

**NFS****Nordic Fertility Society**

## **Clinical guideline**

The NFS clinical guidelines are an aid to fertility clinic staff. They should be viewed as the best recommendations available at the time of writing for principles relating to the examination and treatment of infertile couples. The examinations and treatments discussed should be seen as suggestions from among several alternatives, and not as the only options that can be used.

Each clinical situation, including the condition of the patient and other information, must be assessed individually by the fertility clinic staff, who should then act based on his or her experience, knowledge, and evaluation. Clinical science is constantly developing. New examination and treatment options may therefore arise. Some of these may be internationally recognised, but not yet assessed in relation to the existing guidelines.

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## **Psychosocial aspects of infertility and treatment**

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## Recommendations

The overall aim of the recommendations is to reduce infertile couples' burden of medically assisted reproduction. The majority of the recommendations are based on scientific literature described in the guidelines.

Infertile couples should be investigated and treated together, as infertility is a condition that has consequences for both partners and both partners are affected by decision-making throughout the treatment process.	D
The couples should be informed verbal and in writing (paper/internet) about investigations, treatments and psychosocial impact of infertility as couples needs this information to take part in the decision-making process.	C
The couple should be informed about which communication and coping strategies have shown to be emotionally beneficial.	B
It is recommended that the couple be informed about alternatives to assisted reproduction, such as adoption, fostering or other alternatives at the commencement of treatment, and at the conclusion of unsuccessful treatment processes.	√
It is recommended that one, or only a few, specialists have responsibility for the continuity of the treatment process for a given couple especially for tracking progress and summing up after treatment failure.	C
Fertility clinic staff should be aware of, have access to, and be able to refer to further mental health professional counseling for those patients who may need it.	D
It is recommended that couples who are in need have access to group-based interventions with an emphasis on teaching and skill training as these interventions are most effective in having a positive effect on psychological well-being.	B
Couples should be informed of the possibility of contacting support groups and organizations for infertile people	√
Fertility doctors should clearly conclude the treatment process for couples who have been unsuccessful after sufficient relevant options have been attempted, so that the couple is well aware that further treatment has a low probability of success.	√
Fertility clinics staff should inform the couple that it is important for children, from childhood, to be aware of their own origins, and that keeping these origins a secret from the child while sharing this information with others can lead to serious psychosocial consequences for the child.	C

The majority of fertility patients are heterosexual, infertile couples. This guideline does not cover psychosocial aspects of fertility treatment among single women and lesbian couples, although some of these fertility patients may also suffer from biological infertility.

When fertility patients are in a couple it is the couple and not the single individual that is the patient. Infertile couples should be examined and treated together. This is in accordance with recommendations from WHO (Rowe et al., 1993) and the British NICE Fertility Guideline (NICE, 2013).

Despite the similarities of the public health care system in the Nordic welfare countries, there are huge differences according to whether or not mental health professionals are employed and part of the clinical work at public fertility clinics. In Iceland, Finland and Sweden a range of mental health professionals (psychologists, social workers, therapists, psychiatrists, counsellors) are employed at or associated with fertility clinics, whereas in Norway and Denmark in general no mental health professionals are employed at public fertility clinics. Consequently, the recommendations in this psychosocial guideline reflect these differences in organisation of public health care within fertility treatment.

## **Literature review**

Searches have been performed in the Pubmed and Psychinfo databases using the following key words: (fertility problem) stress, anxiety, depression, mental well-being, quality of life, coping, patient satisfaction, patient-centred care, drop-out, discontinuation of care, psychological intervention, support group, psychotherapy, randomized controlled trial (RCT), meta-analysis, review, cohort studies, infertility, and assisted reproduction, in various combinations. References from retrieved articles have also been consulted. Whenever possible we have preferred publications based on meta-analysis, systematic reviews, longitudinal cohort studies or RCT for intervention studies. Literature relating to non-industrialised countries has been excluded, as infertility is experienced and assessed differently in different cultures. In line with this, we have - when possible - selected studies from the Nordic welfare countries as Nordic countries are all organized by a dual- bread-winner policy where both women and men combine family formation and being on the labour market. This societal organisation could potentially have an impact on how infertility and permanent involuntary childlessness are experienced.

Please, be aware that the highest evidence level for studies investigating psychosocial consequences of infertility and its treatment is evidence level 2a (non-randomized studies, cohort or case-control studies) as neither randomized control studies (RCT) or meta-analysis of RCT (evidence level 1a) is possible to conduct in this research area. For interventions the highest evidence level possible is RCT or meta-analyses of RCT (evidence level 1a or 1b).

The far majority of studies about psychosocial consequences of infertility are based on samples of fertility patients, and scientific knowledge about consequences of infertility among those couples not seeking treatment is very limited.

This guideline focuses on 1) the psychosocial consequences of infertility and treatment, 2) how communication and coping strategies are related to the level of infertility-related stress, 3) fertility patient's needs and assessment of treatment, 4) how to reduce the patients' burden of medically assisted reproduction (MAR), and lastly 5) the important problem that the majority of parents disclose to some other people how the child came into the family but do not always tell this knowledge to the most important person – the child.

## **Psychosocial consequences of infertility and treatment**

### **Strain**

For many couples, infertility and its associated treatment causes psychosocial strain for the individual, for the couple's relationship, and for their relationships to family, friends and colleagues. Infertility is often a key issue in relation to identity, and infertile persons may experience impaired gender identity. Being infertile represents a loss in relation to expectations for how one's life is going to play out, and a loss of control. Many infertile persons experience repeated existential crises, where they begin to doubt that life has meaning. Infertile couples also often experience unwanted exclusion from various social contexts. Nearly all studies confirm that women in infertile relationships report higher level of infertility-related stress than their partners (Greil et al., 2010) (evidence level 3).

### *Mental health prior to fertility treatment*

Systematic reviews confirm that in general infertile women and men do not differ from the background population according to emotional status (Greil, 1997; Verhaak et al., 2007a) (evidence level 3). In general women with infertility treatments has fewer hospitalizations due to psychiatric disorders compared to the background population (Yli-Kuha et al., 2010; Sejbaek et al., 2013) (evidence level 2a). Based on a Danish national register-based study among women in

assisted reproductive technology treatment (ART) 380/42880 (0.9%) had had a diagnosis for depression in the national Psychiatric Central Register prior to ART treatment; of which 65% had their most recent depression diagnosis within a 5-year period prior to ART (Sejbaek et al., 2013) (evidence level 2a). Longitudinal cohort studies based on self-reported questionnaires have shown prevalence of having severe depressive symptoms or a major depression of 11-15% among women and 5-6% among men at fertility treatment initiation (Volgsten et al., 2008; Lund et al., 2009) (evidence level 3). Any anxiety disorder was reported among 15% of the women and 5% of the men (Volgsten et al., 2008).

#### *Mental health during fertility treatment*

A systematic review of studies on women's emotional adjustment to IVF showed that during treatment the level of depression increased after one or more unsuccessful treatment cycles in all reviewed studies, whereas level of anxiety increased in the majority of the studies reviewed (Verhaak et al., 2007a) (evidence level 2a). A longitudinal cohort study among couples in unsuccessful treatment showed that 15% of women and 6% of the men have developed severe depressive symptoms at the 1-year follow-up (Lund et al., 2009) (evidence level 2a). Women showed a decrease in depression and anxiety level after successful treatment, but among men no changes in depression and anxiety were found after unsuccessful or successful treatment (Verhaak et al., 2005) (evidence level 2a).

#### *Pre-treatment stress and probability of achieving pregnancy*

For years it has been questioned whether high levels of distress (anxiety and depressive symptoms) among women in fertility treatment are predictors of lower probability for achieving pregnancy. Two recent meta-analyses of prospective psychosocial cohort studies showed that pre-treatment level of depressive symptoms was not related with treatment outcome (Boivin et al., 2011a; Matthiesen et al., 2011) (evidence level 2a). With regard to pre-treatment level of anxiety one of the meta-analyses' found no association between anxiety and treatment outcome (Boivin et al., 2011a). However, the second meta-analysis reported a small, but statistically significant negative association between anxiety level and clinical pregnancy but no significant association between anxiety and serum pregnancy test or live birth rates (Matthiesen et al., 2011). These differences in associations indicate, as also recommended by the authors, to be cautious regarding this latter finding.

#### *Treatment strain and discontinuation of treatment*

Medically assisted reproduction (MAR) treatment is in itself a multidimensional stressor. The treatment itself is most likely to evoke anxiety and the unpredictable outcome of treatment is another major stressor (Verhaak et al., 2007a). Besides the emotional strain during treatment, many fertility patients also experience a relief in being in professional care (Schmidt, 1996) (evidence level 3). A longitudinal interview study of couples' decision-making process during treatment showed that the core was to maintain control in an uncertain situation, when trying to keep focus on the goal to become parents (Sól Ólafsdóttir, 2012).

Discontinuation (drop out) of treatment refers to patients who after a failed cycle decided not to proceed with further treatment despite a favourable prognosis (Boivin et al., 2012). Even in countries with tax-financed fertility treatment in the public health care sector up to 30% end treatment prematurely due to the psychological burden (Olivius et al., 2004). A systematic review has shown that the main reason for discontinuing treatment is the emotional strain during treatment (Gameiro et al., 2012). For men, difficulties in partner communication and for women, frequent partner conflicts are predictors of treatment termination after one year of unsuccessful treatment. Furthermore, low support from family is also a predictor for treatment termination (Vassard et al., 2012) (evidence level 2a).

### **A stronger relationship**

While infertility is a psychosocial burden, some infertile couples also find that it strengthens their relationship and draws them closer together (Daniluk, 2001; Schmidt et al., 2005a; Sól Ólafsdóttir et al., 2013) (evidence level 3). A longitudinal cohort study with 5-year follow-up among couples in unsuccessful treatment showed that nearly a third of women and men experienced high marital benefit (Peterson et al., 2011) (evidence level 2a).

### **Sexual relationship**

A systematic review of the few existing studies on sexual disorders causing infertility estimated conservatively that up to 5% of infertility is caused by sexual dysfunctions (Wischmann, 2010) (evidence level 3). However, being infertile has a potential severe impact on the couple's sexual relationship and both men and women experience loss of control and confidence in their body (Peterson et al., 2012). Many couples undergoing fertility treatment frequently experiences that their sex life deteriorates during the treatment process, but also following the conclusion of treatment (Greil, 1997; Wischmann, 2010; Peterson et al., 2012) (evidence level 3). A longitudinal cohort study among couples receiving IVF/ICSI treatment found that women's dissatisfaction with their sex life increased, regardless of the outcome of treatment. For men, dissatisfaction with their

sex lives only increased in the group where the couple achieved pregnancy (Verhaak, 2003). A 10-year follow-up study (Wischmann et al., 2012) and a 20-year follow-up study of fertility patients (Sydsjö et al., 2011) reported no differences in sexual satisfaction between childless women and men and mothers/fathers (evidence level 2a).

### **After unsuccessful treatment**

A systematic review of studies on women's emotional reactions to IVF concluded that "in general most women adjust well to unsuccessful IVF, although a considerable group showed subclinical emotional problems" (Verhaak et al., 2007a) (evidence level 2a and 3). A longitudinal, prospective cohort study has shown an increased level of anxiety and depressive symptoms among women who did not achieve pregnancy following IVF treatment, six months after the last treatment cycle (Slade et al., 2007; Verhaak et al., 2005) (evidence level 2a). Women who had not achieved a live birth 3-5 years after treatment termination showed depression and anxiety levels similar to the pre-treatment levels. Higher levels of depression and anxiety were found among those women still pursuing a desire for pregnancy (Verhaak et al., 2007b) (evidence level 2a). Among men increased levels of depressive symptoms and a lower degree of satisfaction with their relationship had been found among those men who were partners to a woman who did not achieve pregnancy (Slade et al., 1997). A qualitative interview study 3 years after end of IVF-treatment found that most men and women were still in the process and had not adopted to childlessness. Women experienced the unsuccessful IVF in terms of grief, whereas the men took a supportive role and did not express grief (Volgsten et al., 2010).

A follow-up study about quality of life among women and men 4-5.5 years after unsuccessful IVF treatment compared to parents after successful IVF treatment and parents without IVF treatment, showed for both men and women in the unsuccessful IVF group a higher level of depressive symptoms, lower general well-being and lower sense of coherence (i.e., global orientation measuring comprehensibility, manageability, and meaningfulness) (Johansson et al., 2009; Johansson et al., 2010) (evidence level 2a). In line with this a population-based study showed that childless women with infertility experience had increased risk of dysthymia and anxiety disorders compared to women without infertility experience, and childless men with infertility experience had a significantly poorer quality of life compared to men without infertility (Klemetti et al., 2010) (evidence level 3).

Besides these findings women and men after having terminated unsuccessful fertility treatment frequently describe their relationship as stable, good or adequate (Sydsjö et al., 2005; Sundby et

al., 2007; Sydsjö et al. 2011) (evidence level 2a and 3). These findings could reflect that couples seeking fertility treatment are in general having strong relationships as this is requirement for overcoming the strains during treatment. Although couple relationships are stable, studies among women report how the infertility experience was a bad memory and had influenced negatively their relationship with their partner for several years (Sundby et al., 2007; Wirtberg et al., 2007). The effect of childlessness was again increased during the years where the women's peer group was becoming grandparents (Wirtberg et al., 2007) (evidence level 3).

## **Conclusion**

The frequently severe psychosocial strain following infertility among couples who have sought fertility treatment is well-documented. Longitudinal cohort studies suggest that such strain continues after having terminated unsuccessful treatment. Both men and women having been through unsuccessful treatment report also in the long run lower general well-being and lower quality of life compared to men and women having achieved parenthood. Knowledge based on large-scale long-term follow-up studies among both men and women continues to be sparse. Finally, there is documentation that around 25-30% of infertile couples may experience that infertility has strengthened their relationship, along with the strain.

## **Coping and communication**

Infertility and its treatment are severe, long-lasting, multidimensional, and low-control stressors. Infertile couples have to learn to cope with their infertility in relation to themselves, their partner and other people. In order to reduce psychological distress infertile men and women use avoidance coping strategies such as avoiding people with children, working more or doing other activities to avoid thinking about infertility, hoping for a miracle, and keeping one's feelings to oneself. However, a meta-analysis of gender differences in coping with infertility (Jordan & Revenson, 1999) as well as longitudinal cohort studies among couples receiving fertility treatment have consistently shown that use of avoidance coping strategies are significant predictors for increased psychological stress (Berghuis & Stanton, 2002; Peterson et al., 2009) (evidence level 2a).

Conversely, coping strategies whereby the person attempts to solve the problem, expresses their feelings to others, seeks support and advice, or is able to find meaning in their infertility, are associated with a lower level of psychosocial strain (Berghuis & Stanton, 2002; Schmidt et al., 2005b; Peterson et al., 2009) (evidence level 2a).



Where a person has difficulty speaking to their partner about infertility, this is a predictor of a higher level of fertility related stress (Schmidt et al., 2005b) (evidence level 2a). Men who keep their infertility secret from other people, are less likely to report that the infertility has strengthened their relationship (Schmidt et al., 2005a) (evidence level 3). There is also evidence to suggest that both men and women who only speak to other people about the factual aspects of infertility, and not the emotional aspects, have a higher risk of experiencing a high stress level (Schmidt et al., 2005b).

## **Conclusion**

Among couples receiving fertility treatment, knowledge now exists about which communication and coping strategies are associated with the risk of high infertility related stress or the probability of a lower level of stress. Information about beneficial coping and communication strategies should be provided to patients.

## **Patient' needs and assessment of fertility treatment**

### **The medical care**

Fertility patients are generally very satisfied or satisfied with the medical treatment (Mounce, 2013). Patients want detailed and timely oral and written information about treatment methods and other information to support their decision-making (Mounce, 2013) (evidence level 3), and 25% reported at the beginning of treatment that they also felt information on adoption was important (Schmidt et al., 2003a). A randomised, controlled trial among men referred to an andrological clinic found that men who had received written information about the examination process prior to the first consultation experienced significantly less psychological strain than the control group (Pook et al., 2005) (evidence level 1b).

Pregnancy and birth following treatment are predictors for a higher degree of satisfaction with treatment (Dancet et al., 2010) (evidence level 2a). Among women, a high level of infertility related stress and/or the fact that the man was infertile were predictors for a lower degree of satisfaction with the medical fertility care. The assessment that infertility had strengthened the couple's relationship was a predictor for a high degree of satisfaction with the treatment (Schmidt et al., 2003b).

### **Psychosocial care**

The patient-centred care covers the psychosocial care and support offered routinely by all of the personnel (Bovin & Kentenich, 2002). The majority of patients report at the commencement of

fertility treatment that patient-centred care is important. A longitudinal cohort study from Denmark having no mental health professionals employed at the fertility clinics, showed that fertility patients in general assessed the psychosocial care as satisfying or good. The care provided regarding how the fertility clinic staff took care of the emotional problems achieved a lower satisfaction rating (Schmidt et al., 2003b) (evidence level 2a). A high level of infertility-specific stress was predictive of lower satisfaction ratings, while having high marital benefit and having achieved pregnancy/delivery at the 1- year follow-up were predictors of higher satisfaction ratings with psychosocial care (Schmidt et al., 2003b).

### **Professional psychosocial services**

These services cover the professional support, advice and therapy provided by people who have been specially trained in these areas (Boivin & Kentenich, 2002; Peterson et al., 2012). The public health care systems in the Nordic countries is different according to whether or not mental health professionals (e.g. psychologists, social workers, therapists, psychiatrists, counsellors) are employed or associated with public fertility clinics or not. In Iceland, Finland and Sweden mental health professionals are employed at or associated with fertility clinics, whereas in Norway and Denmark in general no mental health professionals are employed at public fertility clinics.

Counselling covers a) implication and decision-making counselling on the implications of the suggested treatments and results and what decisions to make; b) support and short-time counselling, covering emotional support before, during and after treatment also after a failed treatment cycle; c) crisis counselling and therapeutic counselling, which aims to help fertility patients handle the situation they are facing (Boivin & Kentenich, 2002; Peterson et al., 2012).

A systematic review of various psychosocial interventions found that the interventions generally have a positive effect on the psychological well-being of the participants. Group-based interventions which emphasised teaching and skill training were more effective than interventions focusing on emotional support and the discussion of thoughts and feelings in connection with infertility treatment (Boivin, 2003) (evidence level 2a and 3). A meta-analysis of psychotherapeutic interventions found corresponding positive effects in terms of reduced anxiety and depressive symptoms (de Liz & Strauss, 2005) (evidence level 2a and 3). In contrast, a meta-analysis examining mental health and pregnancy rates after psychological interventions reported no significant effect regarding mental health (depression, anxiety, mental distress), but a positive

impact on pregnancy rates only among patients receiving other medically assisted reproduction treatments than ART (IVF/ICSI) (Hämmerli et al., 2009) (evidence level 1b).

### **Patient-centred care**

Recently the concept patient-centred medicine has been brought into medically assisted reproduction treatment as patient-centred reproductive medicine (Dancet et al., 2010). Patient-centred care is defined as “care that is respectful of and responsive to individual patient preferences and needs and that is guided by patient values” (Corrigan, cited from Dancet et al., 2010).

A systematic review showed that overall fertility patients had besides the need for medical skills, accessibility, information and coordination a need for: respect for the patient’s values, preferences and needs; emotional support and alleviation of fear and anxiety; partner involvement; and a good attitude of and relationship with fertility clinic staff including continuity and transition (Dancet et al., 2010) (evidence level 2a and 3). A cross-sectional study found significant associations between reporting higher levels of patient-centred care and lower levels of anxiety and depression or higher levels of quality of life, respectively (Aarts et al., 2012) (evidence level 3).

### **Conclusion**

Fertility patients consider both medical care and psychosocial care to be important. Fertility clinic staff (e.g., doctors, nurses, biologists, embryologists, laboratory technicians, administrators) should provide the medical and the psychosocial care, whereas to offer professional psychosocial services requires mental health professionals. Psychosocial interventions involving teaching, skills training, counselling and/or therapy, reduce the stress load on couples. It is not yet clear whether reducing the stress level leads to a subsequent improved probability of achieving pregnancy. The concept patient-centred reproductive medicine is of importance for delivering MAR treatments of high quality.

## **Reducing the fertility patients' burden**

It is of importance to offer medically assisted reproduction (MAR) treatment of high quality, which among other things includes efficient treatment with high success rates (singleton live births); treatments being safe for the child and the patients; well-organized treatment; and treatment reducing the patients' burden of MAR.

### **Psychosocial care**

As mentioned psychosocial care is the care routinely provided by all fertility clinic staff. Strategies for reducing the burden of MAR covers among other things: development of patient information and education materials, identifying patients at high risk for psychological vulnerability, ensuring both partners involved in treatment, improve organization of care and simplified treatment protocols (for further suggestions and details, see Boivin et al., 2012).

### **Professional psychosocial services**

In countries with mental health professionals (MHP) employed at/associated with fertility clinics the MHP offers to those patients' in need infertility counselling and possibly short-term psychotherapy mainly focused on depression and anxiety.

Instruments for psychosocial screening have been developed: SCREENIVF is a pre-treatment screening tool for women initiating ART treatment and the test is highly predictive of high treatment stress (Verhaak et al., 2010). The Fertility Quality of Life Tool (FertiQoL) (see [ww.fertiqol.org](http://www.fertiqol.org)) is available in 23 languages and internationally developed to assess the impact of fertility problems and treatment on personal, social and relational life domains (Boivin et al., 2011b).

Besides offering counselling the MHP is conducting psychosocial evaluation of patients before treatment when needed, contributes to patient information and educational material, discuss couple's treatment process with medical staff, offer group-based educational and training interventions for patients, is involved in educating the fertility clinic staff in psychosocial aspects of infertility and its treatment, and initiate and conduct psychosocial infertility research. (for further details and suggestions, see Peterson et al., 2012).

## Disclosure and non-disclosure

Overall studies shows that families established after MAR are not different from other families. The children develop cognitively and psycho-emotionally as children conceived without use of MAR treatment (review, Hammarberg et al., 2008).

Studies have consistently reported that the majority or almost all parents have disclosed to someone else that their child was conceived after MAR treatment. Most of the parents have told or intended to tell the child how the child came into the family.

However, having used semen donation is a significant predictor for not planning to disclose to the child (Rosholm et al., 2010) (evidence level 2a). In Sweden, where identifiable donation has been the only legal treatment since 1985, a follow-up among all couples having a donor conceived child during 1985-1997 showed that only 11% had disclosed to their child, but 59% had told someone else (Gottlieb et al., 2000) (evidence level 3). More recent studies indicates an increase in percentage of disclosure both in families with children conceived with anonymous gametes and with open-identity donation (Isaksson et al., 2011; Sälevaara et al., 2013; Söderström-Anttilla et al., 2010) (evidence level 3). Some parents request additional information and support on how to tell their child how the family was established (Isaksson et al., 2011; Sälevaara et al., 2013).

Relatively few interview studies have been carried out involving youths and children born following treatment with donated gametes. Overall, studies based on offspring after semen donation suggest there is a clear difference between those who have been aware of their origins throughout their childhood, and those for whom their origins have been kept secret and discovered probably by accident. Those who had been aware of their origins since childhood expressed happiness about having been created, and the feeling of being especially wanted. For those who had discovered their true origins by accident as adults, this typically gave rise to an identity crisis, a breach in the person's own life narrative, and mistrust of their parents and other people who had kept such significant knowledge secret (Kirkman, 2003) (evidence level 3). Jadva et al. (2009) has in a descriptive study among donor conceived youths and adults shown that disclosure after the age of 18 was associated with increased level of feeling confused, shocked, upset and angry compared to participants where their origin has not been a secret to them (evidence level 3).

**Conclusion**

Narrative identity is of importance for all people. It is important that fertility clinic staff inform couples of the major significance of the child being aware throughout childhood of how the child came into the family (Daniels, 2007) – that this account of origin forms part of the natural narrative of the child's life. It is also important that fertility clinic staff inform the couple of the potential serious consequences for their child later in life if the child's origin is kept secret from the child, but have been disclosed to other members of family and friends. However, there is no empirical evidence that full non-disclosing to both the child and to all other people would be harmful towards the child. Furthermore, it is of importance to provide information and if needed to refer to professional psychosocial service for providing support on how best to inform the child.

## References

Aarts JWM, Huppelschoten AG, van Empel IWH, Boivin J, Verhaak CM, Kremer JAM et al. How patient-centred care relates to patients' quality of life and distress: a study of 427 women experiencing infertility. *Hum Reprod* 2012; 27: 488-495.

Berghuis JP, Stanton AL. Adjustment to a dyadic stressor: a longitudinal study of coping and depressive symptoms in infertile couples over an insemination attempt. *J Consult Clin Psychol* 2002; 70: 433-438.

Boivin J. A review of psychosocial interventions in infertility. *Soc Sci Med* 2003; 57: 2325-2341.

Boivin J, Domar A, Shapiro DB, Wischmann TH, Fauser BCJM, Verhaak C. Tackling burden in ART: an integrated approach for medical staff. *Hum Reprod* 2012; 27: 941-950.

Boivin J, Griffiths E, Venetis CA. Emotional distress in infertile women and failure of assisted reproductive technologies: meta-analysis of prospective psychosocial studies. *BMJ* 2011a; 342: d223.

Boivin J, Kenter H, eds. Guidelines for counselling in infertility. ESHRE Monographs. ESHRE, 2002.

Boivin J, Takefman J, Braverman A. Development and preliminary validation of the fertility quality of life (FertiQoL) tool. *Hum Reprod* 2011b; 26: 2084-2091.

Dancet EAF, Nelen WLDM, Sermeus W, De Leeuw L, Kremer JAM, D'Hooghe TM. The patients' perspective on fertility care: a systematic review. *Hum Reprod* 2010; 16: 467-487.

Daniels K. Donor gametes: anonymous or identified? *Best Pract Res Clin Obstet Gynecol* 2007; 21: 113-128.

Daniluk J. Reconstructing their lives: A longitudinal, qualitative analysis of the transition to biological childlessness for infertile people. *J Couns Dev* 2001; 79: 439-449.

de Liz TM, Strauss B. Differential efficacy of group and individual/couple psychotherapy with infertile patients. *Hum Reprod* 2005; 20:1324-1332.

Gameiro S, Boivin J, Peronace L, Verhaak CM. Why do patients discontinue fertility treatment? A systematic review of reasons and predictors of discontinuation in fertility treatment. *Hum Reprod Update* 2012; 18: 652-659.

Gottlieb C, Lalos O, Lindblad F. Disclosure of donor insemination to the child: the impact of Swedish legislation on couples' attitudes. *Hum Reprod* 2000; 15: 2052-2056.

Greil AL. Infertility and psychological distress: a critical review of the literature. *Soc Sci Med* 1997; 45:1679-1704.

Greil AL, Slauson-Blevins K, McQuillan J. The experience of infertility: a review of recent literature. *Soc Health Illness* 2010; 32: 140-162.

Hammarberg K, Fisher JRW, Wynter KH. Psychological and social aspects of pregnancy, childbirth and early parenting after assisted reproduction: a systematic review. *Hum Reprod Update* 2008; 14: 395-414.

Hämmerli K, Znoj H, Barth J. The efficacy of psychological interventions for infertile patients: a meta-analysis examining mental health and pregnancy rate. *Hum Reprod* 2009; 15: 279-295.

Isaksson S, Skoog Svanberg A, Sydsjö G, Thurin-Kellberg A, Karlström P-O, Solensten N-G et al. Two decades after legislation on identifiable donors in Sweden: are recipient couples ready to be open about using gamete donation? *Hum Reprod* 2011; 26: 853-860.

Jadva V, Freeman T, Kramer W, Golombok S. The experience of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type. *Hum Reprod* 2009; 24: 1909-1919.

Johansson M, Adolfsson A, Berg M, Francis J, Hogström L, Janson PO et al. Quality of life for couples 4-5.5 years after unsuccessful IVF treatment. *Acta Obstet Gynecol Scand* 2009; 88: 291-300.

Johansson M, Adolfsson A, Berg M, Francis J, Hogström L, Janson PO et al. Gender perspective on quality of life, comparisons between groups 4-5.5 years after unsuccessful or successful IVF treatment. *Acta Obstet Gynecol Scand* 2010; 89: 683-691.



Kirkman M. Parents' contributions to the narrative identity of offspring of donor-assisted conception. *Soc Sci Med* 2003; 57: 2229-2242.

Klemetti R, Raitanen J, Sihvo S, Saarni S, Koponen P. Infertility, mental disorders and well-being – a nationwide survey. *Acta Obstet Gynecol Scand* 2010; 89: 677-682.

Lund R, Sejbaek CS, Christensen U, Schmidt L. The impact of social relations on the incidence of severe depressive symptoms among infertile women and men. *Hum Reprod* 2009; 24: 2810-2820.

Malin M, Hemminki E, Räikkönen O, Sihvo S, Perälä M-L. What do women want? Women's experiences of infertility treatment. *Soc Sci Med* 2001; 53: 123-133.

Matthiesen SMS, Frederiksen Y, Ingerslev HJ, Zachariae R. Stress, distress and outcome of assisted reproductive technology (ART): a meta-analysis. *Hum Reprod* 2011; 26: 2763-2776.

Mounce G. An overview of information giving in fertility clinics. *Hum Fertil* 2013; 16: 8-12.

NICE (National Institute for Health and Clinical Excellence) Clinical Guideline 156. Fertility: assessment and treatment for people with fertility problems. 2013, UK.

Olivius C, Friden B, Borg G, Bergh C. Why do couples discontinue in vitro fertilization treatment? A cohort study. *Fertil Steril* 2004; 81: 258-261.

Peterson B, Boivin J, Norré J, Smith C, Thorn P, Wischmann T. An introduction to infertility counselling: a guide for mental health and medical professionals. *J Assist Reprod Genet* 2012; 29: 243-248.

Peterson BD, Pirritano M, Block JM, Schmidt L. Marital benefit and coping strategies in men and women undergoing unsuccessful fertility treatments over a 5 year period. *Fertil Steril* 2011; 95: 1759-1763.

Peterson BD, Pirritano M, Christensen U, Boivin J, Block J, Schmidt L. The longitudinal impact of partner coping in couples following 5 years of unsuccessful fertility treatments. *Hum Reprod* 2009; 24: 1656-1664.

Pook M, Krause W. Stress reduction in male infertility patients: a randomized, controlled trial. *Fertil Steril* 2005; 83: 68-73.

Rosholm R, Lund R, Molbo D, Schmidt L. Disclosure patterns of mode of conception among mothers and fathers – 5-year follow-up of the Copenhagen Multi-centre Psychosocial Infertility (COMPI) cohort. *Hum Reprod* 2010; 25: 2006-2017.

Rowe PJ, Comhaire FH, Hargreave TB, Mellows HJ. WHO manual for the standardized investigation and diagnosis of infertile couples. Cambridge University Press, Avon 1993.

Schmidt L, Holstein BE, Christensen U, Boivin J. Does infertility cause marital benefit? An epidemiological study of 2250 women and men in fertility treatment. *Patient Educ Couns* 2005a; 59: 244-251.

Schmidt L, Holstein BE, Christensen U, Boivin J. Communication and coping as predictors of fertility problem stress: cohort study of 816 participants who did not achieve a delivery after 12 months of fertility treatment. *Hum Reprod* 2005b; 20: 3248-3256.

Schmidt L, Holstein BE, Boivin J, Sångren H, Tjørnhøj-Thomsen T, Blaabjerg J, Hald F, Nyboe Andersen A, Rasmussen PE. Patients' attitudes to medical and psychosocial aspects of care in fertility clinics: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. *Hum Reprod* 2003a; 18: 628-637.

Schmidt L, Holstein BE, Boivin J, Tjørnhøj-Thomsen T, Blaabjerg J, Hald F, Rasmussen PE, Nyboe Andersen A. High ratings of satisfaction with fertility treatment are common: Findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. *Hum Reprod* 2003b; 18: 2638-2646.

Sejbaek CS, Hageman I, Pinborg A, Hougaard CO, Schmidt L. Incidence of depression and influence of depression on the number of treatment cycles and births in a national cohort of 42 880 women treated with ART. *Hum Reprod* 2013; 28: 1100-1109.

Slade P, Emery J, Lieberman BA. A prospective, longitudinal study of emotions and relationships in in-vitro fertilization treatment. *Hum Reprod* 1997; 12: 183-190.

Sól Ólafsdóttir H. Nordic and infertile. A study of options and decisions. [PhD dissertation]. Nordic School of Public Health, Gothenburg, Sweden, 2012.

Sól Ólafsdóttir H, Wikland M, Möller A. Nordic couples decision-making processes during assisted reproduction treatments. *Sex Reprod Healthcare* 2013; 4: 49-55.

Sundby J. Long-term psychological consequences of infertility: a follow-up study of former patients. *J Womens Health* 1992; 1: 209-216.

Sydsjö G, Ekholm K, Wadsby M, Kjellberg S, Sydsjö A. Relationships in couples after failed IVF treatment: a prospective follow-up study. *Hum Reprod* 2005; 20: 1952-1957.

Sydsjö G, Skoog Svanberg A, Lampic C, Jablonowska B. Relationships in IVF couples 20 years after treatment. *Hum Reprod* 2011; 26: 1836-1842.

Sälevaara M, Suikkari A-M, Söderström-Anttila V. Attitudes and disclosure decisions of Finnish parents with children conceived using donor sperm. *Hum Reprod*, E-pub ahead of print August 1, 2013.

Söderström-Anttila V, Sälevaara M, Suikkari A-M. Increasing openness in oocyte donation families regarding disclosure over 15 years. *Hum Reprod* 2010; 25: 2535-2542.

Verhaak CM. Emotional impact of unsuccessful fertility treatment in women [PhD dissertation]. Ponsen & Looyen BV, Wageningen 2003.

Vassard D, Lund R, Pinborg A, Boivin J, Schmidt L. The impact of social relations among men and women in fertility treatment on the decision to terminate treatment. *Hum Reprod* 2012; 12: 3502-3512.

Verhaak CM, Lintsen AME, Evers AWM, Braat DDM. Who is at risk of emotional problems and how do you know? Screening of women going for IVF treatment. *Hum Reprod* 2010; 25: 1234-1240.

Verhaak CM, Smeenk JMJ, Evers AWM, Kremer JAM, Kraaijmaat FW, Braat DDM. Women's emotional adjustment to IVF: a systematic review of 25 years of research. *Hum Reprod Update* 2007a; 13: 27-36.

Verhaak CM, Smeenk JMJ, Nahuis MJ, Kremer JAM, Braat DDM. Long-term psychological adjustment to IVF/ICSI treatment in women. *Hum Reprod* 2007b; 22: 305-308.

Verhaak CM, Smeenk JMJ, van Minnen A, Kremer JAM, Kraaijmaat FW. A longitudinal, prospective study on emotional adjustment before, during and after consecutive fertility treatment. *Hum Reprod* 2005; 20: 2253-2260.

Volgsten H, Skoog Svanberg A, Ekselius L, Lundkvist Ö, Sundström Poromaa I. Prevalence of psychiatric disorders in infertile women and men undergoing in vitro fertilization treatment. *Hum Reprod* 2008; 23: 2056-2063.

Volgsten H, Skoog Svanberg A, Olsson P. Unresolved grief in women and men in Sweden three years after undergoing unsuccessful in vitro fertilization treatment. *Acta Obstet Gynecol Scand* 2010; 89: 1290-1297.

Wirtberg I, Möller A, Högström L, Tronstad S-E, Lalos A. Life 20 years after unsuccessful infertility treatment. *Hum Reprod* 2007; 22: 598-604.

Wischmann TH. Sexual disorders in infertile couples. *J Sex Med* 2010; 7: 1868-1876.

Wischmann T, Korge K, Scherg H, Strowitzki T, Verres R. A 10-year follow-up study of psychosocial factors affecting couples after infertility treatment. *Hum Reprod* 2012; 27: 3226-3232.

Yli-Kuha A-N, Gissler M, Klemetti R, Luoto R, Koivisto E, Hemmeinki E. Psychiatric disorders leading to hospitalization before and after fertility treatments. *Hum Reprod* 2010; 25: 2018-2023.