

Illness representations, coping and psychological morbidity in infertility.

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Illness representations, coping and psychological morbidity in infertility.

Sharon Steddy

Abstract

This study used a cross sectional survey design to explore the illness representations, coping strategies and levels of psychological morbidity of patients planning IVF treatments. The aim was to develop a theoretical understanding, within the framework of the self-regulation model, of the factors which predict anxiety and depression in this group. Fifty patients completed a demographic questionnaire, the Illness Perception Questionnaire, the COPE and the Hospital Anxiety and Depression Scale. Chance, stress and age were the most commonly endorsed causal factors. Those without a diagnosis were more likely than those with one to think that chance had caused their infertility, but there was no difference between groups in belief in psychological causes. The coping style of this group of patients was characterised by planning and active coping within the ethos of acceptance. Overall, they used adaptive strategies significantly more than maladaptive, and this pattern did not differ between men and women. As a group, these patients' anxiety and depression scores did not fall into the clinically significant range and there were no significant differences in distress scores between groups. The relationships between illness perceptions, coping and distress were examined. Stepwise multiple regressions revealed that both illness perceptions and coping strategies predicted anxiety and depression. An adapted version of the self regulation model shows that belief in a psychological cause for infertility, lack of coherence, and high levels of emotionalism and emotional lability were associated with use of maladaptive coping strategies; and increased anxiety and depression. Theoretical and clinical implications of the research are presented, along with a critique of the research; and ideas for future research are discussed.

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1.0 Introduction

1.1 Definition, incidence and prevalence of infertility.

Infertility is defined as failure to conceive after one year of unprotected intercourse (Human Fertilisation and Embryology Authority (HFEA), 2002) although this failure will not necessarily mean people will be unable to conceive naturally. In couples of proven normal fertility, the conception rate per monthly cycle is between 15 and 30 per cent. This means that just by chance 10 per cent of couples take more than one year to conceive (Mc Shane, 1997). The definition is not helpful in distinguishing between those who are physically completely unable to have children (sterility); those for whom the difficulty is mechanical, such as in cases of sexual dysfunction; and those who, in the absence of mechanical problems, are having difficulties conceiving, who may be more accurately termed sub-fertile. Although the terms are sometimes used interchangeably, throughout this thesis the term infertility will be used, as defined by the HFEA.

Approximately 1 in 6 couples have difficulty conceiving (Brkovich & Fisher, 1998). Infertility can be classified as primary or secondary, depending on whether either partner has a child already. This highlights the nature of the problem as a shared one, despite the fact that the reproductive system of only one partner may not be functioning. In the USA, where figures from the last decade are available, the National Survey of Family Growth found that approximately 2.4 million married couples experience infertility, with further numbers of infertile unmarried people, and people who have not yet attempted conception, unknown (Abma *et al.*, 1997).

Although much of the assessment of infertile couples is carried out within gynaecology departments, specialist treatments (the assisted reproductive technologies) are carried out in assisted conception units. There are 116 such clinics in the UK, all overseen by the Human Fertilisation and Embryology Authority. They offer a range of treatments, both on the NHS and /or privately, although the provision of NHS treatment is dependent on the patient's local health authority contracts. Private treatment is costly; for example, for the 75 per cent of IVF treatments paid for privately, the cost can be as much as £3,000 per cycle.

Domar and Seibel (1990) explain the enormous significance of infertility as being due to the powerful desire, particularly of women, to have a child. In studies on motivation for parenthood among childless couples, primary motives have been found as happiness and well-being (van Balen & Trimbos-Kemper, 1995) and fulfilling gender role requirements for women, and a desire for marital completion for men (Newton *et al.*, 1992). Domar and Seibel (1990) suggest conception itself is viewed as the ultimate expression of love between a man and a woman. Furthermore, although not uncommon, difficulty in conceiving is almost always unexpected, and the unpleasantly ironic discovery of the problem usually follows an extended period of scrupulously trying to avoid conception (Lieblum & Greenfeld, 1997).

1.2 *The Medical Background*

1.2.1 Investigation

Most couples will be investigated for causes of their infertility after at least one year of unsuccessful attempts to conceive. In some couples, where risk factors for infertility such as older age, previous pregnancy loss, or history of sexually transmitted disease are issues, this time constraint may not apply. Initially, semen quality, ovulatory function, sperm/ cervical mucus interaction and tubal/ uterine anatomy are examined. If these investigations do not provide a diagnosis, more invasive and surgical procedures such as hysteroscopy and laparoscopy, techniques used to examine the reproductive organs internally, may be used. None of these investigations are simple. Even determining the presence of ovulation, which can be done with home testing kits, is time consuming and expensive; while sperm analysis requires masturbation, which can be embarrassing, and even culturally unacceptable. The post coital test which examines sperm / cervical mucus interaction necessitates timing intercourse around a visit to the clinic, and the more invasive procedures for women can be uncomfortable if not painful. Furthermore, any surgical procedure carries with it the normal risks associated with anaesthesia (Mc Shane, 1997).

1.2.2 What causes infertility?

The causes (and consequences) of infertility have not only been well documented but hotly debated over the last forty years, and it is still unclear to what extent physical and emotional factors interact.

Approximately 90 per cent of patients will be given a causal diagnosis following an infertility investigation (Mc Shane, 1997). There are a great many known physical causes of fertility problems, which can be crudely classified as female factor, male factor, or both. In females these include ovulation dysfunction, damage or obstruction to fallopian tubes, or damage to the uterus (Penney, 2001). In males, rather more simply, the problem usually lies with semen quality, or problems with sperm count, motility, form and forward progression (Mc Shane, 1997). Among diagnosed couples, 35 per cent of the diagnoses can be classified female factor, 35 per cent male, and 20 per cent both. Couples for whom no organic cause can be found are said to be experiencing idiopathic (unexplained) infertility (Lieblum, 1997).

1.2.3 Treatment Options

Table 1.1 illustrates the various options available to couples. For female factor infertility, the simplest treatment, and the one that carries the best prognosis, is ovulation induction therapy. Where tubal or uterine problems are present, treatment is often surgical. Chances of pregnancy vary from 10- 50 per cent depending on the patient's age, diagnosis and treatment. However, since the improvement in in- vitro fertilisation (IVF) less tubal surgery is performed.

Table 1.1 Treatment options for infertile couples.

Treatment	Indications	Brief explanation
Ovulation Induction	Ovulation disturbance	Drugs regulate a woman's hormonal cycle and stimulate egg production
Surgery	Blocked, damaged fallopian tubes. Ovarian cysts. Adhesions.	Repair to damage is attempted. Removal of cysts. Separation of adhesions.
Intrauterine Insemination		Sperm is produced, washed and introduced to the uterine cavity artificially.
Gamete Intrafallopian Transfer	Poor sperm quality. No female factor.	The insertion of a mixture of eggs and prepared sperm into the fallopian tube.
In vitro fertilisation and embryo transfer (IVF-ET)	Used for any of the diagnoses, and is the treatment of choice when donor gametes are involved.	Carried out either on a natural cycle, or drugs are used to regulate a woman's hormonal cycle, and stimulate the development of eggs. Mature eggs are removed from the ovary by aspiration, fertilisation is then conducted in the laboratory, and a number of the resulting embryos are transferred back into the uterus.
Intracytoplasmic sperm injection (ICSI)	Poor sperm quality. Presence of female factor also.	An advanced method of fertilising the egg by injecting one sperm directly into it. Embryos are transferred as IVF
Frozen Embryo Transfer	As IVF	A number of viable embryos produced in a cycle of IVF are frozen and stored, then defrosted and used for later attempts at conception.

For male factor infertility, the prognosis is less optimistic. The presence of poor sperm quality reduces the chance of pregnancy in all cases. Intrauterine insemination can be used with some success in cases where impairment is not severe, as can gamete intrafallopian transfer (GIFT), although the latter has poor success rates, and is not

offered in many clinics. In more severe cases, in vitro fertilisation and embryo transfer IVF -ET, and intracytoplasmic sperm injection (ICSI) have all given couples more options (Mc Shane, 1997). The process of IVF for the couple is the same in both cases (Pasch & Christensen, 2000). Couples can also elect to freeze spare embryos for use at a later date. Success rates for IVF treatments vary according to each case, but overall chances of conceiving at the first attempt are about 23% (American Society for Reproductive Medicine, 1998).

Data available for one of the clinics used in the study show that in the year 2001-2002, there were 134 cycles of IVF (20.1% successful), 254 of ICSI (17.7% successful) and 226 frozen embryo replacements (10.5% successful) where success was measured by live births.

1.3 Patients' Experiences of Infertility Investigation and Treatment.

In order to investigate their difficulties and arrive at a diagnosis, a couple presenting with problems conceiving will have experienced numerous tests and interviews. The subsequent process of infertility treatment is characterised by cycles of decision making, ethical dilemmas, stressful treatment regimens, optimism and expectancy followed by (most commonly) frustration and disappointment when conception does not occur (Lalos *et al.*, 1985; Lieblum & Greenfeld, 1997). It is perhaps understandable that years of struggling to become pregnant, followed by the rigours of the treatments can cause psychological distress.

Kirkman (2001) has conducted qualitative research amongst infertile women in Australia to explore their perceptions and experiences of infertility treatment. She

carried out 31 interviews, using narrative analysis, to establish women's own stories.

Who to tell and how to tell people that they were infertile were big issues, and sometimes a variety of stories were constructed about why the women did not have children. There was a dichotomy between those suggesting making the issue public was helpful, 'I do try to say a bit because it's a way of admitting to yourself that its happening, you know, because otherwise you sort of deny it' (p. 528) and those who found it unhelpful, 'people suddenly create a soap opera around your life which isn't how you're experiencing it' (p. 527).

Many of the women chose not to tell people at work, retaining a professional identity free from infertility. Women struggled with the fact that often they had to justify wanting a child, and furthermore to explain their responses to not being able to attain that, particularly as time went on.

The investigations and treatments themselves were described by one woman as 'being poked and prodded', and there were also considerable concerns about side effects of hormonal treatment and possible risk of later cancer. In other research, timed intercourse has been found to be a burden, causing problems with desire, anorgasmia, and erectile dysfunction, with sexual satisfaction overall decreasing (Lalos *et al.*, 1985). Their study involved semi-structured interviews with couples over a two-year period of investigation and treatment. The authors also found shame, embarrassment and anxiety were commonly reported by men about semen analysis, and half the women and one in three men were anxious and afraid about invasive investigations.

IVF –ET is the last treatment option for most couples. Kirkman found a dichotomy between couples who viewed this as 'the end of the road', and hence frightening, and those who were more philosophical, with the view that if they gave IVF a go, at least they would have tried everything (Kirkman & Rosenthal, 1999). Daniluk (2001) conducted narrative analysis on accounts of 65 couples who had not achieved pregnancy through assisted reproductive technologies. A strong theme emerged that couples felt swept along by an uncontrollable process towards an unrealistic end. As treatment went on couples reported they talked through options they had previously considered unacceptable, and highlighted the difficulty in not being able to think clearly about the options: 'you're lying to yourself because you're doing something you probably would never consider if you were in your right mind', 'we got to the point where we had nothing else, ... it got to be so big, so huge that we just weren't a couple anymore' (p. 126).

The process of infertility treatment was summarised by one woman as feeling like emotional rape (Daniluk, 2001).

1.4 The Psychological Impact of Infertility

The following section examines the literature on the links between the mind and the body's reproductive function. The issue of whether psychological factors cause or contribute to problems conceiving is first discussed, then the psychological consequences of infertility are outlined. The social impact is described, followed by the literature on psychological morbidity, both in general then focusing on the specific areas of gender, ethnicity, stage of treatment and diagnosis.

1.4.1 Infertility: distress as cause or consequence?

Although in most cases a diagnosis will be given, for some couples no clear explanation can be found for their difficulty conceiving. It is suggested that psychological distress is highly prevalent in these couples (Edelmann *et al.*, 1994). Whether or not this is a consequence or a cause of their problems has attracted a considerable amount of research interest. In the past, emotional factors were thought to account for about 50 per cent of cases where couples could not conceive (Davis & Dearman, 1991), and research argued that in these cases women were either psychologically disturbed (Eisner, 1963) or had unconscious conflicts about motherhood which were impacting on their ability to conceive (Ford, 1953). This argument dominated research for over 20 years but controlled studies matching groups of fertile and infertile couples generally find no differences in their personalities (Lieblum & Greenfeld, 1997). Despite the wealth of studies into this area, none has yet managed to confirm a causal relationship between distress and infertility (Brkovich & Fisher, 1998), and early studies suffered from methodological flaws such as failing to differentiate between women who had a medical diagnosis for their infertility and those who did not, and using fertile women as control groups to compare with. With medical advances and the new assisted reproductive technologies, a physical cause can now be found in 90- 95 per cent of cases (Domar & Seibel, 1990).

Whilst debate exists over whether or not psychological factors, or stressors, are the primary cause of infertility, there is growing awareness that they may contribute to the problem. Indeed, an unusual prospective study of first time pregnancy planners, Hjolland *et al.* (1997, cited in Henriksen, 1999) found those with high levels of general stress were less likely to become pregnant. There is also support for this hypothesis

from research with men. Harrison *et al.* (2000) argue that stress has a deleterious effect on quality of collected semen through reduction of number and motility of sperm, which can reduce by half the likelihood of successful conception (Harrison *et al.*, 1987, cited in Tarabusi, *et al.* 2000). In their own research, 45 men, with no differences in demographic details or number and motility of sperm, were given the Stroop Test on day of semen collection. This test requires the respondent to read as many colour words written in black and the actual colour as they could, and then to identify the colour when colour and word were incongruent as quickly as possible. Respondents were told this test clearly revealed how well they coped with stress. Those whose partners did not become at least pre-clinically pregnant had higher heart rates during testing, suggesting that vascular response to stress impacts on successful conception (Tarabusi, *et al.* 2000.)

There is evidence for a link between anxiety and successful conception; Demyttenaere *et al.* (1988) found women with higher levels of trait anxiety on the State Trait Anxiety Inventory (STAI) (Spielberger, 1983) took significantly longer to conceive from donor insemination, and were significantly more likely to miscarry than those with lower levels. Similarly, the effect of depression in couples has been evaluated, and found to be related to conception rates. In a prospective study of couples planning a cycle of IVF; Thiering *et al.* (1993) found twice the rate of pregnancy in those who were not depressed compared to those who were; while retrospectively Boivin (1996), noted that her 'non pregnant' group had experienced significantly more distress than the 'pregnant' group during the treatment.

In the (likely) event of IVF treatment not resulting in pregnancy, it has also been found that depression during treatment is a clear predictor of poorer adaptation to the lack of conception (Litt *et al.*, 1992).

The question of how stress impacts on biological functions has been investigated in other areas of health research. Broadly, it is felt that stress can affect people in two major ways. The first is behaviourally. In couples having problems conceiving, higher levels of stress may contribute to lack of sexual desire and consequent infrequent or poorly timed intercourse (Daniluk, 1988). The second is via a neuro - endocrine mechanism. There are a variety of proposed mechanisms for this. One important discovery has been that catecholamines (stress hormones) regulate Gonadotrophin Releasing Hormone (GnRH), which stimulates key reproductive hormones, and influences ovulation. Fluctuations in catecholamines therefore disturb GnRH, and consequently the chances of conception (Barnea & Tal, 1991). Another proposed mechanism is stress- induced hyperprolactinemia. High levels of prolactin have been found in infertile couples and it is an ovarian regulator in rats, however its function in humans is uncertain. Finally, there is a suggestion that antigens and antibodies which could affect sperm in the cervix may be affected by mood (Brkovich & Fisher, 1998).

In contrast to these studies, a review of controlled studies into psychosocial distress and infertility found similar levels of stress among women with tubal and ovulatory related diagnoses, which fails to support the hormonal hypothesis (Wright *et al.*, 1989).

Whatever the mechanism, it is of relevance and importance to health care professionals that some studies have found distress can have a significant effect on treatment outcome, and the role of stress in reproductive failure should not be underestimated (Barnea & Tal, 1991). Although it would be extremely difficult to partial out the effects of distress when there are so many other variables which impact on conception, Bevilacqua (1998) suggests these findings do offer support for the growing role of

counsellors in all infertility clinics and for the need to understand patients' perceptions of their experiences. The focus of most research into distress in infertility is therefore on the consequences of experiencing difficulty conceiving, and the ways couples find to cope with this.

1.4.2 The Social Impact

Relationships, both partner and social, have been key research issues in the field of infertility (Griel, 1997). Research on marital relations has revealed inconsistent results; Freeman *et al.* (1987) found no significant differences on marital satisfaction between infertile couples and controls, whilst Callan (1987) found that infertile couples in fact had higher relationship satisfaction scores than controls. Gerrity (2001) argues that this lack of clarity results from classifying infertile couples as one homogenous group, and her study looked at people at different stages of treatment. Results showed marital happiness differed significantly over the five stages of treatment, with 'beginners' significantly more happy than 'persisters'. However, this was a cross sectional study, leaving the reader unable to come to any firm conclusions.

Domar (1997) suggests that women report high levels of stress from other relationships, particularly when friends, colleagues, and relatives conceive. As described above, many women choose not to tell others about their difficulty, and a common coping strategy may be to avoid family gatherings, thereby increasing isolation. Furthermore the rigours of investigation and treatment often mean patients are late to work, or avoid travel during ovulation, which can lead to difficulties at work. Careers may be put on hold to

maintain flexibility to cope, and the cost of treatments may preclude other activities such as holidays.

Although there are clearly many potential consequences of infertility for a couple, the rest of this chapter will focus on what will be termed distress. This includes anxiety, depression and stress, as defined by each study.

1.4.3 Psychological Morbidity

In a thorough review of the literature in 1989, Wright and colleagues concluded that 'there is incontrovertible scientific evidence that, taken as a whole, patients diagnosed and treated in infertility clinics are more psychosocially distressed than normal control groups' (Wright *et al.*, 1989). This argument is well supported by controlled studies such as the frequently cited study by Domar and colleagues (1992). They compared 338 infertile women with 45 with no known infertility, and found twice the incidence of depression using The Beck Depression Inventory (Beck, 1996) in the infertile group (Domar *et al.*, 1992). In a later study the same group found that these levels are similar to those experienced by patients with chronic medical conditions (Domar *et al.*, 1993). Other studies have shown significantly higher levels of depressive symptoms in infertile as compared to fertile women, and significantly higher scores on depression scales than norms (Domar & Seibel, 1990).

Two studies using the State Trait Anxiety Inventory (Spielberger, 1983) found state anxiety above community norms (Thiering *et al.*, 1993) and raised in comparison with couples with children (O'Moore *et al.*, 1983), although trait anxiety was found to be within the normal range.

Downey *et al.* (1989), evaluated levels of mood disorder in 59 infertile women and 35 women with no known infertility. They found scores indicative of current major depression in 8.5 per cent of the infertile group, and 2.9 per cent of controls. Furthermore, the infertile group reported more subjective distress. Downey and McKinney (1992) repeated the study with 118 infertile women, and 83 with no known infertility, and figures were 11 per cent in the infertile group and 3.6 per cent in the control group. These scores do suggest higher levels of depression in infertile groups, but general prevalence rates of depression in the normal population have been found to be up to 10 per cent (Gilbert, 2000) so these scores are not necessarily unusual. Furthermore, the women were at different stages of investigation and treatment, and some already had children, making it difficult to determine the precise effects of infertility. In addition, in the first study there were no differences between those who had had treatment and those who had not, suggesting either that depression becomes evident early on during the process of assisted reproduction, or that infertile women who experience depression have already suffered from it before. The latter explanation is supported by the finding in the second study that 11 of 13 depressed infertile women had had a past history of depressive episodes.

Much of the research on particular reproductive treatments has focused on in vitro fertilisation (IVF) as it has been argued that women undergoing IVF treatment are likely to be the most distressed of all infertile people because it represents 'the last chance' (Dennerstein & Morse 1988). Support for this idea comes from studies such as that of Garner *et al.* (1984) who found depression, measured on the Beck Depression Inventory, in 34 per cent of women pre IVF, and 64 per cent after an unsuccessful cycle.

Unsurprisingly, it is particularly failure of IVF that is associated with problems; Baram and colleagues found 66 per cent of women reported increased depression on questionnaires following IVF failure (Baram *et al.*, 1988).

However, not all studies on infertility treatments have found evidence of distress. Patients attending for IVF have shown little variation from norms on the State Trait Anxiety Inventory (STAI) (Edelmann *et al.*, 1994); and Bevilacqua (1998) found women presenting at their initial consultation for IVF were not more depressed or anxious than those at the same stage awaiting other treatments, and generally scored within the normal range on psychological assessments.

These findings highlight a particular problem in research into distress in infertile people. Sample groups have often contained a great mix of respondents, making it extremely difficult to make any generalisable conclusions about characteristics of the group. If samples include couples at different stages of investigation and treatment, those with primary and secondary infertility and a range of different diagnoses, and do not distinguish between these groups, conclusions will be hard to draw (Brkovich & Fisher, 1998). Furthermore, most of the research, until recently, has been on females, and the experiences of men have been neglected (Band *et al.*, 1998). In an attempt to distinguish between groups and effects, some have argued that factors such as diagnosis and stage of treatment have a significant effect on distress, and studies have indeed looked at these issues.

There follows an examination of the literature on comparing distress levels between men and women, people planning a first cycle of treatment and those on subsequent

cycles, and between those with and without a diagnosis. There is also a reflection on the cultural research in this area.

1.4.4 The Gender Difference

There is general agreement that there are differences in the impact that infertility has on men and women (Wright *et al.*, 1989). There is an argument that women are more distressed, partly because socially women are seen as more responsible for conception and delivery than men, and consequently problems in this area have more of an impact on their sexual identity and self-efficacy (Edelmann & Connolly, 2000; Tarabusi *et al.*, 2000). However, there is also recognition that treatment is more invasive for women (Tarabusi *et al.*, 2000).

In their review, Wright *et al.* (1989) revealed that women exhibit more anxiety, stress, depression, loss of self-esteem, and poorer psychological, sexual and marital adjustment than their partners. A recent study of the similarities and differences in experiences of treatment within couples also showed a difference in attitude, and a significantly higher level of distress in women (Merari *et al.*, 2002). However, this does not illustrate the whole picture. In a study of referrals to IVF treatment, although women were significantly more distressed than the men, twice as many men as women had high enough scores to be potential psychiatric cases (Laffont & Edelmann, 1994).

Other studies have found differences between gender responses but qualify this with reference to other important factors. In 200 couples planning IVF treatment, although women self-reported more stress, the factors affecting stress levels were similar for both partners, the major one for both being their intense focus on having a child (Collins *et*

al., 1992). Edelman and Connolly (2000) also found the anticipated gender differences in distress levels in couples at assessment, and first IVF treatment, but argue that these did not differ from normative scores for men and women, so conclusions cannot be drawn about whether these are infertility related, or generic.

These authors also discuss issues in studies on gender differences such as: a) the studies showing high female distress also had high proportion with female factor diagnosis, b) men are more inclined to deny problems, c) hormonal treatment for women has emotional side effects and d) the fact that stress may not affect men's mood, but their behaviour. They note in their conclusion that it is highly likely men and women perceive, appraise and cope with infertility differently whilst distress levels can often remain comparable (Edelman & Connolly, 2000).

1.4.5 The Stage of Treatment

As has been suggested, one of the reasons for the lack of clarity about whether or not infertile couples experience significant psychological distress, is that research focuses on groups of people at particular but different stages of the assessment and treatment process (Berg & Wilson, 1991). This highlights a problem in infertility research: that of the lack of prospective studies. Of the studies below that debate this issue of the effects of stage of treatment, none follow a particular sample group or cohort through the process.

Emotional strain at the point of infertility investigations has been documented.

Takefman (1990, cited in Berg & Wilson, 1991) notes increments in state anxiety over the diagnostic period at clinics, and puts this down to the cumulative effect of the

stressful rigours of investigation and treatment. Indeed, women have reported that the psychological suffering resulting from anxieties about surgical procedures is in fact more difficult to cope with than the physical pain and complications (Lalos *et al.* 1985).

When infertility is prolonged, and investigations move towards treatment regimes, some studies agree that depression becomes more of an issue (Domar *et al.*, 1992; Thiering *et al.* 1993). This finding is in support of Welzien (1983) who found a positive correlation between treatment length and depression, although the limitations of correlational designs leave the reader unable to make conclusions about the direction of causality. Thiering *et al.* (1993) in a cross sectional study, found that whilst first time IVF patients were not depressed, women attending the clinic for repeat cycles were significantly more depressed than both 'first timers' and norms. By mid cycle 'first timers' had scores that were comparable, suggesting that depression increases with time, although this was not a repeat measures study, and the groups were different.

Boivin (1995) suggests a curvilinear model, where repeated treatment failure brings an acceptance of the situation that actually mediates distress. His study compared groups of women who had received no treatment, with those who had been unsuccessful with early stage treatments such as ovulation induction, and with those who had been unsuccessful with more surgical techniques and were now considering IVF. The middle group were the most distressed. In contrast, another study comparing women who had been undergoing treatment for one, two or three years on the Symptom Check List - 90R (Derogatis, 1993), found women in their first year of treatment had borderline levels of depression, women in their second year had significantly lower levels, but women in their third year had significantly higher, and clinically significant levels of

depression (Berg & Wilson, 1991). They also found that although levels of anxiety fluctuated across women who had been in treatment one, two, or three years, their anxiety scores on the SCL- 90R did not reach clinically significant levels. In contrast, it has also been found that state anxiety does not differ significantly between those in the early stages of treatment, and those who have been attending clinics for a long time (Thiering *et al.* 1993).

Clearly this is a complicated issue, and as each study presents its own methodological flaws, it is hard to draw conclusions. Golombok (1992) suggested that overall anxiety may be present during treatment but afterwards, unsuccessful treatment is more likely to lead to depression.

1.4.6 The Diagnosis

A further contributing factor thought to mediate distress, is the type of diagnosis given. Part of a diagnosis is the question of whether this is primary (the couple have no child) or secondary (difficulty conceiving subsequent to having a child). The presence or absence of a child already has therefore been evaluated, and it is generally agreed that although having a child does not buffer couples from the effects of stress (Litt *et al.* 1992), this group experience significantly lower levels of depression than the childless (Bevilacqua, 1998; Collins *et al.* 1992). More significantly, it has been argued that distress levels differ between those with a diagnosis (explained infertility); and those without (unexplained infertility).

It is often suggested that people with unexplained infertility will be more distressed than those with a diagnosis, as the uncertainty makes planning and directive action difficult

(Lieblum & Greenfeld, 1997). This is in support of Wasser and colleagues, who found women with 'functional' infertility had more distress than those with an organic diagnosis (Wasser *et al.*, 1993). However, in her study of couples over the period of investigation and six weeks after diagnosis, Daniluk (1988) found no difference in distress levels between the two groups, and conversely it has also been found that women with a known cause experience more depression than those without (Domar *et al.*, 1992).

Men appear to experience less distress than women about infertility. Some research indicates the impact on men seems to be determined by the presence or absence of a male factor cause (Domar & Seibel, 1990). This has been shown to cause the most distress to both partners, indeed it has been suggested that women react to male factor diagnoses in the same way as they would if the cause was located within them (Nachtigall *et al.*, 1992) and that the presence of a male factor is a useful predictor of need for counselling services (Owens & Reid, 1984). One recent investigation however, looked at 51 men with sole male factor infertility, and found depression and state anxiety in only a small percentage (Band *et al.* 1998), whilst a literature review concluded that response to infertility is not much affected by which partner receives a diagnosis (Griel, 1997).

1.4.7 Culture and ethnicity

A literature search on PsychInfo and Medline revealed very little in the way of research into infertility in different cultures and ethnic groups. Studies have been done in Africa, often among rural communities, examining beliefs about infertility and 'treatment' choices. These predominantly revolve around spiritual and faith healing, although

concurrently men and women might commit adultery, take another spouse or adopt children in an effort to relieve their childlessness (Gerrits, 1997; Runganga *et al.*, 2001).

In a review of issues pertinent to infertile couples from ethnic minorities in the United States, Molock (1999) notes the paucity of research, but draws on international studies to make suggestions for people working with these groups. She highlights difficulties in communication about sensitive subjects, potential conflicts over procedures such as pelvic examinations and masturbation, and suggests that although some infertility treatments might be acceptable, religiously and culturally others may not.

Whilst this review provided no information on the differences in psychological response to infertility of different ethnic groups, one study has attempted to do this. Nasser (2000) developed a questionnaire for use in Iran, which she argued would measure concepts found to be significant in the West. Thirty-seven infertile couples were given the questionnaire three times, and the author's conclusion was that the pattern of high levels of psychological stress and social withdrawal amongst couples at assessment and after an unsuccessful cycle were comparable to data available for Western patients.

It is impossible to draw conclusions about cultural similarities and differences in response to infertility based on such little research. Furthermore, none has been done in the UK, and none amongst Indian / Pakistani Asians who form the largest ethnic group in the areas where this research was conducted. However, Molock (1999) states that cross-culturally infertility is universally seen as a crisis, and consequently one might make predictions that responses to it will be similar to those found in white populations.

1.4.8 Summary of research into psychological morbidity.

In a review of studies, Wylie (1993) argues that there is little evidence for major mood disorder with a diagnosis of infertility, but that patients perceive themselves to be significantly affected, for example frequently reporting depression. Lieblum & Greenfeld (1997) also agree that clinically significant psychopathology in this population is rare, but allow that infertility is undeniably stressful. There is agreement from specific studies on this, for example Freeman *et al.* (1987) showed patients described IVF treatment as extremely stressful, but this did not result in distress after treatment, and psychiatric symptoms were infrequent.

There are two explanations for these findings. The first is the issue of methodology. Studies using self-report of couples do elicit apparently high levels of psychological distress, for example the claim that infertility is the worst crisis of their lives (Freeman *et al.* 1985; Mahlstedt *et al.* 1985). Edelman *et al.* (1994) take the argument with methodology further, and criticise the research heavily for basing results on anecdotal narratives or self-report, for using non standardised measures, not using suitable controls, or for classing all couples as a homogenous group. Their conclusion is that infertility does not cause distress. This concurs with Berg and Wilson (1991) who concluded from a review that many studies looking at men and women presenting initially to infertility clinics do not show a difference between samples and fertile controls on measures of psychological symptoms, or diagnoses of severe psychiatric disorders.

The second issue is defining distress. There may be a conceptual difference between the distress that infertile couples experience as 'the worst crisis of their lives' and what is

viewed by mental health services, or scored on questionnaires as depression or anxiety. Indeed it is important to remember that it is infertility that is the problem for the couple rather than the emotional response to it, in most cases (Pfeffer, 1987). Infertile people are declaring themselves to be distressed, but are not presenting with acute mental health problems. The fact that there have been no studies following a group of people from the time of deciding to try for a baby right through the process, no studies which have tried to take into account medical and psychological factors in determining what affects conception, and very few that have controlled for previous psychiatric history mean that we cannot say conclusively, even now, that being infertile itself will cause a person distress.

Given the wealth of studies on this issue, a further focus of infertility research has been on how people manage or cope with their infertility. Coping as a concept has been extensively researched (Coyne & Racioppo, 2000), and models of coping have been applied to health problems. Essentially these models describe coping as a means of maintaining a position of stability and homeostasis, but there is debate about how effective particular strategies, or types of strategies are in achieving that end. A brief review of the coping literature and models relevant to health problems follows.

1.5 Coping with Chronic Illness.

Coping has been defined as 'the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person' (Lazarus & Folkman, 1984). Much of the early work was done on coping with stress and what moderates the stress experience. The process of coping and the strategies a person chooses have been shown to play a major role in their well-being. Lazarus and Folkman (1984) proposed a

cognitive model of stress and coping. They argued that when an individual is faced with a stressful event, they assess the meaning of the event for them personally; does it have positive, negative or neutral meaning? This primary appraisal contributes to the emotional reaction to the stressor i.e. if it is considered a threat, the individual may feel anxiety or anger; whilst if it is considered a challenge, the emotional reaction may be excitement or enthusiasm. Secondary appraisal refers to what the person does to manage both the stressor and the emotional reaction (coping strategies).

Some researchers have applied these models to coping with health threats and stresses. For example, Moos and Schaefer (1984) have applied crisis theory to physical illness; arguing that illness can cause significant changes in life, which are exacerbated by factors such as the unpredictability of illness, lack of clarity about it, and the fact that most of us have limited prior experience of it. They stress the importance of cognitive appraisal of the illness, and suggest this leads to both adaptive tasks (dealing with symptoms and practical issues, and striving to maintain emotional balance), and coping skills. The aim of these is to return the individual to their 'normal' state, hence this model regards people as self-regulators.

An alternative, but again self-regulatory, model is that proposed by Taylor (1984). Based on interviews with cancer and cardiac patients, Taylor concluded that coping with threatening events consists of three processes: a search for meaning, a search for mastery, and the process of self-enhancement. The search for meaning includes both seeking answers as to why something has happened (seeking a cause), and what the implications for the person's life will be (consequences). Understanding the cause and consequences of the illness gives it meaning, and meaning contributes to the process of

coping. The second process they describe is the search for mastery, which is about managing the problem and preventing further occurrences of it. The key aspect of mastery is whether or not the individual believes they have any control over it, and if not, how to develop this. The third process is self-enhancement, designed to bolster self-esteem, which is likely to have been damaged by the experience of illness. Taylor argues that people use a form of social comparison whereby they select people worse off than they are to compare themselves with, and thus improve their self-esteem (Taylor, 1984).

The definition and the models described above stress that coping is a dynamic process, a set of responses that occur over time relative to both individual and environmental factors (Taylor, 1999). This points to the notion that coping, and choice of coping strategies is situation specific rather than due to dispositional style, although there has been much debate on this issue. Cohen and Lazarus (1979) argue that there is little consistency in individual's choice of coping strategies across situations, and they advocate a focus on situation specific coping. They are supported by recent arguments in the literature that researchers should examine the coping responses of one specific situation at a time to allow a broader, more conceptually sophisticated understanding of the construct to develop (Somerfield, 1997).

In most of the models, responses to stressors have been classified either as approach or avoidant strategies; or as problem focused (attempts to do something constructive about the situation), or emotion focused (efforts to regulate emotions experienced because of the event) (Taylor, 1999). However, the point is made that one might use a strategy that in one situation is problem focused, and in another is emotion focused (Lazarus &

Folkman, 1984). There have also been attempts to classify coping strategies as generally adaptive or maladaptive, with the suggestion that problem focused approach strategies are more helpful than emotion focused or avoidant ones. However, these distinctions have been found to be too simplistic, and people will use a variety of strategies more or less adaptively depending on the situation (Lazarus, 1993).

These models have been applied in research examining the relationship between coping and outcome in chronic illnesses. In a study of the adjustment to four different illnesses, Felton and Revenson (1984) found problem focused coping had a positive impact, whilst emotion focused strategies had a negative effect. However, there has been an argument that in circumstances where nothing can be done to change the situation (as in many chronic or severe illnesses), emotion focused strategies may be the best choice (Collins *et al.*, 1983). Still other studies have found that a coping style characterised by being active, expressive and thinking positively results in higher levels of functioning and psychological well being (Maes *et al.*, 1996). This mixture of strategies could be classified as both problem and emotion focused.

Given that infertility has been described as a chronic illness (Bevilaqua, 1998) it is interesting to examine the research to explore the coping strategies of infertile couples, and to establish whether there are similar patterns. The following section is a brief review of studies in this area.

1.6 Coping with Infertility.

In a large qualitative study, Davis and Dearman (1991) interviewed 30 women and, using content analysis, revealed the women had established 6 ways of coping. These

were: distancing yourself from reminders, regaining some self-control, increasing self-esteem or making an effort to feel better about aspects of treatment, looking for hidden meaning in the infertility, expression of feelings, and sharing the burden with others. These are coping strategies that the literature suggests can be more or less helpful. For example, sharing the burden could be seen as emotional or support seeking, considered to be a good coping strategy, but distancing yourself from reminders may be considered avoidance which has been correlated with poorer psychological adjustment.

There is an argument that the best coping strategies for the problem of infertility involve active, problem focused planning, networking, and information seeking (Lieblum & Greenfeld, 1997). In fact couples who actively seek ways of solving problems have been found with lower rates of depression than those who escape or avoid (Hunt & Monarch, 1997; Litt *et al.*, 1992). In their study of 152 couples going through IVF treatment, Edelmann *et al.* (1994) agreed that taking direct action, and accepting your position was effective in reducing psychological distress. The authors noted that the fact the couples favoured this strategy was not surprising as it was consistent with their behaviour.

It is not only active strategies that have been found to be useful. Optimism has been noted as a very powerful predictor of coping well with infertility (Litt *et al.*, 1992), however thinking positively in infertile couples seems to equate with overestimating chances of success in becoming pregnant. (Collins *et al.*, 1992; De Zoeten *et al.*, 1987). If this were true, it could be a factor in the level of distress at failure of infertility treatment, although Litt *et al.* (1992) also found that optimism was not related to expectancy of success. Using the distinction of approach and avoidant coping strategies,

Berguis and Stanton (2002) found that avoidant strategies increased distress in couples attempting artificial insemination, whilst approach oriented strategies, which included both problem focused coping and emotional expression and processing, predicted decreased distress.

There are styles of coping that are suggested to be less helpful. Lieblum and Greenfeld (1997) cite self or partner blaming and avoidance-denial as counter productive and destructive. This is supported by studies such as that of Morrow *et al.* (1995) who used the Symptom Checklist-90R (Derogatis, 1993) and Ways of Coping questionnaire (Folkman & Lazarus, 1988). They found that use of self-blame and avoidance as coping strategies was highly correlated with psychological distress. Furthermore in the study by Litt and colleagues, women who felt responsible for IVF failure had the poorest adaptation to lack of conception (Litt *et al.*, 1992).

Interestingly, one study has found extremely high levels of all coping strategies they looked at (active problem solving, avoidance and emotional expression) were linked with lower pregnancy rates after IVF treatment (Demyttenaere *et al.*, 1992). The authors suggested that endocrinological processes mediated this result, and another study provides evidence that sperm concentration may be reduced by high levels of active coping (Pook *et al.*, 2000).

Given that infertility is a stressor that affects a couple together, a recent meta analysis of studies using the Ways of Coping Questionnaire (Folkman & Lazarus, 1988), has examined the differences of coping styles between men and women. They concluded that there are more similarities than differences, but that women did use the strategies of

escape / avoidance, positive reframing and seeking social support to a significantly greater degree than men (Jordan & Revenson, 1999). In terms of the extent to which coping influences outcome, it has been found that individual coping style within a couple is not enough to account for their adjustment, and that interactions between the two need to be taken into account. This is particularly pertinent for women, for example they appear to benefit from their partner's problem focused coping attempts (Berguis & Stanton, 2002).

One study looked at the coping strategies of men and women at five different stages of treatment. The only significant differences in coping strategies employed were between those who had concluded treatment, and everybody else (Gerrity, 2001).

Very little research has been conducted on whether or not choice of coping strategy is affected by diagnosis. No longitudinal studies have been carried out but three of four cross sectional studies show that there is little evidence that the diagnosis affects coping (Pook *et al.*, 2002).

All the studies above looked at coping styles and the effects these had on distress and conception outcome. There are some clear indications that the coping styles of couples seeking infertility treatment are likely to be active and problem focused (since they are willing to put themselves through treatment), within the ethos of accepting their position and having some optimism about treatment. These are likely to be helpful strategies, whilst blaming and avoidance are likely to be unhelpful.

It is clear from the literature that coping can be seen as dynamic and situation specific. It is also clear that there is debate about the value of particular strategies in determining outcome. Thus questions are raised about how coping is itself determined, and to what extent it contributes to outcome. Within the field of infertility literature, factors which influence coping and outcome, such as self-esteem, interpersonal conflict and perceived internal control (Abbey *et al.*, 1992) have been researched, but as yet have not been developed into models of experience. Indeed most of the research is atheoretical and lacking a framework, so that, up to now, no attempt has been made to establish the factors that *determine* someone's emotional response. In other areas of research into chronic illness, this has been addressed through use of social cognition models.

1.7 Social cognition models and health related behaviour.

It has been found that in order to make sense of and respond to their problems, patients create their own models of their illness; and that adjustment to illness is more accurately predicted by these cognitive factors than by disease related variables (Sensky, 1997). Cognitions about illnesses are influenced by social as well as individual factors. Current thinking in health psychology argues that the best way to understand a person's response to illness is by understanding the way they construe and give meaning to it (their illness representations) (Leventhal & Coleman, 1997). Sensky (1997) suggests that people's beliefs about their illnesses can have a profound effect on every stage of their clinical management, and thus understanding them should be an integral part of optimum service delivery.

There are a number of different social cognition models, which are discussed briefly. The first model to include psychological variables to explain health behaviour was the health belief model (Becker, 1974), and was developed in an attempt to explain the various factors influencing health behaviours, particularly preventative behaviours. The model suggests that the likelihood of a person undertaking a particular (preventative) behaviour is mediated by their perceptions of their susceptibility to the illness, how severe they believe the threat of the illness to be, and their evaluation of the benefits and costs of undertaking that particular behaviour.

The theory of planned behaviour (Ajzen & Fishbein, 1980) focuses on the idea that human behaviour is voluntary, and can be predicted by intention. An individual's intention to perform a health related behaviour is said to be determined by the person's own attitude to performing the behaviour, and social norms.

Health locus of control is another model used to predict whether or not an individual will engage in a particular health related behaviour. This model suggests that those with a strong internal sense of control (who take responsibility for themselves, and believe they have control over their 'fate') are more likely to engage in health behaviours than those with strong external sense of control (who attribute responsibility for events or experiences to outside forces) (Seeman & Seeman, 1983).

Although these models are useful in helping to predict what might encourage people to protect themselves against health threats by engaging in preventative behaviour, they are not so useful for exploring beliefs and perceptions about illness once it has actually occurred. In this study, all the patients had been acknowledged as infertile, and thus

were dealing with reality rather than threat. A model that enabled exploration of beliefs about the health problem, and the response to it was required for the purposes of this study. Illness representations form part of the self-regulation model that provides a framework to do this.

1.8 The self-regulation model and illness representations.

1.8.1 The model.

In 1980, Leventhal and colleagues presented their model of understanding how people interpret and cope with health threats. This model is now the basis of many studies into cognitive processes in illnesses. Underpinning their model is the concept that people are motivated to maintain themselves in a state of normality (health), and will therefore aim to minimise or regulate any health risks, threats and problems.

There are four basic assumptions to the model. The first is that our behaviour and experiences are directed by an active, current information processing system. Thus our experiences of the world are created on a 'moment to moment' basis. The second is that two parallel pathways operate in this processing system. One is the development of an objective view of the illness which influences choice of coping strategy for managing it, and the other is the development of an emotional response to the problem which influences choice of coping plan for managing emotion.

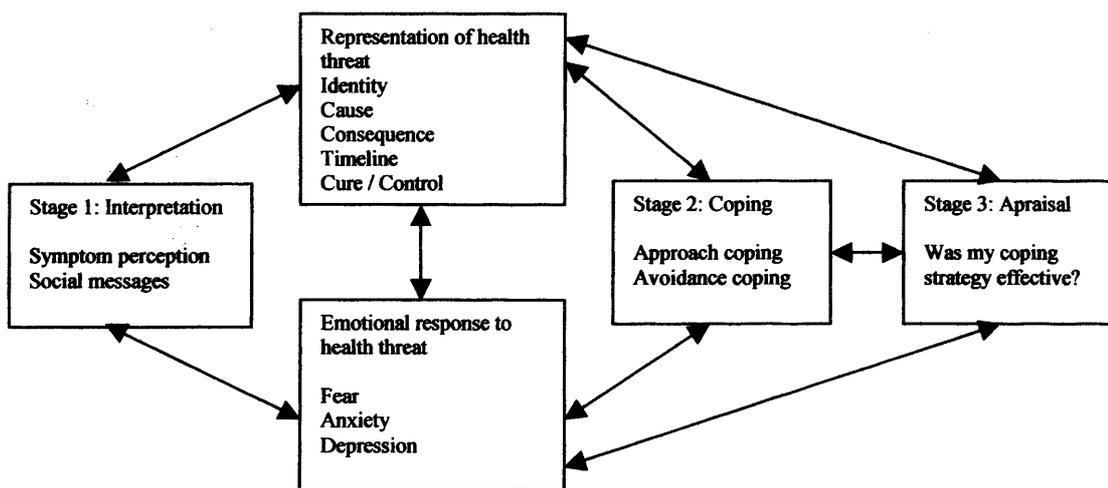
The third assumption is that there are several stages to the processing system. Firstly the representation of the illness, and an accompanying emotion is created. This influences the development and execution of coping strategies for the problem and the emotion in

the second stage. Finally, in the third stage, the person appraises their coping, and information from this appraisal is fed back into the loop, potentially influencing both the representations the person holds, and their coping strategies.

The fourth assumption is that the processing system operates on both a concrete and an abstract level, in that an individual's experience will be made up of objective markers, such as pain; and beliefs, ideas and feelings about that symptom. There is therefore the opportunity for discrepancy between the two levels, in that one may receive information at the abstract level that does not fit with the concrete experience (for example that no organic cause for the pain can be found).

The model is shown diagrammatically in Figure 1.1 (Ogden, 2000).

Figure 1.1 Leventhal's self-regulatory model of illness behaviour.



In common with other 'problem solving' models, there are three stages: interpretation, or making sense of the problem; coping - dealing with the problem in order to regain normality; and appraisal - assessing how successful the coping strategy has been.

Illness representations are the result of the stage of interpretation. Interpretation is the process by which an individual begins to define and understand a symptom in order to 'solve the problem'. This process is influenced by a number of factors including: cultural information about illness and health; social communication such as symptom comparison with friends, and consultations with medical professionals; and the individual's previous illness experience (including the illnesses of other people they know). Thus each individual's representation of the same initial sensation may well be different, and consequently the way they cope will be too (Leventhal *et al.* 1984).

Research into serious illnesses identified four major components of illness representation. In defining the problem a person will be keen to identify and *label* what it is. The person is likely to seek a *cause* (or a number of causal possibilities depending on the different labels they may have). They are likely to have ideas about the *consequences* of their problem, and within this, some sense of the *duration* of it (Leventhal *et al.* 1984). Subsequently, a fifth component, *cure / control*, was proposed by Lau and Hartman (1983) as a result of their research into less severe, more common illnesses.

1.8.2 Empirical research in support of the model

A number of methods of assessing illness representations have been devised. Leventhal himself recommends interviews, as he argues they avoid the possibility of priming the subjects (Ogden, 1996). Bishop and colleagues (1987) carried out experimental studies with healthy subjects, presenting them with descriptions of patients experiencing six different symptoms. They found that responses to questions about labelling, and an open ended question about what else might be associated with the person's situation,

elicited responses which closely fit with the dimensions of illness representations described above.

In an alternative design, Schiaffino and Cea (1995) studied the illness representations of both healthy students and patients with regard to three illnesses: rheumatoid arthritis, multiple sclerosis, and human immunodeficiency virus. They used the Implicit Models of Illness Questionnaire (Turk *et al.*, 1986), which although developed to assess illness representations, uses the four factors of seriousness, personal responsibility, controllability and changeability to do so. Their main finding was that illness representations differed across illnesses and respondent status. This suggests that illness representations differ as a function of personal experience and relevance, and offers support for the concept of their uniqueness for each individual. Interestingly however, although the authors claim their results are in the 'spirit' of Leventhal's model, factor analysis revealed a structure different to both that, and the model around which the questionnaire is based. They suggest that the search for a common underlying factor structure for all illnesses may be misguided, however these studies are criticised for using non patient samples, rather than focusing on patients' own representations (Lau *et al.*, 1989; Weinman *et al.*, 1996).

Much of the research using the concept of illness representations with patient groups also looks at coping strategies, as the model suggests the former influences the latter; and examines how both influence patient outcome factors. A brief review of these studies follows.

1.8.3 Illness representations, coping and outcome in patient populations

In a review of studies using this model, Scharloo *et al.* (1998) found that a favourable course of illness was associated with high scores on personal control; and a more positive outcome is associated with a belief that the illness will be intermittent, and a low level of perceived seriousness. In their own study, they examined illness representations, coping and outcome in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. They used the Illness Perception Questionnaire (Weinman *et al.*, 1996), which was developed specifically to assess the five components of illness representations, consistent with the original model. They found that a strong illness identity, belief in a long illness duration, and more severe consequences were associated with worse outcome, as was passive coping. If patients had higher beliefs about the controllability of their illness, and coped by seeking social support, they were functioning significantly better.

Control appears to be a key factor in research into health problems. A study using a sample of patients with Irritable Bowel Syndrome (Rutter & Rutter, 2002) also showed that weaker control beliefs were associated with higher depression scores. The authors found that more severe consequences and psychological causal attributions were positively correlated with both depression and anxiety. Illness representations were also related to coping strategies. Timeline was associated with acceptance; the consequences subscale was positively correlated with restraint coping, venting, and mental and behavioural disengagement but negatively correlated to acceptance; cure / control was associated with active coping, planning and positive reinterpretation, and 'psychological cause' was positively correlated with venting, behavioural disengagement and use of alcohol.

Rutter and Rutter (2002) present path analyses predicting anxiety and depression. They found that in their population, the illness representations subscale of consequences, and their amalgamated variable 'psychological cause' accounted for 33.6 per cent of variance in anxiety, and venting emotions (coping strategy) added a further 7.4 per cent. Their model for depression was more complicated, with consequences (illness perception) predicting the most variance, followed by behavioural disengagement (coping strategy), and restraint coping, seeking emotional support and suppression of competing activities (all coping strategies) explaining the rest of the 30 per cent accounted-for variance.

Although the original model advocates a linear relationship between illness representations, coping and outcome, other studies are less conclusive on this matter; finding that illness representations are stronger predictors of outcome than coping in that they explain the most variance, (Heijmans, 1998, 1999; Moss-Morris *et al.*, 1996; and Scharloo *et al.* 1998).

Kemp *et al.* (1999) used the model in their research with patients with epilepsy. Illness representations were associated with coping: strong illness identity and consequences scores were associated with wishful thinking and avoidance, whilst belief in personal control was associated with problem-focused coping. Coping variables were indeed associated with outcome, avoidance was predictive of poor psychosocial adjustment, whilst problem focused coping was predictive of good psychosocial adjustment. In predicting distress however, when coping was controlled for, illness representations predicted additional variance.

One study used the first versions of the IPQ and the COPE (Helder *et al.*, 2002).

Their results showed the illness perception variable of identity was positively correlated with the coping strategy mental disengagement, whilst timeline was negatively correlated with it. Stronger beliefs that there might be a cure for the illness were related to seeking social support and mental disengagement, and beliefs about controllability were associated with positive reinterpretation and growth. Coping in turn was related to outcome; 'maladaptive' coping strategies were negatively related to well-being, whilst coping strategies directed at accepting the illness were positively related to well-being. Their predictive model of well-being found that both illness perceptions (symptoms), and coping strategies (venting, behavioural disengagement and mental disengagement) explained a significant amount of variance in patient's well-being over and above demographic and illness related variables.

Studies about appraisals in infertility are only recently being carried out, and are briefly reviewed below.

1.9 Representations, coping and distress in infertility.

Hansell *et al.* (1998) found infertile women appraised infertility either as a loss or a challenge. Their appraisals were not only linked to their choice of coping strategies, but also their distress levels. Bolter (1997) looked at the thoughts of 58 women undergoing infertility treatment. Three distinct reactions to their infertility - action, hope and detachment – emerged. Correlations and multiple regressions revealed that these ways of thinking about their infertility were significantly related to adaptation.

In another study a questionnaire examining cognitions about infertility was given to seventeen couples with idiopathic infertility. Four categories of thoughts were measured including: stress-reducing thoughts (I will have a contented life even if I don't have children), emotion focused thoughts (I am deeply depressed again), problem focused thoughts (I should think more intensely about my childlessness), and thoughts of helplessness (There is nothing I can do to change not having children). Results indicated that stress-reducing thoughts represented a coping strategy for couples, whereas emotion focused thoughts provided a measure of perceived distress. High levels of problem focused thoughts indicated cognitive involvement in infertility and were correlated with more active coping strategies. Helplessness though was related to poorer social and medical resources, and higher levels of distress (Tuschen-Caffier *et al.* 1999). The study, which used a cognitive behavioural programme aimed at optimising the chances of conception, saw a reduction of helplessness over the duration of the programme. The authors suggest this was a result of reappraisals and changed attitudes; for example, rather than considering timed intercourse to be a burden and not about pleasure, by the end of the intervention it was seen as a means to an end, and task oriented which indicated the couple had become more actively involved in trying to resolve the fertility problem.

As already highlighted, sense of control is an important aspect of people's attributions about illness. Within the problem of infertility there are many anecdotal reports that lack of control is a big problem for couples (Davis & Dearman, 1991; Domar & Seibel, 1990). In a study of 41 women before and after an IVF cycle it was found that those with the poorest adaptation to treatment failure had previously reported feeling a loss of control which increased their anxiety (Litt *et al.* 1992) giving credence to anecdotal

reports. Half of the women had not felt there was anything they could do to help themselves or increase their chances of success.

1.10 Rationale and aims for current study

Given that research into infertility treatments has suggested that distress can affect conception rates, it would seem vital for effective clinical management that we begin to explore not only the understanding people have about their infertility, but also the way this affects their choice of coping strategy, and distress levels (Sensky, 1997).

Some studies have begun this work, but lack a clear, theoretically based conceptual framework. This project aims to make use of the available models of understanding and coping with illness to try and identify the factors which impact on couples' experience of their infertility. In line with recommendations (Somerfield, 1997) it focuses on one specific point of a chronic stressor (planning IVF treatment). Psychological morbidity (distress) is the term used for both anxiety and depression, as measured on the Hospital Anxiety and Depression Scale. For the purposes of analysis they will be evaluated separately.

The main research questions for this study are

1. What are the illness representations of infertile couples planning IVF treatments?
2. What are the coping strategies of infertile patients planning IVF treatments?
3. What is the extent of psychological morbidity in patients planning IVF treatments; and are there differences between men and women, between ethnic

groups, between 'first timers' and 'repeaters', and between those with and without a diagnosis?

4. How are illness representations, coping and psychological morbidity (distress) related in this group?

From the start point of these questions, and in the light of research using these models in other health populations and in the field of infertility, the following hypotheses were derived.

- 1a People planning IVF treatments will have low symptom and self-control scores (below 2.5), and high time line, emotional representations and consequence scores (above 2.5).
- 1b Those without a diagnosis will be more likely to endorse psychological causes than those with a diagnosis.
- 2a People planning IVF treatments will endorse active, problem focused strategies more frequently than avoidance or emotion focused strategies.
- 2b Women will endorse avoidance and emotion focused strategies such as denial and behavioural disengagement, emotional support and positive reframing more than men.
- 3a People planning IVF treatments will not exhibit clinically significant levels of anxiety or depression.
- 3b There will be no significant differences in distress between groups.

Conclusions drawn from the literature seemed to indicate that significant distress in this population is rare, and there is little difference between groups of patients in this regard,

thus hypotheses 3a and 3b are specifically recorded as null hypotheses in order to gain evidence to support this point.

There will be a relationship between illness representations and coping strategies.

- 4a Symptom scores will be positively correlated with positive reframing, self-distraction and behavioural disengagement.
- 4b Timeline scores will be positively correlated with acceptance
- 4c Consequences will be positively correlated with venting, behavioural disengagement and self-distraction, and negatively correlated with acceptance.
- 4d Control subscales will be positively correlated with active coping, planning and positive reinterpretation.

There will be a relationship between coping strategies and distress levels.

- 4e Positive reframing, active coping and acceptance will be negatively correlated with distress.
- 4f Denial, self-distraction, behavioural disengagement and self-blame will be positively correlated with distress.

There will be a relationship between illness representations and distress levels.

- 4g Control and illness coherence will be negatively related to distress.
- 4h Symptoms, consequences, psychological cause, and emotional representations will be positively related to distress.

2.0 Method

2.1 Design

This study used a cross sectional, survey design. The time constraints of this project meant that using a sample of a clinic population at a particular point in time was the only feasible way of answering the research questions. Questionnaires were used to enable the couples to complete them in their own time, and to avoid the need for patient and researcher co-ordinating further visits to the clinic.

2.2 Participants

Patients were recruited from three assisted conception units in Acute Trusts in the Midlands. These were selected from the HFEA website, and contacted initially by phone. Meetings were arranged with the clinic manager or senior nurse, and the project was discussed in detail. This was to establish the clinic system in each of the centres, and to ascertain the most practical and workable procedure for the study. The aim was to be able to recruit both partners, so establishing a time they might both attend the clinic was essential.

Ethical approval for the study was obtained from the relevant local research ethics committees (Appendix 1). The inclusion criteria for patients were that they were planning a cycle of IVF treatment, which included ICSI and frozen embryo transfer procedures. Exclusion criteria were non-fluency in English, as not all the measures used have been standardised in other languages, and unwillingness to take part.

Couples planning their first cycle of treatment (first timers), and those attending for a repeat cycle (repeaters) were potential respondents. Both partners of each couple were asked to complete forms individually. However, the study was not designed to look at the similarities and differences in couple's experiences, so the questionnaires were not coded or analysed in pairs.

Power analysis was conducted prior to the study, using power tables for the main analysis test, correlation (Clarke-Carter, 1997). Taking a medium effect size of 0.5 on a two-tailed Pearson's Product Moment Correlation Coefficient, in order to reach a sufficient level of power (0.8) (Cohen, 1988) a sample size of 30 was required.

2.3 Measures

Participants were asked to complete four questionnaires (Appendix 3).

2.3.1 Demographic Questionnaire

This was designed by the researcher in order to gather basic demographic data about the participants. It included questions about age, ethnicity, length of time trying to conceive, and number of previous IVF cycles. It also asked participants to identify which partner, if either, had received a diagnosis by ticking boxes marked 'male factor', 'female factor', 'both', or 'unexplained'.

2.3.2 The Illness Perception Questionnaire – Revised (IPQ-R) (Moss-Morris *et al.*, 2002).

This is a revised version of the measure developed by Weinman *et al.* (1996) which aimed to provide a quantitative assessment of the various components of illness representation (Leventhal *et al.*, 1984). The exploration of illness perceptions began before this scale was developed and therefore alternative methods of gathering similar information, such as content analysis of interviews about disease prototypes (Bishop *et al.*, 1987), have been used. Lau and Hartman (1983) interviewed college students about health problems. They used the then four components of Leventhal and colleagues' model (Leventhal *et al.*, 1980) as the basis for open ended questions, and proposed a fifth component, 'cure'. They found evidence to support this five-component model, which has formed the basis of this questionnaire.

In 1986, Turk and colleagues developed the Implicit Models of Illness Questionnaire, designed to measure illness representations (Turk *et al.*, 1986). The 45 item questionnaire has four dimensions: seriousness, personal responsibility, controllability, and changeability; and was found to be a valid tool for assessing illness cognitions in a study examining the beliefs of students and patients about three different illnesses (Schiaffino & Cea, 1995).

Despite these other methodological possibilities, it was felt that the IPQ-R was the tool of choice as it fits the original model more closely, is adaptable to the particular patient population, and has been used successfully in a number of other research studies.

It is a self-completed questionnaire, divided into three sections, all demonstrating good internal reliability. The first examines illness identity ($\alpha = .75$), and requires the participant to say whether they have experienced any of the listed symptoms as part of their illness. There are fourteen commonly experienced symptoms on the list, which can then be adapted or added to depending on the particular patient group being studied. For the purposes of this study, the following symptoms were added: tearfulness, irritability, spotting / bleeding, anxiety, low mood, bad dreams, racing heart. These were chosen as symptoms that infertile couples might experience, after discussion with medical staff at the clinics. It is also worth noting that the word illness was replaced throughout the IPQ-R by phrases such as 'difficulty conceiving' or 'your problem'. This was again agreed with clinic staff, as patients rarely feel that infertility is an illness as such.

The second section of the IPQ-R gathers respondents' views about their illness. It includes the original dimensions of: time line (acute / chronic ($\alpha = .89$) or cyclical ($\alpha = .79$)) which indicates their perceptions about the likely duration of their problem; consequences ($\alpha = .84$) which is concerned with the severity and impact of the illness; and control (personal ($\alpha = .81$) and treatment ($\alpha = .80$)) which reflects the respondents' beliefs about how amenable the illness is to cure or control. The new dimensions are: illness coherence ($\alpha = .87$) which reflects the person's beliefs about how useful their representation is at providing an understanding of the illness (a type of meta cognition), and emotional representations ($\alpha = .88$) which aims to address the emotional components of respondents' illness representations. There are fifty statements with which the respondent rates their agreement on a five point Likert scale: *strongly agree*, *agree*, *neither agree nor disagree*, *disagree*, *strongly disagree*. These are scored 0 (strongly disagree)- 4 (strongly agree), and for descriptive purposes a cut off of 2.5 was

chosen to indicate a high or low score on each scale. This was chosen as just above the midpoint where the lower range of scores indicated the respondent did not agree with or experience the statement. However due to the reverse scoring system on some of the scales, a high score on some (for example self control) indicated a positive response, whereas on others it indicated a negative response (for example consequences).

The third section of the questionnaire contains eighteen items which make up the causal dimension. These are rated on the same Likert scale, and are divided into categories of psychological attributions, risk factors, immunity, and accident or chance, although are often taken as individual items (Helder *et al.*, 2002). The Cronbach alphas for these factors range from .23, to .86.

According to Weinman and colleagues, the revision has strengthened the psychometric properties of the original scale. They collected data on 711 patients, and conducted two principle components analyses. They report that in the majority of cases the items loaded onto one factor, and they disregarded those that loaded onto more than one, or none. Test-retest reliability was measured over three weeks and six months, and was found to be acceptable with correlations ranging from .46-.88. The authors note that the scale also demonstrates good discriminant, known group and predictive validity.

2.3.3 The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983).

This is a fourteen item self-report questionnaire, designed to identify levels of anxiety and depression in hospital and medical (out) patients. There are seven items in each scale. The items have been selected in order to eliminate contamination from the effects

of physical illness, and participants respond to each 'symptom' by choosing one of four statements indicating how frequently or intently they experience it. It is a well used measure, which patients find quick and easy to complete (Silverstone, 1994).

A recent validation study provided confirmation that the HADS is still performing satisfactorily in distinguishing between anxiety and depression, whilst differentiating both from the effects of physical illness (Johnston *et al.*, 2000). This study used the HADS as a repeat measure on three groups of patients, and internal consistencies of the scales were found to be acceptable (range $\alpha = .76-.94$). However, some studies have carried out factor analysis on the HADS items and found support not for the described concepts of anxiety and depression, but for a four factor solution (Andersson, 1993), a three factor solution (Dunbar *et al.*, 2000), or a two factor solution different from the original (Andersson, 1993). Despite these, a recent literature review of 71 studies using the HADS stated that most factor analyses revealed a two factor solution in accordance with the original subscales (Bjelland *et al.*, 2002). This study also looked at the sensitivity of the HADS in finding 'cases' of anxiety and depression. Again they concluded that in most studies an optimal balance between sensitivity and specificity was found when 'caseness' was defined by a score of eight or above.

A number of brief questionnaires, such as the Beck Depression Inventory (Beck, 1996) and the State Trait Anxiety Inventory (Spielberger, 1983) have been developed for use in assessing mood disorders. Furthermore, screening tools, such as The General Health Questionnaire, have been extensively used in a wide variety of contexts to provide information on the likelihood of psychiatric problems. These questionnaires would have been acceptable for this study in terms of their validity and brevity, however the HADS

was felt to be the measure of choice when using a hospital outpatient population (such as this one) as it was designed specifically for the purpose.

2.3.4 The COPE (Brief version) (Carver, 1997).

This is an amended version of the COPE (Carver *et al.*, 1989), which omits two of the previous scales whilst adding one new one, and reduces the questionnaire to two items per scale. The original measure was developed from the model of coping put forward by Lazarus and Folkman (1984) and Carver and Scheier's (1981) model of behavioural self-regulation. There are 28 questions making up 14 subscales, which can be used selectively according to the researcher's needs. The version used in this research is the retrospective, situational format, as described in the original paper. The participant is required to state to what extent they *have been using* each coping method on a four point scale, ranging from *not at all* to *a lot*.

Lazarus and colleagues themselves developed The Ways of Coping, a measure to study their theoretical model (Folkman & Lazarus, 1980). This distinguished between two general types of coping: problem focused and emotion focused. However, other studies found that the scale formed more than two factors, and that activities which could be classified under either category might be very different from each other; indeed the revised version reveals an eight factor structure (Folkman & Lazarus, 1985). In their critique of this and other coping measures, Carver *et al.*, (1989) highlight a number of problems, including the empirical rather than theoretical construction of scales, ambiguity about what items are measuring, and the lack of opportunity they provide to measure the diversity of coping responses.

They set out to develop a theoretically based measure that would measure all the domains they felt to be of import. The original instrument began with thirteen scales, which were administered to 978 students as a dispositional measure of how they usually coped in stressful situations. Factor analysis revealed 14 factors (the majority of which with high internal consistency), and another was added after the conclusion of the study. The authors argued that although the correlations between scales were relatively low, they clustered in conceptually meaningful ways, i.e. theoretically adaptive strategies, and unhelpful strategies

The COPE was also designed to be used as a situational measure of coping, and as such the items were rewritten in situational format, and administered to a further group of undergraduates. Results were similar, if not better in terms of factor structure and reliabilities, and the same clusters of scales emerged.

As a sixty item instrument with four questions per scale the COPE was recognised as a long questionnaire, with some redundant items (Carver *et al.*, 1993). The Brief COPE was therefore developed to both address this issue, and to modify some of the scales. A new scale was also added. Some of the scales clustered in a similar way to the original, revealing eight different factors. A study using the Brief COPE on women undergoing treatment for breast cancer provided supporting evidence for the reliability and validity of the measure (Fillion *et al.*, 2002).

The original COPE has been used in infertility research (Berghuis & Stanton, 2002). This study looked at coping and distress in couples over an insemination attempt. The researchers used five scales in their analysis. These were seek social support, problem

focused coping, avoidance, positive reinterpretation and growth, and religion, with alpha coefficients ranging from .71 to .95. Using the scales as they are constructed in the Brief COPE, this suggests there might be support for the eight scales Carver (1997) identified: seek support (including use of emotional support and use of instrumental support), problem focused coping (including active coping, planning and positive reframing and acceptance) distraction (including venting and self-distraction), denial (together with self-blame), and substance use, religion, humour and behavioural disengagement.

A summary of the measures is presented in Table 2.1.

Table 2.1 Summary of Measures

Measure	Subscales with alpha coefficients where applicable
Demographic Questionnaire	age ethnicity length of time trying to conceive number of previous IVF cycles diagnosis male factor female factor both unexplained.
The Illness Perception Questionnaire – Revised (Moss-Morris <i>et al.</i> , 2002).	illness identity ($\alpha = .75$), time line - acute / chronic ($\alpha = .89$) cyclical ($\alpha = .79$) consequences ($\alpha = .84$) control - personal ($\alpha = .81$) treatment ($\alpha = .80$) illness coherence ($\alpha = .87$) emotional representations ($\alpha = .88$) psychological attributions ($\alpha = .86$) risk factors ($\alpha = .77$) immunity ($\alpha = .67$) accident or chance ($\alpha = .23$)
The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).	anxiety depression
The COPE (Brief version) (Carver 1997).	active coping ($\alpha = .68$) planning ($\alpha = .73$) positive reframing ($\alpha = .64$) acceptance ($\alpha = .57$) humour ($\alpha = .73$) religion ($\alpha = .82$) using emotional support ($\alpha = .71$) using instrumental support ($\alpha = .64$) self-distraction ($\alpha = .71$) denial ($\alpha = .54$) venting ($\alpha = .50$) substance use ($\alpha = .90$) behavioural disengagement ($\alpha = .65$) self-blame ($\alpha = .69$).

2.4 Procedure

Patients were recruited as they attended the clinics for their pre treatment planning appointment. This involved patients meeting either the consultant or a nurse to discuss the treatment cycle and clarify what was required of them. It was important to select participants before they embarked on treatment as the side effects of the hormone injections could have manifested as emotionalism and mood swings, and contaminated the distress scores.

The planned procedure was that medical staff would identify potential participants, briefly describe the study to them, and if they expressed interest in the project, would give them the Patient Information Leaflet to read (Appendix 2). If patients were willing to continue, they were then asked for written consent (Appendix 2), which was stored in their files at the clinic. This ensured the researcher had no access to patient identifying details, which was essential in this group of patients as it is illegal for infertility clinics to give out identifying information about patients to anyone (including GPs) without written permission from the couple. (Human Fertilisation and Embryology Authority, 2002). This procedure was satisfactory in one clinic. In the second, the researcher described the study to patients who had been identified by the medical staff, which increased the number of recruits significantly. The third clinic adapted the procedure further. Nursing staff identified patients who might be suitable, and who were due to come to the clinic in the subsequent two weeks. They telephoned them, explained the study, and asked if the patients would be interested in taking part. A pack including the information sheet, consent forms, and questionnaires was sent to interested parties, with

a covering letter form the clinic, and they were asked to return the questionnaires.

Consent was kept by the clinics in all cases.

All patients had the opportunity to complete the questionnaires (Appendix 3) at home and return them in a pre paid envelope. This was to maximise the amount of time they had to participate in the study without feeling under pressure in the clinic. However some of them completed the questionnaires in the clinics, as it was more practical to do so. Also within the questionnaire pack was a letter to their GPs (Appendix 4), which they were asked to pass on if they so wished. This maintained the boundaries of confidentiality whilst aiming to keep GPs informed about their patient's participation in a research study. The questionnaires were returned to the researcher for coding and analysis.

2.5 The Pilot

The pilot study was conducted in one of the clinics as a way of ensuring face validity of the questionnaires, checking clarity of the instructions, information for patients and consent forms; and assessing completion times. A presentation was given by the researcher at the Infertility Support Group, which was run by, and for, current and past patients of the clinic. Members of the support group who attended the presentation were then asked if they would wish to participate by completing the set of questionnaires which would form the study, and a further questionnaire (Appendix 5) in which they were asked their views on the questionnaires.

Five people agreed to take part. Having read the patient information and completed the main questionnaires booklet, respondents filled in the questionnaire designed by the researcher to assess whether there were any obvious problems with the research material. All five respondents felt the information for patients was clear and easy to understand, and of the four who answered the question, all thought patients were given enough information to make an informed decision about taking part. The questionnaires were universally thought to be clear and easy to understand, although three people felt there were ambiguous items. On the demographic questionnaire one respondent was unclear whether *'How long have you been trying to conceive?'* included the period before consulting doctors. One respondent was not sure what *'Our difficulty conceiving will improve in time'* meant, whilst another noted she was not sure how time line differed from control / cure. These points were taken into consideration when producing the final set of questionnaires. The ambiguous items were reworded slightly to *'Our situation will improve in time'*, and *'How long have you been trying to conceive in total?'* giving the respondents the chance to interpret them in any way that was meaningful for them; and the final questionnaire did not separate items into categories on the paper as the first had, so eliminating possible confusion over how they were divided. No one felt that any of the items were irrelevant or pointless, or would cause distress.

In response to the open ended questions about how they had found the questionnaires, three respondents said they would take part if they had been asked to do it, and one indicated that taking part in research like this was a way of making her feel she was doing something positive in a negative situation. Furthermore, there were comments from both the men about how interesting it was to complete the questionnaires. One

highlighted the value of having to be honest about his feelings, and the other found it useful to analyse how he coped. The time range for completion of the questionnaires was 15-18 minutes.

The results of the pilot suggested that the information given to patients was clear and comprehensible, and that patients would be able to make informed decisions about taking part in the study. The questionnaires were largely clear and relevant, and changes were made to suggested items. It was not thought likely that anyone would become distressed by completing these questionnaires.

In the period of time between the pilot and the start of the project, the revised version of the IPQ came out. It was felt that as the new version was more comprehensive it would be advisable to use this. Ethical approval for the change was obtained and the questionnaires were rewritten. The pilot study was not repeated with the new questionnaires, as the support group was closed over the summer, and during the subsequent relocation of the clinic in the autumn.

3.0 Results

3.1 Analysis plan.

The main research questions for this study were:

1. What are the illness representations of infertile patients planning IVF treatments?

In order to answer this question, descriptive data is presented on dimensions of illness representations. Based on the illness representations and infertility literature, a couple of hypotheses were generated in relation to this question, and are presented below.

- 1a People planning IVF treatments will have low symptom and self-control scores (below 2.5), and high time line, emotional representations and consequence scores (above 2.5).
- 1b Those without a diagnosis will be more likely to endorse psychological causes than those with a diagnosis.

2. What are the coping strategies of infertile patients planning IVF treatments?

Descriptive data is presented in order to answer this question. Hypotheses were generated from literature on coping with infertility.

- 2a People planning IVF treatments will endorse active, problem focused strategies more frequently than avoidance or emotion focused strategies.
- 2b Women will endorse maladaptive strategies more than men.

3. What is the extent of psychological morbidity in patients planning IVF treatments, and are there differences between men and women, between ethnic groups, between 'first timers' and 'repeaters', and between those with and without a diagnosis?

Levels of psychological morbidity for the sample are presented. Tests of difference between group means were suitable for analysing whether or not there were significant differences in distress amongst the different groups. The following hypotheses were stated in line with the infertility literature:

- 3a People planning IVF treatments will not exhibit clinically significant levels of anxiety or depression.
- 3b There will be no significant differences in distress between groups.

4. How are illness representations, coping and psychological morbidity (distress) related in this group?

The self-regulation model (Leventhal *et al.* 1984) suggests that there is a relationship between these three variables. Tests of relationships between the variables, and regression analysis were judged appropriate to provide answers to this question.

However the constraints of correlation mean it is not possible to be conclusive about causal direction, and the interpretation of results was completed with caution in the light of this. The hypotheses developed from previous research in relation to this question were

Illness representations and coping.

- 4a Symptom scores will be positively correlated with positive reframing, self-distraction and behavioural disengagement.

- 4b Timeline scores will be positively correlated with acceptance.
- 4c Consequences will be positively correlated with venting, behavioural disengagement and self-distraction, and negatively correlated with acceptance.
- 4d Control subscales will be positively correlated with active coping, planning and positive reinterpretation.

Coping and distress.

- 4e Positive reframing, active coping and acceptance will be negatively correlated with distress.
- 4f Denial, self-distraction, behavioural disengagement and self-blame will be positively correlated with distress.

Illness representations and distress.

- 4g Control and illness coherence will be negatively related to distress.
- 4h Symptoms, consequences, psychological cause, and emotional representations will be positively related to distress.

3.2 *Selection of Tests*

Before any analysis was carried out, the data were examined to see if they fit the criteria for application of parametric statistics. The main criteria for this is that the data should be normally distributed (Clarke-Carter, 1997). The major variables were inspected visually using histograms with the normal distribution curve imposed on them. They were also subject to the Kolmogorov- Smirnov One – sample test. This revealed that 28 of the 42 variables tested were not normally distributed, although 18 of them formed the

'cause' subscale of the IPQ. Thus a mixture of parametric and non-parametric tests were used. Since parametric assumptions were not extensively violated, multiple regressions were used to assess the extent to which specific variables contributed to the variance in the outcome scores (anxiety and depression).

In common with most psychological research, the alpha level was set at .05 (Clarke Carter, 1997). However, in some cases and for specific reasons, where stated, this was changed to .01.

All of the statistical analyses were carried out using Statistics Package for the Social Sciences (SPSS) for Windows, version 10.

3.3 Sample Characteristics

Questionnaires were returned by 50 patients attending the assisted conception units. Staff did not note the total of patients asked to participate, but estimate that 100 questionnaires were given out. If this is accurate, it indicates a return rate of 50%.

18 couples and 14 individuals returned questionnaires, making a sample of 20 men and 30 women. The mean age of the sample was 34 (range 25-50 years), and the mean length of time trying to conceive was five years (range one year three months to 17 years two months). 39 patients recorded their ethnicity as white. Two did not record their ethnicity, two were Afro Caribbean, and seven, Asian.

On average the patients had been receiving treatment for their infertility for two and a half years (range three months to 10 years). 19 patients recorded themselves as having unexplained infertility (classified as the 'unexplained' group). Nine endorsed 'male factor', 13 felt their cause was due to a 'female factor', and nine endorsed 'both', making a total of 31 in the 'diagnosed group'.

10 patients were planning their first cycles and were classified as first timers. 21 patients had been through one cycle of IVF or ICSI, 11 had been through two, six had been through three, and two patients had undergone five cycles (a total of 40 repeaters).

3.4 What are the illness representations of infertile patients planning IVF treatments?

3.4.1 Descriptive data on illness representations

The IPQ -R combines all its items into eight subscales, and a section on causes. Data on the subscales is presented below, including internal reliability scores for the IPQ-R subscales for this sample. These were computed as it is the first time this measure has been used with infertile patients. Descriptive data is used to examine whether there is support for the first hypothesis:

- 1a. People planning IVF treatments will have low symptom and self-control scores (below 2.5), and high time line, emotional representations and consequence scores (above 2.5).

Table 3.1. Alpha scores, means, range and standard deviations for the Illness Perception Questionnaire Subscales.

IPQ Subscale	Internal consistency	Mean	Range	SD
Symptoms		1.92	0 -10	2.75
Timeline	.40	2.34	1- 3.6	0.63
Consequences	.75	2.39	0.67 - 4	0.79
Personal control	.77	1.82	0 - 3	0.70
Treatment control	.60	2.28	1 - 3.75	0.62
Illness coherence	.92	2.11	0 - 4	1.06
Timeline cyclical	.83	1.59	0 - 3.25	0.82
Emotional representations	.80	2.45	0.67 - 3.83	0.70

Taking the mid range score of 2.5 as cutoff, Table 3.1 illustrates that this group of infertile patients had low scores on all the subscales. Most people (60%) were asymptomatic in relation to their infertility, and did not find that their symptoms were changeable or unpredictable. There were low levels of emotional representation, and low perceived consequences of their infertility. However, this group had a very low sense of personal control over their problem, and only a slightly stronger belief in the idea that treatment would be effective. Thus the hypothesis is supported in two of its predictions. Although few people reported they were experiencing symptoms, a variety were endorsed, as illustrated in Figure 3.1.

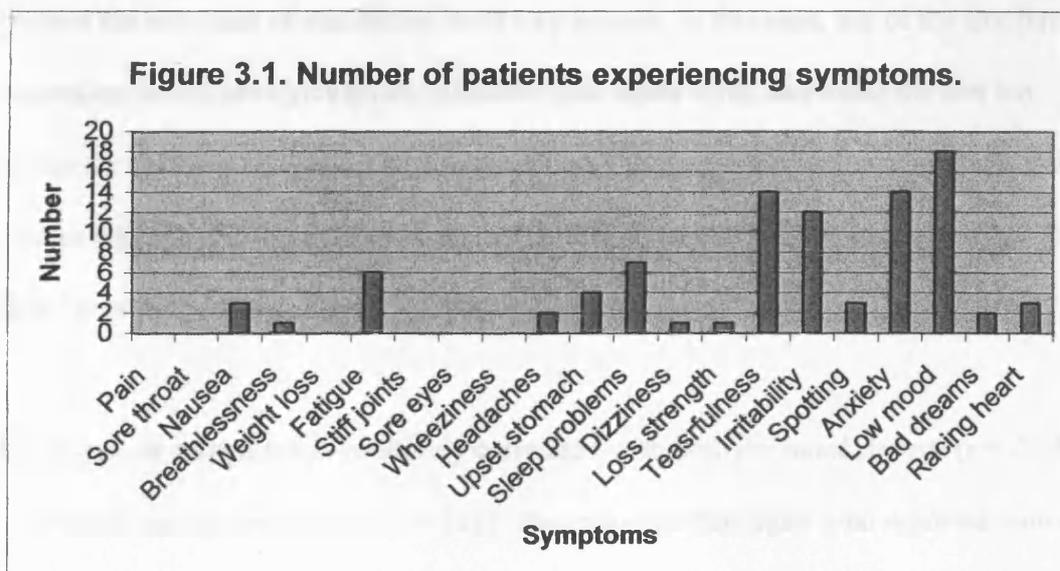


Figure 3.1 indicates that the most commonly endorsed symptoms were low mood (N=18), anxiety and tearfulness (N=14), and irritability (N=12). These were all symptoms added by the author as potentially significant to this group, and could all be classified as emotional or psychological symptoms.

3.4.2 Relationships between subscales

In common with other studies using the IPQ (Moss-Morris *et al.* 1996, Rutter & Rutter, 2002) the subscales of the measure were correlated with each other, using two-tailed Pearson Product Moment correlations. This test is a parametric test of covariance between two variables, and seven of the eight subscales met the criteria for use of this test. As the symptom subscale was not normally distributed, Kendal's Tau was used for these correlations. This statistical test was chosen as it has been recommended for use with non parametric data as it provides a better estimation of the true value than does Spearman's rho (Howell, 1997). The results of the tests are shown in Table 3.2.

Due to the high number of correlations performed, a correction needed to be applied to prevent the detection of significant results by chance. In this case, use of the Bonferroni correction would have yielded an extremely low alpha level, and make the test too stringent. Therefore it was decided to accept only those correlations where p was less than or equal to .01, as significant. Applying this alpha level, there were a number of significant correlations, shown in Table 3.2.

The *symptom* subscale was positively correlated with both *personal control* ($r = .314$) and *emotional representations* ($r = .323$). This suggests that those who reported more

symptoms were more emotional, but also felt they had more control over their infertility. *Emotional representations* were negatively related to *illness coherence* ($r = -.444$) and positively related to *timeline cyclical* ($r = .518$). These results show that those who were more emotional had a less clear understanding of their infertility, and experienced difficulties in cycles. *Timeline cyclical* was also negatively correlated with *illness coherence* ($r = -.489$), indicating that those who perceived their difficulties to be cyclical were also less clear about them. The *consequences* scale was positively correlated with the *timeline* scale ($r = .371$), indicating that people who believed their problem would last a long time also perceived a greater effect on their life.

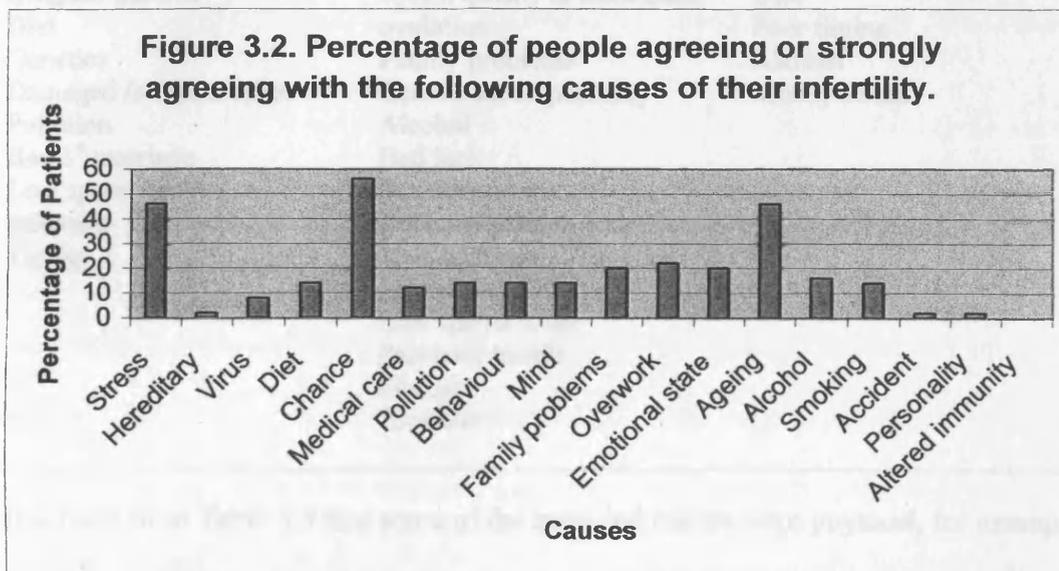
Table 3.2. Correlations between Illness Perception Questionnaire subscales.

	Symptom (Kendal Tau)	Timeline	Consequences	Personal control	Treatment control	Illness coherence	Timeline cyclical
Symptom							
Timeline	-.001						
Consequences	.063	.371 **					
Personal control	.314**	-.194	-.088				
Treatment control	-.043	-.186	-.062	-.011			
Illness coherence	.000	-.099	-.079	.129	.267		
Timeline cyclical	.189	-.157	.215	.088	-.3*	-.489**	
Emotional representation	.323**	.011	.316*	.219	-.071	-.444**	.518**

* p= <0.05 ** p=< 0.01

3.4.3 Descriptive data on causes

Moss-Morris *et al.* (2002) recommend that the 'causes' section needs to be analysed separately. Thus each individual 'cause' was examined to establish the extent to which the participants agreed it was related to their difficulty conceiving (see Figure 3.2). *Chance* (56%), *stress* (46%) and *age* (46%) were causes (Figure 3.2), that respondents most frequently agreed or strongly agreed were a cause of their infertility. *Altered immunity* was not endorsed as a cause by any of the participants.



In addition to recording the extent to which they agreed each cause was relevant to them, the participants were asked to list the top three most important causes for them. These could be causes which appeared in the IPQ -R list, or self-generated ideas. Table 3.3 shows the results of the 44 respondents (88%) who answered this question. *Bad luck* was recorded as one of the top three causes fourteen times, as was *age / ageing*. The most frequently cited cause was *stress*, with 15 respondents ranking that in the top three most important causes.

Table 3.3. Responses to the question: *Please list in rank order the three most important factors that you now believe caused your difficulty conceiving.*

Most important (N)	Ranked second (N)	Ranked third (N)
Bad luck (8)	Stress (6)	Bad luck (5)
Age (6)	Ageing (3)	Stress (5)
Stress (4)	Overwork (3)	Ageing (5)
Mucus incompatibility (2)	Eggs (2)	Weight (2)
Childhood accident (2)	Smoking (2)	Anxiety
Overworked	Hereditary (2)	Pollution
Poor medical assessments/ care	Scarred / blocked fallopian tubes (2)	Previous medical treatments
Smoking	Medical problem	Infection
Sperm quality	Knowledge of possible treatments.	Hormone imbalance
Ovarian cyst	Sperm quality & inadequate ovulation	Anaemia
Irregular periods	Family problems	My emotional state
Diet	Genetic incompatibility	Diet
Genetics	Alcohol	Poor timing
Damaged fallopian tubes	Bad luck	Alcohol
Pollution	Endometriosis	Money issues
Bad 1 st marriage	Period problems	
Low sperm count	Own behaviour	
Infection	Lots of x-rays	
Timing	Low sperm count	
	Past poor health	
	Fibroids	
	Poor diet	

It is clear from Table 3.3 that some of the recorded causes were physical, for example, low sperm count or endometriosis; whilst others were psychological and some environmental. Given that those with unexplained infertility are not given a physical cause for their problems, it was hypothesised that:

- 1b Those without a diagnosis will be more likely to endorse psychological and chance causes than those with a diagnosis.

In order to test this hypothesis, a new variable 'psychological causes', based on the work of Moss-Morris *et al.* (2002) was computed. The participant's score on this variable was

the mean of the summed scores of the following items: *stress, my own behaviour, my mental attitude, family problems, overwork, my emotional state and my personality* ($\alpha = .87$). The variable *chance* was already included in the scale. Mann -Whitney Tests were carried out to examine whether those without a diagnosis ('unexplained' group) were more likely to think *chance* or *psychological factors* were causes than those with ('diagnosed' group). The results show there was a significant difference between groups on belief in *chance* as a cause ($U= 19.5, p = .04, 2$ tailed), in that the 'unexplained' group were more likely to believe infertility was a matter of *bad luck*, but there were no differences in belief in *psychological causes* ($U= 25.4, p= .417, 2$ tailed), thus the hypothesis was partially supported.

3.4.4 Relationships between causes and other subscales.

The causes variables were also correlated with the rest of the IPQ subscales, using Kendal's Tau. Not all the results are presented due to the volume of them, however, there were a number of interesting relationships, significant at the .01 level. The *symptom* subscale was positively correlated with the perception that the person's own *mental attitude* ($r = .355$), or their *emotional state* ($r = .338$) had caused their infertility. *Emotional representations* were also positively related to both *mental attitude* ($r = .304$) and *emotional state* ($r = .299$). *Timeline cyclical* was positively correlated with belief that *poor medical care* ($r = .321$) and *pollution* ($r = .340$) had been causes of their infertility. It was also related to the more psychological causes of *overwork* ($r = .296$), the person's *own behaviour* ($r = .373$), or their *personality* ($r = .331$).

Illness coherence was negatively related to both the belief that infertility was a result of *chance or bad luck* ($r = -.306$), and *age* ($r = -.357$). Finally, *treatment control* was

negatively correlated with belief that the person's *own behaviour* was involved ($r = -.319$), that their *emotional state* had caused their infertility ($r = -.296$), and that *age* had ($r = -.371$).

3.4.5 Summary of results relating to illness representations.

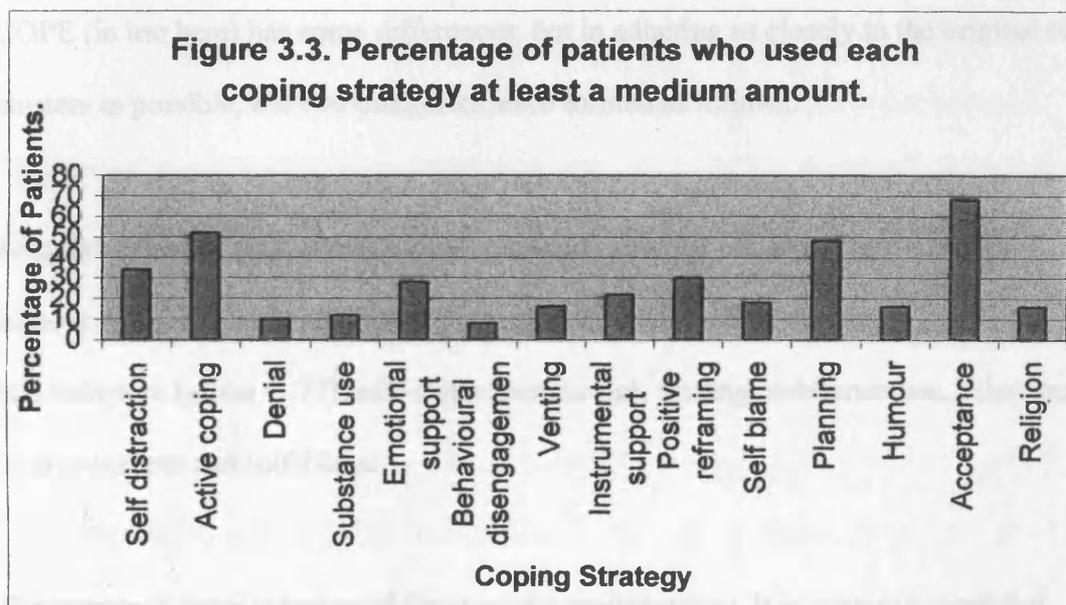
In summary, patients in this sample had low scores on all IPQ subscales. 60 per cent of people were asymptomatic, but of those who were experiencing symptoms, most endorsed emotional symptoms such as tearfulness, anxiety, irritability, and low mood. Those who reported more symptoms felt more emotional, but also believed they had more control over their infertility. Those who were more emotional had a less clear understanding of their infertility, and experienced difficulties in cycles. Those who perceived their difficulties to be cyclical were also less clear about them. People who believed their problem would last a long time perceived a greater effect on their life.

Chance or bad luck, stress and age were the most commonly endorsed causes for infertility, although some people recorded their specific diagnoses. Those with a diagnosis were no less likely than those without one to think that psychological factors might have been causes of their difficulties, but they were less likely to think it was a matter of chance. Those who believed that psychological factors had caused their infertility experienced more symptoms, felt more emotional and less emotionally stable, and less hopeful about treatment. People who believed age had been a factor in their problems were less clear about them and less hopeful about treatment. Those who thought that infertility was a result of bad luck had a poorer understanding of their problems.

3.5 What are the coping strategies of infertile patients planning IVF treatments?

3.5.1 Descriptive data on coping

Respondents were asked to record the extent to which they used each coping strategy, on a four point scale ranging from 'not at all' to 'I've been doing this a lot'. Figure 3.3 illustrates that *acceptance* was the most commonly used strategy, with 68 per cent using it a medium amount or a lot. *Active coping* (52%) and *planning* (48%) were also commonly used strategies.



3.5.2 Between groups differences in coping strategies.

The literature suggests that people going through IVF treatments are likely to be problem focused, active copers by the very nature of the treatment regimen. Thus it was hypothesised (2a) that this group would show the same characteristics.

2a People planning IVF treatments will endorse active, problem focused strategies more frequently than avoidance or emotion focused strategies.

In order to test this hypothesis, two new variables were computed. Although the COPE is designed so that all subscales can be analysed separately, an attempt was made to subsume all the subscales into two broad categories: adaptive coping and maladaptive coping. The categories (and the content thereof) were taken from Carver *et al.*'s (1989) first paper on the COPE, which discusses clusters of correlations found amongst the coping strategies. They loosely termed these 'adaptive' and 'the other group'. The Brief COPE (in use here) has some differences, but in adhering as closely to the original two clusters as possible, the two categories were formed as follows:

Adaptive (alpha = .74): active coping, planning, positive reframing, acceptance, humour, religion, using emotional support, using instrumental support.

Maladaptive (alpha = .77): self-distraction, denial, venting, substance use, behavioural disengagement and self-blame.

The term maladaptive was used for ease of comprehension. It is acknowledged that although this implies these coping strategies are unhelpful, some research would indicate that they can be helpful for some people in certain situations. As the new variables met the criteria for parametric tests, a paired samples t-test was used. This test is appropriate when comparing each person's score on one variable with their score on another to see whether there are significant differences, and is sometimes referred to as a repeated measures, or correlated t-test (Brace *et al.*, 2000). The results showed that patient's mean score was higher on the adaptive subscales than the maladaptive

subscales ($t= 5.765$, $df = 49$, $p= <0.0002$, one tailed). This provides evidence in support of the hypothesis.

The literature has also examined differences in gender in relation to coping, although these are not universally accepted as reliable. Thus this project aimed to investigate the differences in choice of coping strategies for this sample. The following hypothesis was tested using a mixed analysis of variance (ANOVA).

2b Women will endorse maladaptive strategies more than men.

A mixed ANOVA is used when designs contain both within subjects and between subjects variables (Brace *et al.*, 2000). In this case, coping was the within subjects variable, with two levels of adaptive and maladaptive; whilst gender was the between subjects variable, also with two levels (male and female).

The results showed that the main effect of coping was significant ($F= 31.418$, $df = 1$, $p= .000$), but that the gender by coping interaction was not significant ($F= 0.005$, $df = 1$, $p= .944$), and neither was the main effect of gender ($F= 3.025$, $df = 1$, $p= .088$). This disproves the hypothesis as use of maladaptive strategies did not differ between men and women.

3.5.3 Summary of results in relation to coping.

Acceptance, active coping and planning were the most commonly used coping strategies by this group; and in general the group used adaptive coping strategies

significantly more than maladaptive strategies. There was no gender difference in use of these two categories of strategies.

3.6 What is the extent of psychological morbidity in people planning IVF treatments?

3.6.1 Descriptive data on levels of anxiety and depression.

The literature has been equivocal on this matter. However, well controlled studies using standardised measures have failed to find significant clinical distress. Thus hypothesis 3a predicted:

3a People planning IVF treatments will not exhibit clinically significant levels of anxiety or depression.

Table 3.4 presents data that supports this hypothesis; this group of patients is not clinically distressed on average, although a high percentage (42%) fell into the clinical range of scores for anxiety.

Table 3.4. Mean, range and standard deviation for distress scores on the Hospital Anxiety and Depression Scale.

Distress	Mean	Range	SD	Number of patients in clinical range (score of 8 or above).
Anxiety	6.34	0-14	4.10	21 (42%)
Depression	3.24	0-13	3.23	6 (12%)

The mean scores are comparable with those of a sample of patients with breast cancer attending a breast care clinic to discuss treatment (mean anxiety score = 6.13, SD = 4.09; mean depression score = 2.86, SD = 2.96) (Johnston *et al.*, 2000).

3.6.2 Between groups differences in levels of anxiety and depression.

Whilst it is useful to apply the theoretical model of illness representations to understand the experiences of infertile patients as a whole, earlier research has been criticised for not distinguishing between groups in the analysis. When they have done, studies have failed to present reliable evidence of differences between groups. This project attempted to differentiate between the experiences of men and women, different ethnic groups, people at different stages of treatment, and those with and without a diagnosis, by comparing their scores on the main outcome variables.

Hypothesis 3b predicted:

3b There will be no significant differences in distress between groups.

Simple between subjects t-tests for differences between groups on anxiety, and Mann Whitney U tests for differences in depression were used. These tests examine the differences between two sample means. For anxiety, all the criteria for use of parametric tests were met, but depression scores were not normally distributed. Tests revealed no significant differences, indicating that no group is any more anxious or depressed than any other (Table 3.5). This is in support of the hypothesis.

Table 3.5. Results of between groups analysis of differences in psychological morbidity.

Distress	Group	Level (N)	Mean	Result	df	p value (2 tailed)	Sig
Anxiety				t- score			
	Gender	Male (20)	5.45	1.260	48	.214	NS
		Female (30)	6.93				
	Ethnicity	White (39)	6.13	-0.561	46	.578	NS
		Ethnic minority (9)	7.00				
	Stage	First (10)	6.10	-0.205	48	.839	NS
		Repeat (40)	6.40				
	Diagnosis	Diagnosed (31)	5.84	1.106	48	.274	NS
		Unexplained (19)	7.16				
Depression				U-score			
	Gender	Male (20)	3.40	-0.283	48	.778	NS
		Female (30)	3.13				
	Ethnicity	White (39)	3.05	-1.256	46	.215	NS
		Ethnic minority (9)	4.56				
	Stage	First (10)	3.30	0.065	48	.948	NS
		Repeat (40)	3.23				
	Diagnosis	Diagnosed (31)	2.81	1.218	48	.229	NS
		Unexplained (19)	3.95				

In order to maximise the power of a between subjects t-test, the aim should always be to keep the group sizes as equal as possible. In this case the group sizes were rather unequal, and in the case of the ethnic group and the first timers group, relatively small. This means the power of the test is compromised, and may be an explanation for the lack of significant results. A retrospective power analysis was calculated on the harmonic mean of the sample sizes (Clarke-Carter, 1997). The harmonic means for the groups, effect sizes for each of the tests comparing groups on anxiety, and the power of each test was calculated (Table 3.6).

Table 3.6. Effect size, power, and probability of Type II error on comparing anxiety scores between groups in this sample.

Group	Harmonic size of each level	Effect size	Power of test	Chance of committing a Type II error
Gender	24	0.36	0.27	73%
Ethnicity	15	0.21	0.13	79%
Stage	16	0.07	0.08	93%
Diagnosis	24	0.32	0.27	68%

Power for non parametric tests is even lower. Table 3.6 shows the power was very low for these tests, and thus the chance of not finding a difference between groups that was present, was high. In order to achieve a power of 0.8 and a medium effect size of 0.5 (Cohen, 1988), the sizes of each group would need to be 50.

3.6.3 Summary of results in relation to psychological morbidity.

In summary, this group of patients were not found to be clinically depressed or anxious, although 42 per cent fell into the clinical category for anxiety, and 12 per cent scored above the cut off for depression. There was no difference between groups on distress measures but the power of the tests was low.

3.7 *How are illness representations, coping and distress related in this group?*

Correlational analyses were performed on these variables, and the results of each set of correlations are presented. As some of the variables were not normally distributed, a variety of Pearson Product Moment correlations and Kendal's Tau (one tailed) were

used. Results from Kendal's Tau analyses are marked. The correlations were performed to examine the relationships between variables, but also to test a number of hypotheses.

3.7.1 Illness representations and coping strategies.

The hypotheses in respect of this relationship were:

- 4a Symptom scores will be positively correlated with positive reframing, self-distraction and behavioural disengagement.
- 4b Timeline scores will be positively correlated with acceptance
- 4c Consequences will be positively correlated with venting, behavioural disengagement and self-distraction, and negatively correlated with acceptance.
- 4d Control subscales will be positively correlated with active coping, planning and positive reinterpretation.

With alpha at .01 to control for the number of correlations performed, there were a number of significant results.

Special Note

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Table 3.7. Correlations between Illness Perception Questionnaire subscales and coping strategies.

	SD	AC #	D #	SU #	ES	BD #	V #	IS #	PR	SB #	P	H #	A	R #
Symptom #	.116	.054	.086	.276*	.118	.175	.351**	.185	-.097	.403**	-.045	.028	-.041	.288*
Timeline	-.015	.102	.174	.081	.000	-.035	.081	.015	-.040	.077	.099	-.014	.156	-.104
Consequences	.127	.261	.014	.021	.111	.063	.179	.072	.087	.112	.253	.081	-.058	-.020
Personal Control	.057	.124	-.160	.204	-.011	.055	.059	.104	.003	.166	-.032	-.108	-.105	.015
Treatment Control	-.075	.334*	-.035	-.200	.071	-.077	-.096	.117	.194	-.179	.453**	.024	.107	.026
Coherence	-.292*	.257	-.309**	-.044	-.092	-.283*	-.321**	.024	-.068	-.342**	.217	-.190	.197	-.171
Timeline Cyclical	.210	-.143	.153	.115	.119	.311**	.341**	.004	.113	.475**	-.039	.091	-.222	.187
Emotional reps.	.448**	.168	.387**	.155	.247*	.454**	.616**	.198	.240	.508**	.250	.123	-.165	.286*

Key: # Kendal's Tau was used in the analysis. * p= < 0.05. ** p= <0.01.

SD – self distraction
 AC – active coping
 D -denial
 SU - substance use
 ES – emotional support
 BD – behavioural disengagement
 V- venting

IS – instrumental support
 PR – positive reframing
 SB- self blame
 P-planning
 H- humour
 A-acceptance
 R- religion

Special Note

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Contrary to the prediction in hypothesis 4a, the *symptom* subscale was not correlated with any of the coping strategies except *venting* ($r = .351$) and *self blame* ($r = .403$), indicating that those who had higher *symptom* scores were more likely to use *venting* and *self blame* to cope. Furthermore, hypothesis 4b was not supported, as *timeline* scores did not correlate significantly with *acceptance*, or indeed any strategy. This suggests that perception of how long the problem would last was not related to ways of coping with infertility.

The *consequences* subscale was not significantly correlated with any specific coping strategy either. This does not support hypothesis 4c, and indicates that choice of coping strategy was not determined by the impact infertility had on patients' lives.

Hypothesis 4d was partially supported by the finding that *treatment control* was positively correlated with *planning* ($r = .453$). However, neither of the two control scales were significantly related to the other coping strategies. This provides evidence that coping was not influenced by perceived control over the problem.

Choice of coping strategy appears to be related more closely to the newer subscales of the IPQ that only appeared in the IPQ-R. These positive relationships involve strategies that could be described as emotion focused, or avoidant coping – generally understood to be less helpful strategies. *Illness coherence* was negatively related to *denial* ($r = -.309$), *venting* ($r = -.321$), and *self-blame* ($r = -.342$). This indicates that those with a clearer understanding of their infertility were less likely to engage in these coping strategies. *Timeline cyclical* and *emotional representations* were positively related to *behavioural disengagement* ($r = .311$, $r = .454$) *venting* ($r = .341$, $r = .616$) and *self-*

blame ($r = .475$, $r = .508$); and *emotional representations* were further correlated with *self-distraction* ($r = .448$) and *denial* ($r = .387$). These results show that those who felt their difficulties with their infertility went in cycles, and those who felt more emotional about it generally, were more likely to engage in these 'unhelpful' coping strategies.

The coping subscales were also correlated with the items making up the cause section of the IPQ. Kendal's Tau was used as none of the items in the cause section were normally distributed. Again this involved a large number of correlations, and the results are presented in Appendix 6. Taking only those results significant at the .01 level as reliable enough to comment on, there were a number of significant relationships.

Belief that infertility *runs in the family* was negatively correlated with *acceptance* ($r = -.328$), indicating that patients who held this belief were less accepting of their position. Thinking that *diet* played a role in infertility was positively related to *venting* ($r = .324$). *Chance* was positively related to *self-distraction* ($r = .309$), indicating that those who put their problems down to bad luck were more likely to try and avoid thinking about them.

Those who believed more strongly that their *attitude* or their *emotional state* affected their ability to conceive were more likely to *blame themselves* ($r = .358$, $r = .339$) and *vent* their emotions ($r = .348$, $r = .448$) to cope.

Belief in *ageing* as a cause of infertility was negatively correlated with *active coping* ($r = -.368$). Thus those who held a stronger belief that age was relevant were less likely to employ active coping strategies.

3.7.2 Coping strategies and distress.

The predictions about this relationship were as follows:

- 4e Positive reframing, active coping and acceptance will be negatively correlated with distress.
- 4f Denial, self-distraction, behavioural disengagement and self-blame will be positively correlated with distress.

Table 3.8. Correlations between the Brief COPE subscales and the Hospital Anxiety and Depression Scale subscales.

	Self Distraction	Active Coping	Denial	Substance Use	Emotional support	Behavioural Disengagement	Venting
Anxiety	.392**	.001	.328*	.333*	.299*	.391**	.631**
Depression #	.363**	.132	.368**	.219	.238*	.455**	.470**
	Instrumental support	Positive Reframing	Self Blame	Planning	Humour	Acceptance	Religion
Anxiety	.246	.090	.540**	.050	.113	-.151	.230
Depression #	.179	.196	.393**	.155	.168	-.022	.270*

Kendal's Tau used in the analysis. * $p < 0.05$. ** $p < 0.01$.

These results show that hypothesis 4e was not supported. *Acceptance* was the only coping strategy negatively correlated with distress, but this was not significant.

However *denial*, *self-distraction*, *behavioural disengagement* and *self-blame* were positively correlated with distress, although *denial* was not significantly correlated with anxiety at the .01 level. This supports hypothesis 4f, that those who use what might be termed maladaptive coping strategies, had higher distress scores. *Venting* was also significantly correlated with both anxiety and depression, and as another coping strategy classified maladaptive, this further supports the hypothesis.

3.7.3 Illness representations and distress.

The predictions stated this relationship would be characterised in the following ways:

- 4g Control and illness coherence will be negatively related to distress.
- 4h Symptoms, consequences, psychological cause, and emotional representations will be positively related to distress.

Table 3.9. Correlations between The Illness Perception Questionnaire -revised subscales and the Hospital Anxiety and Depression Scale subscales.

	Symptom #	Time line	Consequences	Personal control
Anxiety	.329**	.067	.193	.095
Depression #	.275**	.034	.141	-.004
	Treatment control	Illness coherence	Timeline Cyclical	Emotional Representations
Anxiety	-.248	-.442**	.590**	.7**
Depression	-.023	-.354**	.376**	.432**

Kendals Tau is reported. ** $p < .01$

The first hypothesis was partially supported as only *illness coherence* was negatively correlated with anxiety and depression (anxiety $r = -.442$, depression $r = -.354$). This finding suggests that those with a clearer understanding of their infertility were less distressed.

The second hypothesis was also partially supported as only *symptom scores* and *emotional representations* were positively related to both anxiety ($r = .329$, $r = .7$) and depression ($r = .275$, $r = .432$). This is evidence that those experiencing more symptoms, and feeling more emotional were more likely to have higher distress scores

A further finding is that *timeline cyclical* was positively related to both anxiety ($r = .590$) and depression ($r = .376$). This indicates that those who found their feelings about infertility vary were more likely to have higher distress scores.

Correlations (Kendal's Tau) of causes with distress are presented separately in Table 3.10.

Table 3.10. Correlations between causes of infertility and anxiety and depression.

	Anxiety	Depression
Stress	.429**	.378**
Hereditary	.087	.116
Germ or virus	.003	.029
Diet	.385**	.204
Chance	.114	.139
Poor past medical care	.153	.109
Pollution	.314**	.303**
Own behaviour	.272*	.209
Own mental attitude	.337**	.315**
Family problems	.276*	.332**
Overwork	.376**	.344**
Own emotional state	.521**	.357**
Age	.107	.163
Alcohol	.107	.230*
Smoking	-.074	.027
Accident or injury	.263*	.223
Own personality	.339**	.363**

* $p < 0.05$. ** $p < 0.01$

As before, with such a high number of correlations, taking a significance level of $p < .01$ was the most appropriate. With this level of significance a number of causes were related to distress.

Those who believed more strongly that *stress* was a cause of their infertility did indeed have both higher anxiety ($r = .429$) and depression ($r = .378$) scores. This was also the case with other psychological causes such as the person's *own attitude* ($r = .337$, $r =$

.315), their *emotional state* ($r = .521$, $r = .357$) and their *personality* ($r = .339$, $r = .363$), and *overwork* ($r = .376$, $r = .344$). *Family problems* as a cause of infertility were also positively correlated with depression scores ($r = .332$). Of the physical, or environmental causes, only *pollution* was related to both anxiety ($r = .314$) and depression ($r = .303$), and *diet* was positively correlated with anxiety ($r = .385$).

3.7.4 Summary of the relationships between variables.

- Treatment control was positively correlated with planning but perceived control did not seem to be associated with any other coping strategy.
- Those with a clearer understanding of their infertility were less likely to engage in maladaptive coping strategies; but those who felt their difficulties with their infertility went in cycles, and those who felt more emotional about it generally, were more likely to engage in them.
- Patients who used maladaptive coping strategies, had higher distress scores.
- Those with a clearer understanding of their infertility were less distressed.
- Those experiencing more symptoms, and feeling more emotional had higher distress scores.
- Patients who found their feelings about infertility varied had higher distress scores.
- Belief that psychological factors had caused infertility was correlated with higher distress scores.

3.8 Predicting psychological morbidity

Although correlations provide a measure of the relationship between two variables, they do not help us to understand the extent of the effect one might have on another, that is they do not allow predictions about one based on the other. Multiple regression analysis allows specific predictions to be made about one variable (the criterion variable), from a combination of other (predictor) variables. It has advantages over simply correlating the predictor variables with the criterion variable, as it eliminates variables which overlap in the variance they explain. Regression allows a mathematical model of the relationship between the variables to be created, which explains and accounts for some of the variance in scores (Clarke-Carter, 1997).

The illness representations model argues that illness perceptions affect coping which in turn mediates distress levels (Leventhal *et al.*, 1984). However, research has found that in fact coping is not necessarily a mediator, illness perceptions can directly affect distress levels (Weinman *et al.*, 1996). This project aimed to examine these relationships in people planning IVF treatments. A stepwise multiple regression was used, with anxiety as the first criterion variable. The first step was to enter coping strategies correlated with anxiety, as the model suggests these are what influence outcome. *Venting* was the only coping strategy shown to predict variance, and accounted for 38.6 per cent ($\beta = .631, p = <.00005$). Causes of infertility were then entered at the next step, and *stress* emerged as a predictor. It added an explanation of a further 13 per cent of the variance ($\beta = .376, p = .001$). In the final step, the other IPQ subscales were added, and the only one adding significantly to the model was *timeline cyclical* ($\beta = .303, p = .007$). In total these three variables emerged as a significant predictor model ($F = 22.849, p = <.00005, \text{Adjusted R square} = .572$) (Table 3.11).

Table 3.11. Step-wise regression analysis with anxiety as the criterion variable.

	Significant Predictors	Beta	t-score	Adjusted r squared	Sig.
Step 1	Venting	.631	5.640	.386	.000
Step 2	Venting	.527	5.062		.000
	Stress caused infertility	.376	3.614	.509	.001
Step 3	Venting	.418	3.994		.001
	Stress	.298	2.946		.005
	Timeline cyclical	.303	2.813	.572	.007

These results show that people were likely to be more anxious if they vented their emotions a lot, thought stress caused their infertility, and found their problem unpredictable, going through cycles in which they felt better or worse. 57 per cent of the variance in anxiety was predicted by these variables, consequently 43 per cent of the variance remains unexplained. The demographic variables age and length of time trying to conceive were entered, but contributed nothing to the model.

As multiple regression is generally considered a parametric test, building a model around depression was potentially less valid. There was an option to transform the data, which allows parametric tests to be carried out on it. However, it was felt that the data would then be too difficult to interpret as results give ratio differences rather than absolute differences, and therefore the analysis was not undertaken. Another option was to examine the skewness and kurtosis of the variables considered to be non-normally distributed. This was done and results showed that the scores for both measures on each

were not significantly different from normal (skewness = .926, kurtosis = .167). It was felt that an exploratory model of depression was therefore valid.

The analysis was repeated using depression as a criterion variable, and results shown in Table 3.12.

Table 3.12. Step-wise regression analysis with depression as the criterion variable.

	Significant Predictors	Beta	t-score	Adjusted r squared	Sig.
Step 1	Illness coherence	-.522	-4.197	.257	.000
Step 2	Illness coherence	-.389	-3.153		.003
	Behavioural Disengagement	.368	2.982	.364	.005
Step 3	Illness coherence	-.306	-2.665		.011
	Behavioural Disengagement	.368	3.280		.002
	My personality caused infertility	.352	3.273	.475	.002
Step 4	Illness coherence	-.348	-3.182		.003
	Behavioural Disengagement	.336	3.159		.003
	My personality	.324	3.173		.003
	Symptoms	.260	2.597	.534	.013

The predictor variables were entered in the same way, and interestingly *venting* was a significant predictor of variance in scores until the final block of entrants when it was discarded from the model. The final model showed that *illness coherence* (beta = -.348, p = .003) accounted for 26 per cent of the variance, whilst *behavioural disengagement* (beta = .33, p = .003), perception of *personality* as a cause of infertility (beta = .324, p =

.003), and *symptom* score (beta = .260, p = .013) together accounted for the rest of the 53 per cent of the variance in depression (Table 3.12). Again this leaves 47 per cent of the variance unexplained.

When using multiple regression, the sample size needs to be sufficient to maximise the reliability of the results. There are various figures suggested for this. The most modest is 5-10 times as many people as predictor variables entered in the analysis, the most cautious is 50 times (Clarke – Carter, 1997). In this case up to eight variables were entered as predictors on occasion, which would clearly not be recommended with a sample size of 50. However, reliability of results can also be suggested by power analysis. The measure of effect size in regression is R squared, which Cohen (1988) suggests as 0.0196 for a small effect, 0.13 for a medium and 0.26 for a large effect size. In the models above, all the R squared scores were above 0.3 indicating a large effect was found. Using the power analysis tables for multiple regression it can be seen that the power of a model with a large effect size and a sample of 50, is above 0.9 and therefore good.

These models provide evidence that whilst illness perceptions do predict coping, they also independently predict distress.

4.0 Discussion

4.1 *Overview of Results*

This section provides a summary of the results in relation to the research questions.

4.1.1 *Illness representations.*

Patients planning IVF treatments had low scores on all IPQ subscales. 60% of people were asymptomatic, but of those who were experiencing symptoms, most endorsed emotional symptoms such as tearfulness, anxiety, irritability, and low mood.

Those who reported more symptoms were more emotional, but felt they had more control over their infertility. Those who were less clear about their infertility were more emotional and experienced their difficulties in cycles. People who believed their problem would last a long time perceived a greater effect on their life.

Chance or bad luck, stress and age were the most commonly endorsed causes, although some people recorded their specific diagnoses. Those with unexplained infertility were more likely than those with a diagnosis to think that chance caused their difficulties, but there was no difference between groups in belief that psychological factors played a role. Those who believed that psychological factors had caused their infertility experienced more symptoms, felt more emotional and less emotionally stable, and less hopeful about treatment. People who believed age had been a factor in their problems were less clear about them and less hopeful about treatment. Those who thought that infertility was a result of bad luck had a poorer understanding of their problems.

4.1.2 Coping

In order to cope with their difficulties, most people (68%) were trying hard to accept them. Active coping and planning were also used to a moderate degree or a lot by 52 per cent and 48 per cent of patients respectively. When combining coping strategies into categories of adaptive and maladaptive, the group mean score was significantly higher on the adaptive subscales than the maladaptive subscales. This did not differ between men and women.

4.1.3 Psychological morbidity.

As a sample, these patients were not clinically depressed or anxious, although 42 per cent fell into the clinical category for anxiety, and 12 per cent scored above the cut off for depression. There was no difference between groups on distress.

4.1.4 Illness perceptions and coping

Treatment control was positively correlated with planning but perceived control did not seem to influence any other coping strategy. Those with a clearer understanding of their infertility were less likely to engage in maladaptive coping strategies; but those who felt their difficulties with their infertility went in cycles, and those who felt more emotional about it generally, were more likely to engage in them.

4.1.5 Coping and distress.

Patients who used maladaptive coping strategies, had higher distress scores. There were positive significant correlations between all the subscales included in the maladaptive

category except substance use, and depression; and between all except denial and substance use and anxiety.

4.1.6 Illness perceptions and distress

There were a few significant relationships between subscales on the IPQ-R and both anxiety and depression scores. A protective factor against distress was higher illness coherence. Experiencing more symptoms, feeling more emotional and indeed finding those feelings fluctuated were related to higher distress scores. Belief that psychological factors had caused infertility was correlated with higher distress scores.

4.2 Results in Relation to Hypotheses

4.2.1 Illness Perceptions

The first hypothesis suggested that

- 1a People planning IVF treatments will have low symptom and self-control scores (below 2.5), and high time line, emotional representations and consequence scores (above 2.5).

Patients were found to have low scores on all the IPQ-R subscales. 2.5 was chosen as the cut off in the absence of guidance on the matter from the literature, and because it is the mid point of the range of scores. It is not surprising that scores on the *symptom* subscale were low, as many items relate to physical illness, which infertility is not. The items that were endorsed were the ones added by the researcher for this project, and were mainly psychological in nature. This helps to explain the significant correlation

between the *symptom* subscale and *emotional representations* (how emotional patients felt in relation to their problem). The reason for the finding that those people who experienced more (psychological) *symptoms* felt more in control of their infertility is unclear and is in direct contrast to the significant negative correlation found between *symptoms* and *control* amongst patients with irritable bowel syndrome (IBS) (Rutter & Rutter, 2002). The level of perceived control over infertility, whilst potentially understandable given that these couples were at the stage of assisted conception, may be of concern, as lack of control has been linked to poorer adaptation to treatment failure (Litt *et al.*, 1992).

The literature suggests patients with infertility may report that the problem is likely to last a long time, be extremely distressing and have major consequences for their lives (Mahlstedt *et al.*, 1987). This study found that this was not the case for this group, but the finding that those who believed their problem was going to last longer perceived more significant consequences is understandable and in line with the research into IBS.

Further significant correlations between illness representation subscales enable more in depth understanding of how patients planning IVF treatments may view their difficulties. That those who did not understand their problems very well, and whose responses to them fluctuated also felt more emotional about them, is not surprising, as adaptation to illness is related to patient's appraisals. Leventhal *et al's* (1984) model suggests it is only once a person has interpreted, or made sense of their problem that they can begin to try and solve it, until then the emotional response to the problem is likely to be characterised by fear.

One of the IPQ sections assesses beliefs about causality of their problem. The most frequently endorsed causes were *chance*, *stress* and *age*, and it was predicted that:

1b those without a diagnosis will be more likely to endorse psychological and chance causes than those with a diagnosis.

Analysis showed that this was partly the case. Although those without a diagnosis were more likely to think *chance* was a cause, they were just as likely as those with one to think that *psychological factors* contributed to their infertility. It is interesting to speculate as to why this might be. Anecdotally there may well be a belief that stress and infertility are linked, which may continue to be held after a diagnosis is given. On the other hand, research is beginning to show that stress affects conception rates even in assisted reproduction, and some couples may be aware of this. Another explanation is that those without a diagnosis might believe that there is a physical cause for their infertility, which has not yet been discovered.

Although *stress* was viewed by many as significant, *chance* and *age* were also felt to be important contributors. Both these would be relevant causal factors to those with both diagnosed or unexplained infertility, as people may have a fatalistic view of their problems whatever the cause, and the decrease in fertility with age is well documented in formal and informal contexts (Pfeffer, 1993). Although they are indeed contributors to infertility, people holding these beliefs were less likely to have a clear understanding of their problems which the model suggests is important for adaptation.

Other psychological causes were related to the subscales measuring emotional response; such as *symptoms*, *emotional representations* and *timeline cyclical* - the implication being that perceiving themselves to blame in some way for their infertility was causing patients to feel worse about their difficulties. Not only were they more likely to use self blame as a coping strategy, but the belief that one's own behaviour or emotional state was causing infertility was also related to less confidence in treatment, and potentially more hopelessness.

4.2.2 Coping

Literature has shown that IVF patients use relatively adaptive, commonly problem focused coping strategies (Lieblum & Greenfeld, 1997). This drove the formation of the following hypothesis:

2a people planning IVF treatments will endorse active, problem focused strategies more frequently than avoidance or emotion focused strategies

which was tested in order to add to the accumulating evidence on coping with infertility. The results supported the hypothesis in that patients used adaptive coping strategies significantly more than maladaptive strategies. Edelman *et al.* (1994) argued that this result is predictable as it is in line with couple's treatment choice. Of all the options that infertile couples could pursue, IVF treatments are potentially the most costly, both financially and emotionally. The motivation to go through with the treatment regimen must be high, and it could be argued that only those couples who are focused, positive and hopeful, and supportive of each other, ever get to the planning stage.

There has been debate in the literature about whether or not men and women differ in their style of coping, particularly within the dyadic relationship; although not much research has been done in this area. In line with previous research findings (Jordan & Revenson, 1999) the following hypothesis was tested:

2b women will endorse maladaptive strategies more than men.

It was found that there was no significant difference between men and women in choice of general strategy. Berguis and Stanton (2002) argue the interaction between the two should be taken into account so there is a possibility that the women in this sample were more influenced by their partners (more problem focused) coping style than in some cases, but it is more likely to be a reflection of the fact that the general coping style for the whole sample was adaptive, as discussed above.

4.2.3 Psychological Morbidity

Given the equivocal nature of much of the research on distress in infertile patients, this study used a reliable and valid, standardised questionnaire to evaluate levels of anxiety and depression in this sample. Although self-report studies suggest high levels of distress, patients have not been found to meet psychiatric diagnostic criteria for anxiety or depression. Neither is there conclusive evidence that differentiating between groups helps to understand what might predict distress. The following hypotheses were developed:

3a people planning IVF treatments will not exhibit clinically significant levels of anxiety or depression and

3b there will be no significant differences in distress between groups.

Analysis revealed that in contrast to some studies (Domar *et al.*, 1992, 1997; Thiering *et al.*, 1993) the group as a whole did not exhibit clinical levels of anxiety or depression. These results concur with other studies focusing on patients planning IVF, which have also failed to find distress scores significantly different from norms (Bevilaqua, 1998; Edelman *et al.*, 1994).

It is more difficult to be conclusive about the finding that there were no significant differences in scores between groups, as the power of the tests was so low. The result may be true but a larger N size would be needed to test this, particularly in the smallest subgroups. Although a literature review in the early 1990s and a recent paper (Merari *et al.*, 2002; Wright *et al.*, 1991) reported differences in distress between men and women, Edelman and Connolly (2000) presented an argument that whilst there might be differences in the experience of infertility, distress levels remain comparable.

It is more difficult to partial out the effects of stage of treatment because of the number of variables involved. One couple may have been trying to conceive for many years before seeking medical help, and then find their only option is IVF, whilst another couple might have gone through numerous other investigations and treatment options over a couple of years before having IVF recommended to them. Whilst both couples are 'first timers', their experiences and perceptions of their infertility are likely to be very different. Thiering *et al.* (1993) found the rate of depression was higher in 'repeaters' than first timers, which is in contrast to this study. Interestingly Berg and Wilson (1991) in their study comparing people after a number of years in treatment,

found that those in their second year were less distressed than those in their first or third. The mean length of time seeking treatment in this study was two and a half years, which offers support for this model of experience.

There is conflicting research evidence about whether or not diagnosis affects distress (Daniluk, 1988; Wasser *et al.*, 1993) but a review concluded that it did not (Griel, 1997). This supports the finding in this study that there were no differences in anxiety or depression between those with and without a diagnosis. Finally, the finding that there were no differences between ethnic groups concurs with the conclusions of Nasser (2000).

This might imply that in fact criticising the literature for combining these sub groups is not valid, and couples planning IVF treatments can be seen as a homogenous group. Another explanation is that the power of the tests in this study was extremely low given the small sample size, and a significant result may have been found had the sizes of groups been larger and more equal.

There were still a substantial minority of people whose distress scores fell in the clinically significant range. Six people (12%) met the criteria for depression. This is similar to some previous studies (Downey *et al.*, 1989; Downey & McKinney, 1992), but substantially lower than one study, which found depression in 34 per cent of women pre IVF (Garner *et al.*, 1984). Perhaps more significantly, 21 patients (42%) met the criteria for clinical anxiety. Examination of the frequencies of scores clarifies the severity of patients' distress: five people fell in the 'mild' range (Johnston *et al.* 1995)

and only one in the moderate range for depression; whilst 12 scored in the mild range, and nine in the moderate range for anxiety. No-one scored in the severe range for either. It may be the case that the higher level of anxiety in comparison with depression is a result of procedural and outcome fears as suggested by Golombok (1992). Alternatively it may be a reflection of anxious personality styles. Previous research has found trait anxiety within normal limits (O'Moore *et al.* 1983, Thiering *et al.* 1993) which suggests the former explanation is more valid. However, there were no differences in anxiety scores between those in the first timers group, and those who had gone through the procedure before which suggests it is not concerns about the procedure which leads to anxiety. This study did not look at fears about outcome or indeed personality so these are still speculations.

It may also be that depression becomes more obvious when treatments fail but only a prospective study would clarify this relationship between distress and time in / stage of treatment, and as yet, surprisingly, none have been done.

Thus, although the number of people scoring above the clinical cut-off on this measure seems important, their scores are not severe, and it is possible they would not meet psychiatric diagnostic criteria for anxiety or depression. This helps to explain the differences between self-report and anecdotal literature which finds couples are very distressed, and that which uses standardised measures which finds less evidence of significant distress.

Given that this study suggests that distress cannot be predicted by demographic variables such as gender and ethnicity, or by infertility variables such as diagnosis or

previous experience of IVF; it also implies that there must be other predictive factors.

The third part of the study was to examine the relationships between what might be contributing variables, and to develop a predictive model.

4.2.4 Illness representations, coping and distress.

There were a number of hypotheses, informed by results of previous studies (Helder *et al.* 2002; Kemp *et al.*, 1999; Rutter & Rutter, 2002).

- 4a Symptom scores will be positively correlated with positive reframing, self-distraction and behavioural disengagement.
- 4b Timeline scores will be positively correlated with acceptance
- 4c Consequences will be positively correlated with venting, behavioural disengagement and self-distraction, and negatively correlated with acceptance.
- 4d Control subscales will be positively correlated with active coping, planning and positive reinterpretation.

Results showed that none of the first three hypotheses were supported. This indicates that illness representations, and their relationship with outcome differ across illnesses as the model predicts (Leventhal *et al.* 1984) and as has been found in previous research (Schiaffino & Cea, 1995). The fourth hypothesis was partially supported, as *treatment control* was correlated with *planning* and indicates that those who have a stronger belief that treatment will be effective, will invest more of their energies into planning it.

Although the hypotheses were not supported, there were other significant relationships, involving maladaptive coping strategies. The finding that *illness coherence* was negatively related to various maladaptive coping strategies is in line with ideas discussed above: that an understanding or interpretation of the illness threat leads to choice of coping strategy which in turn re-influences the interpretation and emotional response. Given that the coping styles of infertile couples pursuing treatment seem to be necessarily characterised by adaptive strategies, it is understandable that those who felt they had a clear understanding of the problem coped in this way; whilst those who were still struggling to make sense of it were less able to cope adaptively.

Those who felt their difficulties with their infertility were cyclical, and those who felt more emotional about it generally, were also more likely to engage in maladaptive coping strategies, and these were also the people likely to be experiencing more (emotional) symptoms. Thus the emerging picture is that those whose perceptions of their infertility were fluctuating, unclear or emotional were also more likely to use the coping strategies classified here as 'maladaptive', such as *venting*.

Although correlations do not indicate causal relationships, and it is therefore uncertain which variables lead to which others, these results can be interpreted as consistent with the self-regulation model. One of the four assumptions of the model is that illness is responded to with the formation of an objective view (perceptions), and an emotional response. These inform two styles of coping; problem focused which aims to solve the problem, and emotion focused, which aims manage the emotional response. Although this study has used the broad classifications of adaptive and maladaptive strategies; *behavioural disengagement*, *self-distraction*, *denial* and *venting* could arguably be seen

as helpful strategies used to manage emotion, particularly as the evidence is that they are being used by more emotional patients.

A further section of the IPQ-R is that which looks at causes. Each cause was correlated with each coping strategy in exploratory analysis as no specific predictions were made. There were a couple of unexpected results, for example the finding that belief in *diet* as a cause was related to *venting*, and belief in the *hereditary* nature of infertility was negatively correlated with *acceptance*. Caution should be exercised in interpreting these findings as only three people recorded *diet* as one of their main causal factors in response to the open question, and only one person recorded *genetics*.

Chance was positively related to *self-distraction*. As *chance* was commonly endorsed as a cause, this suggests *self-distraction* would be an important coping strategy for the group. In fact it was the fourth most commonly used strategy, with 34 per cent of patients using it a medium amount or a lot. Although this was classified as a maladaptive strategy, it could be argued that for this group *self-distraction* is helpful as it could prevent excessive focus on both the treatment regimen and the menstrual cycle (which indicates success or failure of treatment).

Those who believed more strongly that their *attitude* or their *emotional state* affected their ability to conceive were, unsurprisingly, more likely to *blame themselves* for their problems. This is an important finding given the research strongly argues that self or partner blame is not only counter productive and destructive (Lieblum & Greenfeld, 1997) but that is highly correlated with psychological distress (Morrow *et al.*, 1995) and poorer adaptation to failure to conceive (Litt *et al.* 1992). This group were also more

likely to *vent* their emotions to cope. Again this ties in with previous findings that more emotional perceptions of infertility were related to maladaptive coping strategies.

The only significant relationship found between causal factors and adaptive coping strategies, was that belief in *ageing* as a cause of infertility was significantly negatively correlated with *active coping*. Again this is important given that many people (46%) felt age was significant. One possible explanation is that people who felt *age* was relevant were less hopeful about treatment succeeding, so tried to cope with their infertility in ways other than focusing on doing something about the problem. This is only speculation as hopefulness was not assessed in this study, however there was a significant negative correlation between belief in *age* as a cause and *treatment control*, which provides some support for this theory.

Further predictions, based on the literature on coping with infertility, were made about the relationships between coping strategies and distress variables.

4e Positive reframing, active coping and acceptance will be negatively correlated with distress.

4f Denial, self-distraction, behavioural disengagement and self-blame will be positively correlated with distress.

Interestingly, and surprisingly, the hypothesis 4e was not supported as there were no negative correlations between coping strategies and distress. This finding is in contrast with the literature on coping with illness and infertility, which shows adaptive strategies

correlated with lower distress scores (Berguis & Stanton, 2002; Edelman *et al.*, 1994) and suggests that positive adaptation in this group is not predicted by adaptive coping but by other factors. Hypothesis 4f was supported by the finding that *self-distraction*, *behavioural disengagement*, *self-blame*, *denial* and *venting* were positively related to the distress variables.

It might then be suggested that those with a fluctuating, unclear or predominantly emotional view of their infertility are more likely to use maladaptive coping strategies and feel more distressed. This raises the question of whether or not illness perceptions themselves are related to distress. Two hypotheses were formed, based on literature using this model in other health problems.

4g Control and illness coherence will be negatively related to distress.

4h Symptoms, consequences, psychological cause, and emotional representations will be positively related to distress.

The finding that those with a clearer understanding of their infertility were less distressed fits the original model, and is in line with research into other illnesses.

Symptoms and *emotional representations* were indeed related to distress, but *consequences* was not. The fact that those experiencing more symptoms, and feeling more emotional were more likely to have higher distress scores might have been expected by their higher use of maladaptive coping strategies. Previous research has also found that distress can be predicted by the level of emotion-focused thoughts that patients have (Tuschen – Caffier *et al.*, 1999).

That *timeline cyclical* was related to both anxiety and depression was also not unexpected given the finding that *timeline cyclical* was related to *symptoms, emotional representations* and *illness coherence*, and that all were related to maladaptive coping.

In terms of how patients' perception of what caused their infertility affected their distress, the findings reflect the earlier discussion around the relationship between belief in psychological cause and maladaptive coping. Those who believed more strongly that *stress* was a cause of their infertility did indeed have both higher anxiety and depression scores. This was also the case with other psychological causes such as the *person's own attitude, their emotional state, their personality* and *overwork*.

Family problems as a cause of infertility were also positively correlated with depression scores. This finding may be suggestive of difficulties for some people over and above infertility, which they attributed their infertility to, but which may also be causing higher levels of distress than other patients experience. Only one study has looked at alternative explanations for distress in infertile couples. Downey and Mc Kinney (1992) looked at previous history of depression in their sample and found that 11 of the 13 people who were depressed had been depressed before.

The relationship between *pollution* and *diet* and distress might be understood in the context of media coverage of environmental and chemical pollutants affecting sperm quality, but apart from the relationship between *diet* and *venting*, it is unclear why people who hold these beliefs might be more distressed than others.

It is clear then that illness perceptions were independently associated with distress levels. Whilst this is not the pattern suggested by the model, it has been seen in other research examining perceptions of infertility and how these influence adaptation. One study found that patients appraised infertility as either a loss or challenge, and this affected both their choice of coping strategies, and distress (Hansell *et al.*, 1998). Other reactions to infertility, such as action, hope and detachment have been linked to adaptation (Bolter, 1997).

4.2.5 Predicting psychological morbidity.

The next stage of the analysis was to develop a predictive model of psychological morbidity from the variables identified as related to it. The results of the regression analysis with anxiety as the criterion variable fit with the emerging results of this study. When all the related coping strategies were examined, *venting* (a maladaptive coping strategy) was the only one left in the analysis as independently predicting any variance in anxiety. This indicates there was a large amount of overlap in the variance explained by other maladaptive coping strategies. A similar pattern was found with the illness representation scales, the only ones of which remained in the analysis were *stress* (a causal factor) and *timeline cyclical*. These three predictors accounted for 57 per cent of the total variance.

Although the results should be viewed with caution due to the non normal distribution of scores, a model was also built around depression. This revealed that *illness coherence* (an illness representation subscale) accounted for most of the variance, with the coping strategy *behavioural disengagement*, the causal factor of *personality*, and the perception of *symptoms*, predicting the rest of the total 54 per cent.

While these are interesting results, thought needs to be given to the meaning of them. An important, and obvious, point is that although over half of the variance in distress scores was predicted by the models developed in this study, almost half remained unexplained. This means that although one can be confident about some of the things that affect distress, a lot remain unclear. Demographic variables did not add anything to the models, so the possibility that age or length of time trying to conceive were important was not supported. Other factors that may contribute to levels of anxiety and depression are history of psychological problems and pre-morbid schema, but these were not assessed, so again this is speculation.

Furthermore, multiple regression is a mathematical model and results fit the data they are applied to. Whether or not the same results might be found in another similar population needs to be inferred from examination of other research.

There is some overlap in the models of previous research and the current study. In this study, *symptoms* were found to predict depression as they had in the epilepsy (Kemp *et al.*, 1999) and Huntington's disease (Helder *et al.*, 2002) samples. *Illness coherence* was also predictive of depression as it had been in the epilepsy sample (Rutter & Rutter, 2002). The causal factors are difficult to compare with the study as the Rutters amalgamated the causes section, however *psychological causes*, which accounted for a large percentage of variance in anxiety, included *stress* and *personality* which were found to be predictive in this study. In terms of coping strategies, *venting* was found to predict anxiety in both this and the study on irritable bowel syndrome (Rutter & Rutter, 2002), and distress in the study by Helder *et al.* (2002); whilst *behavioural*

disengagement influenced depression in this study, as it had in others (Helder *et al.* 2002; Rutter & Rutter, 2002).

The overlap in results between previous research and this study is important as more research that is undertaken using this model may generate more evidence that there are certain ways of thinking about and coping with health problems are unhelpful to patients' well-being. Common themes emerging amongst studies provide support for the results found in this study. The differences in results between studies are also important as they indicate differences in adjustment to the different problems, and advocate against thinking about all chronic illnesses in the same way.

Comparison with other studies is one way to assess the reliability of results. An alternative way is to split the sample into two halves and repeat the regression analysis, to see how well the predictions for one half match the predictions for the other (Clarke – Carter, 1997). However, the original sample here is not large enough to do this.

Another issue is that some of the variables were not normally distributed, and there is argument about whether or not this test is suitable for non-parametric data. However, care was taken to ensure the variables did not differ significantly from normal, and as this study is exploratory in nature, the regression models should be seen as a first step in understanding what predicts distress in infertile couples planning IVF treatments.

4.3 Theoretical Implications

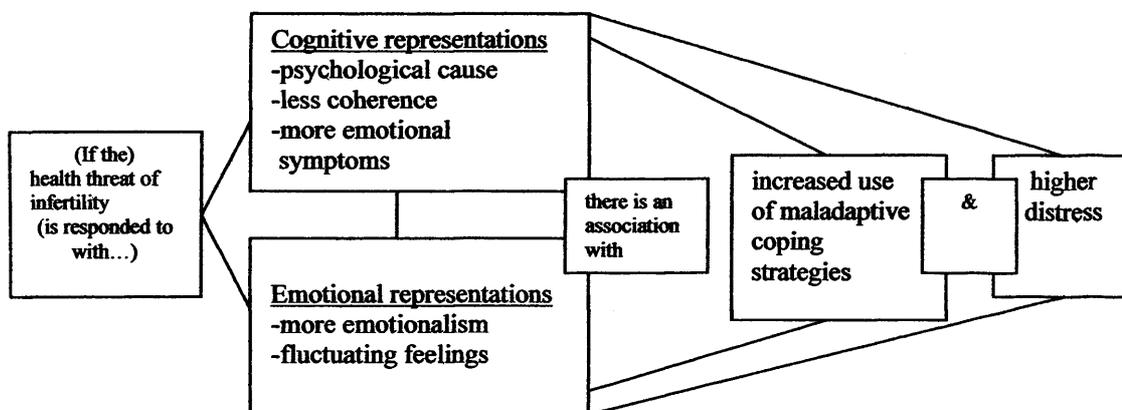
This section explores the implications the results have for theory development in the field of illness representations and infertility.

The original self-regulation model argued that illness perceptions influence coping which influences distress, but other studies have found that illness perceptions can directly and independently influence distress. This study offers more support for the latter view, and challenges the idea that coping is necessarily a mediator. Although *venting* (a maladaptive coping strategy) predicted the most variance in anxiety, *stress* (a perception of cause) and *timeline cyclical* (illness perception) explained a further 19 per cent. The same pattern was seen with the model for depression, in that most of the variance was explained by an illness perception, *illness coherence*. The coping strategy *behavioural disengagement* significantly added to the model, but *personality* (cause) and *symptoms* (illness perception) explained the rest. This suggests that people's beliefs about their health problems are important for adaptation irrespective of how they choose to cope with them. Some of the more recent papers using the model have started to look at illness representations in relation to adherence to treatment (Whitmarsh *et al.*, 2003), which would seem the logical next step given the growing evidence about the importance of perceptions.

The results of the analysis into coping provide support for the established literature which argues that some coping strategies are linked with positive outcomes, and others with worse outcomes. It does not, again in common with other coping literature, provide us with evidence about the causal direction of that relationship but does begin to look at other factors that might be involved.

The results of this study are also useful in terms of developing theories about the experience of infertility. It is clear that the inability to have children naturally, although stressful, does not itself cause clinical anxiety or depression. The model below summarises the factors this study found were involved, in an adaptation of the self-regulation model (Figure 4.1).

Figure 4.1. The relationship between illness representations, coping and psychological morbidity in infertility.



This is a hypothetical model, based on the evidence from this study. Although the model may suggest differently, due to the correlational nature of the analysis it is impossible to be clear on causal direction. This model therefore represents one interpretation of the data, and as already explained, there are still unidentified factors that predict distress. It is also reductionist, in that it has condensed a number of specific variables into broad categories, and does not include all of the significant findings. Despite these criticisms, it is an important first step in building a theoretical understanding of the implications of infertility. An experimental study manipulating the variables could begin to provide evidence as to whether or not this model has validity.

4.4 Clinical Implications

This section discusses the implications of the study for mental health professionals working with couples presenting with difficulties conceiving.

4.4.1 Predicting psychological morbidity in infertile couples.

The evidence that, overall, infertile couples pursuing IVF treatments are not clinically depressed or anxious is important for assisted conception clinics as it supports the current policy that counselling is not recommended for all couples. Counselling is part of specific treatment options such as use of donor eggs and sperm, but not IVF treatments per se. Although in this study a number of people did score in the clinical range of anxiety and depression, they fell within the mild to moderate range. This suggests that, in the majority of cases, infertility-specific counselling may be appropriate to help patients adjust to their difficulties and manage their distress. It is likely that only patients who have had previous episodes of depression, or have additional psychological difficulties would need to see a clinical psychologist.

There were no group or demographic variables which helped to predict who would be most distressed; and thus who may benefit from psychological help. From a service delivery perspective this is a potential difficulty as knowing the population who may require intervention helps with planning and budgeting; for example in deciding how many sessions to employ counsellors for. In clinical settings medical staff have limited time with patients, and recognising significant distress may be difficult. In order to establish whether or not people are at risk from significant distress, despite some helpful predictors, the best option remains to administer a short assessment, for example the

HADS. This is convenient enough to enable nurses to include it as part of an initial assessment. Those scoring in the clinical range might be encouraged to consider a counselling assessment, and services could consider where the needs of those scoring in the severe range might best be met. Given the evidence of the effects of distress on conception (Barnea & Tal, 1991; Demyttenaere *et al.*, 1988; Tarabusi *et al.* 2000; Thiering *et al.*, 1993) recognising distress and intervening before treatment begins may increase chances of successful conception.

Although the evidence suggests only a small percentage of patients would need professional help for their psychological difficulties, the results of this study are potentially helpful for directing assessments, and focusing treatments.

4.4.2 Assessment

The relationships between variables show that patients who are unclear about their infertility, feel very emotional and whose feelings fluctuate and / or believe that their infertility is caused by psychological factors are likely to use maladaptive coping strategies, and be more distressed. Certainly the amount of information that a couple has to take in, particularly the first time they go through IVF, is significant, and there is scope for ambiguity and misunderstanding. The clinic where the majority of the study was completed ran hour -long nurse-led information sessions for couples but time for these was extremely limited, and other activities often had to take precedence. This is an implication for service delivery in terms of use of nurses' time, and one of the counsellor's roles may therefore be to ascertain whether or not patients understand their situation, the treatment options and the chances of achieving pregnancy.

As part of assessing patient's understanding of their infertility, this study suggests that discussing patients appraisals of cause would be important. Even in cases where there was a clear physical problem and a medical diagnosis, patients still felt psychological factors were contributing to their infertility. Whilst this has a basis in fact according to some research evidence, these beliefs were more likely to lead patients to maladaptive coping strategies, and to higher levels of anxiety and depression. Counsellors may helpfully clarify the extent to which psychological factors are related to infertility, whilst discouraging the client from excessive focus on this in order to prevent maladaptive coping.

Assessing the extent to which patients feel emotional, and the extent to which these feelings fluctuate would seem to be another important role for a counsellor, as again these link with maladaptive coping. Some fluctuation is to be expected as the treatment is cyclical in nature, but this information could give counsellors a good indication of whether or not the person is likely to be very distressed.

It would seem important for professionals to assess coping, particularly whether or not patients are venting their emotions a lot, as this was the strongest predictor of anxiety. The strongest coping predictor of depression was behavioural disengagement, which has been linked to helplessness and subsequent interference with problem focused coping (Rutter & Rutter, 2002). Other coping strategies that were related to distress were denial, self-blame and self-distraction. Whilst the first could be argued to interfere with active, problem solving attempts, and the second has been shown to be destructive, the third is surprising. Given that the mechanics of assisted conception are largely out of patients' control, self-distraction would appear useful. It may be that the motivation for

distracting oneself is important. If it is driven by avoidance and denial then it might be unhelpful and lead to more distress, as is the case here.

4.4.3 Intervention

The results of the study are also helpful in considering interventions for psychological difficulties. Although this study did not include measurements of psychological well-being, it is possible that amelioration of the factors that predict distress would increase positive adaptation. For example, helping patients achieve a clearer understanding of their infertility and allowing them to express their feelings in a safe and supportive environment might allow a reduction in distress. Helping patients to have a realistic idea of how much they are 'to blame' for their infertility through their own emotional state and personality could also be important. Finally, promotion of adjustment should, according to Bombardier *et al.* (1990), involve interrupting maladaptive coping strategies, and improving adaptive ones. The most important coping strategy to foster would seem to be acceptance. This has been found to contribute to patient's emotional stability (Lazarus & Folkman, 1984) (clearly important in this group of patients), and is linked to how patients integrate their experience of illness with their self-concept. This, argue Nerenz and Leventhal (1983), is perhaps the central issue in chronic illness.

4.5 Research critique

A review of the research is presented, including a discussion of the rationale for the study, and a critique of the design, participants, procedure and measures used in the research.

4.5.1 Rationale

In this section the rationale for each aspect of the study is critically discussed. Infertility as a social and medical phenomenon is described first, then the arguments for and against using the self-regulation model to gather information on groups of people are put forward. The section concludes with a critical review of research on coping.

In examining the context of the experience of infertility, Pfeffer (1993) concludes that it is dominated by politics and money. She claims that successive governments have failed to support effective medical services for the investigation and treatment of infertility, and that over the years a variety of arguments against investment in the problem have been made. She highlights issues such as the investment in contraception in the 1960s in an attempt to contain the population expansion, and the current focus by the NHS on returns for investment.

Pfeffer suggests this lack of investment is related to controversy about infertility treatment: both public, for example the moral panic that arose around artificial insemination in the 1940s; and medical, for example the practices of semen analysis and the post-coital test are questioned for their usefulness, particularly since the parameters used to determine "the norm" have not been adequately researched amongst people of proven fertility. Indeed, she argues, there has been a distinct lack of well designed clinical trials in the area of infertility assessment and treatment.

A discussion programme on Radio 4 (Life as an Adult, 22 October, 2002) went further in terms of criticising funding in infertility services, and argued that investing in

assisted conception of any sort is side-stepping the issue, as research should be directed at investigating the causes of infertility. Whilst these are interesting debates about the usefulness of investing in research into the consequences and management of infertility, the fact remains that many couples want to have a baby, and will pursue assisted conception for as long as they can. Understanding and supporting couples through the psychological concomitants of this process is therefore a necessary fact of life whilst the rate of fertility problems is so high.

The use of the self-regulation model to examine the illness perceptions of groups can itself be questioned. As Leventhal *et al.* (1984) argued, illness perceptions will differ between individuals as a function of their environment and culture, their communication about the illness and their previous experience of it, so the idea that a group of people may have shared beliefs about their shared illness has developed independently of the model. A body of literature looking at group means on the subscales of questionnaires is indeed evolving, but the clinical relevance of this may be questionable. However, research using both qualitative and quantitative measures of illness representations has not revealed significant differences in what was reported (Weinman *et al.*, 1996), and research using groups gives a more generalisable guide from which to work individually as a clinician.

Not only do illness perceptions differ between people, they differ across time. The model postulates that an interpretation of a symptom is made, influences choice of coping strategy, and then is reappraised in the light of that strategy. Thus this research, along with other studies applying the model, can only provide a 'snap shot' view of beliefs and perceptions of infertility, which are likely to change.

Not only is there a debate around the validity of research into the consequences of infertility, but there is also an argument that this type of research into coping is of little theoretical or clinical use. Coyne and Racioppo (2000) argue convincingly that the two principles underlying this type of research; namely that one checklist can be used across different populations with different stressors, and that coping is related to psychological distress in a clear causal way; are erroneous. Firstly, the use of general checklists leaves respondents unable to select the same specific stressors to report on, and does not give them the opportunity to report on key coping strategies they have used to manage secondary stressors. For example in this study, respondents were asked how they had been coping with their difficulty conceiving. Whilst one respondent might have focused on the feelings they were having about the loss of natural conception, another might have related the question to the investigations they had gone through, and still another might have focused on how they coped when people asked them when they were going to have children. Hence the results are arguably unclear and ungeneralisable as there is no way of telling what was influencing coping or to what stressors the respondent was referring. Another problem with checklists relates to the reduction of a number of specific strategies to summed scores, in questionable categories of problem focused versus emotion focused coping, or active versus avoidant.

The second argument relates to the idea that most coping research, as this study does, evaluates coping by the extent to which it is associated with psychological distress, with the assumptions being that reduction in distress is the goal of people's coping choices, and that positive correlations mean the coping strategy is ineffective. Again, the argument is that people approach situations with different goals so in this study the goal of one respondent might be to let themselves grieve their loss, whilst another goal might

be to avoid enquiries about children. Furthermore, there are many factors other than coping which influence outcome, and to ignore these, the authors argue, is to overemphasise spurious relationships between the two things (Coyne & Racioppo, 2000).

In relation to this study, it may have been more useful and clinically relevant to have applied the questionnaires to one specific element of infertility, such as how individuals coped with their investigations, and to ask people to record what their goals of coping had been and whether they thought they were effective in achieving them. However this study has gone further than other coping research in examining the involvement of other factors, namely perceptions people held about their infertility.

4.5.2 Design

The cross-sectional design of the study was appropriate for its exploratory nature, and the results provide enough evidence for more hypotheses to be generated, and further research to be conducted. Using a cross sectional design does, however, limit the extent to which results can be generalised, and does not allow examination of how understanding and managing infertility changes over time. Furthermore, a control group of known fertile couples attempting conception was not used, so conclusions cannot be drawn about the specific effects of infertility as opposed to the emotional sequelae of trying to become pregnant.

The point has been made that in anecdotal research, patients report high levels of distress which is not borne out by standardised or diagnostic measures. Whilst this

study did use a standardised measure of anxiety and depression, it was still completed by the patients themselves. This could have biased the results in terms of patients under or over reporting symptoms, and no subsequent psychological assessment could be carried out in the time available to verify the results. Furthermore, although patients and partners were encouraged to complete their questionnaires independently, they were not generally observed and may have discussed them as they were doing them. This could potentially have contaminated the individual's responses.

4.5.3 Sample and Procedure

Despite careful consideration of the procedures in the clinics, there were significant problems with recruitment which is important when considering how representative the sample was. This difficulty was partly due to the relocation of one clinic to another building, which effectively prevented staff from having time to think about the study for two months, and the absence of the embryologist in another, leaving them unable to plan IVF procedures. This caused difficulties at the beginning of the recruitment period. In latter months the consultants reported that they did not have the time to mention the study to patients, and other doctors such as senior house officers and research fellows either did not know about the study or were disinclined to mention it.

Following discussions with both clinics, it was decided that nurses would take a more active role in recruitment and then inform the doctors if their patients had agreed to the study. However, nurses did not always see patients before or after the doctor had, which made it difficult for them to speak to all potential recruits.

There were a differing number of potential respondents. In one clinic there was an average of eight potential couples per clinic and clinics were held three times a week. In the other original unit, clinics were held less often and there were only two couples on average seeing the consultant. It was therefore decided that the author would go to the first clinic and speak to identified patients herself, as there was a reliable flow of patients. This significantly increased the recruitment rate, although there were still problems with patients not attending their appointments, or just missed through lack of awareness and communication. The other clinic continued as they had been doing.

Another, private clinic joined the study and used a slightly different procedure. This was extremely effective in terms of protecting confidentiality and ensuring a low non-returned rate, but it was time consuming for staff and probably only practical for the short time the clinic was involved.

Very few patients who were spoken to about the study refused to take a questionnaire pack although figures were not collected. When nurses did not ask the patients if they would like to be involved they reported that this was because the patients were too upset. If this was the case, then it has implications for the results. The question of whether the people who returned their questionnaires were less distressed and better adjusted than those who did not is raised. Unfortunately there will always be some element of selection bias in research studies such as these, and this study could not begin to compare patients who did take part with patients who did not. Furthermore, due to confidentiality, the researcher was unable to gather data from records on couples who had attended the clinics in the previous months. One way of being more confident

that the findings of this study are generalisable, would be to repeat the study with different clinics, or a different sample.

Another area where the validity and the reliability of a study can be questioned is in the use of specific measures.

4.5.4 Measures

The Illness Perception Questionnaire – revised was used to measure illness perceptions. The IPQ has been validated with a number of different illness populations, and is adaptable within each population so was considered appropriate. This study is one of the first to use the revised version, and internal consistency of all the subscales, except timeline, were acceptably high. This may be explained by the fact that it is difficult for infertile couples to predict how long their problem is going to last, as it is largely dependent on the success of treatment, which can potentially go on for years.

One of the new subscales, timeline cyclical was added to be of use in illnesses that are not simply acute or chronic but variable. There is an option to omit the scale, which was very nearly done in this case as infertility was not thought of as a problem where symptoms fluctuate as might be the case in IBS or eczema. However, the results of the study clearly show that a number of people did experience their problems in a cyclical way, lending support to the inclusion of this scale with illnesses regardless of their type.

The revised questionnaire also includes questions about how emotional patients feel in relation to their problem. Emotionality was clearly a significant factor in this patient

group, and given that the model suggests patients develop emotional as well as cognitive representations, the subscale is a valid addition.

The self-regulation model was constructed using data collected during interviews with patients about their illnesses. Weinman *et al.* (1996) argue that this method of collecting information about patient's experiences is both too time consuming and restrictive of sample size to be of clinical use, hence the development of the scale. However, they used a structured interview as well as the questionnaire as part of their validation study of the IPQ. They found a close fit between the interview and questionnaire data, and patients reported that the questionnaire was easier to complete if they had been interviewed first. This lends support to use of a questionnaire measure, with a primer interview being helpful for respondents. Due to time constraints this was not done in this study.

One possible criticism of the choice of this measure in this study is it's focus on illness, and illness related concepts. Although infertility is sometimes seen as a chronic illness, it does not have the definite aetiology, physical symptoms and treatment plans as many other chronic illnesses. Some might even argue the treatment is to resolve a social rather than a medical problem, and patients can continue receiving treatment for as long as they can pay for it. However, the results of this study do seem to indicate that patients hold cognitive models of their infertility in the same way as they might for other health problems, suggesting that in terms of the self-regulation model at least, infertility is not conceptually different to other illnesses.

The Brief COPE is a relatively new measure and has not yet been used with many populations. It was chosen for its theoretical basis, its brevity and the fact that it does not amalgamate coping strategies into broad, over-inclusive categories. However, although the measure attempts to avoid reductionism, it has still been practical in this and other studies to combine scores into fewer categories, potentially reducing validity. Furthermore, even the COPE cannot possibly hope to measure all the variety of ways one might cope with a stressor.

The Hospital Anxiety and Depression Scale was an appropriate tool to use, as it was developed for hospital outpatients. The problem still remains that it only provides a guide to who may be experiencing anxiety or depression, it is not a diagnostic tool. As stated, previous research has been criticised for not clarifying the difference between self-reported distress and what might be considered clinical distress by psychiatric diagnostic standards. Use of this measure then means that conclusions about clear psychiatric morbidity still cannot be drawn.

4.6 *Future Research*

4.6.1 *Research using the self-regulation model with infertile patients.*

Whilst this study attempts to use a theoretical framework, it still only represents the views of a small number of patients in the midlands, pursuing one particular treatment option. It would be advisable to repeat the study with another group of patients pursuing assisted conception to examine how reliable the results are.

The cross sectional nature of the study makes it impossible to predict what the views and feelings of patients at different stages of treatment might be, how they might change over time, and how they relate to past experiences. Future studies could now begin to examine the views of those who find themselves infertile and decide not to pursue assisted conception, or the beliefs people hold at the point of deciding to stop pursuing treatment.

Since much of the data collected was from couples, further analysis should reveal similarities and differences in the way couples view their difficulties, how they cope, and how they are affected. This information could contribute to the theoretical debate over whether couples have a shared, individual or mutually affected experience of the stressors they share.

Focusing on the results of this study suggests future research at a more micro level. The key illness representations in this sample seemed to be illness coherence, symptoms and timeline cyclical as they predicted variance in anxiety and depression. The fact that some patients are unclear about their infertility may be a result of the fact that definite answers about cause of the problem and outcome of treatment can rarely be given. On the other hand it may be that patients are not given or cannot retain enough information to have a clear understanding of their situation, which could potentially be a service issue. A service evaluation regarding levels of information and time allocated for discussion in the context of high demand for services and a long waiting list would begin to clarify this issue.

Overall there were low levels of symptoms reported, but there was a clear relationship between level of symptoms and depression. The reasons that someone might be depressed when going through infertility treatment have not adequately been researched, and although this study provides some ideas, more work needs to be done. A pilot, qualitative study, focusing on emotionalism within this population might guide theory development, which could then be empirically tested. This might also be helpful in exploring what makes patients anxious. A quantitative study including the use of personality inventories might also be appropriate. The argument that anxiety is more prevalent during a treatment cycle, and depression after unsuccessful completion should be tested with a prospective study. Ideally this should begin before prospective parents start trying to conceive to fully explore the changing relationships between psychological morbidity and conception.

Some patients found their responses to their infertility fluctuated, i.e. they felt better sometimes and worse at others. Why this should be remains a question to be answered by future research looking at whether this is a result of cycles of treatment eliciting hope and despair, menstrual cycles providing repeated reminders that pregnancy has not occurred, or just natural shifts in focus. Given the relationship between this variable and maladaptive coping strategies and distress, it would seem important to examine in more detail.

4.6.2 Intervention Research.

Whilst the study makes suggestions about assessment and treatment, these are theoretically based and empirical support from an intervention study would be useful in evaluating how relevant these variables really are. Furthermore, the implication from

the literature is that conception is affected by psychological variables. Thus a randomised controlled outcome study, comparing live birth rates for people who are classified as non distressed, and those who are initially classified distressed but who go through counselling focusing on their illness perceptions and coping strategies, would be the most robust way of testing whether the model has clinical use with this group of patients.

This study focused on psychological morbidity as the outcome variable, but most of the sample were relatively psychologically healthy, and presumably had adapted to their infertility. That the opposite of what predicts distress might predict adaptation, is only speculation, and the field of infertility counselling could benefit from a study exploring the factors which predict adaptation, and an experimental study comparing promotion of these with normal counselling.

4.6.3 Research using alternative methodologies.

Another issue is that this was a questionnaire study. Exploring the relative merits of quantitative and qualitative research methodologies is beyond the scope of this thesis, but questionnaires necessarily reduce human experience to numerical form. Whilst this has some value, so much is missed. The overall aim of this study was to try to explore what makes individuals with infertility problems distressed (whether that is defined by the individual or a diagnostic tool). It might have been useful to carry out in depth interviews with a number of patients about their experiences as a precursor or adjunct to this study, as indeed is recommended by the creators of the IPQ. This then is a project that remains to be done, and may generate factors linked to distress which could then be

empirically tested. These factors may allow expansion of the regression models to account for more of the variance in distress scores.

4.7 Conclusions

This study has examined the illness representations, coping strategies and extent of psychological morbidity in patients planning IVF and ICSI treatments, in an attempt to provide a theoretical framework from which to understand why some patients in this situation are more distressed than others.

Overall, patients had low symptom scores, and did not find their symptoms changeable. They did not believe infertility was having major consequences in their lives, and were not excessively emotional. However, they had low perceived control over their infertility, and had little hope in treatment control, although did not believe it was likely to last for a long time. They did not have a clear understanding of their infertility.

Chance, stress and age were the most commonly endorsed causal factors. Couples with idiopathic infertility were more likely than those with a diagnosis to think that they were infertile by chance, but there was no difference between the groups in belief in psychological causes. Those who held stronger beliefs about psychological causes experienced more symptoms, felt more emotional and more emotionally unstable. Those with stronger beliefs about age and chance had a poorer understanding of their problems.

As predicted, the coping style of this group of patients was characterised by planning and active coping within the ethos of acceptance. Overall they used adaptive strategies significantly more than maladaptive, and this pattern did not differ between men and women.

As a group, these patients' anxiety and depression scores did not fall into the clinically significant range. However, 42 per cent of patients had scores in the mild to moderate range for anxiety, and 12 per cent scored in this range for depression. There were no significant differences in distress scores between men and women, between first timers and repeaters, between those with and without a diagnosis, and between ethnic groups.

Correlations were performed on the subscales of illness perceptions, coping and distress, and a number of significant results emerged. These results were then used to create predictive models of anxiety and depression. Venting emotions to cope, belief that stress caused infertility, and the extent to which people's feelings fluctuated all predicted 57 per cent of the variance in anxiety. Illness coherence, behavioural disengagement, the causal factor of personality, and the perception of symptoms, predicted 54 per cent of the variance in depression.

The results provide some support for the self-regulation model, but also contribute to the growing evidence that illness representations are not simply mediated by coping, but contribute directly to outcome. The model was adapted and used to develop a theoretical understanding of distress in infertility. This suggested that if infertility is perceived as caused by a psychological factor, and is responded to with fluctuating emotions and confusion, then patients are much more likely to use maladaptive coping strategies, and feel more depressed and anxious.

Further research could begin to examine the extent to which these patterns of experience are shared by other infertile couples, and examine the theory empirically.

5.0 Appendices

Appendix 1

Copies of approval letters from the Leicestershire and Coventry Health Authority ethics committees.

LJSC/PJP

Ms Sharon **T**eddy
Trainee Clinical Psychologist
32 Wych Elm Drive
Leamington Spa
CV31 3QR

Coventry Health Authority
Christchurch House
Greyfriars Lane
Coventry
CV1 2GQ

Telephone: 024 7655 2225
Facsimile: 024 7622 6280

17 December 2001

Please reply to
Administrative Office, Coventry Research
Ethics Committee, University Hospitals
Coventry & Warwickshire NHS Trust,
Clifford Bridge Road, Coventry CV2 2DX
Telephone: 024 7653 5219
Fax: 024 7653 5168

Dear Ms **T**eddy

7.03 (01/02) – Please quote this reference number on all correspondence.

**Understanding Fertility (Ms Sharon Teddy, Trainee Clinical Psychologist,
University of Leicester & Leicester & Rutland NHS & Centre for Reproductive
Medicine, Walsgrave Hospital) Project**

Thank you for the above study, which has been considered under the procedures for
Chairman's review.

The following documentation has been reviewed:

- Your CV
- Research Protocol dated December 2001, version 2.
- Letter to Patients from Consultant/Trainee
- Patient Information Sheet, version 1, dated 19 September 2001
- Consent Form, headed 'Understanding Fertility', no version
- Patient Information Questionnaire, no version, undated, this includes 2 pages of questions under the heading 'COPE'
- The Hospital Anxiety & Depression Scale Questionnaire
- Letter from Professor E Miller, Director of Centre for Applied Psychology, University of Leicester, dated 5 December 2001
- Letter dated 8 August 2001 from Richard Kennedy, Consultant, Walsgrave Hospital

I am pleased to inform you that approval to proceed with the study is granted.

I am bound to add that confirmation of approval will be considered by the Committee in full session at its meeting on 15 January 2002 and, should any variation be agreed, I shall inform you accordingly.

The study must be started within twelve months of the date on which Local Research Ethics Committee approval is given. If for any reason you do not meet this deadline you must resubmit your study to the Committee.

All protocol amendments, or unexpected events must be notified.

You must inform the Committee of any new authoritative guidance or persuasive scientific evidence that may cause the Committee to reconsider approval or rejection of a protocol.

We look forward to receiving progress reports as appropriate and in due course, an end of trial summary.

The standard Patient Information Sheet recommended for use by researchers informs the patient about Consumers for Ethics in Research (CERES) who publish a leaflet entitled 'Medical Research & You', which gives information about medical research and gives advice on the sort of questions patients may wish to have answered. The Committee suggests that the researcher hold a stock of the leaflet to hand to the patients.

For researchers who are based at the University Hospitals Coventry & Warwickshire NHS Trust the Research & Development Committee holds a stock of these, but they will not be supplied to researchers. They will be supplied only to patients, at the request of the patient.

In future, unless we hear to the contrary, the title of all research trials approved by the Committee will be made available to bona fide interested parties.

We thank you for your co-operation in these matters.

I enclose, for your files, a list of members of the Committee.

Yours sincerely



L J SANT CASSIA
CHAIRMAN
COVENTRY RESEARCH ETHICS COMMITTEE

Enc. List of Members of Committee

Melanie Sursham
Direct Dial 0116 258 8610

Gwendolen Road
Leicester
LE5 4QF

15 January 2002

Miss S L Steddy
Trainee Clinical Psychologist
32 Wych Elm Drive
Leamington Spa CV31 3QR

Tel: 0116 2731173
Fax: 0116 2588577
DX 709470 Leicester 12

Dear Miss Steddy

Understanding Infertility – our ref no 6569 (UHL 7594)

Further to your application dated 26 November, you will be pleased to know that the Leicestershire Research Ethics Committee at its meeting held on the 4 January 2002 approved your application to undertake the above-mentioned research.

Your attention is drawn to the attached paper which reminds the researcher of information that needs to be observed when Ethics Committee approval is given.

Yours sincerely



**P G Rabey
Chairman**

Leicestershire Research Ethics Committee

(NB All communications relating to Leicestershire Research Ethics Committee must be sent to the Committee Secretariat at Leicestershire Health Authority. If, however, your original application was submitted through a Trust Research & Development Office, then any response or further correspondence must be submitted in the same way.)



Appendix 2

Patient Information Leaflet and Consent Form (example)

PATIENT INFORMATION LEAFLET

1. Study Title

Understanding Infertility

2. What is the purpose of the study?

The study aims to describe how infertile couples understand their infertility, and what beliefs they have about it. It will examine whether there are differences between men and women, and between those with and without a diagnosis. Finally the study will evaluate whether the way couples think about infertility is associated with the coping strategies they employ, and whether this affects the levels of distress they experience. The results could inform and enhance the care given in reproductive clinics, and enable the counseling services to efficiently direct their resources.

3. Why have I been chosen?

All couples attending this clinic who are planning to undergo a cycle of IVF will be asked to participate. In order to get enough information to draw conclusions, approximately 80 – 100 people will have to take part.

4. Who is organizing the study?

Sharon Steddy, a Trainee Clinical Psychologist at the University of Leicester is carrying out the study in conjunction with the clinic. It will last for about a year.

5. What will happen if I do not want to take part?

If you do not wish to participate in this study or if you wish to withdraw from the study you may do so without justifying your decision and your future treatment will not be affected.

6. What will happen to me if I take part?

If you would like to participate in the study, please sign the attached consent forms which will be stored securely with your identifying code. Give one back to the nursing staff. You will then be given four questionnaires to fill in. These questionnaires are all relatively short. You will not be contacted again to fill in more questionnaires.

You can fill them in at the clinic or take them home. Your partner will fill in the same questionnaires but **you must both complete them separately** in order for a comparison between men and women to be possible. When you have finished you can either discuss your responses with your partner, or not, its up to you. Each persons responses will be kept confidential by the researcher.

Please bring both sets of questionnaires with you when you next attend the clinic or send them back in the enclosed envelope. They will be passed on to the researcher. Results of the study will be made available in the clinic after completion.

7. Are there any disadvantages / side effects in taking part in this study?

You may begin to feel distressed as you think about your infertility. If so please tell the researcher or a member of staff at the clinic. You may also talk to the counsellor who knows about this study if you wish.

8. What are the possible benefits of taking part in this study?

This study aims to make a contribution to the way infertility treatment is delivered, and will hopefully be beneficial to this group of patients in the future.

9. Is my doctor being paid for including me in the study?

No

10. What if something goes wrong?

Medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

11. Complaints

If you wish to make a complaint about the study please follow the Trust guidelines for complaints. These are available in the clinic.

12. Confidentiality – who will need to know I am taking part in the study?

All your questionnaires will be taken away by the researcher for analysis. They will only have your identifying code on them, and will be treated with the usual degree of confidentiality under the data protection act.

You will not be identified in any documents relating to the study, or the results when they are released.

Your questionnaire pack includes a letter about your participation in the study, which you may give to your GP as a matter of courtesy, if you wish.

13. LREC Approval

This project has been approved by xxxx Research Ethics Committee.

14. What will happen to the results of the study?

A copy of the research report will be available in the clinic.

15. Contact for further information.

Principle Investigator : Sharon Steddy

You may contact Sharon Steddy via the clinic.

You can also speak to your consultant or one of the clinic sisters about the project.

If you would like further information on research you can obtain a copy of the leaflet "Medical Research and You" from

xxxxxxxxxxx

Thankyou for reading this leaflet, please let staff know if you are willing to take part in the study, and sign the consent form. You may keep this leaflet but please give the consent form back to the staff.

Patient Information Sheet Version 1 19 September 2001

Title of Project: **Understanding Infertility**

Name of Researcher: **Sharon Steddy**

1. I confirm that I have read and understood the Patient Information Leaflet, version no 1 dated 19 September for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected.

3. I agree to take part in the above study.

<hr/>	<hr/>	<hr/>
Name of Patient	Date	Signature

<hr/>	<hr/>	<hr/>
Name of Person taking consent	Date	Signature

1 for patient

1 for hospital notes

Appendix 3

Questionnaire booklet

Understanding Infertility

Thank you for agreeing to take part in this research. In this booklet you will find the questionnaires for you to answer. They will take approximately twenty minutes. Please then return the booklet to one of the nurses, or send it back in the envelope. The results of the study will be made available to the clinic.

Special Note

Page 1 missing from
the original

Please answer all the questions.

About You

Age _____

Sex _____

Ethnicity _____

About your treatment

How long have you been trying to conceive in total ?

How long have you been seeking treatment in total ?

How many cycles of IVF have you undergone ?

What is your diagnosis? (if applicable)

Please tick : "male factor" "female factor" "both" "unexplained"

In general

Please add any other information you think might be helpful.

- IPQ

Listed below are a number of symptoms that you may or may not have experienced. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since you have had difficulty conceiving, and whether you believe that these symptoms are related to your difficulty conceiving.

	I have experienced this symptom since my difficulty conceiving		This symptom is related to our difficulty conceiving	
	YES	NO	YES	NO
Pain	YES	NO	YES	NO
Sore Throat	YES	NO	YES	NO
Nausea	YES	NO	YES	NO
Breathlessness	YES	NO	YES	NO
Weight loss	YES	NO	YES	NO
Fatigue	YES	NO	YES	NO
Stiff joints	YES	NO	YES	NO
Sore eyes	YES	NO	YES	NO
Wheeziness	YES	NO	YES	NO
Headaches	YES	NO	YES	NO
Upset stomach	YES	NO	YES	NO
Sleep difficulties	YES	NO	YES	NO
Dizziness	YES	NO	YES	NO
Loss of strength	YES	NO	YES	NO
Tearfulness	YES	NO	YES	NO
Irritability	YES	NO	YES	NO
Spotting or bleeding	YES	NO	YES	NO
Anxiety	YES	NO	YES	NO
Low mood	YES	NO	YES	NO
Bad dreams	YES	NO	YES	NO
Racing heart	YES	NO	YES	NO

I am interested in your own personal views of how you now see your difficulty conceiving.

Please indicate how much you agree or disagree with the following statements about your difficulty conceiving by ticking the appropriate box.

		strongly agree	agree	neither agree nor disagree	disagree	strongly disagree
1	Our problem will last a short time					
2	Our difficulty conceiving is likely to be permanent rather than temporary					
3	Our difficulty conceiving will last for a long time.					
4	This will pass quickly					
5	Our difficulty conceiving is a serious condition					
6	Our difficulty conceiving has had major consequences on my life					
7	Our difficulty conceiving has not had much effect on my life					
8	Our difficulty conceiving has strongly affected the way others see me					
9	Our difficulty conceiving has serious economic and financial consequences					
10	Our difficulty conceiving causes difficulties for those who are close to me					
11	There is a lot which I can do to control things					
12	What I do can determine the outcome of this problem					
13	The course of our problem depends on me					
14	Nothing I do will affect our problem					
15	I have the power to influence our problem					
16	My actions will have no effect on the outcome of our difficulty conceiving					

		strongly agree	agree	neither agree nor disagree	disagree	strongly disagree
17	Our situation will improve in time					
18	There is very little that can be done to improve our situation					
19	Our treatment will be effective					
20	The treatment can control the problem					
21	There is nothing which can help this problem					
22	The symptoms of this problem are puzzling to me					
23	Our difficulty conceiving is a mystery to me					
24	I don't understand our difficulty conceiving					
25	Our difficulty conceiving doesn't make sense to me					
26	I have a clear picture or understanding of our problem					
27	The symptoms of our problem change a great deal from day to day					
28	The symptoms come and go in cycles					
29	Our problem is very unpredictable					
30	I go through cycles in which I feel better or worse					
31	I get depressed when I think about our problem					
32	When I think about our problem I get upset					
33	Our difficulty conceiving makes me feel angry					
34	Our difficulty conceiving does not worry me					
35	Having this problem makes me feel anxious					

		strongly agree	agree	neither agree nor disagree	disagree	strongly disagree
36	Our problem makes me feel afraid					
37	Our difficulty conceiving has become easier to live with					
38	Our difficulty conceiving has strongly affected the way I see myself as a person					

Please do not tick more than three or four important factors, though you may tick any number of your difficulty conceiving, you may tick any of the factors from the list above, as you may have additional ideas of your own.

I am also interested in what YOU consider to be the causes of your difficulty conceiving. As people are very different, there is no correct answer for this question. I am most interested in your own views about the factors that caused this problem, rather than what others, including doctors or family, may have suggested to you. Below is a list of possible causes. Please indicate how much you agree or disagree that they are causes for you by ticking the appropriate box.

	strongly agree	agree	neither agree nor disagree	disagree	strongly disagree
Stress or worry					
Hereditary – it runs in the family					
A germ or virus					
Diet or eating habits					
Chance or bad luck					
Poor medical care in my past					
Pollution in the environment					
My own behaviour					
My mental attitude (thinking about life negatively)					
Family problems or worries					
Overwork					
My emotional state (e.g. feeling down, lonely, anxious, empty)					
Ageing					
Alcohol					
Smoking					

	strongly agree	agree	neither agree nor disagree	disagree	strongly disagree
Accident or injury					
My personality					
Altered immunity					

Please list in rank order the three most important factors that you now believe caused YOUR difficulty conceiving. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me (us)

1 _____

2 _____

3 _____

• **The Hospital Anxiety and Depression Scale**

There is a growing awareness that emotions play an important part in most medical problems. This questionnaire is designed to give an indication about how patients feel. Read each item and circle the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or wound up

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

I still enjoy the things I used to enjoy

- Definitely as much
- Not quite as much
- Only a little
- Hardly at all

I get a sort of frightened feeling, as if something awful is about to happen

- Very definitely, and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

I can laugh and see the funny side of things

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

Worrying thoughts go through my mind

- A great deal of the time
- A lot of the time
- From time to time, but not often
- Only occasionally

I feel cheerful

- Not at all
- Not often
- Sometimes
- Most of the time

I can sit at ease and feel relaxed

- Definitely
- Usually
- Not often
- Not at all

I feel as if I am slowed down

- Nearly all the time
- Very often
- Sometimes
- Not at all

**I get a sort of frightened feeling,
like butterflies in the stomach**

Not at all
Occasionally
Quite often
Very often

I feel restless as if I have to be on the move

Very much indeed
Quite a lot
Not very much
Not at all

I get sudden feelings of panic

Very often indeed
Quite often
Not very often
Not at all

**I have lost interest in my
appearance**

Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

**I look forward with enjoyment to
things**

As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

**I can enjoy a good book, or radio
/TV programme**

Often
Sometimes
Not often
Very Seldom

- **The COPE**

I am interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with difficult times. Obviously people deal with things in different ways, but we are interested in how you've tried to deal with your difficulty conceiving.

Respond to each of the following items by circling one number for each, using the response choices listed just below. Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make them as true FOR YOU as you can. Don't answer on the basis of whether it seems to be working or not – just whether or not you are doing it.

1= I haven't been doing this at all.	2= I've been doing this a little			
3= I've been doing this a medium amount	4= I've been doing this a lot			
1 I've been turning to work or other activities to take my mind off things	1	2	3	4
2 I've been concentrating my efforts on doing something about the situations I'm in	1	2	3	4
3 I've been saying to myself "This isn't real"	1	2	3	4
4 I've been using alcohol or other drugs to make myself feel better	1	2	3	4
5 I've been getting emotional support from others	1	2	3	4
6 I've been giving up trying to deal with it	1	2	3	4
7 I've been taking action to try to make the situation better	1	2	3	4
8 I've been refusing to believe that it has happened	1	2	3	4
9 I've been saying things to let my unpleasant feelings escape	1	2	3	4
10 I've been getting help and advice from other people	1	2	3	4
11 I've been using alcohol or other drugs to help me get through it	1	2	3	4

12 I've been trying to see it in a different light to make it seem more positive	1	2	3	4
13 I've been criticising myself	1	2	3	4
14 I've been trying to come up with a strategy about what I can do	1	2	3	4
15 I've been getting comfort and understanding from someone	1	2	3	4
16 I've been giving up the attempt to cope	1	2	3	4
17 I've been looking for something good in what's happening	1	2	3	4
18 I've been making jokes about it	1	2	3	4
19 I've been doing something to think about it less, e.g reading / daydreaming /sleeping / shopping	1	2	3	4
20 I've been accepting the reality of the fact that it has happened	1	2	3	4
21 I've been expressing my negative feelings	1	2	3	4
22 I've been trying to find comfort in my religious or spiritual beliefs	1	2	3	4
23 I've been trying to get advice or help from other people about what to do	1	2	3	4
24 I've been learning to live with it	1	2	3	4
25 I've been thinking hard about what steps to take	1	2	3	4
26 I've been blaming myself for things that happened	1	2	3	4
27 I've been praying / meditating	1	2	3	4
28 I've been making fun of the situation	1	2	3	4

That is the end of the questionnaires: thank you for completing them .Please now give or send them back to one of the nurses at the clinic.

Appendix 4

GP Letter (example).

October 2002

GPs of Participants in a research study

Dear Dr.

Re: Understanding Infertility Research Study

I am writing to inform you about a research study currently being carried out at the xxxxx. The study has been designed to investigate how people understand their infertility, and how that affects both the ways they cope and the distress they feel. Patients are being asked to complete questionnaires about their infertility.

Your patient has agreed to take part in this study during their treatment at the hospital. If you need any further information please do not hesitate to contact me on xxxx

Yours sincerely

Sharon Steddy
Trainee Clinical Psychologist

Appendix 5 Pilot Study Questionnaire

Understanding Infertility - the pilot

Thankyou for agreeing to take part in this pilot study. It will take a few minutes to read through the information, about fifteen minutes to complete the main questionnaires then a couple more to do this one. **Mark the time you start at the top of the page.**

Before you start please be aware that one of these questionnaires is a screening tool for depression. If, when I score the questionnaires, I find someone has a score that indicates they may be depressed, ethically I will have to phone Sally and let her know. If you know you're going through a rough patch and likely to score highly on this questionnaire, please scribble a note to me at the bottom of the page!

Information	YES	NO
Was the information for patients clear and easy to understand?	<input type="checkbox"/>	<input type="checkbox"/>
Did it offer patients enough information to make a decision?	<input type="checkbox"/>	<input type="checkbox"/>
How would you feel about the study if you were being asked to do it in the clinic?		

Are there any changes you could suggest?

Questionnaires	YES	NO
Were the instructions clear and easy to understand?	<input type="checkbox"/>	<input type="checkbox"/>
Were there any ambiguous or unclear questions?	<input type="checkbox"/>	<input type="checkbox"/>
Were there any items you would consider irrelevant or pointless?	<input type="checkbox"/>	<input type="checkbox"/>
Were there any items you would consider insensitive or likely to upset someone?	<input type="checkbox"/>	<input type="checkbox"/>

How long did the questionnaires take you? _____
How did you feel about completing these questionnaires? _____

Appendix 6

Correlations between the Illness Perception Questionnaire section on causes and use of coping strategies.

	Stress	Genetic	Virus	Diet	Chance	Medical care	Pollution	Behaviour	Attitude
Positive Reframing	.003	.155	.206	.179	.143	.005	.142	-.022	-.110
Self Blame	.169	-.017	.008	.142	.107	.128	.181	.278*	.358**
Planning	.007	-.101	.126	.122	.033	.134	.241*	-.169	-.098
Humour	-.008	-.071	.127	.001	.017	-.011	.015	.016	.125
Acceptance	-.003	-.328**	.028	.047	-.050	-.016	-.040	.011	-.186
Religion	.004	.042	.058	.087	.017	.048	-.006	-.040	.157
Venting	.269*	.005	-.064	.324**	.084	.083	.222	.172	.348**
Instrumental Support	-.009	-.005	.014	.260*	-.006	-.027	-.056	-.142	-.052
Behavioural Disengagement	.227	.182	.033	.087	-.006	.031	.134	.064	.177
Emotional Support	.009	-.062	.018	.143	-.069	-.025	.154	-.070	-.079
Substance use	.191	-.083	-.063	.048	.046	-.036	.089	.029	.259*
Denial	.232*	.044	-.094	-.023	.057	.041	.120	.016	.245*
Self Distraction	.066	.150	.118	.126	.309**	.044	.119	.080	.190
Active Coping	-.160	-.132	.201	-.062	.099	.029	.017	-.127	-.106

Correlations between "causes" and coping strategies continued...

	Family problems	Over- work	Emotional state	Age	Alcohol	Smoking	Accident	Person- ality
Positive Reframing	-.052	-.059	.130	-.276*	-.081	.068	.087	-.045
Self Blame	.154	.190	.339**	.201	.163	.044	.137	.262*
Planning	-.088	.066	-.074	-.275*	-.056	.172	.081	.091
Humour	.062	.091	.141	.007	.050	.099	-.001	.136
Acceptance	-.042	.017	-.167	-.187	.182	.245*	.006	-.106
Religion	.069	.021	.142	-.026	-.006	.009	-.079	-.026
Venting	.288*	.246*	.448**	.026	.093	.007	.103	.198
Instrumental Support	.052	-.007	.076	-.291*	-.179	-.067	-.107	-.165
Behavioural Disengagement	.263*	.228	.142	.027	-.022	-.005	.218	.118
Emotional Support	.029	-.040	.017	-.148	-.076	-.170	-.183	-.103
Substance use	-.013	.131	.298*	.282*	.267*	.120	.025	.127
Denial	.100	.150	.204	.252*	.020	-.000	.0	.250*
Self Distraction	.075	.161	.121	-.059	.100	.084	.230	.085
Active Coping	.051	-.083	-.111	-.368**	-.084	.119	.073	-.203

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