Review Article

Infertility Counselling: Alleviating the Emotional Burden of Infertility and Infertility Treatment

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Abstract

This article provides an overview of international developments in the area of infertility counselling. It informs about the development of international organizations and relevant professional standards and describes the need to make counselling accessible to all patients, especially those who experience great distress or display previous vulnerability. Whereas in previous years counselling focused on psychopathology; research shows that on average, men and women experiencing infertility are as healthy as others. Therefore, the aim of counselling is to reduce the emotional burden of infertility, help couples to consider the implication of family building alternatives and provide therapeutic care where relevant. In some instances, counsellors also have the task to carry out psychological assessments. For the sake of transparency, it is important to clearly differentiate between these two interventions. Last but not least, this article argues that much of our current knowledge is based on research carried out in Western societies, therefore lacking understanding and appreciation for the meaning of infertility in other cultures. Therefore we need more international debate across cultures to further our understanding and to honor different cultural values.

Keywords: Infertility, Medical Psychology, Counselling, Professional Organization

Introduction

There is increasing recognition that infertility counselling is a specialist type of counselling. This article provides an overview of relevant qualifications for psychosocial experts in this area, outlines which patients should be counselled and describes a variety of different counselling settings. It also addresses aims and effectiveness of counselling and the challenge of counselling versus assessment.

Qualification of infertility counsellors

For many years, patients have requested professional emotional support when undergoing medical treatment for infertility. This need has been addressed by individual psychosocial experts, who in some countries as early as the 1990s, have established professional associations for infertility counselling, such as the Mental Health Professional Group of the American Society for Reproductive Medicine in the USA; the British Infertility Counselling Association in the United Kingdom, the Australian and New Zealand Infertility Counselling Association, and the Beratungsnetzwerk Kinderwunsch Deutschland (Counselling Network for Infertility Germany) in Germany. Furthermore, in 2003, the International Infertility Counselling Organization was founded as an umbrella organization for national associations (1). These associations have not only facilitated academic and clinical collaboration among psychosocial professionals and between these and medical experts but have also developed professional standards for counselling in the areas of infertility and assisted reproductive technologies (ART). Although global qualification guidelines have not been developed, not least because of varying legal frameworks and cultural diversity, there is emerging agreement regarding professional standards. Most organizations require or at least recommend a university degree in the area of psychology or social work and in some countries, medical professionals and nurses with specialist counselling credentials are accepted. Many also necessitate professionals to have completed training in psychosocial counselling or therapy and to belong to a relevant professional body. This ensures knowledge and experience in counselling in general and adherence to professional codes. Furthermore, infertility counsellors must of course be knowledgeable about the psychosocial aspects of infertility and ART as well as relevant legal issues. Some organizations have developed their own codes of practice and accredited members must adhere to these (2). In Germany, as an example, this code stipulates that accredited infertility counsellors must be knowledgeable and experienced in the following areas (3):

• Psychology of infertility (typical and atypical responses to infertility and medical treatment,

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bereavement, crisis intervention)
• Individual (such as the impact of infertility on self-esteem), marital (such as gender differences and the impact on a couple's sexual relationship) and societal issues (such as the stigma and taboo associated with infertility)
• Family building alternatives (adoption, third party reproduction, living without children)
• Individual and couple counselling
• Medical treatment possibilities
• Pregnancy and birth following ART
• Alternative medicine relevant for infertility
• Legal and ethical issues related to ART.
Furthermore, they must have a minimum of clinical experience in infertility counselling and undergo regular supervision and continuing education.

Who should be counselled?
From a medical perspective, it is sometimes assumed that only individuals or couples suffering from severe distress should be referred to see a counsellor. However, from a psychosocial perspective, it is more helpful if counselling is routinely offered to all patients. Research suggests that men and women experiencing infertility have a positive attitude towards counselling (4). They consider this to be an opportunity to gain information prior to starting ART and desire counselling before invasive treatment and after treatment has failed. However, concern is also raised regarding the fear of stigmatization by making use of counselling and the experience of additional emotional strain. This is understandable as in some cultures the use of psychosocial support may be associated with a stigma because the uptake of counselling is unusual or because counselling and psychotherapy are associated with severe mental disorders. This elevates the threshold of accessing counselling as couples may consider counselling to be taken up only by those with serious psychological problems. Studies indicate however, if counselling is routinely offered, it is taken up by some 80% of patients and expected to be helpful by the majority (5). Although it is recommended to see both partners (4), there are gender differences and women are more likely to see a counsellor. It can be helpful to explain that infertility is a couple's issues and therefore necessitates both partners to attend at least the initial counselling session together. It can also be helpful to reframe counselling in a way that facilitates men the uptake, for example by offering information sessions on psychosocial aspects of infertility.
Many counsellors and infertility counselling organizations have become supportive of counselling to be routinely offered to all patients prior to treatment (6). This ensures that patients are informed about the availability of counselling and can access it if they feel it may be helpful. Research indicates that approximately 20-25% of couples make use of counselling (7), but research to date is limited to Western countries. The uptake of counselling in other cultures, especially in Islamic countries, may vary significantly from these numbers. The following criteria help to indicate which patients should be recommended to see a counsellor (6, 8):
• Individuals who experience great distress (individual or marital distress)
• Individuals who are psychiatrically at risk (previous psychiatric conditions)
• Couples who are indecisive or ambivalent
• Couples who require genetic counselling
• Women pregnant with multiples
• Couples who experience pregnancy loss
• Recipients of donor gametes

Setting for counselling
There are two distinct ways of providing counselling. A clinic can employ a counsellor who is part of the treatment team with equal status or a clinic can collaborate with a counsellor working independently. Both settings have advantages and disadvantages and it may be best to be able to offer both to patients. A counsellor working within a clinic symbolizes a high level of acceptance for the psychosocial issues related to infertility and provides easy access to counselling. In addition, commonly the counselling service by an in-house counsellor is free of charge. At the same time, it must be ensured that confidentiality is respected. Some patients prefer to see an independent counsellor as this makes it easier for them to separate between the physical and emotional issues related to infertility. It may also be easier to come to terms with infertility and accept a life without children if counselling is located outside the medical context (9).
Further settings include individual, couple and group counselling. Patients' needs and diagnosis can indicate a specific setting, for example, the appropriateness for couple counselling when there is marital distress. The value of group work should not be underestimated. Groups are helpful to reduce feelings of isolation, to normalize emotional reactions and to provide a network of like-minded people for on-going support (10). Groups are also an excellent forum for providing information and education to patients. Counsellors should be knowledgeable in and able to provide at least individual and couple counselling. It is helpful to establish contact with patient organizations or self-help groups or even to help initiate such groups so that couples can empower themselves (11).

Aims and effectiveness of counselling
Counselling should focus on the patients' needs and therefore, the aims may vary. Counselling

should provide information about infertility and treatment options and ensure that this information is understood. It should explore and discuss treatment options and consequences, including third party reproduction, adoption and living without children. It should also assist in the development of alternatives and long-term adjustment. Supportive and therapeutic counselling can improve the psychosocial well-being, reduce infertility-related stress, improve the tolerance for infertility, and facilitate communication and interaction among the couple and significant thirds.

Previously, when infertility was considered to be at least partially attributable to psychological causes, counselling was recommended in order to alleviate such psychological stressors and, as a consequence, to enable to couple to conceive. However, as men and women experiencing infertility are on the average as healthy as others [only approximately 15 – 20% suffer from psychological disorders (12)] counselling is unlikely to have an impact on pregnancy rates. Nevertheless, research indicates that psychosocial interventions are effective in:

• Reducing emotional distress such as anxiety (which can reduce drop-out rates from treatment)
• improving areas negatively affected by infertility and ART
• Teaching skills such as coping skills, relaxation techniques, reducing obesity
• Managing the implications of third party reproduction and
• Facilitating communication (13, 14)

Gender differences should be taken into account: although men and women may benefit equally from psychosocial interventions, men are more likely to seek and benefit from information and practical advice whereas women profit from sharing and validating emotions.

The following provides an outline of questions that can be raised by medical and psychosocial professionals with couples and individuals in order to gain a better understanding of their situation and in order to explore where patients can benefit from emotional support and counselling:

• How long have you had a wish for children?
• How has infertility and the wish for a child affected you private life, your marital relationship (incl. your sexual relationship), your ability to work and the contact you have with family members and friends?
• How satisfied are you with your professional situation? Do you have a lot of stress? Has infertility had any impact on your work satisfaction?
• Has your life changed in any way since you have tried to conceive?
• Do you have friends or family members with whom you can share your grief and who provide emotional support for you? If not, who could be supportive?
• Who of you is more upset, the male or the female partner? How do you manage this difference? What do you think your partner expects from you? How do you support each other? How can you enjoy marital life despite the fact that you are experiencing infertility?
• When did you start medical treatment? How many physical, emotional, and financial resources do you have to continue medical treatment? How would you notice if you have reached the limits of what you could bear?
• Have you considered other options such as gamete donation, adoption, or living without children? Who of you could accept gamete donation, adoption or a life without children more easily? What would your life look like in 5 years time if you remained without children? What possibilities of a life without children have you explored until now (4, 15)?

Counselling versus assessment

Although counselling and assessment are carried out by the same profession, these interventions serve to fulfil very different needs. Counselling addresses the patients' needs regarding support, assessment addresses the clinic's and/or society's needs regarding the appropriateness of service provision. It is vital for patients to understand the difference and for clinics to be transparent in what they offer or require. Whereas there is increasing consensus that counselling should be offered to all couples undergoing ART, there is only emerging discussion regarding a psychological assessment. In those cases where assessment is required, this is often mandated in order to ensure the welfare of the future child. In 2004, the American Society for Reproductive Medicine (ASRM) published a report on "Child-rearing ability and the provision of fertility services" (16). This report describes the competing interest between the infertility clinic, the couple seeking treatment and the potential child and established the following two exclusion criteria for medical treatment:

• A couple's inability to provide adequate child rearing and
• The likelihood of significant harm to offspring (i.e. previous history of child abuse or neglect, substance abuse, psychiatric illness).

Individuals with disabilities should not be denied access to ART unless there are well-substantiated concerns. The report also suggests clinics to develop written policies and procedures for determining when to withhold treatment and recommends decisions regarding the denial of access to be taken not by an individual but by a team.

Further challenges and controversies regard the entitlement of various groups accessing ART. In some countries such as the USA, Canada, United King-

dom and Australia, medical treatment is not restricted to heterosexual couples. Homosexual couples as well as single women and (so far in rare cases) single men can and do undergo treatment. In some of these countries, antidiscrimination legislation ensures that all individuals, independent of their marital status or sexual orientation, have a right to be treated; whereas in others, such as Germany, they are not excluded by legislation but by medical guidelines (17, 18). In other countries such as Iran, procreation is regarded to be only allowed within a family consisting of a mother and a father and homosexuality is considered to be a crime; thus, medical treatment is restricted to heterosexual and married couples (19).

In the last years, family building using third party reproduction has received increasing attention. Whereas previously, it was considered the best practice for medical professionals to recommend secrecy, (i.e. parents should inform neither child nor friends or family members of the child's conception with donor gametes), psychosocial professionals in Western cultures now recommend information sharing as well as counselling prior to treatment (20-22). In many countries, the welfare of the child and respect for the autonomy of people conceived with the assistance of donor gametes has contributed to this change.

Conclusion

The area of infertility counselling is extremely dynamic with increasing knowledge emerging as a result of clinical practice and research. It is important for counsellors to base their professional practice on current and evidence-based approaches. Thus, infertility counsellors must adhere to professional standards and undergo continuing education. In order to respect cultural differences such standards can be developed nationally while at the same time, sharing professional experience on an international level can contribute to further professionalization and to increasing awareness of cultural differences in this area. Much of the current debate in this area is based on Western values and assumptions. Couples' management strategies regarding the psychosocial implications of infertility, however, can only be understood in the context of their specific culture and religion. We therefore need more international debate across cultures to further our understanding and to honor different cultural values.

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