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The role of beliefs about infertility on psychological adjustment: a systematic review

Caroline Lafarge | caroline.lafarge@uwl.ac.uk
School of Psychology, Social Work and Human Sciences, University of
West London

Pauline Fox | pauline.fox@uwl.ac.uk
School of Psychology, Social Work and Human Sciences, University of
West London



Beliefs about an illness can influence psychological adjustment. This relationship has been studied using the Common Sense Model (CSM). This systematic review explores the association between perceptions of infertility, measured by the Illness Perception Questionnaire (IPQ), and psychological adjustment among patients with difficulty conceiving.

Six electronic databases were searched between 1996 and 2012 yielding 32 potential sources which met the selection criteria. Further evaluation identified 3 papers for the systematic review

Results indicate significant relationships between perceptions of infertility and psychological adjustment. Perceptions of more severe consequences, longer timeline and lower controllability contributed to greater distress and lower well-being. Individuals' perceptions influenced partner's psychological adjustment. Gender differences were also observed.

The review suggests that the CSM is an appropriate framework to study infertility. Thus, interventions based on modifying perceptions of infertility may improve psychological well-being. Given the limited number of studies available and methodological limitations, further research is needed to ascertain the IPQ's contribution to research on infertility.

Keywords | *infertility; psychological adjustment; psychological well-being; Illness Perception Questionnaire; Common Sense Model of Self-regulation*

Introduction

Infertility is defined as failing to get pregnant after two years of regular unprotected sex (National Institute for Health and Clinical Excellence, 2004). Among women aged 20 to 45 it is the second most common reason for visiting a GP after pregnancy (Human Fertilization and Embryology Authority, 2008). One in seven women experience problems conceiving. Although 85% of women conceive within a year and 92% within two years, the conception rates drop to 77% within 3 years for women aged 38 and over (National Institute for Health and Clinical Excellence, 2004). Given that the age of childbearing is rising and more couples delay starting a family, infertility has become a significant health issue (Office for National Statistics, 2010). The number of IVF treatments has increased by 8% in 2008, compared to 2007 (Human Fertilization and Embryology Authority, 2008). However, access to fertility treatment in the UK remains unequal and little is known about the long-term psychological impact of infertility and the lack of access to treatment (Great Britain. Department of Health, 2010).

Until the 1980s, infertility was primarily attributed to psychological factors (psychogenic hypothesis). Infertility was framed within a psychodynamic paradigm and failure to conceive was mostly considered a result of women's ambivalent feelings about maternity (Stanton and Dunkel-Schetter, 1991). This psychogenic hypothesis has since been discarded mainly due to technological progress that enables more precise diagnosis of biomedical causes of infertility in women, as well as in men. Of the psychological factors thought to be involved in infertility, stress is possibly the most salient as research has shown that it is an important factor in fertility (Williams et al., 2007). Relaxation techniques have been found to enhance conception rates (Domar et al., 1992). Similarly, daily stress levels of women undergoing IVF were shown to be higher for those who failed to conceive compared to those who were successful (Boivin and Takefman, 1995). Among male patients, stress has been linked to decreased sperm quality (Clarke et al., 1999). Yet, if stress is an important element in infertility, it is now widely considered a consequence rather than a cause of infertility.

Infertility has been linked to psychological distress (Greil, 1997; Wischmann, et al.,

2001; Greil et al., 2010). A literature review, however, reveals a fragmented picture (Greil, 1997; Greil et al., 2010). While qualitative studies suggest that infertility has negative psychological consequences for those involved (Earle and Letherby, 2007), quantitative studies are more contrasted. Research has indicated that levels of distress experienced by patients with infertility are similar to those suffering from chronic disorders (Domar et al., 1992). Similarly, when compared to control groups, women who suffer from infertility tend to display higher levels of distress, although on the whole they do not present clinical levels of psychological morbidity (Fekkes et al., 2003). Nevertheless, some studies have found no evidence of psychological mal-adjustment to infertility (Dunkel-Schetter and Loebe, 1991; Edelman and Connolly, 1998; Greil et al., 2010). Other studies have emphasized the role of women's own negative perceptions of infertility. A study by Downey et al. (1989) suggested that although infertile women did not clinically differ from control groups in terms of distress, they felt that infertility had negative psychological consequences for them. This highlights the importance of perceptions of a particular illness or condition.

The role of illness perceptions in psychological adjustment has been widely researched. How people feel about their illness or condition has been shown to influence the way they manage and cope with it, which ultimately influences their health outcome. The Common Sense Model of Self-Regulation (CSM) developed by Leventhal et al. (1980) has been used as a framework to understand these beliefs and their impact on health. The model posits that illness disturbs individuals' balance, which individuals try to restore. The drive to restore equilibrium is referred to as self-regulation. Leventhal et al. (1980) proposed that beliefs are organised around five dimensions: the identity of the condition (driven by symptoms experienced); the timeline (long-term or short-term); the consequences (degree of severity); the causes attributed to the condition (external or internal); and finally, the perceived control over the condition. Based on these elements, individuals form cognitive representations of their conditions and devise coping strategies. These, in turn, determine how well they adjust to their illness or condition.

The concept of illness perception is relevant to infertility. It is likely that the way couples think about infertility will impact their conception rate and their psychological adjustment to it.

In this research area, the Illness Perception Questionnaire (IPQ) (Weinman et al., 1996) has been shown to be a psychometrically robust tool to assess illness perceptions. Few studies focus specifically on illness perceptions as measured by the (IPQ) and infertility. To our knowledge, this study is the first systematic review to be carried out on this subject. This paper therefore aims to understand the relationship between perceptions and psychological adjustment to infertility.

Methods

Search strategy and inclusion criteria: Six bibliographic databases were individually searched from 1996 to 2012 (week 16): EMBASE, PsycARTICLES, CINAHL, MEDLINE, PubMed and Academic Search Elite. The search was initiated from 1996 because the IPQ was published that year and one of the inclusion criteria for this review was that illness perceptions were measured using the IPQ. Different search terms were used to cover the concept of illness perceptions and the condition of infertility, using the Boolean operator 'AND'. Illness perception was defined as illness perception, illness representation, illness cognition, illness perception questionnaire, IPQ. Infertility was defined as infertility, sterility, IVF, childless. The search was conducted on titles, abstracts and texts. It covered peer-reviewed literature in English. Reference sections of the selected articles were examined for additional records. To be included in the review, papers had to be based on participants experiencing difficulty conceiving, use the IPQ (long or short version) to measure perceptions of infertility and use reliable measures of psychological adjustment as outcome variables.

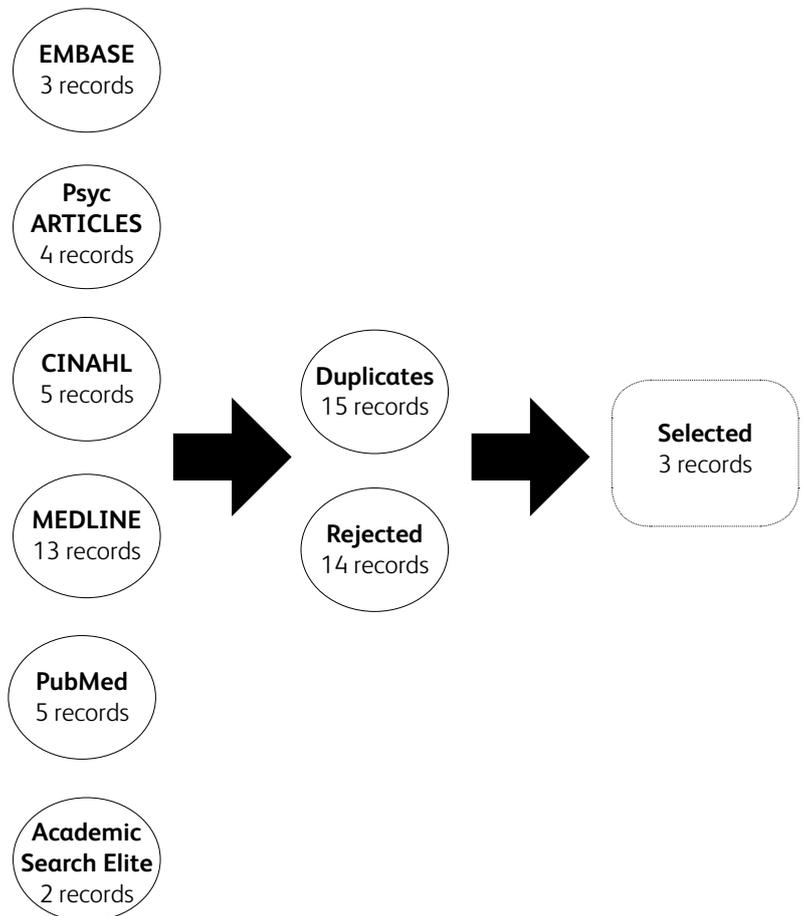
Data extraction: Data extraction was undertaken based on the following criteria: authorship, year and place of publication, overview of the study's aims, participants' profile and selection, measures used for infertility perception and psychological adjustment, and finally results based on descriptive and inferential statistics. Study quality was assessed through a rigorous qualitative assessment of each paper. Due to a lower sample size (50), the study by Lord and Roberston (2005) was given less credence than other studies (Benyamini et al., 2004; 2009). The data were analysed qualitatively. No

further statistical analyses were undertaken due to the heterogeneous nature of the papers' methodologies.

Results

Study selection and characteristics: Thirty two articles were initially selected based on title, abstract and text search. Of those, 15 were duplicates. Titles, abstracts and texts of the remaining 17 articles were examined. Fourteen articles were rejected because they did not fit the selection criteria, leaving three articles for this review. Figure 1 illustrates the selection process.

Figure 1



Selection of studies for inclusion in the review:

The studies have a number of characteristics, which are displayed in Table 1. All used a cross-sectional design. Two were from the same authors (Benyamini et al., 2004; 2009) but covered different populations. One focused specifically on dyadic experience and on the influence of partner's perceptions on emotional outcomes (Benyamini et al., 2009) while the other concentrated on women's perceptions. Thus, these two studies were deemed sufficiently different to make a valuable contribution to this review. Sample sizes varied from 50 (Lord and Robertson, 2005), 242 (Benyamini et al., 2009) to 310 participants (Benyamini et al., 2004). All three studies used clinical samples of patients attending fertility clinics. One study focused on women (Benyamini et al., 2004), whilst the other two also included men (Lord and Robertson, 2005; Benyamini et al., 2009). Participants' profile varied in terms of time since diagnosis, average length of treatment, cause of infertility, but all were of similar age (29-34).

Two studies used the IPQ (Benyamini et al., 2004; 2009) focusing on the timeline, consequence and controllability dimensions and the third used the IPQR, a revised version of IPQ (Lord and Robertson, 2005) to assess infertility perceptions. Two studies measured coping strategies: one using the Brief COPE (Lord and Robertson, 2005) and the other using the Coping with Infertility Scale devised by the authors (Benyamini et al., 2004). Psychological outcomes were measured using the Stanton Short Infertility Well-being and Distress Scale (Benyamini et al., 2004; 2009) and the Hospital Anxiety and Depression Scale (Lord and Robertson, 2005). The study by Benyamini et al. (2009) examined the difference between patients attending a fertility clinic for the first time vs. those already engaged in the treatment process. However, because the outcome data were not collected from men during their subsequent visit to the clinic, some interactions between gender and first vs. non-first visits categories could not be examined.

The studies used different inferential statistics to assess the predictive nature of infertility perceptions on psychological adjustment: Multiple Regression (Lord and Robertson, 2005), Structural Equation Modelling (SEM, Benyamini et al., 2004) and the Actor-Partner Interdependence Model (APIM, Benyamini et al., 2009). The latter was used to model the

interdependence of scores between partners and the interaction of actors' and partners' infertility perceptions on psychological distress.

Data analyses and outcomes: The three studies reported significant relationships between perceptions of infertility and psychological adjustment. The *descriptive analyses* provided a clearer picture about this relationship than the multivariate analyses. Benyamini et al. (2004) showed that perception of longer timeline, more severe consequences and less controllability were linked to greater distress and lower well-being, with consequences having the strongest impact on the adjustment variables. This was echoed by Benyamini et al. (2009) with severe consequences and lower controllability relating to poorer emotional adjustment. Lord and Robertson (2005) found significant positive correlations between identity, time line, cyclical emotional representations and both anxiety and depression, and a negative correlation between illness coherence and both anxiety and depression.

Coping was linked to both infertility perceptions and psychological adjustment. Benyamini et al. (2004) suggested that timeline and consequences perceptions had significant relationships with coping strategies. In turn, inward-anger coping was associated with greater distress and lower well-being, while self-nurturing coping was associated with higher well-being, and problem solving with greater distress. Lord and Robertson (2005) also identified a link between coping and psychological adjustment and revealed a significant positive relationship between maladaptive coping strategies, such as self-distraction, denial, behavioural disengagement, venting, self-blame, and both depression and anxiety. However, they showed that, on the whole couples made greater use of adaptive coping strategies than maladaptive ones.

The multivariate analyses aimed to demonstrate the predictive value of infertility perceptions on psychological adjustment, but the results were less consistent across studies. Consequences and controllability were shown to predict distress and well-being (Benyamini et al., 2004). In the dyadic study (Benyamini et al., 2009), distress and well-being were related not only to individuals' own perceptions of infertility but also to their partners', a finding valid for both men and women. Partner's perception of more severe consequences

contributed to greater distress (on top of own distress). Similarly, partner's perception of greater controllability and longer timelines contributed to greater well-being. In the Lord and Robertson (2005) study, timeline cyclical and stress as a cause of infertility contributed to explaining 19% of the variance in anxiety, but venting coping was the main predictor with 38%. Illness coherence, personality as a cause of infertility and identity explained 43% of the variance in depression with a further 10% explained by behavioural disengagement coping.

Gender differences in cognitive representations of infertility were also identified, with women holding more negative views of infertility (more severe consequences, lower controllability) than men (Benyamini et al., 2009), a finding reported elsewhere (Greil, 1997; Greil et al., 2010). In addition women were found to place more importance on the congruence between their own and their partners' perceptions. Women with perceived low controllability displayed higher level of distress if their partners' perceived controllability was high, compared to women whose partners also had low levels of perceived control. There was no evidence of gender differences in the Lord and Robertson (2005) study, possibly a result of low sample sizes.

Finally the role of coping as a potential mediator of psychological adjustment was examined. Lord and Robertson (2005) study did not find any evidence for it, whilst Benyamini et al. (2004) only found partial support for it, showing that coping only partly mediated the influence of the 'consequence' perception on distress.

Authors	Study looked at	Participants	Measures
Benyamini Gozlan and Kokia 2004 Israel Cross-sectional	Relationship bw illness perceptions, coping and distress Coping as a mediator between perceptions and adjustment	Population: women at fertility clinic (n=310) Recruited at clinic Participation rates: 80 % Mean age: 30.6 (SD: 5.0) Time since diagnosis: 5 months to 3 years + Treatment: pill (32%), injection (43%), IVF (16%), other (5%) none (4%) 71% completed up to 3 cycles	Illness perceptions: IPQ Timeline Consequences Controllability Coping: Benyamini et al. Coping with infertility Inward-anger Self-nurturing Problem management
Lord and Robertson 2005 UK Cross-sectional	Relationship bw illness perceptions, coping and distress Coping as a mediator between perceptions and adjustment	Population: 18 couples & 14 individuals at conception units (n = 50) 20 men & 30 women Recruited at clinic Participation rate not given Mean age: 34, (25-50) SD not provided Majority white (78%) Trying to conceive: 5 years Source of infertility: unclear (38%), female (26%), male (18%), both (18%) Treatment length: 2.5 years No of cycles: 1st IFV (20%), 1 cycle (42), 2 cycles 22%, 3+ (17%)	Illness perceptions: IPQR Identity Timeline Consequences Controllability Illness coherence Emotional representation Causal dimensions Coping: Brief COPE 28 items for 14 subscales <i>Adaptive coping:</i> active coping, planning positive reframing, acceptance, humour, religion, emotional support, instrumental support. <i>Maladaptive coping:</i> self-distraction, denial, venting, substance use, behavioural disengagement, self-blame
Benyamini Gozlan and Kokia 2009 Israel Cross-sectional	Relationship between illness perceptions and emotional adjustment Dyadic approach: how partners' perceptions influence emotional adjustment	Population: couples at fertility clinic Sample 1 (S1): 1st visit to fertility clinic (n=72 couples) Recruited at clinic Participation rate: 76 % Mean age: women 29 (SD:5) Men: 32 (SD: 5) 43% no previous treatment, 38% previous treatment, 19% recent treatment Source of infertility: unclear (42%), female (25%), male (21%), both (12%) Sample 2 (S2): regular visit to fertility clinic (n=49 couples) Recruited at clinic Participation rate: 80 % Mean age: women 31 (SD:5) Men: 34 (SD: 7) Treatment type: 70% pills, 19% IVF, 12% other Source of infertility: unclear (32%), female (27%), male (18%), other (23%) Time since diagnosis: 26 mths Number of cycle: 2.8	Illness perceptions: IPQ Timeline Consequences Controllability

Outcome variables	Main Results	
Emotional adjustment: Stanton Short Distress and Well-being Scale	Intercorrelations 1) Longer timeline, more severe consequences related to higher distress (0.29***, 0.59***) 2) Longer timeline, more severe consequences & lower controllability related to lower well-being (-0.26***, -0.36***, -0.31***) 3) Perceptions of timeline & consequences related to coping but not controllability 4) Inward anger related to greater distress (0.63***) and lower well-being (-0.24***) 5) Self-nurturing related to greater well-being (0.19**) 6) Problem management related to greater distress (0.21***)	Structural Equation Modelling 1) Consequences predicted distress (0.26*) and well-being (-0.43*) 2) Controllability predicted distress (-0.24*) and well-being (0.35*) 3) Consequences indirect impact on adjustment mediated by coping strategies, particularly linked to inward-anger (0.71*) and inward-anger linked to distress (0.73*) Partial support for mediation
Emotional adjustment: Hospital Anxiety and Depression Scale 14 items (7 in each) Higher scores - higher level of distress	Intercorrelations 1) Positive correlations bw IPQR and anxiety/depression Identity (0.33**; 0.28**) Timeline cyclical (0.59**; 0.38**) Emotional representations (0.7**; 0.43**) 2) Negative correlation bw IPQR and anxiety/depression Illness coherence (-0.44**; -0.35**) 3) Adaptive coping more used than maladaptive (t=5.77, p<0.0002) 4) Positive correlations bw. maladaptive coping and anxiety & depression Self-distraction (0.39**, 0.36**) Denial (0.33*, 0.37**) Behavioural disengagement (0.39**, 0.46**) Venting (0.63**, 0.47**)	Hierarchical Regression Anxiety: 57 % variance explained 1) Venting coping (38%) 2) Stress as a cause (13%) 3) Timeline cyclical (6%) Depression: 53 % variance 1) Illness coherence (26%) 2) Behavioural disengagement coping (10%) 3) Personality as a cause (12%) 4) Symptoms (identity) (5%) No support for mediation
Emotional adjustment: Stanton Short Distress and Well-being Scale Data collected among women from S1 & S2 but only among men from S1	Differences between partners 1) Women have higher perceptions of consequences than men (2.91 vs. 2.65 d=0.34) across sample 1 & 2 Interaction between gender and sample 1) Timeline shorter in S1 than S2: 2.34 F and 2.53 M for S1 2.60 F & 2.71 M for S2 2) Women in S2 lower perceptions of controllability than men in S2 (3.37 vs. 3.67) 3) Women in S2 lower perceptions of controllability than women in S1 (3.37 vs. 3.72, p=0.01)	APIM 1) Severe consequences related to higher distress in S1 men: 0.41***, women: 0.53** and to higher distress in S2 Women (0.45**) 2) Lower controllability related to higher distress in S1 men : - 0.31*** 3) 3-way interaction between gender, actor and partners' perception of controllability Women low on controllability more distressed if partner high on controllability

Discussion

In this review, there is evidence of a relationship between perceptions of infertility and psychological adjustment among patients who attend fertility clinics, although the relationships uncovered are of modest magnitude. The consequences, timeline and controllability dimensions of the IPQ/IPQR were related to psychological adjustment. This demonstrates the relevance of the CSM as a framework to understand infertility. It also implies that interventions based on modifying negative perceptions of the condition may alleviate some of the distress experienced, a finding echoed by Hagger and Orbell (2003). However, a number of comments have to be made with regards to generalising these findings.

First, there was a variation in the measures used to assess both perceptions of infertility and psychological adjustment. Benyamini et al. (2004; 2009) only used the IPQ dimensions of consequences, timeline and controllability while Lord and Robertson (2005) used all dimensions of the IPQR. To measure psychological adaptation, the studies by Benyamini et al. (2004; 2009) used an infertility specific scale while Lord and Robertson (2005) used the generic HADS. These differences make comparisons difficult. They also raise an important issue. Although all studies identified a link between infertility perceptions and psychological adjustment, only one indicated whether the levels of distress reported were clinically significant (Lord and Robertson, 2005). Using a tested and reliable measure of distress (HADS) enabled Lord and Robertson (2005) to compare the findings for this group against other populations. The results indicate that although the mean scores for anxiety and depression were clinically insignificant, 42% of the sample fell within the clinical range for anxiety and 12% for depression. This finding is in line with some of the literature (Fekkes et al., 2003). The difference between scales used to measure psychological outcome raises the issue of which (general or infertility specific) is most appropriate. While general measures enable comparisons with other populations, they may be too general to pick up dimensions relevant to the infertile group (Greil et al., 2010).

A second issue relates to the use of control groups. None of the studies used a control group, an issue often reported as a methodological flaw (Greil et al., 2010). Again,

this limits the scope of the review. Edelmann and Connelly (1998) have suggested that use of clinical samples may lead to distress being over-reported because physicians see patients most in need of help. Thus, how representative these clinical samples are of the population of infertility sufferers remains to be determined. This is particularly important since in the USA, for example, it is estimated that only half of infertile couples seek help (McQuillan et al., 2003). Hence, this review's findings are more likely to relate to the perceptions of people undergoing treatment for infertility rather than the perceptions of the infertile population as a whole. Although some recent studies have attempted to include more representative samples (King, 2003), they are still few and far between. Further research would be needed to generalise these findings to the infertile population.

The studies' designs also brought up important points. First, the three studies relied exclusively on self-reports. Couples being treated for infertility may feel under pressure to appear psychologically robust for their treatment to be regarded as medical and not psychological (Greil, 1997). Hence, psychological distress may be under-reported. In addition, owing to social norms and gender roles, men may also have under-reported distress in an attempt to appear emotionally strong. Second, the studies used a cross-sectional design and thus, no causality between perceptions of infertility and psychological adjustment could be established. Third, although the predictive power of perceptions of infertility, coupled with coping styles, on psychological adjustment was satisfactory, predicting 57% of the variance in anxiety and 53% for depression (Lord and Robertson, 2005), almost half of the variance remained unexplained. This implies that other variables may play an important part in perceptions and adjustment to infertility, but these were not included in the original design.

The time at which participants were interviewed is another important consideration. Clinical studies of infertility are faced with a challenge in that infertility treatment is a long process regulated by fertility cycles. Where people are in the process may influence psychological outcomes (McQuillan et al., 2003). Hynes et al. (1992) measured the mental well-being of women with infertility and controls at baseline (time 1) and after one cycle of IVF (time 2). No difference in depression scores was observed at baseline but

elevated levels of depression were reported at time 2 among women whose IVF attempt had failed. Therefore, some of this review's findings may reflect psychological distress related to distinct stages in the fertility treatment process rather than individual differences. The studies in this review included people at different stages in the process, which makes comparisons difficult.

Finally, it is possible that cultural variations influence perceptions of infertility. Although the studies by Benyamini et al. (2004; 2009) did not provide respondents' ethnic profile, the study by Lord and Robertson comprised mainly white participants. This demographic bias has been reported in the literature. This raises two issues. First, one may wonder how representative these studies are of their own multi-ethnic societies, as differences in perceptions of infertility have been observed within the same country. A study by Sewpaul (1999) conducted in South Africa has shown that people conceptualise infertility in different ways depending on where they live. Second, cross-cultural studies have shown that infertility perceptions as well as causal attributions differ across countries. While the biomedical model of infertility tends to be dominant in high-income countries, it is less prevalent in low- or middle-income countries where traditional beliefs are still widespread (Greil et al., 2010). In this review, no conclusion on the impact of causal attributions of infertility on psychological adjustment could be drawn, given that only Lord and Robertson (2005) included this dimension in their study.

The need to assess infertility as a social construct has been a recent point of discussion (Greil et al., 2010). Key aspects of this social construct include policy making and social norms. Population policies and the extent to which a country promotes population growth or birth control influence perceptions of infertility. They also affect individuals' expectations about achieving a socially desirable role (Greil et al., 2010). In a country that promotes population growth, it is therefore possible that infertility will be perceived negatively, thus distress might be more prevalent. Conversely, policies about access to infertility treatment are likely to influence people's perceptions and psychological adjustment (Great Britain. Department of Health, 2010).

Conclusions

This review is the first systematic review of the relationship between perceptions of infertility, as measured by the IPQ, and psychological adjustment. Thus, it makes a valuable contribution to the body of evidence on infertility. However, the paucity of the literature suggests that it is currently a neglected area of research. As the literature based on the use of IPQ in relation to infertility grows, it would be useful to revisit and extend the scope of this review. Research on the psychological impact of infertility would benefit from the use of more homogeneous measures, including all dimensions of the CSM, as well as homogeneous measures of psychological adjustment. It would also be advisable to control for the timeframe involved in treatment and for cross-cultural elements. The initial findings from the review indicate that the CSM may be appropriate to study infertility and indicate that interventions based on modifying individuals' perceptions may reduce distress. Cousineau and Domar (2007) pointed out that psychological interventions among the infertile population have a positive impact on psychological well-being, in particular those focusing on stress management and coping skills. However, a review by Boivin (2003) about the effectiveness of interventions on individuals seeking infertility treatment has shown that further research is needed to ascertain how useful these interventions truly are. Finally, the impact of stress and distress on pregnancy rates remains unclear (Schmidt, 2010) and further research is needed in this area to complete the picture of infertility and psychological distress.

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