Developing Skills for Infertility Counselling

Proceedings of the ESHRE Campus Workshop

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Introduction

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For many years, it has been recognized that patients undergoing assisted reproductive technology (ART) procedures do not need only state-of-the-art medical treatment but also emotional support. This need has been addressed by psychosocial professionals, who as early as in the 1980's in some countries, established professional organisations for infertility counselling: In 1985, the Mental Health Professionals Group (MHPG) within the American Society for Reproductive Medicine (ASRM) was founded, followed in 1988 by the British Infertility Counselling Association (BICA) and one year later by the Australian and New Zealand Infertility Counselling Association (ANZICA). To promote international cooperation the ESHRE Special Interest Group (SIG) "Psychology & Counselling" was launched in 1993 and ten years later, in 2003, the International Infertility Counselling Organisation (IICO), the international umbrella organisation, was founded. Several other national organisations such as the German Society for Fertility Counselling, the FertiForum in Switzerland and similar organisations in Japan, Argentina, Spain and France have been established since then. These organisations have not only facilitated academic and clinic cooperation amongst psychosocial professionals and between these and medical experts but have also developed professional standards for counselling in the area of infertility and ART.

Most of these organisations require infertility counsellors to have a university degree in the area of psychology, social work, medicine or nursing and in some countries medical professionals with specialist counselling credentials are accepted, as well. Several organisations such as the British and the German one have developed their own codes of practice and accredited members must adhere to these. Such codes include:

- Completed training in psychosocial counselling or therapy,
- Membership to a relevant professional body,
- Knowledge in
    - the psychology of infertility (i.e. bereavement, crisis intervention, typical/atypical responses),
    - marital and family issues related to infertility,
    - family building alternatives (adoption, gamete donation, child-free living),
    - medical, legal and ethical issues related to ART,
- skills in individual and couple counselling,
- clinical experience and
- continuing education.

In order to promote training and education for counsellors interested in or already engaged in the domain of infertility / ART, the ESHRE Special Interest Group Psychology & Counselling carried out a one-day workshop in September 2009 in Basel, Switzerland. This workshop focussed on the fundamental psychological aspects of infertility and its treatment. It provided participants with basic skills for counselling in different settings and an understanding of the counsellor's role in the provision of ART so that they were able to develop or refine their personal professional profile.

The workshop attracted 41 participants from 15 different countries. The participants' professional background ranged from physicians to psychologists and nurses working within, as well as independently from an infertility clinic. Many of the colleagues had some or even extensive experience in infertility counselling, for others, this workshop was a first opportunity to gain some understanding in this area.

The following proceedings summarize most presentations and workshops of the first ESHRE Campus Workshop of the SIG "Psychology & Counselling". The chapters also include some of the discussions during the workshop and some suggestions for further reading as well as the contact details of the contributors.

As the participants indicated high interest for more training opportunities, similar workshops will be organised in the future. Colleagues interested in participating in a workshop can contact the ESHRE website of our SIG to get information about dates and locations.

Further reading and references

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Medical treatment from a psychological perspective

Tewes Wischmann

Objectives

- Estimation of the prevalence of psychogenic infertility
- Understanding of the psychological impact of assisted reproductive technology (ART)
- Knowledge of psychological development of couples/families after successful vs. unsuccessful ART
- Basic knowledge of special psychosocial aspects of third-party reproduction

Involuntary childlessness: only a minor problem?

Approximately 3-9% of couples trying to get pregnant are involuntarily childless; the absolute numbers in Germany are approx. 0.5-1.5 Mio. couples. The lifetime prevalence of infertility is higher: every third woman trying to get pregnant waits one year or longer for the pregnancy. In the US, infertility affects approx. 7.3 Mio. couples – approx. 12% of the reproductive-age population. The mean age of women giving birth to their first child is increasing. In (West-) Germany, the mean age of a woman giving birth to her first child was 24.9 yrs in 1977, but as high as 30.5 yrs in 2004. In Switzerland, the mean age increased from 25.0 yrs in 1969 to 30.1 yrs in 2006. The fertility of a woman decreases with age: a woman aged 38 years has only half the chance of getting pregnant as a woman aged 28 years. It is very likely that this development will lead to an increase of the rate of infertile couples over the next decades.

Medical treatments for infertility

Approximately 50% to 75% of infertile couples seek some form of medical treatment. Most infertility cases (85% to 90%) are treated with conventional medical therapies such as medication or surgery. In vitro fertilization (IVF) and similar treatments account for less than 3% of infertility services in the U.S. The average cost of an IVF cycle in the United States is $ 12,400 (in Germany: € 3,200).

Increase of treatment cycles

From 1985 through the end of 2006, almost 500,000 babies have been born in the United States as a result of reported Assisted Reproductive Technology (ART) procedures. Between 1997 and 2006, 104,674 ART-Children were born in Germany. The total number of children conceived by ART worldwide lies between 1,000,000 and 3,000,000.

Live-birth rates

In Germany, from 1997 to 2004 approx. 470,000 treatment cycles were conducted, resulting in approx. 70,000 deliveries. This signifies a live birth rate of 14.9% per treatment cycle. The equivalent data for Switzerland 2007: 7,125 cycles resulting in 1,253 deliveries, resulting in 17.6% birth rate per cycle. The data for France for ICSI in 2006: 29,786 cycles resulting in 6,046 deliveries (20.3% birthrate per cycle). Much more interesting are the cumulative live birth rates: After two treatment cycles, the probability of a live birth lies between 37 and 40%, after three cycles between 45 and 53%, and after four cycles between 49 and 62% (according to a US study). Assuming that a majority of couples will drop out of ART treatment before completing the fourth cycle, approx. half of all couples end treatment without having delivered a child. In the general population, the "take-home-baby" rate after ART is overestimated. In Germany, for example, the general population thinks that an average ART cycle results in a live birth rate of 44%.

Psychological effects of infertility

Many women experience infertility as the most severe emotional crisis in their life, the emotional impact being comparable to a severe illness or the loss of a loved relative or friend. Their male partners describe themselves more or less unaffected, but men with an andrological factor diagnosis describe themselves as more anxious and uncertain compared with the norm.

Psychological characteristics of infertile couples

On average, infertile women are more anxious, depressive, have lower self-esteem and are more limited in their social network than their partners and in comparison with the norm population. This finding can be interpreted as the result of medical diagnosis/therapy, because the strength of the symptoms increases with the duration of desire for a child ("psychological consequences model"). There are no psychologically relevant differences between idiopathic infertile couples and organic infertile couples. The average couple with a wish for a child is psychopathologically inconspicuous. General findings only show slightly higher rates of depression, anxiety and physical complaints in women.

Psychological effects of assisted reproduction

Women are usually more emotionally affected compared to their male partners, and ART for them is emotionally stressing. Emotional stress increases with the number of unsuccessful treatment cycles. ART can lead to identity problems, religious/spiritual problems, problems with work and with the social network. The quality of partnership and sexual satisfaction decrease during treatment, but remain within the norm. If one member of the couple feels responsible for the infertility, he or she may feel guilty and consider separation. Partners may have conflicting attitudes concerning further medical treatment measures. Up to 60% of the couples experience restrictions in their sexual life during ART. For many women (and men) the emotional stress in the waiting time after embryo transfer is a greater burden than the diagnostic or medical treatment measures of ART (e. g. laparoscopy for the examination of the fallopian tubes). Nearly one half of all couples stop treatment before the maximum number of reimbursed cycles is completed. In retrospect, the main reasons to

discontinue fertility care is the "emotional distress of ART" first and foremost, "poor prognosis" ranking only second.

Third-party reproductive treatment

A special topic is the psychosocial impact of third-party reproductive treatment. Counselling issues here include managing the taboo, social stigma and legal uncertainties, the meanings attributed to the donor for the intended parents and the child, the donor's anonymity or identifiability as well as sharing the information with the child and significant others.

The "psychogenic infertility model"

Currently, the incidence of idiopathic or unexplained infertility is thought to be 5 to 15 per cent. However, in the 1960's, 50 per cent of all causes of sterility defied diagnosis. This gave room to various speculations about psychogenic infertility. To give an example: Approx. 50 years ago, a review on "Personality Factors in Female Sterility" resulted in the following personality factors considered to be "typical for sterility":

1. Physical and emotional immaturity,
2. aggressive-masculine types (resenting the female role),
3. combination of 1 and 2,
4. hostile mother identification,
5. motherly type,
6. feminine erotic type,
7. obsessive-compulsive type,
8. disturbed, impoverished, and chronic worriers.

Obviously, every woman (attempting to conceive or not) will experience at least one of these "factors". Male infertility apparently did not exist in the 50's of the last century!

What about the "psychogenic infertility model" today? A very recent report on "timesonline" stated "that 'unexplained infertility' accounts for up to 23 per cent of infertility cases, and 80 per cent of these could be down to the mind. The cause could be a subconscious fear of having a baby or the stress that comes from worrying about being unable to conceive." (from: "IVF and fertility problems? Just relax", www.timesonline.co.uk, February 21, 2009). An antipole is set rightly by the chapter heading "The road to hell is paved with 'just relax'" in the excellent guidebook "Navigating the land of If" by Melissa Ford, which can be recommended to all women with fertility problems (and their partners).

The definition of psychogenic infertility according to the German guidelines "Psychosomatics in Reproductive Medicine" reads as follows: Psychological factors exist as a (partial) cause of a fertility disorder if:

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

b. a couple does not have sexual intercourse on fertile days or one (or both) of them suffers from a non-organic sexual dysfunction,
c. a couple consciously consents to a medically indicated infertility therapy but then fails to go through with it.

What about the correlation between stress and infertility? Two recent studies with large sample sizes demonstrated no significant correlation between stress and infertility: A prospective study of 783 women before and during IVF/ICSI treatment came to the result: "Even a very strong rise in anxiety level just before ovum pickup did not influence the chance of conceiving". Another prospective study of 430 Danish couples who were trying to become pregnant for the first time showed that "the effects of a man‘s daily life stress on his semen quality is small or nonexistent".

The same myths apply to conception following adoption: Systematic studies failed to demonstrate any connection between adoption and subsequent pregnancy. In the "Heidelberg Study" 32 couples had given up their desire for a child. Among these couples one woman became pregnant again after taking in a foster-child (= 3.1 percent). "Those cases that do occur are so well publicized that the relative frequency of the occurrence is in turn overemphasized".

Conception after counselling / psychotherapy

The results of meta analyses and reviews of studies concerning the conception rates after infertility counselling or psychotherapy are inconclusive, therefore "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).

Risks during pregnancy and at birth

The miscarriage rate is approx 20-34% higher compared with couples conceiving spontaneously. The risk of pre-eclampsia is increased by 55%, the risk of preterm delivery by approx. twofold and the risk of placenta praevia by approx. threefold. There is a greater risk of stillbirth. Babies after ART have a lower birth weight and a higher risk of being small for gestational age compared with spontaneously conceived babies. The greatest risk for children conceived by ART is being born as multiples.

Experience of pregnancy and birth

The frequently conducted caesarian sections after ART (as high as 30% even for singletons) are disappointing for many women and this may lead to problems such as higher anxiety and difficulties with breast feeding. General anxiety in pregnant women after IVF is inconspicuous. Specific fears of child injury or miscarriage are higher after preceeding miscarriages. Men show higher anxiety concerning IVF pregnancies compared to controls, but the same prenatal attachment.

Development of the couples' relationships

Studies indicate that partnerships of IVF-parents are comparable with controls at time of the child‘s birth, but better than in a control group one year later; no differences are found between the two groups when the children are five years old. From the women‘s point of view, undergoing ART treatment and coping with the crisis of infertility as a couple "welds" both partners together. Five to ten years after IVF, 3-21 percent of the childless couples are separated and 6-8 percent of the parents (the average divorce rate is between 15 and 20 percent).

Development of families after ART

No noticeable problems can be found in the social and psychological development of singletons after ART. The same applies to the parents' relationships and to the parent-child relationships. NB: Multiples and children with major abnormalities were not included in the "European Study of Assisted Reproduction Families“. Families with multiples are families at risk also from a psychological point of view: children’s risk for behavioural and speech disorders, mothers' risks for depression, and the risk of parental separation is higher. The financial expense for the health care system is threefold for twins and tenfold for triplets in comparison to singletons.

Physical development of children after ART

The rate of numerical sex-chromosome abnormalities is increased in pregnancies after ICSI, the risk of major malformations by about 30%. The specific risk of the two rare imprinting disorders (Angelman’s syndrome and Beckwith-Wiedeman-syndrome) may also be raised. Overall, there is a higher risk of cerebral palsy in children born after ART.

Long-term psychological effects of infertility

There are only small differences in the quality of life between involuntarily childless couples and parents. A favourable prognosis can be given in those cases when childless couples positively reappraise and accept the situation, actively search for alternatives and for social support. The prognosis is unfavourable if there is still ruminating and avoidance coping, feelings of powerlessness, and restriction on children as the only meaning of life. NB: One third of the couples are non-responders to the catamnestic studies, so we do not know anything about a large proportion of long-term infertile couples.

Expectations about/experiences with psychosocial infertility services

Of 1169 women and 1081 men studied, the following percentages would engage in professional psychosocial services if these were available: workshops about childlessness: 13.9% (women), 8.9% (men); psychologists: 18.7% (women), 7.5% (men); sex therapists: 8.9% (women), 5.7% (men); professionally facilitated support groups: 10.0% (women), 4.1% (men). For approx. 15 - 20 % of patients, the emotional distress is so severe that they need psychological counselling. Psychosocial characteristics of women and men attending infertility counselling are the following: women take up

counselling if they feel distressed, suffer from childlessness and depression and if they assume that subjective excessive demand is a potential cause for infertility. The higher distress for men in the counselling group was associated with relative dissatisfaction with partnership and sexuality and with higher levels of depression in the female partner.

90% of the women who were asked their opinion several years after completing IVF treatment agreed with 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.

Summary

- Infertile couples still underestimate the psychosocial impact of ART ("emotional roller-coaster") and of multiples as the outcome of ART (risk group) but overestimate the chances of ART ("take-home-baby rate")
- For a large portion of infertile couples sexuality is negatively affected during medical treatment
- Couples still do not disclose their fertility problems and the reproductive medicine treatment to others
- Women tend to be more affected emotionally by ART than their male partners (and this may lead to a couple communication problem)

Conclusions for counselling

- Infertility can be one of the most stressful and life-changing events a couple can face. Counsellors have to validate the clients' experiences and normalize them
- The main focus in infertility counselling should be to help couples to cope with infertility and to detect health-risk behaviour, not to uncover unconscious conflicts towards parenthood
- Psychological counselling should be offered to all infertile couples independent of their individual diagnoses or the stage of medical treatment

Further reading and references

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Developing Skills for Individual Counselling

Uschi Van den Broeck

Many different theoretical frameworks have been adapted for use within an infertility context in the last decades. For an extended overview of psychodynamic theoretical frameworks, cognitive-behavioral therapy, solution-focused brief therapy, crisis intervention and grief counseling, we refer the reader to the Chapter on 'Individual Counselling' in the Infertility Counselling Handbook (2nd edition, 2006) by Covington and Burns. In accordance to this multitude of approaches, a theme for this workshop was found in C. Jung's quote: 'The shoe that fits one person pinches another. There is no recipe for living that suits all cases.' The diversity and variation in frameworks, approaches and techniques that infertility counsellors use in individual counselling certainly illustrate the many shoes in our closet. However, the core concept of 'the wish for a child' warrants further interest as a dynamic framework that can guide and supplement other well-established psychotherapeutic approaches.

The wish for a child

A central, but often inexplicit question is 'Why do we want children?' A sample taken at random quickly reveals that there are as many answers as respondents. 'I don't know, I just know I want children' or 'It has something to do with a legacy or passing something on to the next generation' are frequent answers. Others think of family building, of motherhood and fatherhood while even others stress it has more to do with beliefs and values, with something greater than themselves. Then there are the more philosophical answers such as 'Children are our beginning and our ending' contrasted with truthful answers such as 'because they're fun and cute'. Whatever the answer may be, it is clear that the wish for a child is a complex phenomenon. Biological parenthood is an implicitly valued and primary role in western society. It is a 'script', a way in which we expect life to unfold and even more, a developmental milestone in the process to adulthood. Until the sixties the motives for parenthood were hardly researched (Van Luijn, 1996) because most people assumed that parenthood was a natural given, an instinct or an innate need. The introduction of birth control pills and the baby boom following World War II gave way to interest in the social sciences on the motivation for wanting children. Nowadays, wanting and having children is no longer a self-evident given (Van Luijn, 1996) but a deliberate choice. And it is exactly the possibility of choice that gives us the illusion of power on 'if and when' we want children. This is part of the grief and the hurt of subfertility if a pregnancy does not occur when we want it to: the illusion of control inevitably places responsibility of getting pregnant with the individual.

The motives for wanting children are clearly multifactorial. First, there are individual motives such as, for example, confirmation of identity, feeling like a 'true woman', the idea of the imaginary child we grow up with in our minds as we engage in fantasy play from early infancy to when we start dating and considering ourselves as future parents,… Second, relational motives arise as a child may be the ultimate sign of love and bonding between a couple, or the idea of having a child might be linked to a wish for a family and a stable relationship and so on. Third, transgenerational motives are an essential part of the wish for a child as we are all embedded in a family that goes back generations

and if we bear children, our parents become grandparents and the family tree expands. Fourth, sociological motives have an impact on the wish for a child because we are part of a larger community, society and culture that determines, at least in part, how we construe a life with or without children as something valuable.

A careful exploration of all these child-wish dynamics with the individual can provide insight into this overwhelming feeling of wanting a child. Furthermore, it can normalize the experience of crisis and hurt for the individual and guide psycho-education. Other important themes and topics in infertility counselling may arise in discussing the wish for a child, such as issues of self-acceptance and (gender) identity, coping and communication, mourning and grieving various losses in life, alternatives for child wish and decision making etc.

Unfulfilled wish for a child

Pregnancy begins psychologically long before it occurs physically (Covington & Burns, 2006). During pregnancy, a process of attachment to the child-to-be-born starts as the couple slowly adjusts to the changing realities. Individuals progress on the continuum of the 'imaginary child' (e.g. a child in our minds – how we fantasize our future child-to-be) towards the 'real child' (e.g. the actual child that is born and can differ from what we hoped or expected it to be). This transition to parenthood, though often a time of happiness and excitement, can also bring about feelings of ambivalence and a period of crisis and change. Individuals confronted with subfertility, however, are unable to move on this continuum as the crisis of infertility strikes as a transition to non-parenthood. When the wish for a child remains unfulfilled the individual is confronted with boundary ambiguity: psychologically, the wished-for-child is present whereas physically, the wished-for-child is absent. The question on who is in or out of the family constitutes a challenge to the couple's task of defining their 'family'. This process can create substantial stress for the individual involved. It is often in this process of negotiating the transition to parenthood or non-parenthood that patients consult a fertility center in their attempt to fulfill their wish for a child.

Fundamental issues in infertility counselling: 'first sessions' – themes of infertility.

Infertility counselling is the opportunity to explore, discover and clarify ways of living more satisfyingly and resourcefully (BICA, 1999). Counseling in general is a notoriously imprecise term that covers many layers of meaning depending on the context. For the purpose of this workshop, infertility counselling is perceived as different from patient-centered care and requires professional qualification (in some form of a mental health degree). Of course, the content of infertility counselling will be different depending on the setting of the counsellor (within the clinic and medical setting or in a private practice) and furthermore dependent on the role of the counsellor in the setting. Some counsellors are responsible for assessment of couples requesting infertility treatment, others counsel couples on specific issues such as third party reproduction, adoption, decision making and so on. Sometimes patients are referred by doctors and other staff and sometimes patients come to the counselor with psychotherapeutic questions. In the workshop a number of elements were addressed that can define a first meeting with patients in counseling. Firstly, the counsellor often needs to be aware of possible hesitation and bias of the patient coming to see the counselor. For

many patients it is the first contact with a mental health professional and they might feel prejudiced or stigmatized on having to come to see someone about such intimate matters as the wish for a child and procreation. Depending on how the counselling session was introduced and communicated by the medical or paramedical staff, patients may fear evaluation and rejection or they might feel like a failure for breaking down in front of their doctor. Secondly, the counsellor should be aware of the added value of infertility counselling for the patient, the clinic and the counsellor in question. The loyalties and responsibilities of the counsellor to the clinic or doctors should be explicit and transparent for the patient in the first session. Thirdly, counsellors should take the various phases on infertility into account when patients present for a first counselling session. The state of mind of both patient and their surrounding medical professionals are, in part, determined on whether a patient comes to the counsellor 'pre-diagnosis' (*they feel they are still in the game*), 'after diagnosis' (*which often signifies a crisis for the individual and the couple*), 'pre-treatment' (*when they feel back in the game and confident and hopeful*) or 'during treatment' (*when they are in the midst of the emotional roller coaster*). Fundamental issues in the first few counselling sessions can be: implications for social life and social support, developing and strengthening coping strategies and decision making, marital and sexual effects of infertility, gender differences, grief and the developmental impact of infertility and finally addressing the emotional roller coaster of infertility treatment.

An intervention model that can be helpful in first session counseling is the PLISSIT model described by Jack Annon in 1976. It is a differential model of treatment, originally used within sex counselling, that provides sensitive and tailored interventions. It builds on the idea that not everyone needs the same things at the same time. The 'P' stand for permission – these are patients who want permission from the counsellor to simply talk about their issues. The 'LI' stands for limited information – these patients have specific questions they want to see answered but nothing more than that. The 'SS' represents specific suggestions – these patients want advice on how to proceed with certain issues and they want tailored suggestions. Finally the 'IT' stands for intensive therapy – these patients represent the smallest group and come to counselling with psychotherapeutic questions and issues.

During the workshop, participants were asked to associate freely on the word 'Infertility'. Responses were as varied as the shoes in our closet. Many answers broached the negative emotional effects and pains of infertility, there was substantial room for the invasiveness and the effort patients put into their infertility struggles. The atmosphere evoked by the word 'Infertility' was gloomy and devastating and strikingly lacking of hope, growth and strengths. However, a case example of a couple taking their first steps into the world of fertility investigations brought forward different associations of the same word 'Infertility'. The answers were much more partner focused, specific and less all-consuming negative. This exercise illustrated a common pitfall for all professionals involved in infertility care: our own perceptions and (personal or professional) experiences of 'infertility' and its many associations find their way into the consultation room and can have an impact on how we perceive the individual or couple before us. As infertility counsellors, we should strive to be aware of our own biases and associations and use them cautiously while allowing enough empty space for the individual or couple before us. After all: 'The shoe that fits one person pinches another. There is no recipe for living that suits all cases.'

Further Reading and references

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Developing skills for couple counselling

Tewes Wischmann

Objectives

- Management of difficulties in infertility counselling
- Knowledge of typical issues in couple counselling
- Understanding the couples' dynamics in infertility treatment
- Estimation of prospects and limitations of couple counselling

Introduction

For many women, emotional stress in the waiting period after embryo transfer is a greater burden than any medical treatment measures of IVF. Reproductive medical treatment is emotionally stressful and the stress increases with the number of unsuccessful treatment cycles. For about 15 to 20% of the patients, the emotional distress is so severe that they need psychological counselling.

Polarization in the couple's relationship

Confronted with the painful experience of infertility, a woman may want to talk about her pain and sadness; whereas her partner may feel helpless and withdraw. This circular pattern can result in polarization and isolation, at a time where both partners need each other the most. This polarization pattern can be shown in the couples' profiles in a German personality test (Giessen Test) in figure I.

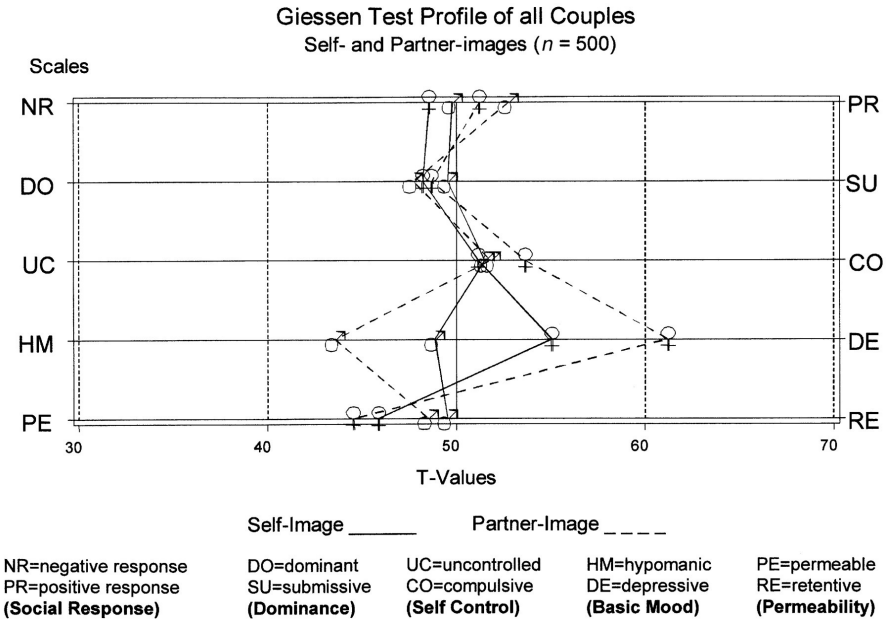

Figure I: Polarization of couples' basic mood (from: Wischmann et al. 2001, © ESHRE 2001)

The fourth scale ("Basic Mood") in Figure I shows the polarization in self- and partner-image of women and men confronted with the infertility experience. Whilst the woman sees her male partner much more unaffected and much less depressive than he evaluates his own mood, he accentuates her depressive mood nearly as dramatically, in contrast to her self-image. In couple counselling it can be helpful to visualize this polarization and to normalize its occurrence. Do men suffer from infertility? In keeping with masculinity norms, many husbands tend to suppress their emotions in an effort to support their wives. Withdrawal might be a way of protecting the woman from her partner's pain. This is one of the major advantages of the couple counselling setting, in that this assumption can be confirmed immediately by asking the male partner.

Structure and Content of Couple Counselling

The couple counselling in context of the "Heidelberg Fertility Consultation Service" (see figure II) has been described in detail in Wischmann et al. 2002. Some of the key questions will be discussed here.

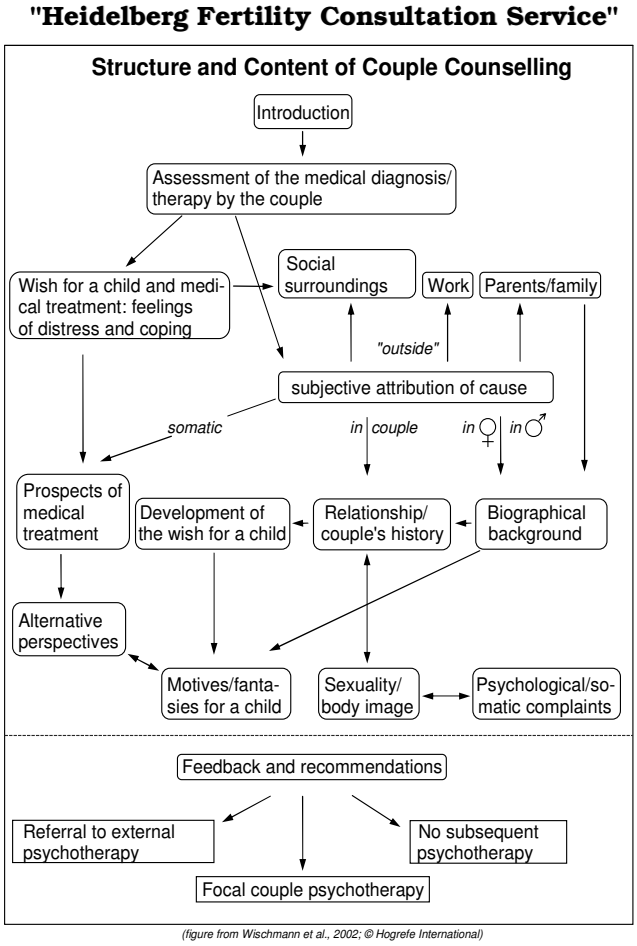

Figure II "Structure and content of couple counselling"

In the introduction part of counselling, it is important to define the objectives of the counselling sessions. If infertility counselling is an integral part of the reproductive medicine treatment, and its course, content and goals are made transparent before it starts, acceptance rates of up to 80% can be reached. During the first counselling session, it is very rare for infertile couples to be in a position to say exactly what they expect from the consultation service. Thus, a definition of infertility counselling at the beginning fulfills a number of important functions. One of them is to act as a corrective to unrealistic expectations, such as the assumption that removing "barriers in the mind" will automatically improve pregnancy prospects. Another function of the introduction part of counseling is to put the ensuing course of therapy on the right "rails" from the outset by establishing a working alliance and defining the roles played by the participants in it.

Another important key element is the question concerning subjective etiologies of the infertility problem, especially for couples with unexplained (“idiopathic”) infertility. This may help to uncover feelings of guilt or depressing fantasies such as infertility indicating that the partners are not “right” for each other.

Managing involuntarily childlessness and the medical treatment. In order to help couples affected by infertility, it is crucial to avoid the "downward spiral" (see figure III).

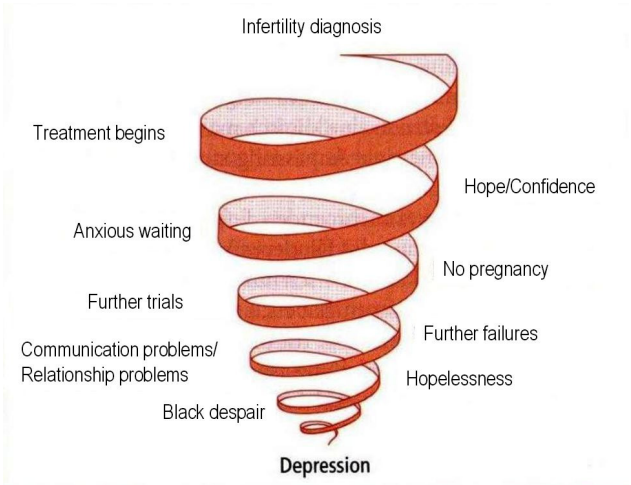

Figure III: The “Downward spiral” (translated from: Rohde & Dorn 2007, © Schattauer Verlag, Stuttgart)

If infertility is diagnosed in one of the partners only, the counsellor should change attribution errors and unfavourable coping styles (“externalizing infertility”): "Feeling guilty" is not the same as "being guilty". It is important to change internal attribution ("I‘m a failure") to external attribution ("This blow of fate is our challenge"). The couple should identify allocation of blame within the partnership and replace it with "accepting my part of the responsibility for our common problem". The counsellor should also strengthen active and meaning-based coping styles, and replace passive and avoidance coping styles in the discussion with the couple. Therefore counselling should promote the couple's communication. The couple (and the counsellor) should accept that in the majority of cases women

and men experience the infertility crisis differently. Men tend to want concrete assistance in coping with stress or "hands-on" advice about how to deal "properly" with the crisis their wives/partners are going through. Women tend to look for emotional support in overcoming the "bouts of depression" they experience. The counsellor should remain neutral towards these differences, and he/she has to identify the before-mentioned dysfunctional role allocations ("depressive woman – helpless man") and make them more flexible in the discussion with the couple.

For nearly all women (and men) struggling with infertility, reproductive medicine treatment is experienced as an "emotional rollercoaster": the recurrent emotional crises during ART have to be anticipated and actively addressed by the counsellor. The counsellor can give advice for the waiting period (which is the most distressing part of ART):

1. to seek distraction as often as possible,
2. to indulge in something special during the two weeks after embryo transfer (e.g. hairdressing, visiting the best friend, going to the cinema etc.) and
3. to do relaxation exercises (such as hearing a CD with relaxation exercises, practicing luna yoga or meditation).

It is important to stress in couple counselling, that as long as the desire for a child exists, frustration will exist as well and the emotional rollercoaster will go on. The couple can limit its amplitudes but cannot level them completely.

As most couples tend to be in a passive position during infertility treatment, it is important to prepare roadmaps and to adjust them („create a choice web"; Ford 2009):

- Aim: To control what can be controlled in this potentially uncontrollable life crisis
- Draw a "satisfaction lifeline" from the beginning of the partnership up to now. Include the ups and downs such as marriage and couples crises. Outline the grades of life satisfaction as a couple with and without children in the near and in the distant future.
- Develop "plan B", "plan C" etc. from the beginning on
- Each partner writes his/her roadmap first, and then the two roadmaps have to be merged and attuned
- Roadmaps can be rewritten if necessary (e.g. after the first failed IVF cycle) but the couple has to set limits to ART

During the ESHRE Campus workshop discussion, the issue of raising a "Plan B" in the first counselling session was controversial because many couples do not seem to be able to discuss "Plan B" at the beginning of ART. In the author's opinion however, this has to be done in infertility counselling as soon as possible to avoid any delay in the mourning process. Considering an alternative perspective very early has the advantage that an already available "Plan B" is placed in the drawer if necessary, and in case of a successful ART treatment, it can stay in the drawer. If "Plan B" is adoption or fostering of a child, a question like: "Do you have sufficient energy to pursue adoption and ART at the same time?" could be introduced in counselling.

Normalization of "negative" emotions and handling the fertility problem in the social network:
Intensive "negative" emotions like despair after a negative pregnancy test or envy towards pregnant women, possible feelings of guilt or blaming the partner, are common, comprehensible and

acceptable. Partial disclosure of the fertility problem towards relatives and friends along with setting clear limits is less "energy consuming“ than white lies.

Sexuality and body image: Since the majority of couples experience sexual difficulties during medical treatment (see Wischmann 2010), it might be an option to separate pleasurable from reproductive sex. The couple can be instructed to differentiate between „Sex for Baby Making“ in the fertile period of the woman’s cycle and „Sex for Fun“ during other times. If the couple develops a severe sexual dysfunction because of the distress and pressure, this separation of task-oriented sex and pleasure-oriented sex can be reinforced. This may even include the use of condoms during the fertile period for a limited number of menstrual cycles (e. g. two to three cycles) until the pleasure in sex has returned.

Last but not least: respect and limit the influence of infertility (Diamond et al. 1999). As long as the desire for a child persists, it will be at the centre of the couple‘s life. The couple has to turn towards life "beyond the desire for a child" actively and has to cultivate this. The mourning process cannot be finalized as long as any chance of getting pregnant continues to exist.

Forthcoming developments

Telephone and internet counselling may become increasingly sought after and something infertility counsellors should be aware of or even develop skills for (see Wischmann 2008 for a review of recent developments).

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Developing skills for group work

Marysa Emery

In the context of infertility counselling, mental health professionals who receive requests from couples or individuals generally initiate the conceptualisation and development of group work. These groups might be oriented toward sharing experiences, gaining communication skills or information, or any other type of psychological support. The development of a group work project deserves much thought and attention to the demands and needs of the participants, the aptitudes and possibilities of the group leaders, and the many practical considerations. In the present workshop, a clinical illustration will precede the theoretical framework and then some practical steps for setting up a group will be proposed.

A clinical illustration

Mary S is now 34 years of age and she has been trying to achieve a pregnancy for 4 years. She is keen on natural methods, and now discovers that her partner presents severe OTA (oligoteratoasthenospermia). Only ICSI (in vitro fertilisation with intracytoplasmic sperm injection) is possible for the couple to have a good chance for a pregnancy. Mary is upset and confused, her partner is feeling useless and guilty.

In this situation, couple counselling allows for both partners to work on acceptance, self-image, adapting to their circumstances and handling their intimacy and their entourage.

Mary discovered that sharing with friends and family doesn't always help. Infertility is often not considered a "serious problem". People's need to give advice or to make light of her situation damaged some of her relationships and hurt her self-esteem. Mary described "not fitting in anymore ", "not being understood", "becoming sad and pessimistic", "putting life on hold", "hating herself for feelings of jealousy towards pregnant women".

She inquired about encounter groups for people with fertility problems and two possibilities were offered: the first was a support group led by a woman who had successfully had two healthy children with ICSI treatment, the encounters are organised sporadically, no professional leadership, no fee. The second was a therapeutic group led by two psychologists (one trained in group psychotherapy and one child psychologist). One free individual encounter for participant selection was offered, and then ten sessions of group work for a total fee of 400 Euros.

Mary finally took part in three non-professionally led sessions, which allowed her to realise that "she was not alone", and that other infertile couples were dealing with similar reactions and worries as herself.

Clearly, other partners in a similar context of infertility but with more inquisitive personalities would consider the therapeutic group for a more in-depth exploration of their psychological situation.

In our centre, the couples confronted with donor issues were the most demanding for group work, particularly for the sharing of experiences. This encouraged us to create and implement biannual professionally led group encounters for the past 5 years.

A theoretical framework

So, what incites individuals to seek out a group setting in order to advance in their issues? And which worthwhile objectives have been identified? Irvin Yalom, in his comprehensive textbook on "The theory and practice of group psychotherapy" (2005), has established that group work allows for: the instillation of hope, universality ("I'm not alone"), imparting information, altruism, corrective recapitulation of the primary family group, development of socializing techniques, imitative behaviour, interpersonal learning, group cohesiveness, catharsis ("letting it out").

More specifically, the different themes encountered in infertility groups have been examined by Sharon Covington in this thoroughly interesting textbook: "Infertility Counselling: A comprehensive handbook for clinicians" (2005). These themes are: grief, the loss of control, gender differences, interpersonal relationships, partnership with the medical team, stress and coping, decision making, pregnant members, gaining knowledge on social and legal aspects of other family building options (gamete or embryo donation, surrogacy, adoption), adapting to pregnancy after MAP, and coming to terms with the possibility of a life without a pregnancy.

Different concepts of therapeutic frameworks are used in order to define the interventions and this choice will depend on the group leaders, their specific skills and training. The group work can be construed as: cognitive-behavioural, emotive-interactional, psycho-educational (our groups with donor insemination couples), staff groups, computer-mediated groups... different types of groups are being created each year and with the progression of internet accessibility, virtual online groups will probably become more clearly conceptualised as this means of interaction becomes even more popular.

While planning a group intervention, cultural factors represent an important concern. Very basically, how group work is seen in the community plays a role in how the recruitment strategy can be set up, for example by asking for the collaboration of specialised physicians or advertising in waiting rooms. How the group is named will be important as well: "sharing information concerning infertility treatments", or "relaxation techniques for stressful procedures" may be more enticing (especially for men) than "reflections on infertility" or "relaxing your body", which may appear too vague and open to interpretation. Furthermore, defining the number and necessary qualifications of the group leaders, the facilities, the agenda and financial issues, all contribute to the time consuming but creative process of setting up a group.

Steps for setting up a group

In conclusion, the following steps should be envisaged for setting up a group in the field of infertility and medically assisted procreation:

- Assess the clinical issues and target population, for example: infertility in general, open to all couples; donor insemination (DI), open to couples concerned with DI; unsuccessful treatment, for individuals or couples who have stopped ART treatment; over-40, for women reflecting on issues related to the limits of age; pregnancy after IVF, for women or couples dealing with the new issues of pregnancy …
- Formulate the main goals: information, alleviating stress, learning a relaxation technique, exchange of experiences, restoring harmony in the couples' relationship ...
- Define the technique: cognitive-behavioural, psycho-educational, computer-mediated ...
- Define the structure: selection and number of participants and of group leader(s), frequency and number of sessions, time and place, detailed outline of the sessions (a well organised session contributes to the serenity of the leaders!), evaluation by the participants (very important for all groups, to redefine the future sessions)

Group work is generally very rewarding, as it answers a basic human need to share a new emotional or a learning process, but the implementation can be difficult, due mainly to cultural or social aspects which inhibit initiative in this direction. Remaining attentive to the expressed needs of individuals and couples is the first step in the direction of group work.

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Developing and strengthening links to infertility clinics

Petra Thorn

Infertility counselling can be provided in various settings: Counsellors can be employed by clinics, they can have an independent practice or they can be independent practice consultants, i.e. use the facilities of a clinic (rooms, secretarial service), pay fees for these but not be employed by a clinic (for a summary of advantages and disadvantages of these different settings see the next chapter by Tschudin). The following will outline the work of independent counsellors working in private practice.

Networking

In many cases, independent counsellors do not come from the field of ART, but from counselling or psychotherapy in other areas. In order to develop professional links, it is important that they use existing networks and create their own local and/or national networks. Counsellors new in the area of infertility can join existing infertility counselling organisations in those countries where they exist and they can also become a member of the medical organisations for ART. Even if they may not qualify for relevant accreditation, membership has the advantage of receiving information on a regular basis and of establishing contact to other professionals in the area of infertility. Contact to relevant local self-help groups or national patient organisations (for infertility, endometriosis, adoption etc.) and to infertility clinics as well as related professionals in the field (gynaecologists, andrologists, general practitioners, couple therapists, national and cross-country adoption agencies, family counselling institutions, etc.) can help counsellors to become known in the field and can contribute to inter-professional exchange. In those countries where there is no infertility counselling organisation, counsellors can contact the International Infertility Counselling Organisation (IICO – www.iffs-iico.org) to receive support in setting up an organisation.

Self-promotion

Self-promotion is likely to be one of the more challenging issues for counsellors. Commonly, counsellors and psychotherapists have an in-depth knowledge of psychology and psychological interventions but during training do not learn how to go about if they want to open a practice. They need to be aware of any professional and/or ethical codes regarding common practices and restriction in the area of public advertisement and can contact professional bodies and/or organisation for psychologists to find out what may be appropriate in their country and for their profession. At a minimum, infertility counsellors should have a business card that they can disseminate to clinics, colleagues and potential clients. Where appropriate (and this is likely to be acceptable in most countries), leaflets with some information on infertility counselling and the expertise of the counsellor as well as a website which can provide more detailed information, can be developed and/or printed. When searching for a practice location, counsellors should ensure that it is accessible, easy to reach both by public transport and by car (parking lots available) as well as affordable. As most couples experiencing infertility are in the working force and prefer late afternoon or early evening appointments counsellors need to offer flexible times and can also consider

scheduling appointments on Saturdays. In some countries, fees for psychologists and/or counsellors are reimbursed by the national health scheme. In those countries where there is no reimbursement for infertility counselling, the fee charged for counselling sessions should both reflect the level of experience of the counsellor and be affordable for clients. In countries such as Germany, Great Britain, Belgium, The Netherlands and Switzerland, fees between € 50,00 and € 90,00 per (50 or 60 minute) session are common. Two possibilities of offering more affordable counselling support is to offer sliding fees (fees adapted to the income of clients) and to conduct group sessions, if counsellors are trained and feel comfortable in this setting.

Develop a pro-active stance

Independent counsellors need to be pro-active in offering their services. In order to establish cooperation with infertility clinics, they need to find a clinic geographically close to them and providing treatment they can provide counselling for. The next step is to develop collaboration with this clinic. Counsellors should show interest in medical treatment, i. e.

- spend some time in the clinic in order to familiarize themselves with the medical procedures,
- introduce themselves not only to the head doctor but to the entire team; nurses commonly have a lot of contact to patients and are a good source for referrals,
- do a presentation on the psychosocial aspects of infertility and the benefits of counselling for the medical team,
- offer training to medical and nursing staff on issues such as “breaking bad news”, “communication with distressed patients” etc.
- suggest and develop together a format for collaboration (In what situations could the clinic benefit from referring to a counsellor? For which patient groups is counselling important?),
- take part in so-called “information evening for patients” organised by the clinic and provide information on the benefits of counselling,
- normalize counselling by drawing attention to the fact that in an increasing number of countries, counselling has become part of the infertility treatment service,
- find an attractive topic in order to organise a public information event on infertility in their practice and invite the medical doctor to discuss the medical aspects of treatment (establish contacts to journalists, to the local media)

When establishing contact to medical professionals, one needs to be aware of different practice styles. In the medical setting, consultations usually last approx. 10 to 15 minutes, whereas counselling sessions last between 50 and 120 minutes. Medical doctors generally offer concrete solutions whereas psychosocial professionals offer hypothesis, explore options and focus on processes rather than solutions. Medical experts commonly expect short and concise feedback or recommendations and reports without hypothesis or speculation. Counsellors need to be able to communicate in a language free of their professional jargon and should be prepared to be challenged on evidence-based interventions: they need to be able to explain what works and what does not work.

Attract clients

In many countries and cultures, counselling and psychotherapy are associated with psychological disorders and only accessed if such disorders are considered to be severe. This can result in infertility counselling being considered a “last resort” both by the medical profession and by individuals and couples. Although of course, infertility counselling can extend beyond crisis intervention and include therapeutic interventions, this is commonly not the case. In many instances, between 5 and 10 sessions of counselling are sufficient to address relevant issues and support clients in alleviating the emotional burden associated with infertility. When designing material on infertility counselling, it can be helpful to stress this. Furthermore, counsellors can devise material that clinics can use for dissemination, that doctors and nurses can use in their consultations and that counsellors and psychotherapists in related areas can use. Such material can be hand-outs with simple indications when counselling can be helpful, a fact sheet promoting self-care or partner-care or a list with relevant educational literature and reputable website

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The benefits and challenges of being a counsellor as part of the infertility treatment team

Sibil Tschudin

Integrated vs. independent counselling

In principle there are two ways to offer infertility counselling, either by an employed, integrated counsellor who is a member of the infertility team, or by an independent counsellor. The position and the advantages of independent counsellors were discussed in the previous chapter by Petra Thorn. I will focus on benefits and challenges of integrated counselling. Integrated counselling can be offered by trained gynaecologists themselves or by psychologists. As Table 1 highlights, a true benefit of having a counsellor in the infertility team is that she/he is fully integrated in the clinic routine and as a consequence counselling is nothing extraordinary but considered to be an integral part of infertility treatment. Support in decision-making and coping with difficulties in the course of the ART may therefore be considered more natural and as a consequence lower the patients' barrier to make use of offers for psychological support. Integrated counsellors, however, could be more prone to violation of confidentiality. They have to be aware of possible coercion and repeatedly check for possible conflicts of interest.

	Independent practice	Independent practice consultant	Integrated counsellor
Coercion	None	Possible +	Possible++
Conflict of interest	None	Possible +	Possible ++
Confidentiality	Guaranteed +++	Guaranteed ++	Guaranteed+
Settings	Counsellor's needs and interests	In agreement with clinic	Clinic's needs and interests
Facilities	Own	Clinic's for a fee	Clinic's
Team	None	Exchange with clinic team Boundary violation / role- confusions +	Integration in clinic team Boundary violation / role- confusions ++
Cooperation	To be developed with clinic(s)	Close cooperation, informal exchange	Standardized cooperation, formal meetings
Significance of counselling	Optional offer	Standardized offer	Integrated component

Table 1: Integrated vs. independent counselling

Infertility counselling University Women's Hospital Basel – an example for integrated counselling

Offering psychological counselling is legally required in Switzerland and in our institution a specifically trained gynaecologist provides it. The offer is optional with the exception of several specified situations e.g. gamete donation, HIV-discordance and psychiatric conditions where psychological assessment and counselling is compulsory.

In 1999/2000 the content of a total of 65 consultations for 25 couples was analysed on the basis of the counselling gynaecologist's written reports. In 15 of 25 cases (60%) the infertility was mainly due to a male factor, in 10 cases (40%) to a female factor. Counselling was always offered to both partners, but in 8 of 25 couples the women came alone. Twenty-nine (44.6%) of the 65 sessions were attended by both partners together. Content analysis of the reports revealed 141 specific interventions (100%): problem assessment and clarification 24.1%, psychosocial exploration 28.4%, patient education 6.4%, decision-making and motivational counselling 12.8% and supportive and coping orientated counselling 28.4%. The mean number of consultations was 2.6 with a minimum of 1 and a maximum of 10. In 5 of the 25 couples (20%) the patient and the counsellor agreed on the need for psychotherapy and the respective patients were referred to a psychotherapist. We concluded that the integrated infertility counselling was an adequate and cost-efficient answer to the needs of a high percentage (80%) of the couples, who made use of this offer on demand. It provides short-term interventions with the aim of motivational clarification, support and empowerment and seems suitable to identify couples with need for more intensive psychotherapy.

Infertility counselling – particularities and requirements

The course of ART – especially in couples requiring support and counselling – is seldom straight forward. Infertility could therefore be characterised as a journey with an unknown destination and an unknown duration, during which momentous decisions have to be made, the couple's intensive cooperation is required and emotional strain is considerable. Psychological interventions that might be required are crisis intervention, assistance in decision-making, facilitating communication and addressing conflicts (partnership, family). Furthermore, relaxation techniques, treatment for sexual problems and discussing alternatives to biological offspring could be proposed. Integrated counsellors may provide some of these interventions more easily, as they are generally more flexible to answer urgent needs and emergencies. They might also be better prepared for some of the predominant intervention strategies, such as clarifying (i.e. medical and technical issues) and debriefing (i.e. of burdensome procedures), as they are more familiar with these aspects due to insight in clinic protocols and exchange with team.

Cooperation between physicians and counsellors

There are some typical differences between physicians and counsellors in communication style and patient approach. Physicians are used to determine the agenda, normally ask closed questions and thus suppress emotions. Counsellors, on the other hand, communicate in a patient-centred style, ask open questions and focus on emotional response. This is coherent when considering their tasks: the physician aims at optimizing treatment success and take-home-baby rate, while the counsellor at optimizing coping with the infertility problem. Ideally the two communication styles should complement each other and be applied according to the patients' needs. With their specific

communication skills, counsellors are also qualified to support the infertility staff. They can teach the various health professionals (i.e. physicians and nurses) communications skills and instruct them on how to meet the couples' needs best. Beyond that they can also support the team itself by providing skills in debriefing and disburdening in emotionally consuming situations, by discussing ethically conflicting cases with them and mediating in team conflicts. In conclusion counsellors play a key role in a holistic and individualised approach to couples with fertility problems. To the benefit of the couples concerned, counselling should therefore be an integral part of fertility treatment.

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