Human Reproduction Vol.16, No.6 pp. 1301–1304, 2001

Guidelines for counselling in infertility: outline version

J.Boivin[1,16], T.C.Appleton[2], P.Baetens[3], J.Baron[4], J.Bitzer[5], E.Corrigan[6], K.R.Daniels[7], J.Darwish[8], D.Guerra-Diaz[9], M.Hammar[10], A.McWhinnie[11], B.Strauss[12], P.Thorn[13], T.Wischmann[14] and H.Kentenich[15]

[1]School of Psychology, Cardiff University, Cardiff, Wales, [2]Department of Obstetrics and Gynaecology, Cambridge University, Cambridge, UK, [3]Centre for Reproductive Medicine, Academic Hospital, Dutch-speaking Free University of Brussels, Belgium, [4]Midland Fertility Services, Birmingham, UK, [5]University Frauenklinik, Basel, Switzerland, [6]Centre for Reproductive Medicine, University of Bristol, UK, [7]Department of Social Work, University of Canterbury, Christchurch, New Zealand, [8]Service de Psychiatrie de Liaison and Unité de Médecine de la Reproduction, Centre Hospitalier Universitaire Vaudois, Lausanne, Switzerland, [9]Servicio de Medicina Psicosomatica, Instituto Universitario Dexeus, Barcelona, Spain, [10]Fertilitetscentrum, Carlanderska sjukhemmet, Göteberg, Sweden, [11]University of Dundee, Scotland, UK, [12]Department of Medical Psychology, Friedrich-Schiller-University of Jena, Jena, Germany, [13]Department of Social Work, Protestant University of Applied Sciences, Darmstadt, [14]Department of Medical Psychology, Heidelberg University Hospital, Heidelberg and [15]DRK Frauenklinik, Berlin, Germany

[16]To whom correspondence should be addressed. E-mail: Boivin@cardiff.ac.uk

The Guidelines for Counselling in Infertility describe the purpose, objectives, typical issues and communication skills involved in providing psychosocial care to individuals using fertility services. The Guidelines are presented in six sections. The first section describes how infertility consultations differ from other medical consultations in obstetrics and gynaecology, whereas the second section addresses fundamental issues in counselling, such as what is counselling in infertility, who should counsel and who is likely to need counselling. Section 3 focuses on how to integrate patient-centred care and counselling into routine medical treatment and section 4 highlights some of the special situations which can provoke the need for counselling (e.g. facing the end of treatment, sexual problems). Section 5 deals exclusively with third party reproduction and the psychosocial implications of gamete donation, surrogacy and adoption for heterosexual and gay couples and single women without partners. The final section of the Guidelines is concerned with psychosocial services that can be used to supplement counselling services in fertility clinics: written psychosocial information, telephone counselling, self-help groups and professionally facilitated group work. This paper summarizes the different sections of the Guidelines and describes how to obtain the complete text of the Guidelines for Counselling in Infertility.

Key words: counselling/guidelines/infertility/psychology

Introduction

The infertility consultation differs from other symptom- or disease-orientated consultations in obstetrics and gynaecology through the following characteristics (Section 1, H.Kentenich):

(a) The central focus of the consultation is an unfulfilled wish or goal in life. As a result, the 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 or 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 involves a cycle of repeated interventions that 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 and 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.

Fertility clinics should therefore aim to address the psychosocial and emotional needs of their patients as well as their medical needs. This aim can be achieved by ensuring that

© European Society of Human Reproduction and Embryology

Table I. Objectives when using adjunct (additional) psychosocial services

Adjunct services	Objectives
Written (or video) information, telephone counselling *(Boivin, Section 6.1)*	• Supplement existing psychosocial care and counselling • Provide information on common emotional/psychological reactions to infertility and information about coping with this condition • Normalise patients' experiences with services such as telephone counselling providing information and emotional support • Provide psychosocial information in a format that is cost-effective and widely accessible • Information must be provided in such a way that patients do not feel excluded if their own experiences differ from the experiences described
Self-help groups *(Thorn, Section 6.2)*	• Empower patients and increase patients' autonomy through the proactive nature of the self-help group structure where each member contributes to the success of the group • Provide medical information and normalise the experiences of the patient • Provide emotional support and coping information
Professionally facilitated group work *(Thorn, Section, 6.3)*	• Inform and educate patients about infertility and the psychosocial and legal aspects of family building using different medical and non-medical options • Explore underlying intra- and interpersonal issues surrounding reactions to infertility • Help couples resolve and come to terms with the failure of treatment and the prospect of a life without children

Table II. Counselling objectives in special situations

Special situation	Counselling objectives
Patients experiencing high distress *(Boivin, Section 2.3)*	• Enable the expression of emotions • Identify the cause(s) of distress • Provide interventions(s) to minimise distress and help patients better manage distress • Discuss high-risk personal, situational, social and treatment-linked factors which may predispose or trigger high distress • Help the individual cope with [repeated] treatment failure
Pregnancy after infertility *(Baetens, Section 4.1)*	• Facilitate transition from infertile patient to pregnant patient • Normalise feelings of disbelief and ambivalence about the pregnancy, the child and future ability to parent
Multiple pregnancy *(McWhinnie, Section 4.2)*	• Provide a realistic picture of what it would be like to parent two or three children of identical age • Prepare patients for the emotional consequences of using foetal reduction
Facing the end of medical treatment *(Wischmann, Section, 4.3)*	• Help couples end treatment despite availability of medical treatments • Discuss the personal meaning of the loss of an important life goal • Address differences between spouses in readiness to end treatment
Sexuality *(Darwish, Section 4.4)*	• Systematically open-up discussion of sexual issues • Evaluate the significance and severity of any sexual problems for the couple and identify factors which may contribute to the problem (e.g., depression, side effects of medication). • Address relationship issues which may arise from discussion of sexual issues • Help patients rebuild their sexuality as a source of pleasure
Patients in migration *(Kentenich, Section 4.5)*	• Make diagnosis and therapy accessible by ensuring medical practice is respectful of patients' sociocultural background • Facilitate communication between patients and the medical team by exploring and understanding the meaning of infertility from the perspective of the couple's culture • Discuss the effect of intense cultural pressure to conceive on the woman, man and couple • Discuss how continued childlessness affects the way the couple, especially the woman, are perceived in their community • Discuss cultural pressure to perceive infertility as a woman's problem

psychosocial care is provided throughout the treatment experience. To help fertility clinics meet these objectives, we have developed the Guidelines for Counselling in Infertility. These Guidelines show how patient-centred care 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 Guidelines for Counselling in Infertility have been discussed and written collaboratively with individuals from many countries. It is hoped this team effort has generated a set of Guidelines that 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 from 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 professionals working with infertile individuals.

The complete Guidelines for Counselling in Infertility could not be included in the journal, and what follows is therefore a summary. However, the full text can be accessed through the ESHRE website (http://www.eshre.com). In the following summary, citations in parentheses refer to specific authors and sections of the complete Guidelines.

Outline

The infertility medical experience can be thought of as a 10-step recurrent cycle that the patient can enter, exit and re-enter at any point (see Section 3, J.Bitzer). 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

Table III. Counselling objectives in third party reproduction

Third party reproduction (gamete and embryo donation, surrogacy) *(Daniels, Section 5.1, Baetens, Section 5.2, Appleton, Section 5.3 & 5.4, Baron, Section 5.5)*	• Help couples acknowledge and come to terms with the implications of using third party reproduction as an alternative to family creation • Address the gender difference in willingness to use third party reproduction • Assess the suitability of recipient couples, donors and/or surrogates for treatment (e.g., mental health screening, drug addiction) • Ensure the well-being of the parent who will not be genetically related to the child • Counsel on secrecy/openness towards the future child and social network about the use of third party reproduction • Address lack of support some individuals may encounter about being part of third party reproduction arrangements • Discuss the legal issues, medical risks and religious and cultural considerations of using third party reproduction • Clarify the role of any known donor or surrogate in the recipient's family and ensure the known donor or surrogate understands the boundaries of their relationship to the child including future access/contact • Discuss the effect of donation (i.e., sperm, oocyte, embryo) or surrogacy on the donor's or surrogate's own family, present or future. • Ensure the decision to donate or become a surrogate was free from coercion (familial, financial)
Further considerations	
Oocyte donation *(Baetens, Section 5.2)*	• In egg-share programmes donors need to be prepared for possibility that the recipient will become pregnant with their oocytes but the donor will not • Recipients need to be prepared for the long waiting list in egg-share programmes, the high risk of drop-out by voluntary donors and the possibility that scarcity of donors means donors can only be matched on ethnicity
Embryo donation *(Appleton, Section 5.3)*	• Couples donating embryos must resolve their feelings about the embryos and be certain they would not want to use them in future • Help couples come to terms with the possibility that other children born from their gametes may exist in their community
Surrogacy *(Appleton, Section 5.4)*	• Evaluate reasons for needing surrogacy (i.e., absence of uterus Vs busy lifestyle) and motives for becoming a surrogate (altruistic Vs financial) • Discuss legal issues concerning the nature of the contract between surrogate and commissioning couple and the legal status of any future child • Address difficulty in defining parenthood in surrogacy especially if social parents are not genetically related to the child
Adoption *(Baron, Section 5.5)*	• To make an informed decision on whether or not to pursue adoption and the implications of being a parent of an adopted child • Help couples make the transition from using medical treatment to achieve parenthood to choosing adoption • Inform couples of State practice and the effect of the limited number of children available for adoption on time to adopt • Discuss issues involved in integrating adopted child into families where other children already exist

Table IV. Additional objectives for counselling in social infertility

Lesbian couples *(Baetens, Section 5.6)*	• Counselling on how to integrate the child into the family and social environment • Help lesbian couples legitimise their desire to have a child and discuss fears and anxieties concerning the effect their sexuality and decision to use insemination may have on the future welfare of the child (e.g., stigma, rejection of parent, etc). • Help couples construct their family structure by discussing the sharing of parental responsibilities, assignment of parental roles and the position of the non-biological mother • Discuss the legal status of the child and non-biological mother • Discuss consequences of the absence of a father in child and family development
Single women without partners *(Boivin, Section, 5.7)*	• Assess the well-being of the women • Help single woman come to terms with the unfulfilled wish to parent a child with a loved partner • Discuss the social and economic implications/consequences of choosing to become a single parent • Discuss the effect of becoming a mother at an older age on the treatment and parenting experience

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 are usually addressed from a medical perspective. However, they can also be addressed from a psychosocial perspective. 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 that patients are unable to express. Some of the typical issues 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 medical cycle, that is, the initial meeting. The Guidelines describe how such patient-centred care can be integrated into 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 (see Section 2.4, H.Kentenich). 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 trained counsellors for this aspect of their treatment experience. In any case, physicians should have good communication skills and a basic knowledge of counselling.

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 that have been the subject of discussion (see Section 2.1, B.Strauss and J.Boivin). 'Patient-centred 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-centred care is expected from all members of the medical team at all times, counselling is typically delivered by someone having received training in the mental health professions (e.g. psychology, social work, counselling). It is important to have both types of care available.

Patient-centred 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-centred care by providing other non-professional services that may be useful to patients. Table I presents some of the objectives and typical issues that might arise from using these additional psychosocial services (see Section 6.1, J.Boivin, Section, 6.2, 6.3, P.Thorn).

Counselling, on the other hand, aims to address the extraordinary needs of some patients (see Section 2.1, B.Strauss and J.Boivin). 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-centred care and counselling is the counsellor's level of training (see Section 2.2, E.Corrigan, K.Daniels and P.Thorn). Guidance concerning qualifications for counsellors working with infertile patients has been provided by different organizations 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-centred care but only professionally trained individuals can provide counselling.

The Guidelines describe some of the practical issues that need to be addressed between counsellors and the team with whom they work. These issues might include 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 represents the majority of patients seen by the counsellor – patients who experience very high levels of distress (see Section 2.3, J.Boivin). 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 a significant proportion of those using professional counselling, they make up only ~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, fetal reduction). Table II describes some of the special situations which may lead to high distress and some of the objectives and typical issues which arise from counselling in these situations.

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'. Table III summarizes some of the objectives and typical issues that arise from counselling with individuals requiring a 'third party' for family building.

The 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 spermatozoa or gay men who use surrogacy fall in this category. While these individuals will also face the general issues described in Table III for third party reproduction, they also face issues that are specific to 'social' infertility. Table IV describes some of the objectives and typical issues that arise in counselling with this group of patients.

Conclusions

Good practice in infertility clinics encompasses more than medical care. Clinics need to be prepared to take into account and deal with the psychosocial issues that confront couples who use their services. The basic aim of any counselling (whether patient-centred 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.