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SOCIAL AND PSYCHOLOGICAL CONSEQUENCES OF INFERTILITY

Social and psychological consequences of infertility and assisted reproduction – what are the research priorities?

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Abstract
The lifetime prevalence of infertility in representative population-based studies from industrialised countries is 17–28%, and on average, 56% of individuals affected seek medical advice. Infertility, as well as being a medical condition, has a social dimension; it is a poorly-controlled, chronic stressor with severe long-lasting negative social and psychological consequences. Although infertility can lead to severe strain in a couples' relationship, it can also have a potentially positive effect. Appraisal-oriented coping strategies including emotional coping are associated with reduced stress in infertility. Long-term studies of involuntary childless women following unsuccessful treatment show that although most adjust well psychologically, their childlessness is a major theme of their lives. Most studies are based on cross-sectional studies among couples seeking fertility treatment and focus on individual characteristics, for example, stress level, anxiety and symptoms of depression. There is a lack of studies investigating the impact of infertility and its treatment on social relations and of studies which have used the couple as the unit of analysis. More large-scale, long-term prospective cohort studies which address the social as well as psychological consequences of infertility are needed.

Keywords: *Assisted reproduction, communication, coping, infertility, psychology, social support*

Introduction

Infertility is the failure to conceive after at least 12 months of unprotected intercourse. Representative population-based studies have shown a cumulative lifetime prevalence of infertility of 17–28% amongst those couples who have tried to achieve a pregnancy (reviewed by Schmidt, 2006; Jacob et al., 2007). The prevalence of involuntary childlessness varies between 2.9% and 5.8% and of being unable to achieve a further childbirth is 3.5–5.9% (Schmidt, 2006).

In the more developed countries the proportion of infertile couples seeking medical care is on average 56.1% (Boivin et al., 2007). In European countries, children born after *in vitro* assisted reproduction technology (ART) treatment comprise 0.2–4.2% of the national birth cohorts (Nyboe Andersen et al., 2008). When the national number of deliveries after intrauterine insemination are included for one country (Denmark, 2002) the percentage increases from 4.0 to 6.2% (Nyboe Andersen & Erb, 2006).

This commentary focuses on research on the social and psychological consequences of infertility and its treatment based on the author's knowledge of this field over the past 15 years. This article is not a structured review; rather, the aim is to increase awareness of the social and psychological consequences of infertility and to highlight gaps in knowledge. The last section contains suggestions for future research.

For many couples, infertility causes a serious strain on their interpersonal relationship, as well as causing personal distress, reduced self-esteem and loss of the meaning of life (Greil, 1997). As well as being a medical problem, infertility has psychological and social dimensions. One of the important challenges faced by infertile couple is learning how to manage infertility and its treatment in a personal sense, in relation with one's partner and in different social arenas (family, friends, co-workers, etc.) (Schmidt, 1996). The focus of this commentary paper is on marriage, social relations, coping and emotional adjustment in relation to infertility. For all these

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topics the aim is emphasise where further knowledge is particularly required.

As some of these social and psychological consequences differ in different cultures (Inhorn, 2004; Dyer, 2007), this commentary paper is focused only on industrialised, Western countries. Nearly all the scientific literature on this topic is based on clinical samples taken from individuals undergoing fertility treatment, and as a result, our knowledge about the consequences of infertility among infertile people not having sought treatment is very limited. Furthermore, most studies are cross-sectional. Despite the huge number of people receiving fertility treatment every year only very few large-scale prospective, longitudinal cohort studies have been carried out on infertile couples (e.g., Abbey et al., 1995; Holter et al., 2006; Schmidt, 2006; Verhaak et al., 2007a; Volgsten et al., 2008).

Marriage – strain and benefit

Infertility can be a relational paradox. Although it can exert a severe strain on a couple's relationship (Greil, 1997), it can also have a potentially positive effect. Qualitative interview studies have shown that infertility can bring partners closer together and strengthen their marriage (Greil et al., 1988; Schmidt, 1996; Tjørnhøj-Thomsen, 1999). We later termed this positive effect of infertility among couples as marital benefit (Schmidt et al., 2005a). In a prospective, longitudinal cohort study of 2250 people beginning fertility treatment, 25.9% of the women and 21.1% of the men reported high marital benefit. Longitudinal analyses in men found that not disclosing infertility to others, having difficulties in partner communication, and a high use of active-avoiding coping (e.g., turning to work or substitute activities to take one's mind off things) were significant predictors of low marital benefit. On the other hand, a high use of meaning-based coping (e.g., feelings that one has grown as a person in a meaningful way, and thinking about infertility problems in a positive light) was a significant predictor of high marital benefit among men. No significant predictors were identified among women and there were no differences in marital benefit when comparing participants who had achieved an ART-delivery and those who had not (Schmidt et al., 2005a). Similarly, Holter et al. (2006) found that a majority of couples undergoing IVF/ICSI treatment reported that treatment had affected their partner relationship for the better.

Studies using standardised measures of marital satisfaction have tended to find high marital satisfaction among infertile couples in treatment or even higher measures when compared with non-infertile groups (Greil, 1997). This could be due to a selection bias if most of the infertile people seeking fertility treatment are those with the strongest, most well-functioning marriages. However, a representative population-based study by King (2003) reported that subfecund women had significantly more symptoms of anxiety and that this association was not changed when analyses were controlled for those who had recently sought medical treatment. These findings could indicate that psychosocial research based on clinical samples of infertile people is generalisable to the larger infertile population.

One of the central functions of marriage is the provision of emotional support. Holter et al. (2006) reported that the majority of the couples felt they understood and could support each other, but in around 20% of cases, either one or both partners responded 'no' to this question. Abbey et al. (1995) showed that increased emotional support from the partner was related to increased marital quality of life for both men and women.

Most couples do not find it difficult to talk with their partner about infertility and its treatment (Holter et al., 2006; Schmidt, 2006, p. 400). However, at the start of treatment 26.9% of the women and 22.0% reported difficulties in infertility-related partner communication (Schmidt, 2006, p. 400). Difficulties in partner communication was a significant predictor of having high stress in personal, marital and social domains (Schmidt et al., 2005b). Pasch et al. (2002) found that husbands' involvement was predictive of wives seeing on overall negative effect of infertility on their marriage. However, husbands for whom having children was important and were involved fully in the attempt to have a baby had a less negative effect on marital communication, and wives perceived then as having a more positive influence on their infertility and their marriage.

To conclude, infertility can exert a severe strain on a couples' relationship while, at the same time, having a positive effect and there is a particular need for more studies investigating these positive aspects of this condition.

Social relations – communication, supportive and unsupportive reactions

Despite the fact that infertility is a social situation, very few studies have investigated the impact of infertility on infertile couples' social relations.

Most infertile people talk to other people about their situation and women confide in more people than men (Abbey et al., 1991a; Van Balen & Trimbos-Kemper, 1994; Schmidt, 2006, p. 400; Slade et al., 2007).

Schmidt et al (2005b) found that keeping infertility a secret was not a predictor of the stress associated

with fertility problems, and that this was the case in men and women. By contrast, Van Balen & Trimbos-Kemper (1994) found that amongst men, non-disclosure was associated with lower well-being. Schmidt (2006, p. 401) distinguished two types of disclosure: the first in which only formal information was shared with others (e.g., type of treatment, number of eggs retrieved) and a second, open-minded strategy when both formal information and emotional reactions of the infertility experience were shared. When comparing the formal with the open-minded strategies, the odds ratios of reporting high fertility problem stress were in all three domains (personal, marital, social) for both men and women not significantly different from 1.00. This indicated a consistent pattern, that of increased risk of high fertility problem stress among those participants who did talk to others without including information about how they experienced the emotional consequences of infertility and its treatment (Schmidt et al., 2005b). There is a need for more studies which investigate not only whether infertile people discuss their condition with others but also what topics they choose to talk about – and do not wish to disclose. Such studies are important to increase our knowledge about the psychosocial consequences of the different infertility-related communication strategies amongst women and men.

Stigma is a negative sense of social difference from others, and infertility is potentially stigmatising (Miall, 1986; Whiteford & Gonzalez, 1995; Slade et al., 2007). In general, those who are infertile find that most other people are supportive. However, studies among infertile women who had talked about their infertility problem to others have also revealed a risk of receiving unsupportive reactions (Miall, 1986). Mindes et al. (2003) showed that receiving infertility-specific unsupportive responses were positively associated with poorer psychological adjustment. Furthermore, the unsupportive reactions predicted depressive symptoms and overall psychological distress among those women who remained infertile at follow-up of 6–12 months later. Slade et al. (2007) found that for both men's and women's perceptions of stigma were related to low social support. For men, stigma was linked to disclosure and support and to higher fertility-related and generic stress. For women, there was a strong direct pathway from stigma to infertility-specific stress. Disclosure was not associated with increased support, and for women, more disclosure was predictive of higher general stress.

To conclude, in order to increase our understanding of the psychosocial consequences for infertile people, there is a need for more research which sees infertility as a complex social situation.

Coping strategies – relationship with stress and gender differences

A generally accepted conclusion amongst those who study coping research is that emotion-focused coping processes are associated with dysfunctional outcomes (Austenfeld & Stanton, 2004). Infertility is a low-control stressor, that is, a stressful situation in which the infertile couple can do little or nothing to influence the nature or the outcome of their situation (Terry & Hynes, 1998). Further, infertility is a chronically stressful situation; a non-event transition (Koropatnick et al., 1993). In response to a low-control situation it is likely that problem-focused coping strategies aimed at managing the situation may have deleterious effects, whereas emotion-focused coping strategies could be adaptive (Terry & Hynes, 1998).

Koropatnick use the concept 'non-event transition' in order to distinguish the infertility experience from other transitions that usually occurs due to events (e.g. being married; becoming parents for the first time). Terry & Hynes use the concept 'adaptive' and 'maladaptive' as the concepts are used in the psychological field – whether a coping strategy contribute to reduce stress (adaptive) or not (maladaptive, i.e. often increases the stress level).

Coping with infertility has been studied using standardised measurement instruments including: Ways of Coping Questionnaire (WOCQ) including eight subscales as, for example, confrontive coping, distancing, self-controlling, escape-avoidance coping (Folkman & Lazarus, 1988; Jordan & Revenson, 1999) or the instrument COPE including subscales for active coping, planning, behavioural disengagement, positive reinterpretation, seeking instrumental support, seeking emotional support, venting emotions and denial (Carver et al., 1989; Verhaak et al., 2005). In contrast, other studies have investigated infertility coping with a new instrument which addresses emotional approach coping through acknowledging, understanding and expressing emotion (Berghuis & Stanton, 2002; Austenfeld & Stanton, 2004), with a revised conceptualisation of coping in adjustment to a low-control stressor (Terry & Hynes, 1998), or with an infertility-specific coping measure based on the WOCQ (Folkman & Lazarus, 1988) as well as information from qualitative interviews with people undergoing fertility treatment (Schmidt et al., 2005b).

In longitudinal studies, Terry & Hynes (1998) found amongst women receiving IVF-treatment that problem-appraisal coping strategies (e.g., trying to step back, be more objective and see the positive side of the situation) were predictive of better adjustment, and approach-oriented coping (including problem-focused coping, emotional processing

and expression) was related to lower distress (Berghuis & Stanton, 2002). In agreement with these findings, Schmidt et al. (2005b) found that active-confronting coping (e.g., expressing feelings somehow, accepting sympathy and understanding from someone, asking others for advice, talking to someone about emotional reactions) was a significant predictor of low fertility problem stress in the marital domain.

Conversely, longitudinal studies have shown that avoidance or escape coping were predictors of poor adjustment to infertility (Terry & Hynes, 1998) and of increased stress after one treatment attempt (Berghuis & Stanton, 2002). In one study, avoidance coping was separated into (i) active-avoidance coping (e.g., avoiding being with pregnant women, leaving when people are talking about pregnancies and deliveries, turning to work or some substitute activity to take one's mind off things) (ii) passive-avoidance coping (e.g., hoping for a miracle to happen, feeling that the only thing to do is to wait, having fantasies and wishes about how things might turn out). Major use of active-avoidance coping amongst both men and women was a significant predictor of high fertility problem stress in the personal and social domains. In contrast, major use of passive-avoidance coping was not a predictor of fertility problem stress (Schmidt et al., 2005b).

A study among infertile couples referred to a university hospital showed that both women and men who engaged in a disproportionate degree of escape/avoidance coping and who accepted responsibility for infertility were more vulnerable to symptoms of depression (Peterson et al., 2006a). Further, these coping strategies were positively associated with infertility stress (Peterson et al., 2006b). In line with this, Lechner et al. (2007) found that a passive coping style was positively associated with health complaints, depression and anxiety.

In general, women and men differ in how they engage in coping strategies (Tamres et al., 2002). Jordan & Revenson (1999) conducted a meta-analysis which included coping studies among infertile couples measured by the Folkman and Lazarus' WOCQ Checklist (Folkman & Lazarus, 1988). Women used the strategies seeking social support, escape-avoidance, planful problem-solving and positive reappraisal to a greater degree than their partners. Peterson et al. (2006b) underscored the point that when women have to contend with a wide variety of strategies, men's lower scores for coping may mask the fact that certain strategies are used less often by men, but still represent their preferred manner of coping. The authors therefore recommend the use of relative coping scores instead of raw coping scores in order to understand more accurately the relationships between coping and relevant social and psychological variables (e.g., fertility problem stress in different domains, social support, anxiety and depression).

Although infertility is a problem for couples, coping strategies have, with a few exceptions, been studied with the individual rather than the couple as the unit of analysis. Studies which have examined the couple as a unit of analysis have found that the coping of one member of the pair can have a direct impact on the individual distress of the partner (Peterson et al., 2006c) For example, in couples where men used high amounts of distancing and women used low amounts of distancing, women reported greater levels of infertility stress and depression compared to women with partners who used low amounts of distancing. Conversely, men in relationships where their partner used high amounts of self-controlling coping and they used low amounts, reported higher levels of infertility stress and lower levels of marital adjustment compared to men whose partner used lower amounts of emotional self-controlling (Peterson et al., 2006c).

To conclude, in order to increase our knowledge about coping with infertility it is recommended that coping instruments developed and validated specifically for a low-control stressor as infertility should be used. It is also recommended that our knowledge on the effects on partner coping be increased because infertility is a problem in most cases related to the infertile couple.

Emotional adjustment – before, during and after treatment

Most studies using standardised measures of general psychological distress and emotional adjustment indicate that infertile people seeking assisted reproduction differ only slightly emotionally from norm groups (reviews on studies among men and women in Greil, 1997; reviews on studies among women in IVF-treatment in Verhaak et al., 2007b). However, this finding is not claiming that infertility does not cause psychosocial strain. It is reasonable to believe that instruments for measurements of general psychological stress and emotional adjustment are unlikely able to capture the specific distress associated with infertility and its treatment.

Verhaak et al.'s (2007b) review showed that when initiating IVF treatment women did not differ from norm groups with regard to depression levels. There were equivocal results regarding the level of anxiety, where some studies reported elevated anxiety among the IVF women compared with norm groups whereas other studies found no difference. During treatment, depression levels increased after one or more unsuccessful treatment cycles with a significant interaction between time and treatment outcome.

Only one prospective cohort study among women and their partners in IVF-treatment investigated anxiety and depression 6 months after their last treatment cycle (Verhaak et al., 2005). Women showed an increase in both anxiety and depression after unsuccessful treatment and no recovery at a 6-months follow-up. Men showed no change in anxiety and depression.

To conclude, there is a need for more large-scale, longitudinal studies including men and women on the psychosocial consequences of infertility and its treatment, which measure, for example, anxiety, depression, as well as of infertility-specific stress (as measured e.g. by Abbey et al., 1991b; Newton et al. 1999).

Long-term adjustment after unsuccessful fertility treatment

Our knowledge about long-term adjustment to involuntary childlessness following unsuccessful treatment is very sparse.

Verhaak et al. (2007a) collected data in their prospective cohort study among couples in IVF-treatment, from start of treatment to the fourth data collection point 3–5 years after the last treatment cycle. Results among those women not having achieved a live birth showed that anxiety and depression at the last follow-up returned to baseline values. Those women who focused on new life goals showed lower levels of anxiety and depression when compared with those who persisted in trying to become pregnant.

Daniluk (2001) interviewed infertile couples who had stopped attempting to conceive in a prospective study with 10-months intervals. She found that in the beginning, the couples experienced relief at having stopped treatment. After some time, the couples attempted to make sense of their lost years and began to re-configure their lives. Thirty-two months after having ended unsuccessful treatment, most of the participants were more comfortable with themselves and with their relationships.

Sundby et al. (2007) reported that 10 years after IVF-treatment two thirds of female participant reported that infertility was one of the worst and most stressful episodes in their life. Around 50% reported that infertility was something in the past. However, most of the women still found it difficult to talk about this period. Wirtberg et al. (2007) interviewed 14 involuntary childless women 20 years after their unsuccessful fertility treatment. For all participants, childlessness had a strong impact on their lives and was a major life theme. Almost all the women reported that during the years they had been trying to conceive, they felt inferior to other women, had lacked self-esteem and felt socially isolated. For half of the women the feeling of social isolation had persisted and became stronger as their peer group reached grand-parenthood. The point is that the childless women first have the experience of their friends becoming parents and then 20–30 years later their friends become grand-parents. This period re-activates the psychosocial consequences of infertility – these are life-long consequences. In all but one, sexual life was affected in a negative and long-lasting way.

To conclude, long-term follow-up studies are sparse and have only recently started to be published. Data regarding long-term consequences of infertility among men is missing.

Conclusion

Infertility is a social situation and infertile people have to learn to manage infertility in relation to themselves. We know from previous research that infertile people find it hard to manage infertility for themselves as individuals, in relation to their partner, and in relation to their different social relations (family, family-in-law, friend, co-workers).

Infertility and its treatment are low-control, chronic stressors with severe long-lasting negative social and psychological consequences. A substantial minority of infertile couples also find that infertility brings them closer together and strengthens their relationship. Talking to others about their infertility may elicit supportive as well as unsupportive reactions. Difficulties in partners communicating with each other is a predictor of high fertility problem stress. Coping with infertility often moderates symptoms. The use of appraisal-oriented coping strategies including emotional coping is related to lower fertility problem stress and better adaptation, whereas escape-avoidance coping strategies are associated with lower mental and physical well-being. In the long-term, most involuntary childless women are well-adjusted psychologically. However, their childlessness is a major life theme even many years after having terminated treatment.

The body of research about the psychosocial consequences of infertility and its treatment consists mainly of cross-sectional studies among couples seeking fertility treatment, whereas only a small number of large-scale prospective, cohort studies have been carried out. Most of the studies focus on individual characteristics, for example stress level, anxiety, depressive symptoms. Furthermore, although infertility is a problem for couples that have to be managed by them, most studies have focussed just on the individual and not the couple as the unit of analysis. Although infertility is a highly prevalent social situation there is a lack of studies on the impact of infertility and its treatment on social relations.

Future research – recommendations

- There is a need for more large-scale, long-term prospective cohort studies on the social consequences and the psychological consequences of infertility and its treatment in men and women.
- Studies on the psychological consequences of infertility and its treatment and on infertility in the broader social context (family, friends, co-workers, society) are important research priorities. These studies should focus on communication, coping, social support and non-supportive reactions.
- There should be increased focus on the long-term consequences amongst men because in most long-term studies only one report results among women who have undergone treatment.
- There should be validation of infertility-specific measures for stress, coping, communication, etc. – (see Abbey et al., 1991b; Terry & Hynes, 1998; Newton et al., 1999; Schmidt, 2006) – in order to capture the consequences of poorly controlled stress in infertility and its treatment.
- More studies are required in which the couple are the unit of analysis and amongst infertile people who have not yet sought treatment.

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