to information and services specific to the laws of the country in which they reside, and referred to specialist counselling in this field. Research in the UK has shown that poor adoption outcome can be related to the adoptive parents not having dealt adequately with the loss of their own reproductive potential and not having moved the focus of their attention from their own needs to those of the child.

<A>Objectives

The objectives are for the patient(s) to make an informed decision on whether or not to pursue adoption, to facilitate their change of focus and move to an alternative route to parenthood away from medical treatment, to be informed of State practice and to be better placed to meet the needs of any child who might be placed with them for adoption as the child moves through life.

<A>Typical issues

A number of issues have been highlighted by those working in the field of adoption and are matters which is felt should routinely be addressed in good adoption practice and counselling prior to a couple receiving a child.

- A child could become idealised as the new parents project on to that child all the expectations of what a natural child could have been for those parents. Dreams and wishes could centre on a child who comes, for example, with the problems of low

achievement or experiences of loss and low self-esteem. A child could be set up to fail and trauma and rejection can come about (Brebner, Sharp & Stone, 1985).

- Some couples come to adoption at different points in the process of adjustment to the losses that come with the diagnosis of infertility. If this happens there is the possibility of marital disharmony or a lack of bonding with one of the adoptive parents (Royal College of Obstetricians & Gynaecologists, 2000).
- There may be an existing family. This would occur in secondary infertility or in the case of a remarriage. In these instances the expectations of older children about such matters as the disruption to their lives need to be taken into account. It could also be that previous children believe they are not sufficient to meet their parents' needs and that they have failed their parents in some way.
- Some infertile people find it difficult to make the adjustment to considering the needs of children waiting for adoptive parents. For many months or years they have been concentrating on their own needs and treatment and it is difficult to focus on the needs of a small child who will grow to adulthood with needs and wishes of their own (Triseliotis, 1973).
- There are patients for whom the loss of self image as a parent to their own child means they deny an adopted child information about the circumstances of their birth or deny access to birth parents. This can lead to adopted children feeling angry or poorly adjusted in later life (Triseliotis, 1973).
- An adopted child from another culture or ethnic group requires parents who can help the child manage its differences with the group in which it is raised. This means that the parents need to understand issues of difference, unintended or intended racism, as well as be prepared to help their child with identity problems that may arise (Thoburn, Norford, & Rashid, 2000).

- When discussing adoption the counsellor needs to be clear that although this is a potential non medical route to parenthood there are few children to adopt and failure may happen once more. The number of children for adoption alone is not the only reason they may not achieve their goal. They will now face the possibility of being assessed on social and personal grounds and this can be even more distressing for some people than finding out they have a medical problem over which they have no control.
- This route to parenthood will take the prospective parents out of the model of care proposed earlier in the Guidelines (see Section 3) and as a result the continuity of care and follow-up could be compromised.

<A>Communication skills

All the communication and counselling skills described in Section 3 are relevant and should be possessed by the counsellor to the highest standard available in the relevant country and not based on the personal view of the counsellor.

In this particularly sensitive area of transfer from a medical to a social route to achieve parenthood it is particularly important that the decision to change a course of action is based on information and education on what might lie ahead for the prospective parents.

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<ST>5.6 REPRODUCTIVE SERVICES WITH LESBIAN COUPLES

Patricia Baetens

<A>Introduction

Donor insemination (DI) may provide an answer for women who wish to become pregnant without a male partner. In such requests there is, in general, no fertility problem in the medical sense of the word. The treatment is justified more on social than on medical grounds since these requests are motivated not by the infertility of but by the absence of a male partner.

However, the controversial nature of these requests cannot be ignored. Consequently, many fertility centres do not accept lesbian couples for treatment. The absence of the influence of a father figure and the homosexuality of the mother(s) are supposed to have a negative impact on the child's development, especially where the psychosexual and social development is concerned. Research concerning children raised in this type of family does not support these assumptions (Brewaeys, 1997).

<A>Purpose

A request from a lesbian couple for DI has very specific implications that cannot be compared to those of single mothers or heterosexual couples. The homosexual partners have a common wish to raise a child from birth in their family. They share the educational responsibility for the child. Since they will reveal the DI origin to the child, parents and children have to deal with the anonymity or otherwise of the donor. In these families no father will be present.

There is very little information about DI available for lesbian couples. In addition, the search for information about other possible solutions to resolve their 'social' infertility can be laborious. Lesbian couples must make a choice: donor insemination in a clinical setting with an anonymous donor or with an identity-release 'yes' donor; self-insemination with a known donor or self-insemination with a man who will also father the child, and, finally, adoption. Although sexual

intercourse is often suggested by the social environment as an option for lesbian women, for the majority of the couples it is not an acceptable solution because it is considered as a threat to the partner relationship and because it does not respect their couple identity. Furthermore, a decision has also to be made about who is going to be pregnant and, if both women wish to become pregnant, who is going to begin with the treatment. These important decisions have an impact on their future family functioning, family concept and parental roles. Couples have to decide how they are going to present their family: as a two mother unit, as a biological mother with a partner who shares the parental responsibility over the child, or as a single mother with a partner who is less involved in child raising. Counselling should focus upon the different solutions in order to give the necessary information to lesbian couples to make a well-informed decision, even if the fertility centre provides treatment only with anonymous donors.

Moreover, for these couples there is no clear-cut family concept and parental roles are not defined as they are in heterosexual couples. This gives lesbian couples the freedom to construct their own family structure but also generates also uncertainty about how to share parental roles and about the responsibility towards the child. The importance of the partner's parental role is not always recognised by the social and family environment. The role of the partner is often denied because of the lack of a biological tie. Moreover, it is not possible to create a legal affiliation between the child and the female co-parent in most countries.

Because of their homosexuality, the social environment will react differently to the lesbian couple's wish for a child and to their family once the child is born. Lesbian couples and their children can, and probably will, be confronted with homophobic reactions. The majority of lesbian couples fear the child's confrontation with the negative reactions of the social environment and are afraid that the child will be stigmatised because of the homosexual nature of the relationship of its parents.

<A>Objectives

Objectives include:

- Informing lesbian couple about the medical aspects of the treatment. Often their visit is also an introduction to a medical setting and they underestimate the treatment and the consequences of the treatment upon their everyday life.
- Informing the lesbian couple on the different options to fulfil their wish for a child. Assessing if an anonymous donor is acceptable. Counselling should focus on the consequences of the use of anonymous donor for themselves, the child and the family.
- Informing the lesbian couple on disclosure of issues such as homosexuality and the use of DI and counsel them about how to inform their child.
- Counselling them on how to integrate the child into their family and their social environment, and help them to deal with their fear of negative reactions. The integration of the child supposes that their parents reveal their sexual orientation (coming out) to family and friends. A particular focus should be on the integration into the family who will not have a genetic tie with the child.
- Helping them to construct their family structure and to share parental responsibility. Discussing the assignment of parenting roles. Helping the couple to secure the position of the non-biological mother towards the social environment (who is frequently an invisible and denied parent). Discussing the legal implications for the non-biological mother.
- Counselling them on the consequences of the absence of a father in their type of family.
- Encouraging them to express their uncertainties about whether or not they are doing the 'right' thing.
- Helping them to cope with their anxiety of stigmatisation of their child.

<A>Typical issues

The majority of the lesbian women have been confronted with homophobic reactions in relation to their own homosexuality and to their relationship, but also to their wish for a child. Often this results in a long period where partners contemplate the implications and social acceptability of raising a child in their family considering all the possible (negative) consequences this might have for their child. Sometimes couples need to be reassured about the legitimacy of their desire for a child.

Some homosexual women might believe that hiding their homosexuality and their relationship increases their chances to be accepted for treatment. They need to be reassured about the acceptability of their request in order to be open about their homosexuality.

Counsellors should be aware that attitude towards homosexuality and their own sexual identity might influence the counselling.

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<ST>5.7 REPRODUCTIVE SERVICES WITH SINGLE WOMEN WITHOUT PARTNERS

Jacky Boivin

<A>Introduction

Recent sociodemographic changes have meant that donor insemination (DI) is increasingly used in cases of social infertility where conception is prevented by the person's social circumstances rather than their medical status. Single women without partners fall into this category and will be the subject of this section.¹

In the past single women who wished to conceive without a partner would have had unprotected intercourse with an unsuspecting man or would have enlisted the help of a co-operative male friend. While in many cultures this remains the most common way for single women to conceive, there is an increasing trend in other countries (such as the United Kingdom) to use clinic-based insemination. This method of child-bearing is becoming more acceptable as it reduces the risk of infection (e.g. HIV, hepatitis) and demarcates clearly the legal rights of the mother and sperm donor.

<A>Purpose

The way in which single women will be helped through the decision-making and preparation process for conception and parenting will be similar to the way couples are prepared for DI (see section 5.1). Common issues include discussing expectations for treatment (success, failure), examining psychiatric history, advantages and disadvantages of DI versus adoption and so on. However, counselling with single women should also accomplish the following objectives.

<A>Objectives

Coping with the unfulfilled wish to parent a child with a loved partner

An important aspect of positive adjustment during and after the transition to parenthood for single women is the need to come to terms with the unfulfilled wish to parent in the traditional way. Research suggests that single women tend to seek treatment at the point in their reproductive years when they need either to forego parenthood or choose an alternative which does not require an intimate partner. While they choose reproductive services most (90%) women would actually prefer to have a family with a partner and most have taken at least one year to 'resolve' emotional issues related to choosing to become a single parent (Leiblum *et al.*, 1995). The extent to which single women accomplish this 'working through' may be an important determinant of readiness for DI.

Discussion of social and economic factors involved in becoming a single parent

Most single women report that family and friends are supportive and have positive reactions to their decision to use DI. However, single mothers receive less practical and emotional support from peers and family when children are growing up. This is an important finding, as social support is a key factor predicting later adjustment in children. The quality of the social network is also important for its ability to provide practical support. Despite their generally high employment status (e.g. as managers or professionals), single women nevertheless work more hours per week and therefore need to be away from the home longer to meet economic needs. In this context, relationships with family and friends may be a more important issue to consider in counselling with single- as compared to dual-parent patients. The social network is also important to ensure the child has other adults and role models with whom they can interact.

Discussion of the effect of older age of the mother on the treatment and parenting experience

Single women are about five years older than other women seeking DI. About a third abandon DI after the first one or two failed cycles. Preparing women for the reduced conception rate in older

women may provide more accurate expectations about the number of cycles needed for pregnancy. Age may also affect the transition to parenthood or adjustment in later life. For example, older single women may experience more isolation from a pregnancy that is developmentally out of phase from those of their friends than older married women who can additionally depend on their partners. Single women who hope to have a partner in the future also need to be realistic about the ways in which having a child at this age will limit future dating opportunities (Casey-Jacob, 1999).

<A>Typical issues

Ease of access

Single women may not be able to find a clinic within their community which will provide them with this service. An informal poll of 69 clinics licensed for donor insemination in the UK revealed that about 15% would inseminate single women unconditionally and 19% would require prior approval by the an ethics committee, whereas 64% would not inseminate single women under any circumstance.

Psychopathology and social adjustment

Limited research is available on the psychological and emotional adjustment of single women using fertility services. The majority of studies with women accepted for DI treatment show that single women are well adjusted.

However, the research base also suggests that a proportion of single women will be refused treatment on the grounds of psychopathology or poor social adjustment (see, for example, Baetens et al., 1995; Englert, 1994). Therefore pre-treatment psychological counselling should be a necessary first step in clinics and should focus partly on identifying risk factors that may compromise the treatment experience and/or future welfare of the child (see Baetens et al., 1995 for details).

<A>Communication skills

All skills involved in counselling are required.

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<ST>6.1 WRITTEN INFORMATION AND TELEPHONE COUNSELLING

Jacky Boivin

<A>Introduction

Additional or adjunct psychosocial services are those interventions which coexist with counselling to increase the availability of psychosocial information in fertility clinics. The most frequently provided adjunct services are written information and telephone counselling.

<A>Purpose

The purpose of adjuncts is to ensure that an adequate amount of psychosocial information is available to all patients, including those who would not access such information through contact with clinic staff or specialised counsellors. Different types of adjuncts fulfil different functions.

Preparatory (written or videotaped) information

Preparatory psychological information provides an account of upcoming event(s) in the experiential process related to a particular condition. Preparatory information can focus on any dimension of the experiential process, including physical, emotional, psychological or social aspects. Information can be very concrete (e.g. step-by-step description of oocyte retrieval) or very abstract (e.g. description of feelings of loss), and can be provided in different formats (e.g. written, videotaped). While patients' reactions to the infertility process can be expected to be idiosyncratic, the consistency in the types of reactions reported across different studies also highlight many predictable elements. Such information can therefore be used to better prepare patients for what to expect at different points in the experiential process.

Telephone counselling

Several infertility associations now offer members access to free counselling services over the telephone. Such services were developed to provide patients with an opportunity to discuss their feelings anonymously. However, monitoring of such services has revealed that patients use the service primarily to clarify aspects of their medical treatment and/or to discuss other medical issues. That being said, about 15% of patients also use the service to talk about the way treatment is affecting them on a personal level (Bartlam *et al.*, 1999).

<A>Objectives

Adjuncts are used to augment psychosocial services available to the patient. Adjunct services can have many advantages. They are

- cost effective: easily and inexpensively distributed to all patients;
- easy access: information can be accessed at any time it is needed;
- informative: more information can be included than would be absorbed during any given consultation; and
- useful: they can fulfil key support needs (e.g. information, normalisation) and can be shared with spouse, family and friends.

Only a few studies have evaluated the effectiveness of written and/or videotaped information with infertile patients. However, these studies suggest that such information can be beneficial for patients, especially when the information is specific to ongoing experiences (Wallace, 1985; Takefman *et al.*, 1990). Similarly, evaluations of telephone counselling have shown that it is used to full capacity (Bartlam *et al.*, 1999).

<A>Typical issues

The psychosocial information patients want is not available. Patients seem to want detailed emotional and coping information about the reactions they might experience in a given situation

and the ways of coping with them. While much written information exists documenting general reactions to infertility, there is less which provides psychosocial information that is specific to particular treatments (e.g. in-vitro fertilisation, insemination).

A related problem is that much of the written documentation available has been sponsored and/or developed by pharmaceutical companies who have a vested interest in promoting the use of their own products and/or the use of fertility treatments which depend on their products. This bias may have an impact on the success rates quoted, the side-effects described and the best treatment options selected.

The information is available but the patients are unable to understand it because it is poorly written or presented. Patients should be consulted when information is developed to ensure that information meets the individual's needs and that it does so in a clear and comprehensible way.

Patients who do not see themselves in the general description provided may feel excluded and/or atypical, which may have negative consequences. Therefore whenever information is provided to patients, it is important they be told about the 'average' quality of such information.

Adjunct services are used in lieu of in-house services. Adjuncts should not replace contact with patients.

<A>Communication skills

Information should be presented in a clear way and medical staff should ensure that patients understand the content of any information. Telephone counsellors should have received some training in the use of this service. In some countries telephone counsellors must have received the same training as counsellors which would be consulted in person. However, in other countries telephone counsellors may be other infertility patients and/or people who have received only a minimal amount of training. Such telephone counsellors should recognise their limitations and be able to refer patients to fully licensed counsellors when necessary.

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<ST> 6.2 SELF-HELP GROUPS

Petra Thorn

<A>Introduction

Self-help groups and patient organisations have been active since the 1970s in the area of assisted human reproduction (AHR) (Shapiro, 1998). In this section the term ‘self-help group’ will be used for support groups organised by lay individuals experiencing infertility. These are local groups which may function independently from any other organisation, or which may belong to a larger consumer organisation serving as an umbrella organisation. The term ‘consumer organisation’ defines national and international organisations founded by a network of self-help groups in order to provide support and information on a national and international level, to raise public awareness on infertility issues and to exert political influence (such as Resolve in the USA, Issue in the UK, Wunschkind in Germany and IFIPA on an international level).

This section focuses mainly on the structure, aims and challenges of self-help groups, as it is these self-help groups that provide direct and personal support. Therefore, in a day-to-day counselling context, they play a more important role than consumer organisations.

Structure

Self-help groups are organised by lay people and take on many different forms. Most groups provide regular meetings which anyone can attend. These meetings may take place as often as once a week or as rarely as once every two months. There is one member who serves as a contact person but this role may well be, like any others in a group, a responsibility rotating among members. Self-help groups are usually free of charge, though sometimes a nominal fee towards the rental of a room or provision for refreshments during meetings is requested. All three aspects – i.e. the lay character and uncomplicated method of establishing contact to a group as well as the low costs involved – signify a low threshold in joining these groups. In addition, due to the absence of a professional counsellor, members may not feel pathologised or psychologically

stigmatised when attending a self-help group.

<A>Purpose

There are several important functions of self-help groups that help infertile patients to cope better with the crisis of infertility on both a cognitive and an emotional level.

New members usually join asking for information on medical treatment and on the physical as well as psychological implications of such treatments. The information given by the medical profession is often considered to be insufficient or too technical, and in many cases patients do not have the courage to request more detailed facts before starting treatment. Having the opportunity to listen to and learn from patients who have gone through several treatment cycles of AHR about their experiences, their coping mechanisms and their decisions taken for or against future treatment can inform others about the technical aspects and raise awareness about psychological issues. Most patients find it easier to ask detailed questions in a personal environment such as this than at the doctor's office.

During treatment, self-help groups provide support and exchange. Sharing emotional responses after failed treatment, such as depressive reactions and lack of self-esteem, has a cathartic and normalising effect, while exchanging coping strategies increases knowledge about different coping styles. Members usually feel that both are easier in a setting with others who have experienced similar problems, and that such a setting quickly generates open communication about these personal aspects.

After treatment has failed or patients have decided against (further) treatment, they have the opportunity to share the grieving process and discuss options about child-free living.

<A>Objectives

The main aims of self-help groups and organisations is to empower patients and to increase their autonomy. On an organisational level, these aims are achieved by increasing public awareness,

by influencing political decisions and by actively seeking contact with relevant professions to facilitate co-operation. On an individual level these aims are achieved by the very nature of self-help groups. As these groups 'help themselves', as there is no facilitator organising the group and assuming responsibility for the topics discussed during meetings, members are motivated to assume these tasks themselves and thus become active. This can be an important step towards coping better with the feeling of powerlessness – a typical problem associated with infertility. Self-help groups are not set up to provide therapeutic counselling but members can become aware of their individual difficulties and may be motivated to seek help from a counsellor.

<A>Typical issues

There are many inherent problems and challenges self-help groups face, especially at the formation stage of a group when all members are inexperienced in organisational issues and group dynamics. The main problems are:

- **Recruiting members**: this is a vital issue at the beginning of a self-help group. It may take some time before physicians and other relevant professionals become aware of the existence of a self-help group and recommend it; in the period before this has been achieved, groups may dissolve. Public awareness and contact with physicians and other relevant organisations or institutions are vital for self-help groups to become known and ensure an influx of new members.
- **Continuity of participation**: due to the informal structure there is a lack of commitment, which may be frustrating for those who wish to share intimate issues such as partnership problems or sexuality. Often, it is possible to talk freely about these sensitive issues only if the composition of the group is stable for a certain number of meetings.
- Group members may seek only factual information and, after having received it, decide against further participation. In addition to reducing number of participants in the group, this approach to group participation can have a negative effect on motivation since it goes against the self-help ethos which is to receive and later give to others.
- **Heterogeneous composition** of a group: there is no one selecting potential members accord-

ing to their suitability. As a result there may be frustration about the differing levels of involvement and contrasting aims.

- Leadership: the group is usually initiated by an individual who is looking for support from and exchange with like-minded people. This person very easily retains this leadership role although s/he may not wish to continue this responsibility; ideally it should be shared among everybody.
- Lack of exploration of emotional issues: giving and receiving information and sharing problems may remain on a purely factual level. Members therefore voice concern about discussing medical facts only and not being able to address underlying emotional and personal issues.
- Collaboration with the medical profession: the self-help movement initially constituted a counter-movement to patriarchal relationships in society. It therefore often met with incomprehension and rejection by professionals. Although this attitude has changed, to a large degree and in many countries a fruitful collaboration between self-help groups, patient organisations, professionals and pharmaceutical companies has developed, in some cases there are still reservations and thus professionals only reluctantly seek co-operation with or provide information on self-help groups and organisations to their patients.
- Conflict of interest between the needs of the organisation sponsoring the self-help group and the members of the group. The organisation sponsoring the self-help group may have the expectation that their perspective on fertility related issues will be promoted. For example, pharmaceutical companies may expect that the self-group will promote treatment rather than child-free living, directors of fertility clinics may expect that members of the group will go to their clinic for treatment and so on.

<A>Communication skills

Group members should be willing to organise and run a meeting, and to ensure a rotation system for key positions in the group, as well as to establish and maintain communication and contact with professionals and others in fields relevant to their issues. They should also be aware of the limitations of self-help groups and suggest other forms of support (e.g. facilitated support

groups, counselling) to those members who do not benefit from self-help. Seeking and continuing active collaboration with medical and psychosocial experts – for example, by organising information evenings on particular aspects of infertility – may help to increase public awareness of self-help groups and to ensure that patients new to infertility treatment learn about this option. Self-help groups are an ideal form of support for those who show reservations about counselling services.

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<ST>6.3 PROFESSIONALLY FACILITATED GROUP WORK

Petra Thorn

<A>Introduction

This section addresses professionally facilitated groups. These groups are also referred to as support or therapeutic groups. The professional facilitator can be a social worker, counsellor, psychotherapist or psychologist. Facilitators are referred to herein as ‘counsellors’, independent of any professional background. In some cases, counsellors are connected to fertility clinics – i.e. they are employed by the clinic, or there is some form of collaboration between the counsellor and the clinic. In other cases, counsellors work in private practice or are employed by other institutions, and therefore provide infertility counselling along with other types of counselling.

Structure

There are many different ways facilitated support groups can be organised and structured. The options range from open-ended groups meeting at various frequencies to one-off weekend groups, from single-sex to couple groups, from open to closed groups and from groups open to all issues related to infertility to groups tailored to particular interests, such as donor insemination, treatment with donor egg/sperm or secondary infertility. In most cases, a fee is charged for attending these groups.

<A>Purpose

As in other types of group settings, information, support and exchange about infertility issues among group members are important elements. In addition, in facilitated support groups the counsellor is responsible for the organisation and structuring of the group, as well as for applying her/his professional knowledge and experience to influence group dynamics for the benefit of its members. Psychoeducative methods may be used to give information on and explore the impli-

cations of certain treatment options. Interactional techniques such as role play or communication exercises help to enhance relationships both within and outside the group setting. Exploratory and analytical approaches can be used to understand intrapersonal and biographical issues and to improve coping skills, as well as to further personal growth. Although there is a difference between support groups focusing on current issues and therapeutic groups with a predominant focus on biographical or long-standing issues, in reality these overlap and a mixed approach is often used.

<A>Objectives

Facilitated support groups focusing on infertility not only inform and educate about infertility issues but also explore underlying intra- and interpersonal issues, as do other therapeutic groups. In connection with infertility, these range from

- alleviating the isolation often associated with infertility;
- providing emotional support before, during and after treatment;
- reducing stress and anxiety levels;
- improving self-esteem;
- exploring the emotional repercussions of infertility and attitudes related to pregnancy, childbirth and parenthood;
- becoming knowledgeable about the social and legal aspects of building a family by donor egg and/or sperm, by surrogacy or by adoption, and considering the implications for all parties involved; and
- coming to terms with failure of treatment and facing the prospect of a life without children (Wheeler, 1998).

Additional aims are to address marital issues such as different coping styles and sexual dysfunction and to explore family-of-origin issues which often arise during the infertility crisis.

There are many therapeutic advantages unique to groups. Infertility is often shrouded in secrecy

and associated with shame and personal inadequacy. Having the opportunity to be part of a group with members facing the similar problems, sharing painful and confusing issues, as well as feelings of stigmatisation (often in the case of treatment with donor egg, sperm or embryo) is considered a tremendous relief (Wheeler, 1998). In this sense, group work breaks down social isolation and has a normalising effect (Thorn, 1998).

<A>Typical issues

Despite these advantages, there are certain typical problems associated with group work.

- Counsellors have to determine whether an assessment procedure is carried out with potential participants, whether to screen out candidates with mental health disorders, (i.e. paranoia, suicidal tendencies, severe depression etc), drug addiction or whether orientation interviews are sufficient for both the counsellor and potential members. To a large degree, these decisions determine the group culture.
- Recruitment of sufficient participants may be difficult. Counsellors may therefore decide to accept any applicant.
- Problems during the life of a group include members getting pregnant and issues of confidentiality as well as absenteeism or being late for sessions.
- The gender of the facilitator can have an impact on the group dynamics and therefore this has to be considered.

<A>Communication skills

As a minimum, counsellors should have a degree in a mental health profession. Many counsellors have completed counselling or therapy training and have knowledge about the physical and psychological aspects of infertility (Qualification Guidelines for Mental Health Professionals in Reproductive Medicine, 1999).

A mainstream model of work with groups includes the counsellor

- helping members to develop a system of mutual aid;

- understanding, valuing and respecting group processes as powerful dynamics for change; and
- helping members to become empowered to function autonomously both within and outside the group (Shapiro, 1998).

Counsellors therefore need a variety of communicative and professional skills, ranging from competence in facilitating groups to a knowledge of various therapy/counselling schools, which may also include an understanding of body/mind approaches such as relaxation and visualisation techniques.

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<ST>7. SUMMARY

Fertility clinics should aim to address the psychosocial and emotional needs of their patients. This aim can be achieved by ensuring that psychosocial care is provided throughout the treatment experience. These Guidelines show how patient-centered counselling can be integrated into the day-to-day activities of the medical team and how professional counselling can be used to meet any extraordinary patient need. The basic aim of any counselling (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.

The infertility medical experience can be thought of as a 10-step recurrent cycle which the patient can enter, exit and re-enter at any point. The process begins with the initiation of the therapeutic relationship and ends with the outcome and evaluation of a given treatment. Each step in the cycle will have a purpose and a set of objectives and each step will present typical issues and will require specific communication skills. These aspects of the consultation can also be addressed from a psychosocial perspective. Indeed the team should be prepared to provide psychosocial care at each step of the cycle. For example, the purpose of the first meeting with patients is to provide a helpful and competent environment, with the objectives being to ensure that patients feel understood, respected and reassured. The communication skills involved at this stage might be as basic as remembering who the patient is (e.g. their names, professions) or as complex as detecting the negative feelings patients may wish to express (e.g. shame, frustration) but feel unable or embarrassed to do. Some of the typical problems encountered in a first meeting are that the team environment does not allow patients to overcome feelings of embarrassment and shame, or that it treats the patient anonymously. This example illustrates how psychosocial care can be integrated in the first step of the cycle, that is the initial meeting. The Guidelines

describe how such patient-centered care can be integrated in other steps of the medical process (e.g., considering treatment options, evaluating treatment outcome).

The physician plays an important part in ensuring that psychosocial care is integrated into patient care through his/her relationship to the patient as well as the entire team. Depending on past training physicians can also be involved in the counselling of infertility patients though for the most part physicians will refer patients to mental health professionals for this aspect of their treatment experience.

The nature of psychosocial care will vary from clinic to clinic depending on the country's legal and social framework. Despite these potential sources of differences, it is possible to identify two broad types of psychosocial care which have been the subject of discussion. 'Patient-centered care' is the psychosocial care provided as part of routine services at the clinic. 'Counselling', on the other hand, involves the use of psychological interventions based on specific theoretical frameworks. Whereas patient-centered care is expected from all members of the medical team at all times, counselling is typically delivered by a qualified mental health professional. It is important to have both types of care available.

Patient-centered care will vary from answering questions to providing support after distressing events such as a negative pregnancy test. Clinics can increase their overall level of patient-centered care by providing other non-professional services which may be useful to patients. For example, patients generally want and appreciate emotional and coping information provided in a 'take-home' format (e.g. written material, videotape). Such information can be used when needed and can be shared with other people in the patients' social network. Take-home information can also be translated into other languages, helping to provide basic medical and psychological information to migrant populations who often form an important segment of large urban clinics. Other interventions which have shown promise are infertility-specific telephone counselling services which may be appealing because of their anonymity and easy accessibility. One such hotline was used 100% of the time it was available. Self-help groups can also be an important source of support and information through the cathartic and normalising opportunities they

provide. The more well-established national and international infertility self-help organisations also lobby governmental and medical bodies to ensure better patient care and services. Clinics should have available the contact details of counselling hotlines and self-help groups and can help to maintain these services through sponsorship and other activities.

Counselling, on the other hand, aims to address the extraordinary needs of some patients. Counselling might include individual and couple therapy and/or professionally facilitated support groups. The content of counselling may differ depending on the patient and the treatment choice but will usually involve at least some form of information and implication counselling, support or therapeutic counselling. Information and implication counselling might focus on ensuring that individuals understand the different psychosocial issues involved in their treatment choice whereas therapeutic counselling might involve an understanding of the emotional consequences of childlessness. A key difference between patient-centered care and counselling is the counsellor's level of training. Guidance concerning qualifications for counsellors working with infertile people has been provided by different organisations and/or governmental bodies. While an agreed set of criteria for 'who should counsel' has yet to emerge, at the minimum counsellors should have received training in one of the mental health professions (e.g., psychology, social work, counselling) as well as training in the medical aspects of reproduction. As noted previously, all staff can and should provide patient-centered care but only professionally trained individuals can provide counselling.

The Guidelines describe some of the practical issues which need to be addressed between counsellors and the team with whom they work. For example, whether the counsellor will be involved in the assessment and/or screening of patients for treatment and whether counsellors will work independently or within the clinic environment. Other issues may arise when, for example, the treating physician is also providing the counselling.

A review of the literature identifies three populations who might benefit from and/or require counselling. The first group represent the majority of patients seen by the counsellor — patients who experience very high levels of distress. The distress may be manifested in different ways

(e.g. depression, anxiety) but is generally perceived by the patient as being overwhelming and difficult to manage. While highly distressed patients form an important proportion of those using professional counselling, they make up only about 20% of all infertility patients. The purpose and objective of counselling in such cases will vary depending on the source of distress.

The Guidelines describe some of the personal characteristics that may place someone at risk for high distress (e.g. pre-existing depression) and some of the situations that may trigger high distress (e.g. failed treatment, foetal reduction). The Guidelines also describe how certain aspects of the patient(s)' life may be more vulnerable to the negative effects of infertility. For example, while infertility tends to strengthen communication and commitment within the marital relationship, it can have detrimental effects on the couple's sexual relationship. Regardless of the source or trigger for distress, the primary task of the counsellor in situations of high distress is to provide a supportive and reassuring environment in which such distress can be expressed and its causes explored. Identifying new ways of managing distress and breaking down unhealthy coping patterns should also be a focus of therapeutic work.

The second group of patients who use counselling are those couples requiring donated gametes, surrogacy and/or adoption to achieve parenthood. So-called third-party reproduction is thought to provoke psychological and emotional issues that go beyond the counselling issues involved in treatments not requiring a 'third party'. There are several key counselling issues involved with this group of patients. One such issue is concerned with the amount of disclosure the individual and/or couple are prepared to make concerning their use of donated gametes. The questions of whether family and friends will be informed and whether the child will ultimately be told of his/her origins need to be explored before treatment. For those who opt for an open relationship, it is necessary to discuss how best to talk to children about their biological origins and how best to handle the child's reactions to the parents' treatment choice. Counselling also addresses the fact that only one parent will be genetically related to the child. All recipients of donated gametes should also have had the opportunity to discuss the advantages and disadvantages of using known or anonymous donors. When known donors are used, counselling must address how donation will impact on the dynamics of the social environment of the recipient, especially when

the donor is a close friend or family member.

Another issue in third party reproduction is whether donors themselves need counselling to decide whether to proceed with donation. Donors should be informed of the clinic policy concerning privacy and concerning whether it accepts single or homosexual patients before deciding whether to donate. In embryo and oocyte donation the donor must undergo invasive treatment to be able to donate. As a result most donors are infertile women who would have had the medical procedures anyway or very close family and friends willing to subject themselves to these procedures because of their relationship to the recipient (e.g. sister). In these circumstances counselling must ensure there was no undue pressure on the donor (e.g. familial or financial pressure) and ensure a clear understanding of health risks. Infertile women donating through egg-share programmes need to prepare emotionally for the possibility that the recipient of their oocytes becomes pregnant but they do not.

A final group of patients who benefit from counselling are those who seek fertility services because of their social circumstances rather than their medical status. Single and lesbian women who use donated sperm or gay men who use surrogacy fall in this category. While these individuals will also face the general issues discussed previously, they also face other issues which are specific to 'social' infertility. Most single women using fertility services do so because they want children but do not have a suitable partner by the time they reach the end of their reproductive years. Some of the issues which will be relevant to single women are coming to terms with the unfulfilled wish to parent in the traditional way and the social and financial disadvantages of becoming a single parent. The issues faced by lesbian users of fertility services are similar to those of heterosexual couples, as most lesbians choose to become parents within a stable partnership. Additionally, the couple must decide who becomes pregnant as well as discuss parental roles and the integration of the co-parent into the social environment. For both single and lesbian users of fertility services, there are the child's reactions to their life choices and the possible negative reactions others may have to the child (e.g. being intentionally fatherless, homophobia) to be considered. Treatment availability for social infertility is still relatively rare and few clinics make this option unconditionally available to individuals; some form of assessment is usually required.

At some point treatment ends for all patients, though the future will differ from patient to patient. Some patients will become pregnant through treatment and, while this will be a happy and welcome event for most, the years of infertility will have some impact on the experience of pregnancy. For many patients there will be initial reluctance to believe in the reality of the pregnancy and fear that the pregnancy will result in miscarriage or that the child will be abnormal in some way. Most of these feelings resolve themselves over the course of the pregnancy, but the birth may trigger yet another period of insecurity about maternal competence. Many patients will have the additional strain of a multiple pregnancy. Patients need to be prepared for the medical and social implications that arise from parenting two and three siblings who are at exactly the same developmental age and who all require the same amount of nurturing and care. Other patients will not become pregnant but will achieve their goal of parenthood through adoption. The counsellor can assist patients not only to decide whether adoption is a suitable option for them but also to help them come to terms with the unfulfilled wish for a child. The transition to parenthood for patients who adopt also has its special demands and these can be explored with the counsellor.

For other patients the end of treatment will be simply that, the end of treatment. Many patients decide to terminate treatment without having fulfilled their goal of parenthood. In the past patients could count on the end of the reproductive years to provide a natural endpoint to their quest for a child. While this remains the case for most patients, advances in reproductive technology means that some must decide to end treatment while there still remains a theoretical possibility of pregnancy. Counsellors can help patients make the transition to childlessness positively and can help patients elaborate a new and fulfilling life plan for themselves.

The Guidelines have been discussed and written collaboratively with individuals from many countries. It is hoped this team effort has generated a set of Guidelines which encompass the psychosocial issues faced by infertile couples and the way in which counsellors from different countries can address them. The Guidelines are intended for both medical staff and mental health professionals and it is hoped that information contained therein will help both groups to maintain good practice with regard to psychosocial care for infertile couples. Naturally the

Guidelines will require revision as new issues emerge and/or some issues become more or less important. Already some topics, for example preimplantation genetic diagnosis which were excluded in this version are planned for the revision of the Guidelines. It is also hoped that the Guidelines can be revised in light of feedback from the community of mental health professionals working with infertile people.

¹ 'Single women' is used throughout this text to refer to single women without partners.

