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From psychosocial care to infertility counselling to psychotherapy – when is what appropiate?

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Campus Workshop

Raising competence in psychosocial care
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Conflicts of Interests: I have no commercial relationships or other activities that might be perceived as a potential conflict of interest.

Objectives

- ✓ Understanding the psychological impact of infertility and of assisted reproductive technologies (ART)
- ✓ Knowledge of different kinds of psychosocial interventions
- ✓ Understanding of strategies to improve the uptake of infertility counselling
- ✓ Basic knowledge of indicators when to refer infertile persons to infertility counselling or to psychotherapy

Psychological effects of assisted reproduction I

Reproductive medical treatment is emotionally stressing
(Boivin et al. 1995; Beutel et al. 1999)

Emotional stress increases with the number of unsuccessful treatment cycles (Wischmann 1998, Beutel et al. 1999, Strauß et al. 2000a)

Women are usually more emotionally affected compared to their male partners (Greil et al. 1988)

ART can lead to identity problems, religious/spiritual problems, problems with work and with the social network
(Peterson et al. 2007)

Psychological effects of assisted reproduction II

If one member of the couple feels responsible for the infertility, he or she may feel guilty and think of separation (Eunpu 1995)

Partners may have conflicting attitudes concerning further medical treatment measures (Stammer et al. 2004)

Quality of partnership and satisfaction with sexuality decrease during treatment, but stay in the norm (Baram et al. 1988, Berg & Wilson 1991, Kerr et al. 1999)

Up to 60% of the couples experience restrictions in their sexual life during ART (Wischmann 2010)

Psychological effects of ART treatment

Nearly one half of all couples stops treatment before the maximum reimbursed cycles are completed.

In retrospect, the main reasons to discontinue fertility care are "emotional distress of ART" first and foremost, then "poor prognosis".

(Schröder et al. 2004, Olivius et al. 2004, Hammarberg et al. 2001, Verberg et al. 2008, Hamilton et al. 2009, Brandes et al. 2009)

Result(s): Forty-seven subjects returned the questionnaire. The most common reason for terminating treatment was stress (39%). Subjects reported that the two main causes of stress were the toll that infertility took on the couples' relationship and being too anxious or depressed to continue. The top-rated suggestions for patient support were written information on how to deal with psychological stress and easy and immediate access to a psychologist or social worker.

(Domar et al. 2009, © ASRM 2009)

Expectations about psychosocial infertility services

Considered the professional psychosocial services as important	Women (n = 1169)		Men (n = 1081)	
• Course about childlessness	14.3%	13.9%	8.6%	8.9%
• Professionally led support group	11.7%	10.0%	5.4%	4.1%
• Psychologist	20.8%	18.7%	8.3%	7.5%
• Sex therapist	10.7%	8.9%	6.6%	5.7%
Would participate if these services were available				

(Schmidt et al. 2003)

Help-seeking behaviour of subfertile women

Women trying to conceive *seeking medical treatment* (N=56)

Discussed fertility with friends or family	83.0%
Read articles on fertility in popular magazines	81.1%
Discussed fertility with others who have experienced similar problems	81.1%
Read a book about fertility	67.9%
Read articles on fertility in technical/scientific journals	66.0%
Looked for information about fertility on the Internet	41.5%
Contacted a support group/health organization for information	28.3%
Asked a healer/alternative medicine practitioner	24.5%
Consulted a therapist or other mental health professional	15.1%
Consulted a minister or other spiritual leader	14.1%

(Greil & McQuillan 2004)

Psychosocial characteristics of women and men attending infertility counselling

For about 15 to 20 per cent of the patients, the emotional distress is so serious that they need psychological counselling (Boivin et al. 1999)

RESULTS: More couples with stressful life events were found in the counselling group. For women taking up counselling, psychological distress, in the form of suffering from childlessness and depression as well as subjective excessive demand (as a potential cause for infertility), was higher in comparison to women not counselled. The higher distress for men in the counselling group was indicated by relative dissatisfaction with partnership and sexuality and by accentuating the women's depression.

CONCLUSIONS: Infertile couples seeking psychological help are characterized by high levels of psychological distress, primarily in women. The women's distress seems to be more important for attending infertility counselling than that of the men.

(Wischmann et al. 2009, © Oxford University Press 2009)

How to define “psychosocial care”?

"A nontherapeutic intervention that helps a person cope with stressors." (McGraw-Hill Concise Dictionary of Modern Medicine 2002)

"The core of this care concept is a supportive and informative relationship." (German guidelines AWMF)

Table I. The six dimensions of quality of healthcare.

Safety	Avoiding unnecessary risks and injuries to patients from the care that is intended to help them
Effectiveness	Providing reliable services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit (avoiding underuse and overuse)
Patient centredness	Being respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions
Timeliness	Reducing waits and sometimes harmful delays for both those who receive and those who give care
Efficiency	Avoiding waste, including waste of equipment, supplies, ideas and energy. Efficient care is well organized and cost-effective, which enables optimal health gains and realizes high quality of life
Equity of access	Care that does not vary in quality because of personal characteristics, such as gender, ethnicity, geographic location and socio-economic status

Source: Institute of Medicine, 2001.

(van Empel et al. 2008, p. 1243)

How to define “infertility counselling”?

"Various treatment modalities (individual, couple/family, support and therapy groups) are used in infertility counseling, based upon theoretical and therapeutic approaches such as

- psychodynamic therapy,
- cognitive-behavioral treatment,
- marriage and family therapy,
- strategic/solution-focused brief therapy,
- sex therapy,
- crisis intervention,
- grief counseling and
- implications/decision-making counseling"

(Hammer Burns & Covington 2006, pp. 14-15)

How to define “psychotherapy”?

"A family of related treatments for emotional and mental disorders that use psychologic, rather than biologic or pharmacologic methods.”

(Mosby's Medical, Nursing & Allied Health Dictionary 2005, 1430)

"Psychotherapy, or personal counseling with a psychotherapist, is an intentional interpersonal relationship used by trained psychotherapists to aid a client or patient in problems of living. It aims to increase the individual's sense of their own well-being."

(http://en.wikipedia.org/wiki/Psychotherapy)

Types of counselling

- Information gathering and analysis
- Implications and decision-making counselling

patient-centered care

- (Crisis counselling)
- Support counselling
- Therapeutic counselling

infertility counselling

psychotherapy

(Strauß & Boivin 2002)

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Declaration on Patient-Centred Healthcare

Patient-centred healthcare is the way to a fair and cost-effective healthcare system

Health systems in all world regions are under pressure and cannot cope if they continue to focus on diseases rather than patients; they require the involvement of individual patients who adhere to their treatments, make behavioural changes and self-manage. Patient-centred healthcare may be the most cost-effective way to improve health outcomes for patients.

To us, the International Alliance of Patients' Organizations, the essence of patient-centred healthcare is that the healthcare system is designed and delivered to address the healthcare needs and preferences of patients so that healthcare is appropriate and cost-effective. By promoting greater patient responsibility and optimal usage, patient-centred healthcare leads to improved health outcomes, quality of life and optimal value for healthcare investment.

Patients', families' and carers' priorities are different in every country and in every disease area, ***but from this diversity we have some common priorities. To achieve patient-centred healthcare we believe that healthcare must be based on the following Five Principles:***

1. Respect - Patients and carers have a fundamental right to patient-centred healthcare that respects their unique needs, preferences and values, as well as their autonomy and independence.

2. Choice and empowerment - Patients have a right and responsibility to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives. This requires a responsive health service which provides suitable choices in treatment and management options that fit in with patients' needs, and encouragement and support for patients and carers that direct and manage care to achieve the best possible quality of life. Patients' organizations must be empowered to play meaningful leadership roles in supporting patients and their families to exercise their right to make informed healthcare choices.

3. Patient involvement in health policy - Patients and patients' organizations deserve to share the responsibility of healthcare policy-making through meaningful and supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre. This should not be restricted to healthcare policy but include, for example, social policy that will ultimately impact on patients' lives. See IAPO's Policy Statement at: www.patientsorganizations.org/involvement.

4. Access and support - Patients must have access to the healthcare services warranted by their condition. This includes access to safe, quality and appropriate services, treatments, preventive care and health promotion activities. Provision should be made to ensure that all patients can access necessary services, regardless of their condition or socio-economic status. For patients to achieve the best possible quality of life, healthcare must support patients' emotional requirements, and consider non-health factors such as education, employment and family issues which impact on their approach to healthcare choices and management.

5. Information - Accurate, relevant and comprehensive information is essential to enable patients and carers to make informed decisions about healthcare treatment and living with their condition. Information must be presented in an appropriate format according to health literacy principles considering the individual's condition, language, age, understanding, abilities and culture. See IAPO's Policy Statement at www.patientsorganizations.org/healthliteracy.

To achieve patient-centred healthcare at every level in every community, the International Alliance of Patients' Organizations is calling for the support and collaboration of policy-makers, health professionals, service providers, and health-related industries to endorse these Five Principles and to make them the centre of their policies and practice. We call upon all stakeholders to provide the necessary structures, resources and training to ensure that the Principles outlined in this Declaration are upheld by all.

Five Principles

1. Respect

2. Choice and empowerment

3. Patient involvement in health policy

4. Access and support

5. Information

(www.patientsorganizations.org/showarticle.pl?id=712&n=312)

Eight Dimensions

- Respect for patients' values, preferences and expressed needs
- Coordination of care
- Information, communication and education
- Physical comfort
- Emotional support
- Involvement of family and friends
- Continuity and transition
- Access to care

(http://pickerinstitute.org/about/picker-principles/)

new visions For Health Care

ideas worth sharing

THROUGH THE PATIENT'S EYES

FROM THE PICKER INSTITUTE | APRIL 1999 | ISSUE 4

The fourth issue of *New Visions for Health Care* features the Picker Dimension of Emotional Support. Emotional support is a complex issue, especially with the diversity of patient populations today. Please let us know if you have developed a successful technique to improve the emotional support you give to patients.

Picker Dimensions of Quality: Through The Patient's Eyes

Based on 10 years of research and more than 350,000 patient survey interviews, The Picker Institute has identified eight dimensions of care that patients value. These are:

- Respecting a patient's values, preferences and expressed needs
- Access to care
- Emotional support
- Information and education
- Coordination of care
- Physical comfort
- Involvement of family and friends
- Continuity and transition

Providing Patients With Effective Emotional Support

As many as 30 to 40 percent of primary care patients enter the healthcare system with significant levels of emotional distress, [1] and nearly one-third of the physical symptoms reported by patients to their physicians are a manifestation of psychological burden. [2] In focus groups and surveys, patients and their family members consistently voice the desire for a true sense of concern for their needs and experiences. In short, patients genuinely require emotional support as they maneuver their way through the healthcare system.

Picker survey data show that patients receiving inadequate emotional support are up to 10 times more likely to say they would not return to a hospital or recommend it to family and friends. Those who received emotional support complied more easily with treatment regimens, experienced less pain, had fewer surgical interventions, left the hospital earlier and had increased survival rates. [2]

SUGGESTION BOX:

1. Develop networks of patients and family members willing to share their experiences with newly diagnosed patients and families.
2. Offer patients information about support groups, church counseling and on-line chat groups.
3. Design training for all staff about how to convey concern and caring – be specific and use role playing.
4. Offer access to alternative therapies, e.g., massage, meditation, music, yoga.

While the need for emotional support is different for each patient, we believe that Camille Wortman's taxonomy of social support for individuals with cancer captures much of what patients say they need. According to this taxonomy, patients want an expression of positive affect such as a message that they are cared for or esteemed. They want to be acknowledged as individuals with unique beliefs, interpretations and feelings, and to be in an environment that supports the open expression of beliefs and feelings. They need access to new and diverse information, as well as tangible support for such things as options for shopping, home care or child care. Finally, they want to feel part of a network built on mutual obligation and reciprocal help. [3]

Who provides counselling?

- Information gathering and analysis — * medical doctor
- Implications and decision-making counselling — * medical doctor/ counsellor
- (Crisis counselling) — * counsellor
- Support counselling — * counsellor/ psychotherapist
- Therapeutic counselling — * psychotherapist

Typical issues in counselling/psychotherapy

• Information gathering and analysis	2nd opinion (e.g. success rates of ART treatment)
• Implications and decision-making counselling	Third-party reproduction? End of treatment?
• (Crisis counselling)	Failed IVF/ICSI cycle
• Support counselling	Grief work (childless)
• Therapeutic counselling	Depression, sexual or marital problems

Contents of the initial counselling interview

- Review of the treatment about to be untertaken
- Implications of the treatment
- Discussion of the perceived stress of the treatment
- Social support for the treatment
- Legal and ethical issues
- Expectations of treatment success
- Treatment plan

(Klock 2006, pp 86-87)

Improving uptake of psychologic counselling

- Introduce the psychologic support before the medical process
- Make personal and direct contact with the patients
- Present counselling as an integral component of the infertility treatment
- Offer support to all patients regardless of their cause of their infertility

=> One-half of the male patients took up psychologic group counselling (Furman et al. 2010)

Effects of psychosocial interventions

Table I. Psychosocial interventions in infertility: Advantages and disadvantages.

Intervention type	Advantages	Disadvantages
Booklets	widely accepted/helpful for giving procedural information	insufficient for emotional matters
Multi-media products	videotape: widely accepted/PC CD-ROM:? (accepted?)	effects not evaluated sufficiently enough (costs, effects?)
Internet	fast access/anonymity/empowerment of patients/ information easy to update	reliability of information (only 2% of the websites met all recommended JAMA standards)/effects not evaluated yet
Telephone counseling	widely accepted/low threshold fear	cannot replace face-to-face counseling/effects not evaluated sufficiently enough
Support groups	effectiveness (emotional matters)/medium threshold fear	time and effort/inconstancy of the groups
Counseling/Psychotherapy	high effectiveness (emotional matters)	high threshold fear/high costs, time and effort/often not available

(Wischmann 2008, p. 87)

Preparatory information: Booklets

In a group of 250 men enrolling for a fertility workup, mailing of a leaflat with preparatory information about this procedure was associated with lower distress scores and a higher attendance rate compared to a group of men who did not receive this leaflat (Pook & Krause 2005)

Empowering the patients

Positive
Reappraisal
Coping
Intervention

(“Take-home”-intervention)

PRCI items
During this experience I will:
Try to do something that makes me feel positive
Focus on the positive aspects of the situation
Find something good in what is happening
See things positively
Make the best of the situation
*Try to think more about the positive things in my life
Look on the bright side of things
Try to do something meaningful
Focus on the benefits and not just the difficulties
Learn from the experience

Pre-counselling checklists for screening

FertiQoL

SCREENIVF

Psychosoziale Beratung bei unerfülltem Kinderwunsch: die BKiD-Checkliste für Paare

BKiD

Liebes Paar mit Kinderwunsch,

sich ein Kind zu wünschen und darauf lange warten zu müssen: dies wird von vielen Paaren und vor allem Frauen als starke psychische Belastung wahrgenommen. Häufig wird der Kinderwunsch Anderen gegenüber verheimlicht, da das Thema immer noch tabuisiert ist. Wenn dazu noch eine aufwändige und auch nicht in jedem Fall erfolgreiche medizinische Behandlung hinzukommt, kann diese Situation selbst ein ansonsten emotional stabiles Paar an den Rand der Belastungsfähigkeit bringen. Spätestens jetzt sollten Sie sich überlegen, eine psychosoziale Kinderwunschberatung in Anspruch zu nehmen, wie sie von den Berater/inne/n von BKiD angeboten wird. Die folgende **BKiD-Checkliste** kann klären helfen, ob Sie diese Beratung aufsuchen sollten:

- „Als Paar haben wir kein anderes Thema mehr als den Kinderwunsch und die medizinische Behandlung."
- „Wenn ich Schwangeren oder Frauen mit Babys begegne, möchte ich am liebsten die Straßenseite wechseln; Familienfeste belasten mich inzwischen oft."
- „Ohne eigenes Kind empfinde ich mein Leben als sinnlos."
- „Da der Befund bei mir liegt, denke ich darüber nach, meine/n Partner/in freizugeben, damit ihr/sein Kinderwunsch in neuer Partnerschaft erfüllt werden kann."
- „Wir haben uns von früheren

PATIENT HEALTH QUESTIONNAIRE (PHQ)

This questionnaire is an important part of providing you with the best health care possible. Your answers will help in understanding problems that you may have. Please answer every question to the best of your ability unless you are requested to skip over a question.

Name_____ **Age**_____ **Sex:** ☐ **Female** ☐ **Male** **Today's Date**_____

1. During the last 4 weeks, how much have you been bothered by any of the following problems?	Not bothered	Bothered a little	Bothered a lot
a. Stomach pain	☐	☐	☐
b. Back pain	☐	☐	☐
c. Pain in your arms, legs, or joints (knees, hips, etc.)	☐	☐	☐
d. Menstrual cramps or other problems with your periods	☐	☐	☐
e. Pain or problems during sexual intercourse	☐	☐	☐
f. Headaches	☐	☐	☐
g. Chest pain	☐	☐	☐
h. Dizziness	☐	☐	☐
i. Fainting spells	☐	☐	☐
j. Feeling your heart pound or race	☐	☐	☐
k. Shortness of breath	☐	☐	☐
l. Constipation, loose bowels, or diarrhea	☐	☐	☐
m. Nausea, gas, or indigestion	☐	☐	☐

2. Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day

Risk factors for high distress

Personal

- pre-existing psychopathology
- primary infertility
- being a woman
- viewing parenting as a central adult life goal
- general use of avoidance coping strategies

Situational or social

- poor marital relationship
- impoverished social network
- "reminders of the infertility"

Treatment-linked

- side-effects of medication
- miscarriage, treatment failure
- decision-making times

(Boivin 2002)

Psychogenic Infertility: Definition

Psychological factors exist as a (part-)cause of a fertility disorder if

a) despite the desire for a child and the corresponding counselling from a doctor the couple continue to engage in behaviour detrimental to fertility (e.g. diet, notably over- and underweight; high-power competitive sport; alcohol, nicotine, tablet abuse; extreme stress, especially at work),

b) a couple does not have sexual intercourse on fertile days or one (or both) of them have a non-organic sexual dysfunction,

c) a couple consciously consents to a medically indicated infertility therapy but then fails to go through with it.

(from: Strauß et al. 2000, Wischmann 2003)

Criteria for referral in psychotherapy

Developing a depressive reaction:

- all areas of life are affected
- no more enjoyable experiences
- increasing listlessness
- rapid fatigability
- problems with sleeping
- social withdrawal

Psychogenic infertility: therapy for eating disorders, drug addicton therapy, sex therapy, psychodynamic or cognitive-behavioral therapy

Psychosocial infertility counselling in retrospect

90% of the women asked some years after the end of IVF treatment agreed to the statement that ongoing counselling should be part of IVF.

Whereas almost 80% of the women agreed that couples should be counselled about the option of stopping treatment, only 16% evaluated the counselors as helpful when deciding to stop treatment.

(Hammarberg et al. 2001)

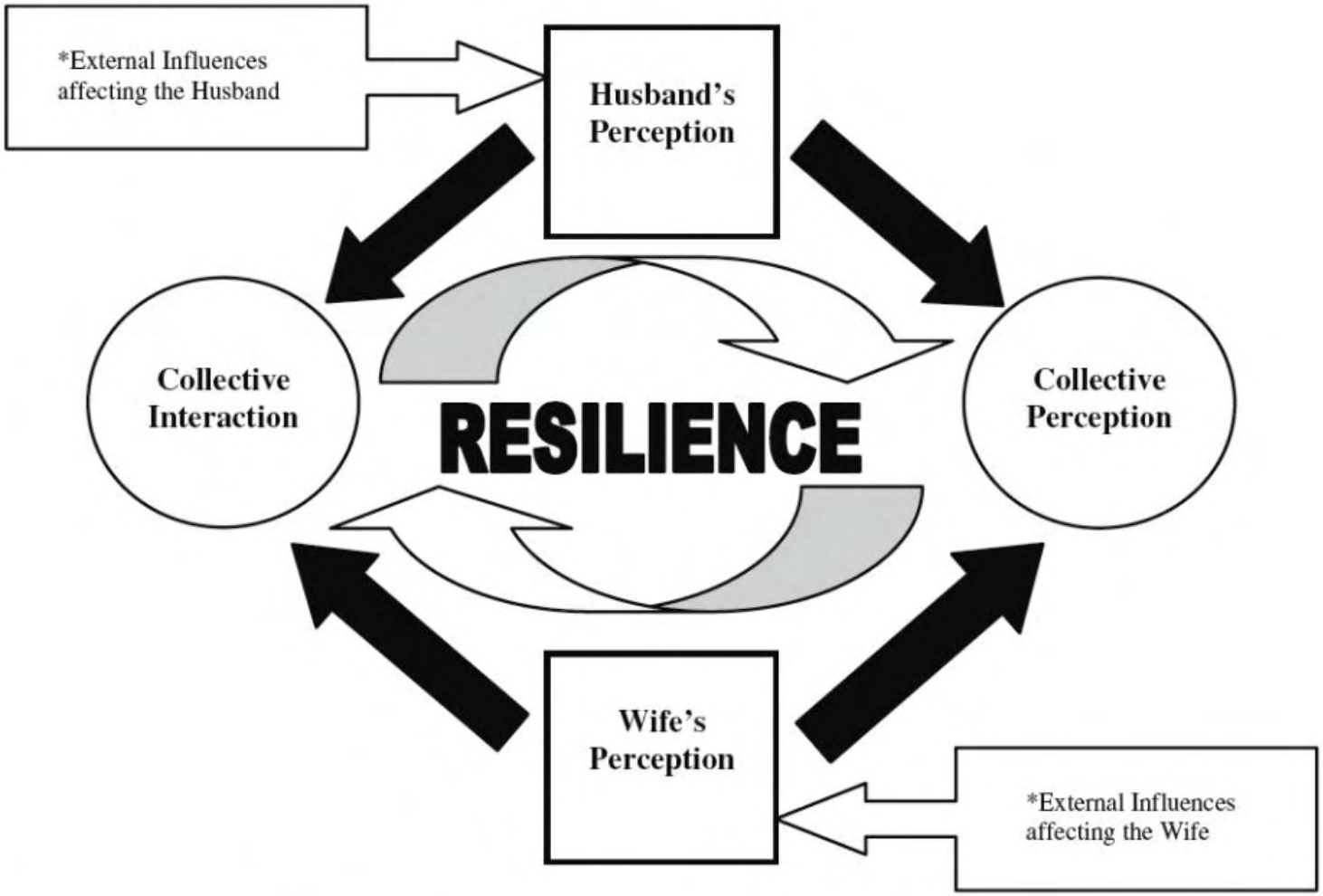

Fig. 1 Conceptual Representation of the Infertility Resilience Model. *External/Environmental Influences include geographic location, diagnosis, socioeconomic status, social support, education, ethnicity, duration of infertility, religiosity, and cultural influences (these influences may be shared or non-shared)

(Ridenour et al. 2008, p. 36)

Conception after counselling / psychotherapy

"It seems clear that more research needs to be devoted to the systematic evaluation of pregnancy effects before psychosocial interventions can be recommended as a way of helping couples improve their chances of achieving a pregnancy"

(Boivin 2003, p. 2335)

(© Boston IVF, Boston)

Summary

- Psychosocial interventions in infertility are used mainly by infertile *patients*, predominantly by female patients
- Providing procedural information about ART (booklets or films) probably facilitates coping with infertility and ART
- Psychosocial care, infertility counselling and psychotherapy are not clearly distinct categories
- Screening instruments are helpful for identifying patients which have to be referred into psychotherapy
- Exact criteria when to refer have to be developed yet

Conclusions for counselling

- Infertility can be one of the most stressful and life-changing events a person can face. Counsellors have to validate the clients' experience and to normalize them
- Psychological counselling should be offered to all infertile couples independent of their individual diagnoses or the stage of medical treatment (and independent of treatment)
- Infertility counselling should be mandatory an integral component of ART and this should become evident for all patients right from the start of treatment

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