

UNIVERSITY OF DERBY

**DOING IT THE BEST WAY THAT WE  
CAN: MEN'S AND WOMEN'S  
EXPERIENCES DURING THE EARLY  
STAGES OF IVF; AN INTERPRETATIVE  
PHENOMENOLOGICAL ANALYSIS**

Eleanor Phillips

Doctor of Philosophy

2012

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## **Glossary and abbreviations**

<b>ART</b>	Assisted reproductive technology: treatments and procedures involving the in vitro handling of human oocytes and sperm or embryos to establish a pregnancy (excludes IUI) (Zegers-Hochschild et al., 2009)
<b>Assisted hatching</b>	Creating a small opening in region surrounding the embryo before transfer into uterus, which may aid embryo hatching (American Society for Reproductive Medicine [ASRM], 2008)
<b>FET</b>	Frozen embryo transfer: A treatment cycle in which extra embryos produced in an earlier IVF cycle and cryopreserved are transferred. Less expensive and invasive than a 'fresh' cycle (ASRM, 2008)
<b>Follics (follicles)</b>	Egg containing structures in a woman's ovaries (Center for Disease Control [CDC], 2010)
<b>ICSI</b>	Intracytoplasmic sperm injection: a procedure where a single sperm is injected into an oocyte (Zegers-Hochschild et al., 2009)
<b>Infertility</b>	Failing to become pregnant after 12 months of unprotected intercourse (ASRM, 2003)
<b>IUI</b>	Intrauterine insemination (Zegers-Hochschild et al., 2009)
<b>IVF</b>	In vitro fertilisation: fertilisation of an oocyte outside the body (Zegers-Hochschild et al., 2009)
<b>Oocyte</b>	Commonly referred to as an egg; female sex cells (ASRM, 2008)
<b>PCOS</b>	Polycystic ovary syndrome: A hormone imbalance leading to lack of ovulation and infertility (Fairley & Taylor, 2003)
<b>Progesterone</b>	Female hormone often administered during fertility treatment
<b>Success rate</b>	Percentage of treatment cycles ending in a live birth (CDC, 2010)
<b>Third party reproduction</b>	Treatment using donated sperm, eggs, or gestational surrogacy where another woman carries the pregnancy (ASRM, 2003)



## **Extent of contribution**

I confirm that this PhD thesis is my own original work. It does not contain material published elsewhere or previously submitted for a degree or diploma at any other institution. To the best of my knowledge and belief, it does not contain any material previously written or published by another person, except where due reference is made in the text.

## **Abstract**

This research examined how men and women experience stress and coping during the early stages of IVF, focusing on time, gender and couples. Both members of three heterosexual couples took part separately in two or three semi-structured interviews over a six-month period, producing fourteen accounts. Interpretative Phenomenological Analysis was used to preserve participants' unique experiences alongside interpretation and generation of broader themes by the researcher. Infertility and fertility treatment were not always seen as stressful, but often as a problem to be tackled in the best way, both emotionally and practically. Stress arose from specific, time-limited issues. Participants' emotional responses were shaped by perceptions of the effect of stress on fertility, a desire to stay positive, and downward comparison with other fertility patients who were perceived to be coping poorly. Participants emphasised their choices as logical, careful decisions, weighing up multiple factors including alternatives like adoption, and temporal and financial investments. Over time, perceptions of IVF changed from a precise, technical process to one subject to luck and chance, although the process itself was perceived as becoming easier with experience. The study was originally positioned within the transactional stress and coping model, but a self-regulatory perspective provided a better fit for the data. The findings are linked to each model where appropriate, and the implications suggest use of the transactional model to understanding specific, time-limited events, and a self-regulatory framework to explore general fertility treatment experiences. Suggestions for future work include greater use of the self-regulatory framework to study infertility and fertility treatment; paying attention to couples' willingness to adopt in shaping infertility experiences; conducting interviews at different times during treatment cycles, and during different treatment cycles; and using alternative data gathering methods including Internet Mediated Research.

## **Acknowledgements**

I want to thank all the people who helped me complete this work. Most importantly, the three couples who graciously shared their time and experiences with me. Also, Nancy Weiss at the Palo Alto Medical Foundation, who was willing to go out of her way to help me, as well as Dr Salli Tazuke for sponsoring the project, and the staff of the Research Institute who helped obtain the required ethical clearances to carry out the research.

I feel incredibly fortunate to have had the interest, support, help and attention of my supervisors, Jane Montague and James Elander. I'm sure it can't have always been easy to supervise a student located so far from the University, and I have appreciated their flexibility in arranging visits and phone-calls to fit my often tight schedule. Additionally, they have been incredibly patient with my learning and concerns over the four years. I owe them a large debt of gratitude from all I have learned. (Thus creating a three-part list!)

Finally, my thanks go to my family. Starting with my patient husband, Jules, who has allowed me to pursue my studies without complaint, but now would like his student wife to go out and get a job. Watching my little man, Ciaran, grow from a newborn to a lively, talkative pre-schooler while I've been working on this, has been a joy, and provided light relief and a valuable counterpoint to my academic activities.

# 1 Introduction

This chapter outlines the thesis content and structure. The first section summarises existing infertility, stress and coping research, and the rationale for further work on these topics. The next section justifies the qualitative, phenomenological approach used to explore these questions. The research question, and aims and objectives that shaped the design and execution of this study are presented next. Originally, the study drew on the transactional stress and coping model, and an overview of the reasons for including the self-regulation model is given. The final section in this chapter explains the thesis structure.

## *1.1 Background and rationale*

For most people, having children is important and becoming a parent is considered an essential life milestone, with strong social pressure to reproduce (Van Balen & Bos, 2004; Miall, 1986). Between 9% and 15% of the population will encounter infertility (Boivin, Griffiths & Venetis, 2011). Increasing use of assisted reproductive technologies (ARTs) such as in vitro fertilisation (IVF) has focused attention on the experiences of around half of infertile couples who pursue fertility treatment (Greil, 1997). Infertility has been found, particularly through qualitative research, to be a distressing and stressful experience (Greil, Slauson-Blevins & McQuillan, 2010). Where qualitative studies have suggested that infertility is perhaps the most difficult experience a couple encounters, quantitative studies have not found infertile individuals to exceed population norms in psychopathology (Lord & Robertson, 2005). To investigate this disparity, research has turned to theoretical frameworks like stress and coping (Stanton & Dunkel-Schetter, 1991b), and paid attention to how infertility experiences are shaped by social environments (Greil et al., 2010).

Lazarus and Folkman's (1984) transactional stress and coping model has generated copious research into infertility and fertility treatment, within which the present study can be located (Peterson et al., 2009; Schmidt, Holstein, Christensen & Boivin, 2005b; Stanton & Dunkel-Schetter, 1991b). This research has mostly concentrated on identifying stressors and coping strategies, and establishing links between coping and outcomes. There is scope for investigating process, context, meaning, and change in relation to stress, coping, and fertility treatment. These complex issues have often been neglected in the existing quantitative literature as they are not easily represented quantitatively (Greil, 1997; Lazarus, 2000), but are suited to qualitative study. The focus on experiences during the early stages of IVF fits

with an increasing trend in stress and coping research towards studying specific experiences, interactions and context (Aldwin, 2007).

Infertility research has moved away from a focus on women's atemporal infertility and fertility treatment experiences. Temporal issues are important because fertility treatment is not a single event, but a process that may last for years (Domar et al., 2000). Fertility treatment may involve repeated treatment cycles with changing diagnoses and treatment protocols (Greil, 1997). Infertility research has moved from cross-sectional designs comparing groups at different treatment stages (Berg & Wilson, 1991; Lord & Robertson, 2005) to large-scale quantitative, longitudinal and prospective studies, such as the Danish series (Schmidt et al., 2005a, 2005b; Verhaak, Smeenk, van Minnen, Kremer & Kraaimat, 2005). Qualitative longitudinal studies have examined the role of information during treatment (Porter & Bhattacharya, 2008), and end of treatment experiences (Daniluk, 2001a, 2001b).

Gender and couple effects are important in infertility research (Jordan & Revenson, 1999). Men's infertility experiences have often been ignored, derived from partners' accounts, or inferred from a lack of response and pre-determined expectations (Lloyd, 1996; Lord & Robertson, 2005). As well as exploring men's perspectives on infertility, this research should contribute to the growing literature on men's perspectives in health psychology (Gough & Robertson, 2010). As infertility impacts the couple together, this is another important perspective, even though only one partner might have a physical impairment (Greil, Leitko & Porter, 1988; Miall, 1986). Analysis at the couple level has begun to emerge in infertility research, although often the couple has been used to gather accounts from both men and women.

## ***1.2 Research approach***

This research used a qualitative approach. There are good reasons to explore infertility stress and coping experiences using qualitative research. Qualitative research enables attention to individual processes, context and meanings during fertility treatment, which are important theoretically in the transactional model (Folkman & Moskowitz, 2000; Lazarus, 1993; 2000). Infertility has been suggested to be an individually varied experience (Pook & Krause, 2005). Qualitative research can explore variations among participants (Pope, Ziebland & Mays, 2000) rather than focusing on variations between averages of infertile populations and fertile controls (Lazarus, 2000). This should contribute to improved understanding of the differences

between small numbers of clinically distressed fertility patients and others who remain well adjusted through treatment (Greil, 1997). Experiences are worthy of study in themselves, not just when resulting in clinical depression or anxiety. Qualitative methods have been used with other stress and coping research in health psychology, including the praised longitudinal HIV/AIDS studies by Folkman and colleagues (Folkman, 1997a; Lazarus, 1999; Moskowitz & Wrubel, 2005).

Qualitative research into infertility, while focusing on diverse experiences of small groups, has tended to focus on describing infertility and treatment experiences, rather than drawing on theoretical models (Imeson & McMurray, 1996; McQuillan, Greil, White & Jacob, 2003; Redshaw, Hockley & Davidson, 2007). The present study aims to improve understanding of how individuals make sense of stress and coping during fertility treatment. This entails moving beyond producing lists of stressors and coping strategies, and investigating participants' "temporal, interpersonal, situational, and sociocultural context" (Danoff-Burg, Ayala & Revenson, 2000, p. 192).

Various qualitative approaches could have been chosen for this present study. Methodology selection and development of the research question are linked, to ensure that the chosen methodology can answer the research question (Henwood & Pidgeon, 1992). A phenomenological approach was selected because it focuses on the individual's perspective and experience as they attempt to understand the situations they encounter (King et al., 2008). While the status of infertility as a disease (The Practise Committee of the ASRM, 2004) is sometimes problematic (Becker & Nachtigall, 1992; Sandelowski & de Lacey, 2002), fertility treatment is a health issue, and subject to the individual variations found in health and illness experiences (Moskowitz & Wrubel, 2005). Interpretative Phenomenological Analysis (IPA) aims to preserve the individual in the analysis (Smith, 2004), while allowing convergences and divergences across groups to emerge, and to position accounts within their social context (Smith, Flowers & Larkin, 2009). IPA has a strong foundation in health psychology, and is a psychological approach drawing on human beings' interpretative, meaning-making nature (Brocki & Wearden, 2006; Rapport, 2005).

### ***1.3 Personal relevance***

Infertility has personal relevance, as I experienced multiple miscarriages, although my husband and I did not pursue fertility treatment. I attended a fertility treatment support group for four years, and have close friends who underwent IVF. My fertility treatment experience

overlaps somewhat with this study's participants: having experienced the desire to have a child and being unable to carry a pregnancy to term, but not having experienced fertility treatment. My interest in infertility as a research topic was influenced by my experiences and the literature portraying fertility patients as desperate and depressed. That seemed a stereotyped and one-sided view of infertility, as other researchers have commented (Letherby, 2002). I reflected on the impact of my personal experiences with infertility throughout the research. The strategies I used are explained in section 3.1.3, giving an overview of reflexivity theory, and section 4.5, explaining the reflexive techniques used. Reflections on my interaction with the research, the participants, my understanding of the topic and my changing perspectives from becoming an adoptive parent during this study are presented in chapter 9.

#### ***1.4 The research question, aims and objectives***

This was a longitudinal, qualitative study of men and women's experiences of stress and coping during fertility treatment. The research question was: 'how do men and women experience stress and coping during the early stages of in-vitro fertilisation (IVF), and does this change over time?' The study's aim was to produce a phenomenological, participant-centred analysis of fertility treatment experiences, focusing on stress, coping, gender, and change over time. This aim was refined into five objectives:

1. To identify interpretative themes relevant to the research question and most prevalent across participants' accounts.
2. To add to psychological knowledge of men's perceptions of fertility treatment, and about how both genders make sense of their experiences as part of a couple.
3. To increase psychological knowledge and understanding about fertility treatment as a changing and dynamic experience, by identifying temporal elements of participants' accounts and the interpretative themes.
4. To extend psychological understanding of the application of stress and coping theory to fertility treatment.
5. To use the interpretative themes and theoretical observations to inform therapeutic practice for individuals and couples undergoing treatment for infertility.

## ***1.5 Study implementation***

Data was gathered through semi-structured interviews with six participants (three heterosexual couples) who were starting IVF at the time of their first interview. Individuals were interviewed two or three times over a six-month period during which time they underwent two or three fertility treatment cycles. The interviews were transcribed and analysed using IPA, generating in-depth analyses of each account that were developed into the group level analysis presented here. Although uncommon, IPA can be used to explore data within a theoretical framework (Brocki & Wearden, 2006). In the present study, coding and analysis was undertaken with an attempt to understand how each individual experienced fertility treatment, but to remain open to all data, not only that perceived to fit within the transactional framework. It emerged that the data better fit the Self-Regulation Model of illness (SRM; Leventhal, Leventhal & Contrada, 1998) so the analysis drew on both models, using the SRM to account generally for the data, with the transactional model applied to specific experiences.

## ***1.6 Thesis outline***

The existing infertility literature is reviewed in chapter 2, summarising general infertility research, the application of stress and coping theory to infertility research, and the literature related to gender, time and couples. Chapter 3 explains the theoretical basis of phenomenology, semi-structured interviewing, and strategies for improving the quality of qualitative research. These issues are linked to IPA, and their implementation in the present study. The data gathering and analysis procedures are explained in chapter 4, building on the theoretical points raised in chapter 3.

The second half of the thesis presents the data analysis, beginning with an overview of all themes in chapter 5, the rationale for theme selection, and a description of the transcription strategy. Chapter 6 is the first empirical chapter, focusing on emotional representations of infertility, and how participants made sense of the emotional impact of fertility treatment within their social environment. Gender differences are explored where appropriate throughout the analysis, and this chapter contains an explicit investigation of men's perspectives on fertility treatment. Chapter 7 investigates how participants made sense of IVF as a solution to a problem, and the issues arising from this problem-solving/decision-making approach. The last empirical chapter, chapter 8, looks at time and treatment, both how



treatment was experienced over time and how perceptions of time influenced views of treatment.

The final chapter, chapter 9, draws together the thesis, with a general discussion of the chapter themes, relating them to the literature, theory and presenting suggestions for applications in therapy and support of fertility patients. This chapter critically evaluates the research against the original goals, to present ideas for future research. The study suggests value in broadening infertility research and fertility treatment experiences from the widely used transactional approach to a broader self-regulation perspective, which has been largely neglected in this area. This reflects the role identified here of participants as problem-solvers, who are active in tackling their situation in the attempt to reach the desired solution, in the best way, balancing their desire for parenthood with their well-being in other areas.

## **2 Literature review: Infertility, fertility treatment and stress**

Fertility treatment, particularly in vitro fertilisation (IVF), is often the last resort for a couple to conceive a biologically related child, so is perceived to be high stakes and stressful (Edelmann, Connolly & Bartlett; 1994; Litt, Tennen, Affleck & Klock, 1992). This perception led to a focus on psychopathology in infertile individuals and couples seeking fertility treatment, with mixed results (Newton, Sherrard & Glavac, 1999; Verhaak, Smeenk, Evers, et al., 2007). Some studies have shown higher rates of clinical depression and state anxiety in infertile populations (Beaurepaire, Jones, Thiering & Saunders, 1994; Cousineau & Domar, 2007) and lower general well-being (Morrow, Thoreson & Penney, 1995). Others have found little difference between infertile groups and fertile controls or population means on measures of distress and adjustment (Greil, 1997; Lord & Robertson, 2005; Slade, Emery & Lieberman, 1997). Most individuals adjust well, even to failed treatment (Litt et al., 1992; Verhaak, Smeenk, Nahuis, Kremer & Braat, 2007) although a “substantial minority” (Lord & Robertson, 2005, p. 328) exhibit clinical depression and anxiety.

During the 1990s, research broadened to include the influences of social context on infertility experiences (Greil, Slauson-Blevins & McQuillan, 2010), and theoretical frameworks, such as transactional approaches to stress and coping, that might explain the range of responses. This chapter reviews stress and coping research in infertility, starting with an overview of the theoretical models drawn on during this study, the transactional framework and the Self-Regulation Model (SRM). Then research applying these models is presented, focusing on what is known about stress, appraisal, control and coping, and describing time, gender and couple effects where appropriate. The next section explains research into time, gender, couples, and the role of context on fertility experiences. The penultimate section makes general critiques of this research, identifying opportunities for further work, leading to the research question, which is presented in the last section of this chapter.

### ***2.1 Stress and coping models***

#### **2.1.1 The Transactional Model**

Most research into infertility stress and coping has used the transactional framework proposed by Lazarus and Folkman (1984), which is a generic model, applicable across stressful situations (Folkman, 2009). Lazarus and Folkman defined psychological stress as a

“relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (p. 19). Within this framework, stress and coping involve an interaction (transaction) between an individual’s appraisal of an event’s meaning, their assessment of their resources to deal with it, and their specific personal and social environment (Aldwin, 2007). The model does not make specific predictions about which coping strategies are adaptive as these are contextually, situationally and individually dependent (Stanton, Tennen, Affleck & Mendola, 1992). The focus on meaning and context makes this a useful model for qualitative researchers, and Richard Lazarus promoted qualitative techniques to research stress and coping (1999, 2000). Some researchers have suggested that the transactional model should be integrated into the SRM, which incorporates the same elements, but has a broader scope with a focus on goal setting rather than just stress (Kraaij, Garnefski, Schroevers, Weijmer & Helmerhorst, 2010; Leventhal, Halm, Horowitz, Leventhal & Ozakinci, 2004).

### **2.1.2 The Self-Regulation Model**

The SRM focuses on health and illness, viewing individuals as problem-solvers trying to achieve a desired goal such as returning the individual to their normal, healthy state when encountering a health challenge (Leventhal et al., 2004). Like the transactional model, it represents this as a cyclical process, which involves goal setting, strategy selection and coping, information acquisition, evaluation and re-adjustment (Boekaerts, Maes & Karoly, 2005; Leventhal et al., 1997). Any situation where an individual is disturbed from their normal state can be subject to self-regulation, as an individual attempts to achieve their goals. The SRM includes two parallel processes; one related to understanding and managing the nature of the illness (illness representations), the other to managing the associated emotions. Illness representations have five dimensions: identity (symptom labels); timeline (perceived duration); consequences (expected outcomes); cause (reason for the illness); and control (Leventhal, Brissette & Leventhal, 2003). Once illness representations and the emotional situation have been identified, coping procedures can be selected, implemented and evaluated, although it can be difficult to separate emotional representations from emotional outcomes (Benyamini, Gozlan & Kokia, 2004).

The SRM has only recently been applied to infertility research (Benyamini et al., 2004; Benyamini, Gozlan & Kokia, 2009; Kraaij et al., 2010; Lord & Robertson, 2005) and there appear to be no qualitative studies in this area. Benyamini and colleagues used the SRM with men and women undergoing fertility treatment (Benyamini et al., 2004; Benyamini et al.,

2009). They found an association between long timelines, severe consequences, and low controllability and greater distress and lower well-being for women undergoing different types of fertility treatment (Benyamini et al., 2004). Coping was only a mediator for the impact of consequences on distress, not timeline or control. In a study of men and women beginning treatment at a fertility clinic or having been patients for some time, they established that women seemed to have more negative perceptions of infertility than men (Benyamini et al., 2009). Lord and Robertson (2005) studied the relationship between infertility beliefs (illness perceptions), coping and distress. They found distress was associated with illness perceptions and coping independently, highlighting the role of factors other than coping in outcomes. Kraaij et al. (2010) found that factors from both the transactional and SRM predicted distress and anxiety, and that an additional factor of goal readjustment contributed. These studies show that the SRM may provide additional nuance and conceptualisation of difficulties to enhance knowledge of the processes occurring during infertility and fertility treatment.

## ***2.2 Current research on infertility, stress and coping***

### **2.2.1 What is known about infertility stress**

Infertility is frequently referred to as the most stressful experience encountered by couples (Freeman, Boxer, Rickels, Tureck & Mastroianni, 1985). As a life crisis, it threatens the attainment of biological parenthood (Abbey, Andrews & Halman, 1991a; Stanton et al., 1992), and disrupts the assumed life course (Glover, McLellan & Weaver, 2009; Wilson & Kopizke, 2002) by failure to achieve the valued social and life goal of parenting (Greil et al., 2010). Consequently, individuals may experience lowered well-being (Callan & Hennessey, 1989, p. 344) and self-esteem (Nachtigall, Becker & Wozny, 1992); stigma (Gannon, Glover & Abel, 2004; Miall, 1986; Nachtigall et al., 1992); and challenges to their identity (McQuillan, Greil, White & Jacob, 2003; Todorova & Kotzeva, 2006).

Research has identified specific stressors occurring during infertility and fertility treatment. Infertile individuals, particularly women, may be uncomfortable interacting with others who are pregnant or have young children (Collins, Freeman, Boxer & Tureck, 1992; Stanton et al., 1992). In some cultures, obligations to carry on a family line lead to role burden when efforts to conceive fail (Chang & Mu, 2008). Marital and sexual relationships may be disrupted by infertility and fertility treatment (Abbey et al., 1991a; Abbey, Andrews & Halman, 1995). Fertility treatment introduces new difficulties, like carrying out treatment procedures,

awareness of uncertainty about treatment outcomes, and the threat of permanent childlessness if treatment fails (Verhaak, Smeenk, Evers, et al., 2007). Managing financial resources and scheduling treatment may be difficult (Blenner, 1992; Cousineau & Domar, 2007; Redshaw, Hockley & Davidson, 2007), as might less tangible concerns, like wasted time and waiting (Imeson & McMurray, 1996; Sandelowski & Pollock, 1986). Receiving an uncertain diagnosis appears to generate stress, particularly when ending fertility treatment (Daniluk, 2001b) and the possibility of long-term side effects from medication, like cancer, might be a stressor (Seibel, 1997). Maintaining physical and mental health becomes more significant while undergoing treatment (Abbey et al., 1991a). Stress has been linked to premature termination of treatment, when a couple ends treatment before conceiving, but with financial and medical resources remaining (Domar, 2004; Olivius, 2004).

These stressors, including marital functioning, sexual well-being, relationships with friends and family, finances, and mental functioning and physical health, identified by the above mix of qualitative and quantitative research, and the “popular” infertility literature (Newton et al., 1999, p. 55), have been used to develop two measures of infertility stress. The Fertility Problem Stress Inventory (Abbey et al., 1991a) and the Fertility Problem Inventory (Newton et al., 1999) assess stress in these realms and as a global measure. These measures allow fertility stress to be quantified and linked to outcomes like depression, anxiety, well-being, and coping. Studies using these instruments have shown that women experience generally higher fertility related stress than men, although not over all domains (Peterson, Newton, Rosen & Skaggs, 2006a). Higher fertility-related stress has been found in couples with poor communications (Schmidt, Holstein, Christensen & Boivin, 2005a), whereas women who perceive themselves as having greater social resources have lower fertility-related stress (Gibson & Myers, 2002).

Positive consequences of encountering infertility have been identified, including strengthening the marital relationship (Abbey & Halman, 1995; Repokari et al., 2007; Schmidt, Holstein, Christensen & Boivin, 2005b); learning about self, spouse or the marriage (Abbey et al., 1991a; Lee, Hui Choi, Chan, Chan & Ng, 2009; Stanton, Tennen, Affleck & Mendola, 1991); the body and reproduction (Schmidt, 1998); or learning to take control and set boundaries (Daniluk, 2001b). For some, religious or spiritual growth is another perceived gain from infertility (Abbey & Halman, 1995; Lee et al., 2009). The positive outcomes of experiences perceived as negative or stressful, like infertility, have been identified as an area requiring more research (Folkman & Moskowitz, 2000).

Finally, there are perceptions that stress adversely impacts fertility (Lord & Robertson, 2005), and infertile individuals have reported receiving unhelpful advice to relax to aid conception (Boivin et al., 2001; Imeson & McMurray, 1996; Letherby, 1999). However, infertile groups are not found to differ significantly from fertile ones on psychological measures, and there is little evidence that psychological factors play a causal role in infertility (Greil, 1997; Slade et al., 1997). Some evidence suggests that elevated stress before and during treatment can reduce chances of a live birth (Boivin & Schmidt, 2005; Boivin & Takefman, 1996; Klonoff-Cohen, Chu, Natatajan & Siber, 2001). A recent review found no connection between pre-treatment distress and outcomes of IVF (Boivin, Griffiths & Venetis, 2011).

### **2.2.2 Appraisal**

A key element of both theoretical models is appraisal: the process through which individuals assess the meaning and significance of an experience (Lazarus, 1999; Leventhal et al., 2003). The transactional framework includes two types of appraisal. Primary appraisal occurs when an individual weighs up the meaning and significance of an event, and secondary appraisal involves establishing and assessing the effectiveness of available actions (Lazarus & Folkman, 1984). After primary appraisal, a situation may be labelled as stressful: harm/loss, threat, challenge; or unstressful: benign-positive, or irrelevant. A challenge appraisal is positive, permitting growth and gain, but may still involve difficulties or demands. Appraisals are not mutually exclusive (a situation may be a threat and a challenge), and may change over time. Although the primary/secondary nomenclature appears sequential and hierarchical, the two forms of appraisal interact, are of equal importance and may re-occur.

In the SRM, situations are appraised for their physical and emotional impact. The five dimensional illness representations along with consideration of the emotional implications provides a more specific picture of the dimensions of the potentially stressful situation than the comparison of the size of the difficulty in relation to coping resources, as occurs with the transactional model (Leventhal et al., 2004). Despite differences between the models in the level and focus of situation representations, both emphasise the central, active role of the individual interacting with their environment, monitoring and interpreting their potentially complex situation, and evaluating and implementing resources to manage them (Leventhal & Mora, 2005). The meaning of an event to an individual is therefore key.

Research based on the transactional model has found individuals to classify infertility as a threat, or loss, or challenge. Infertility may threaten life goals for the couple and masculinity

for the men, and entail a physical threat for women pursuing treatment (Dunkel-Schetter & Lobel, 1991; Glover et al., 2009). It represents a potential loss of pregnancy and biological children (Dunkel-Schetter & Lobel, 1991). The women studied by Hansell, Thorn, Prentice-Dunn and Floyd (1998) almost equally divided their rating of infertility between loss and challenge appraisals. A challenge appraisal resulted in significantly less distress than a loss appraisal. Multiple appraisals may occur. Stanton et al. (1991), using the transactional model, found that couples rated infertility as both a threat and a challenge, and men whose partner perceived infertility as a challenge were less distressed. Glover et al. (2009) speculated that a loss appraisal might become more prevalent over time as childlessness becomes more likely. Lord and Robertson (2005) compared patients at different stages of treatment and suggested that as time progresses, understanding of the condition develops (illness perceptions from the SRM) and influences appraisal of the individuals' situation and potential outcome. Each type of stressful event (loss, threat and challenge) has been endorsed by different studies, leaving no clear picture of whether infertility should be considered one or all of these, or how appraisal might differ between individuals or over time.

Qualitative research has investigated individuals' interpretations of causes and implications of infertility. Sandelowski, Holditch-Davis and Harris (1990) found that couples defined themselves on a continuum from permanently infertile, through fertile with a problem conceiving at a specific time, to being cured of infertility by having a baby. The meaning of infertility appears more variable between individuals than the medical definition of inability to conceive in a year of unprotected intercourse. Religion may play a role in meaning-making, although Greil, Porter, Leikto and Riscilli (1989) found that individuals generally failed to create a satisfying religious meaning for their infertility before having a child. Infertility can impact life meaning in working for a future for children (Imeson & McMurray, 1996). Glover et al. (2009) studied the meaning of fertility problems to couples, having found no similar research, attempting to understand similarities and differences in partners' appraisals of their fertility problems and how differences were managed. They found that couples tended to downplay their differences. Abbey et al. (1991a, p. 302) asked men and women to answer the question "why me?" and found that women tended to be less satisfied with their answer than their husbands, although these answers themselves were not included. Research into appraisal has tended to investigate the meaning of issues like infertility at a level of overall life significance, rather than its impact on daily experiences. Moskowitz and Wrubel (2005) tackled this during their research with HIV+ men. The men in their study

appraised their situation in relation to day-to-day encounters and experiences, rather than in relation to their nominally identified group (HIV+ men). Moskowitz and Wrubel identified five different appraisal types within their participants, including an additional group of men who changed their appraisal of their situation during two years of the study. This indicates different ways of approaching the same stressor, as each group used different coping strategies and could benefit from different support, highlighting the connection between primary and secondary appraisal. There appears to be no work investigating how individuals select or appraise strategies to cope with infertility.

### **2.2.3 Control**

Control over an event is another important factor in both theoretical models (Lazarus & Folkman, 1984; Leventhal et al., 2003). From a transactional perspective, controllability of an event influences its primary appraisal and indicates appropriate coping strategies (Folkman, 1984). Problem-focused coping is considered useful in a controllable situation, whereas emotion-focused coping is seen as more useful when little control is possible (Benyamini, 2009; Stanton, 1991). In the self-regulatory model, control is one of five domains of illness representations, encompassing the patient's understanding of the extent to which they or their doctor can control their illness (Benyamini et al., 2004). The individual's understanding of their illness as a whole shapes their efforts to regulate their emotions and regain their normal state. Lack of a sense of control is associated with poor adaptation to infertility and treatment failure (Benyamini et al., 2004; Litt et al., 1992).

Fertility treatment is often described as a low-control stressor, based on patient control over the course and treatment outcome (Glover et al., 2009; Verhaak, Smeenk, Evers, et al., 2007; Webb & Daniluk, 1999). Feelings of loss of control may be common, but not universal. Litt et al. (1992) found that 65% of the women in their study felt that they had not lost much control. Fertility treatment may combine controllable and uncontrollable elements (McQueeney, Stanton & Sigmon, 1997). Pursuing treatment has been interpreted as accepting loss of control and surrendering it further (Greil, 2002; Litt et al., 1992), but also as regaining control (Edelmann et al., 1994; Glover et al., 2009; Stanton et al., 1991). Women have been found to have a greater sense of control over the solution to infertility than men, although there seems to be less difference after a year in treatment (Abbey & Halman, 1995; Abbey et al., 1991a). Litt et al. (1992) speculated that there might be various ways in which sense of control can be achieved. The concept of secondary control has been applied in infertility research. Where primary control entails an individual's direct control over a situation,



secondary control involves trusting an expert (vicarious control), thinking differently about a situation (interpretative and cognitive control), and may provide benefits (Mendola, Tennen, Affleck, McCann & Fitzgerald, 1990). Abbey and Halman (1995) suggested that fertility patients might experience secondary control through selecting a good physician and following treatment protocols.

Control evaluations by researchers frequently draw on treatment outcomes, but fertility patients often rate their chances of success more highly than objective success rates (Slade et al., 1997). Chances of a live birth during a single (non-frozen) treatment cycle were around 30% in the US in 2008 (CDC, 2010). Klonoff-Cohen et al. (2001) found that women in their study rated their chances of conception at 50%, and Callan and Hennessey (1988) found that 70% of the women in the study rated their chances of success as moderate to high during their first IVF cycle, although with later attempts, no women rated their success at this level. Although the outcomes of infertility and fertility treatment are objectively uncontrollable, it is not clear that this reflects how control is perceived by patients. There is often no differentiation between general control of infertility and treatment outcomes, and daily control, which are theoretically distinct concepts (Benyamini, 2009; Folkman, 1984). Although some research has focused on control in specific situations, like an IVF cycle (Litt et al., 1992; Terry & Hynes, 1998), it is unclear whether researchers' concepts of a specific situation are consistent with patients' perceptions.

#### **2.2.4 Coping and adjustment**

Research into relationships between coping strategies and adjustment has been one of the most productive areas in quantity of research. This review is divided into sections, starting with an overview of general and infertility-related coping, then coping related to time in treatment, gender and couple effects, and ending with issues of meaning, and applications of coping research.

##### **2.2.4.1 General and infertility-related coping**

Coping strategies are implemented in response to a stress appraisal (Lazarus & Folkman, 1984), or to regulate a situation to an individual's desired state (Benyamini et al., 2008). Coping is an important determinant of adjustment (Danoff-Burg, Ayala & Revenson, 2000). The two major coping categories are problem and emotional focused, where the former involves taking action to solving the problem and the latter relates to regulation of the associated distress, and both are operationalised in the Ways of Coping checklist (Lazarus &

Folkman, 1984). Problem-focused coping is considered more adaptive in controllable situations, where action can be taken, whereas emotion-focused coping is more suited to managing the outcomes of uncontrollable situations (Aldwin, 2007).

Other categories of coping have been added to the problem-emotion model, principally meaning based coping, which covers re-appraising events, revising goals, making use of spiritual beliefs and focusing on positive events, and was included to account for positive emotional states found during stressful situations (Folkman, 1997b). Other forms of coping include avoidance (Carver, Scheier & Fulford, 2008); religious coping (Aldwin, 2007); anticipatory coping, where an individual attempts to prevent a stressful event from occurring (Coyne & Gottlieb, 1996); and proactive coping where individuals prepare for the outcome of a stressful event (Aspinwall & Taylor, 1997). Instruments have been developed for use with infertile populations, to tailor items to infertility experiences, and avoid confounding psychopathology with infertility issues (Wilson & Kopitzke, 2002). Infertility-specific Ways of Coping questionnaires have been used (Morrow et al., 1995; Schmidt et al., 2005a, 2005b), and the Coping with Infertility Questionnaire (Benyamini et al., 2008).

Infertility coping research has found strategies that increase distress. Avoidance, escape coping (hoping for a miracle, wishing the problem would go away, and keeping busy) and self-blame relate to greater infertility stress, marital dissatisfaction and depression for men and women (Berghuis & Stanton, 2002; Morrow et al., 1995; Peterson et al., 2006a, 2006b; Stanton et al., 1992); and increased depression after a failed cycle (Berghuis & Stanton, 2002; Hynes, Callan, Terry & Gallois, 1992; Litt et al., 1992; Terry & Hynes, 1998). Venting, or expressing emotions to others, has been linked to increased anxiety (Lord & Robertson, 2005), although it is unclear of the direction of the relationship.

Lord and Robertson (2005) found that, among their generally well adapted sample, the most frequently used coping strategies were acceptance, active coping and planning, which are all considered adaptive coping. Acceptance has been linked to decreased distress (Edelmann et al., 1994). Approach-oriented coping (e.g., problem-focused coping, emotional processing, and expression) has been linked to a better response to a failed treatment attempt (Berghuis & Stanton, 2002; Terry & Hynes, 1998). Problem-focused planning has been linked to lower rates of depression (Litt et al., 1992). However, Terry and Hynes (1998) found that problem-management was maladaptive whereas problem-appraisal was adaptive. Similarly, positive re-appraisal of a situation has been associated with good adjustment (Stanton et al., 1992).

#### **2.2.4.2 Time, gender and couple coping**

Infertility is a general stressor, and individuals use multiple strategies depending on the exact situation (Abbey et al., 1991a; Danoff-Burg et al., 2000; Edelman et al., 1994; Terry & Hynes, 1998). Attention has been paid to variations in coping at different time points. Self-blame might be initially adaptive in motivating action to solve infertility, but might become maladaptive over the longer term (Abbey et al., 1991a; Litt et al., 1992; Stanton et al., 1992). Use of social support related to adverse effects on depression, self-esteem and self-confidence in women after a failed IVF cycle (Hynes et al., 1992), despite being effective in reducing stress for couples in treatment pre-IVF (Stanton et al., 1992). Ending treatment may require a shift from “active, treatment-focused” coping to a cognitive coping engaging adjustment of life goals (Verhaak, Smeenk, Evers, et al., 2007; p. 33).

Researchers have looked for coping differences between men and women. Some research suggests that men use more problem-focused coping than women (Peterson et al., 2006a; Stanton et al., 1992), but other work has found that women are more likely to use problem-solving than their partners (Abbey et al., 1991a) and that women tend to make more use of problem-solving coping than emotional forms of coping (Lukse & Vacc, 1999). Men are more likely to use distancing and self-control, and women to use avoidance and escape (Abbey et al., 1991a; Peterson et al., 2006a; Stanton et al., 1992). Women have been found to seek more social support during treatment (Collins et al., 1992; Jordan & Revenson, 1999) and find it more helpful (Abbey et al., 1991b; Greil et al., 1998). Support appears more beneficial for women than men (Peterson et al., 2006a; Stanton et al., 1992). Peterson et al. (2006a) found that social support was the preferred coping strategy for both genders. However, a meta-study by Jordan and Revenson (1999) found more similarity than difference. By looking at relative use of coping strategies, Peterson et al. (2006a) found that similar patterns of male and female coping were obscured by women’s greater general use of coping. Coping patterns may be fairly similar between men and women.

Increasing attention has been paid to interactions of coping between a couple, or dyadic coping, and its impact on outcomes for each partner. Stanton et al. (1992) only found one interaction between coping and adjustment between the couple: women who used more self-controlling coping had husbands who were more distressed. Women reported less depression when their partner used more active coping after a failed intrauterine insemination (IUI) cycle (Berghuis & Stanton, 2002). Avoidance coping adversely impacts own and partner coping, whereas meaning based coping is beneficial for both over the short-term (Peterson, Pirritano,

Christensen & Schmidt, 2008) and longer-term (Peterson et al., 2009). Helpful strategies for one individual might have an adverse impact on the other, for example, distancing from a problem may reduce stress for men, but their partner may see it as unhelpful (Peterson et al., 2006a). Levin, Goldman Sher and Theodos (1997) studied the relationship between intracouple coping concordance and psychological and marital distress. High marital satisfaction in women occurred when both members used high levels of task oriented coping, and in later stages of treatment, where men used less emotion-oriented coping. Emotion oriented coping by both partners related to the most psychological distress for men, and mismatches in emotion coping, particularly when the husband is more strongly using this mechanism, reduces marital satisfaction for women.

Individuals might evaluate their own coping against others'. Stanton (1992) asked couples experiencing infertility to compare their own coping with that of their partner, and with other patients of their own gender. She found that 83% of men and 45% of women believed that they were coping better than same-sex others, and around 50% of men and women suggested they were coping as well as their partner. Stanton attributed women's lower coping assessments related to other female patients to a greater consideration of their "shared fate" (p. 398) than men found. This suggests that women's assessments of their coping may be more shaped by interactions with others than men's are.

#### **2.2.4.4 Meaning and Applications**

Research suggests that participants and researchers attach different meaning to coping checklist items, and individuals may engage coping strategies for multiple objectives (Danoff-Burg et al., 2000; Folkman & Moskowitz, 2000). Men's use of avoidance and denial strategies has been linked to a strong faith in medical technology rather than with avoiding confronting the problem of infertility (Glover et al., 2009). Coping choices may be shaped by situation. Men are found to be less likely to confide in others (Hjelmstedt et al., 1999; Throsby & Gill, 2004), but other research has suggested that men can be open about fertility treatment, and seek support when they wish (Peronace, Boivin & Schmidt, 2007). That they do so less may result from having fewer similar experiences to refer to (Malik & Coulson, 2008b), and may reflect a tendency to expect the same types of coping between men and women (Jones & Hunter, 1996). Applications of coping research have included coaching that reduced distress for a group of women receiving fertility treatment (McQueeney et al., 1997). As the waiting period between embryo transfer and pregnancy test has been identified as

particularly stressful, a coping intervention based on positive reappraisal was developed that women rated as helpful at this time (Lancastle & Boivin, 2008).

### **2.2.5 Section summary**

This section explained what is known about infertility and fertility treatment as stressors, on appraisal and coping, and coping and adjustment, which comprises most of the research using the transactional framework in infertility. The next section explores general infertility research, and focuses on time, gender, couples, and context.

## ***2.3 Other dimensions in infertility research***

### **2.3.1 Time and treatment**

Fertility treatment is not a discrete event, but may last months or years with multiple treatment attempts (Domar et al., 2000), creating a treatment “trajectory” (Greil, 1997, p. 1689). Research into the temporal nature of infertility has looked at particular events and treatment cycles, time in treatment, and ending treatment.

#### ***2.3.1.1 Specific events***

Events studied include beginning treatment, and specific treatment attempts, like an IUI (Berghuis & Stanton, 2002) or IVF cycle (Holter, Anderheim, Bergh & Möller, 2006, Hynes et al., 1992; Litt et al., 1992; Terry & Hynes, 1998). The first IVF cycle is perceived as a stressful time, because IVF is considered the treatment of last resort (Cousineau & Domar, 2007), and pre-treatment stress has been linked to poorer treatment outcomes (Klonoff-Cohen et al., 2001). It is unclear to what extent the first cycle is generally stressful. Individuals tend to be well adjusted (Holter et al., 2006), perhaps because there is a tendency to over-estimate chances of success (Collins et al., 1992). Men seem to be particularly hopeful and optimistic (Slade et al., 1997). Stress at this time has been linked to insufficient information about the process (Slade et al., 1997). What is not known is how couples make the decision to start IVF (Verhaak, Smeenk, Evers, et al., 2007). Treatment failure, rather than the process itself, has been linked to short-term stress and distress (Boivin & Takefman, 1996; Holter et al., 2006). Edelman et al. (1994) pointed out that a failed IVF cycle is inherently disappointing and upsetting, and an impact on women’s well-being is to be expected. Taking action by undergoing diagnostic testing might lead to short term well-being (Connolly, Edelman, Cooke & Robson, 1992).

The focus on specific events has been developed in detailed studies using daily measures. Boivin and Takefman (1996) found that women experienced more stress, physical distress and optimism during an IVF cycle compared to a menstrual cycle without treatment. Boivin et al. (1998) identified egg retrieval, embryo transfer and waiting time for pregnancy test as the most difficult parts of an IVF cycle. This type of study shows daily fluctuations and impacts of particular events that are even shorter than a single cycle. This highlights the difficulty in considering fertility treatment as one stressor when so many individual events may impact stress and adjustment. There is a question of the extent to which participants can (or are asked to) focus on specific events when reporting on them. Terry and Hynes (1998) contrasted their study with Litt et al. (1992), who described their study as being of a failed IVF cycle but studied infertility in general. Some studies do not mention which treatment cycle participants are engaged in, or if participants are all on the same treatment cycle (Berghuis and Stanton, 2002; Hynes et al., 1992). This is important because the cycles perceived to be remaining might impact adjustment (Verhaak, Smeenk, Evers, et al., 2007), as each cycle is imbedded in on-going treatment.

#### **2.3.1.2 Time in treatment**

Where specific events, like a treatment cycle, are seen as acute stressors (Cousineau & Domar, 2007), fertility treatment becomes a chronic stressor as treatment progresses (Newton et al., 1999). Repeated cycles have been linked with changes in the way treatment is perceived. The sense that treatment is a perceived control over infertility may reduce over time (Abbey & Halman, 1995). The hormonal medications required for treatment have an increasing effect (Boivin et al., 2011). Time can be a stressor, with women aware of their biological clock and diminishing fertility (Glover et al., 2009). Failure, and repeated failing treatment, has been suggested as the biggest stressor during treatment (Boivin et al., 2011), although questions about failure have not been included in stress instruments. A longer time without success reduces well-being (Verhaak, Smeenk, Nahuis, Kremer & Braat, 2007).

More significant might be the meaning of failure for couples. Glover et al. (2009) found that treatment failure challenges the perception of fertility treatment as a solution to infertility.

The relationship between time and distress appears complex. Berg and Wilson (1991) found that while couples seemed to respond to fertility treatment as an acute stressor during the first year and a chronic stressor in the third, during the second year of treatment, psychological functioning returned to normal. Berg and Wilson attributed this pattern to familiarity with processes. However, their study relied on cross-sectional data from different groups.

Markestad, Montgomery and Bartsch (1998) found poorer psychological functioning for husbands during the second year of treatment, but found little psychological distress in couples in treatment for more than two years. They suggest that couples need to adjust to continue to pursue treatment. Lukse and Vacc (1999) found no relationship between time in treatment or previous treatment and distress. Links between time in treatment and psychological functioning are therefore variable.

### **2.3.1.3 Ending treatment**

For some couples, treatment ends in success: the birth of a child. But with success rates for IVF of around 30% (CDC, 2010), treatment failure and the decision to end treatment are more frequent issues for couples attempting IVF (Verhaak, Smeenk, Evers, et al., 2007). In the long-term (after 2-3 years) couples who ended treatment unsuccessfully adjusted to similar levels of well-being as those who were successful, albeit with slightly reduced life satisfaction (Hammarberg, Astbury & Baker, 2001; Slade et al., 1997). Recent research has focused on couples who end treatment while financial or medical resources remain available to them rather than exhausting all resources before considering treatment unsuccessful. This is seen as something to be tackled and reduced (Olivius, 2004). The decision to end treatment is dependent on a couple's financial resources, relationship status and medical prognosis (Domar, 2004). Concerns about the long-term effects of medication may influence this decision (Daniluk & Tench, 2007; Hammarberg et al., 2001). Psychological burden or emotional exhaustion accounts for 26% to 50% of decisions to end treatment (Daniluk & Tench, 2007; Olivius, 2004). The momentum of "emotional and financial investment" (Wilson and Kopitzke, 2002, p. 198) may push couples into further treatment without sufficient consideration, giving rise to dissatisfaction later (Glover et al., 2009). Dropping out of treatment may be seen more as a failure than a choice with a cultural approval for persistence in pursuit of parenthood (Sandelowski, 1991).

Ending treatment is not necessarily a distinct time point, as couples may return to it at a later date, if they become aware of medical advances that might help them (Sandelowski, 1991; Wilson & Kopitzke, 2002). This may be why many studies about ending treatment are retrospective, with participants reflecting on treatment experiences after the fact (Peddie, van Teijlingen & Bhattacharya, 2005; Redshaw et al., 2007), or describing adjustment to biological childlessness (Daniluk, 2001a; Daniluk & Tench, 2007; Matthews & Matthews, 1986). Couples sometimes have children at this point, looking back at events through the lens of "present success" (Greil et al., 1989, p. 216; Webb & Daniluk, 1999).

#### **2.3.1.4 Other temporal perspectives**

The last three sections looked at time as an underlying variable against which change in relevant psychological variables is marked (Davies, 1996). The meaning of time has also been investigated. Time may be seen as a resource to be used or as waiting time (Redshaw et al., 2007), a worry as it passes and is wasted (Jones & Hunter, 1996; Martin-Matthews & Matthews, 2001), and might represent being left behind others (Newton et al., 1999) when comparing progress along the “social time structure” (Earle & Letherby, 2007, p. 246). Multiple temporal perspectives may exist, from short-term like a menstrual cycle to lifetime, depending on the focus and context in which time is considered (Sandelowski & Pollock, 1986). Infertility research is moving away from the assumption that experiences at one point in time represent infertility experiences in general. There is scope for more longitudinal work (Aldwin, 2007; Verhaak, Smeenk, Evers, et al., 2007), and concurrent research with participants at the same point in treatment. There is little research about how stressors may change over time, and how individuals perceive time itself, which can be best studied using qualitative approaches.

#### **2.3.2 Gender**

As well as gender differences in coping, general differences between men and women’s experiences have been studied. Infertility may arise from male (e.g. low sperm count) or female factors (e.g. ovulation problems, blocked fallopian tubes), which each account for about 30% of infertility diagnoses (Human Fertilisation and Embryology Authority [HFEA], 2010). Around 10% of cases arise from joint impairments and 10-25% of cases are unexplained (ASRM, 2003; HFEA, 2010). Because childlessness and treatment are perceived to burden women more than men, research often focuses on women (Collins et al., 1992; Greil et al. 1988; Jones & Hunter, 1996; Webb & Daniluk, 1999). Fertility treatment has been found to have less impact on men’s personal, social and sex life (Abbey et al., 1991a; Newton et al., 1999; Schmidt et al., 2005a). Women experience more anxiety, depression, lowered self-esteem and reduced well-being (Beaurepaire et al., 1994; Holter et al., 2006; Stanton et al., 1991), whereas men’s distress is suggested to arise from witnessing the impact on their partner (Abbey et al., 1991a; Greil et al., 1988). Accounts of women’s dominance in initiating and organising fertility treatment have reinforced the greater impact infertility has on women (Greil et al., 1988). Men are more optimistic about fertility treatment outcomes (Slade et al., 1997), perhaps unrealistically so (Glover et al., 2009). Based on these



differences, men's experiences have often been minimised (Greil, 1997; Holter, Anderheim, Bergh & Möller, 2007; Malik & Coulson, 2008b).

Men's responses can be stronger than women's. Men report greater home life stress (Abbey et al., 1991a) and are more likely to experience clinically elevated state anxiety during treatment (Beaurepaire et al., 1994). Some studies have suggested that when one partner is diagnosed as responsible for the infertility, which is equally likely to be the man as the woman, they experience more stress than their partner (Connolly et al., 1992), whereas others have found no significant effects of diagnosis (Pook & Krause, 2005). Male infertility may carry greater stigma (Miall, 1986), being equated with a lack of virility or masculinity (Gannon et al., 2004; Lloyd, 1996), and may cause men to feel isolated, even from their partners (Webb & Daniluk, 1999). Male infertility may have greater impact on the marital relationship and cause emotional distress for both partners (Connolly et al., 1992; Nachtigall et al., 1992; Newton et al., 1999).

The focus on which gender is most affected obscures that both men and women find infertility significant (Collins et al., 1992; Nachtigall et al., 1992). Both genders experience similar patterns of responses, like social stress (Schmidt et al., 2005a), global distress (Stanton et al., 1992) and distress through an IVF cycle, though women may report stronger responses (Boivin et al., 1998; Holter et al., 2006). General trends may not represent all men or all women. Women may desire parenthood more than men (Holter et al., 2006; Newton et al., 1999), but some men value parenthood more (Peterson, Newton & Rosen, 2003) or similarly to their partner (Fisher, Baker & Hammarberg, 2010). Men may regard infertility as disappointing but not tragic (Greil et al., 1988), but still find childlessness and failed treatment difficult (Peronace et al., 2007; Webb & Daniluk, 1999). Peterson et al. (2003) found that women were twice as likely to be stressed by infertility than their husband, but around 25% of men were more stressed than their partner. And Hjelmstedt et al. (1999) found that while women were more likely to be the lone partner who initiated treatment, 40-50% of couples decided together.

The dominance of female responses has been attributed to general gender trends (Edelmann & Connolly, 2000), a better fit of instruments to female responding (Holter et al., 2006), and to women's greater willingness to report distress (Jones & Hunter, 1996; Slade et al., 1997). Jones and Hunter (1996) suggest that female experience and emotional expression is seen as normative. Men may be equally invested and distressed by the infertility experience, but less open about their feelings (Collins et al., 1992), tend to try to downplay them to focus support

on their partner (Malik & Coulson, 2008b), and frequently have few acceptable outlets for their distress (Webb & Daniluk, 1999).

There is increasing focus on the role that social expectations of masculinity play in shaping men's experiences of health and illness (Gough, 2006; Gough & Robertson, 2010; de Visser & Smith, 2006). Men may be marginalised in infertility settings that are accustomed to treating individuals and are focused on the female body (Malik & Coulson, 2008b; Meerabeau, 1991). Men are frequently responsible for setting limits on treatment, as women may be restricted to conform to social pressure for motherhood (Throsby & Gill, 2004). Gendered scripts may allow men limited opportunities to express stress and difficulty about infertility (Gannon et al., 2004), while it is acceptable for women to acknowledge fertility-related stress (Collins et al., 1992). Men's experiences may have been minimised by the feminist focus of much infertility research (Lloyd, 1996). Fatherhood has been neglected in research (Throsby & Gill, 2004) and men are assumed to have less interest than women in having children, indicated by their unwillingness to participate in infertility research (Lloyd, 1996). Lloyd analysed interpretations of male non-response to fertility related studies, and suggested that interpretations were based on evidence obtained indirectly from partners and assumptions about the meaning of infertility for men (it is sensitive and stigmatising), and are propagated by repetition rather than evidence.

Edelmann and Connolly (2000) argue that the gender differences observed in infertility research are the result of "outdated gender stereotyping" (p. 365). Recent research has questioned assumed links between fertility and virility (Edelmann et al., 1994; Peronace et al., 2007), and men's lesser distress about childlessness (Fisher et al., 2010). General acceptance of assisted reproductive technologies (ARTs) may have led to changes in perceptions of infertility (Peronace et al., 2007), with medical advances, like intracytoplasmic sperm injection (ICSI) allowing men with impaired fertility to father a biological child (Holter et al., 2007). Men's experiences are overlooked because they are often less strong than their partners', although this is not always the case. Stereotyping of male behaviour may restrict research into men's infertility experiences (Edelmann & Connolly, 2000; Fisher et al., 2010), and lack of sensitivity to differences in expression between men and women (Holter et al., 2007). Interview data may provide a more accurate reflection of men's experiences (Nachtigall et al., 1992).

### **2.3.3 Couples**

Attention to individual experiences and gender differences may overshadow that infertility is experienced as a couple. Work on gender and couple effects often overlaps, and the couple is sometimes a source of gendered experiences rather than the unit of analysis (Benyamini et al., 2008; Morrow et al., 1995; Schmidt et al., 2005a). Research with couples has identified divergent significance of infertility for husbands and wives (Greil et al., 1989), and often emphasises the disparity between partners' desire for a child and commitment to treatment (Greil et al., 1988; Steuber & Solomon, 2008). Despite this and the gender variations discussed in the previous section, fewer intra-couple differences have been found than might be expected (Jordan & Revenson, 1999; Stanton et al., 1991). Peterson et al. (2003) found congruence between partners' responses, and established that some couples rated social infertility stress and need for parenthood equally, and that they experienced less stress during fertility treatment and better marital adjustment. General gender differences may not translate to within couple differences, and intra-couple effects may be simultaneously positive and negative, for example, expressing experiences as a joint activity, using 'we', alongside a negative impact from differences in investment in treatment (Steuber & Solomon, 2008). Measures of marital and sexual functioning have often had little impact even with time in treatment (Edelmann et al., 1994; Markestad et al., 1998).

### **2.3.4 Individual, social and medical contexts**

The role of social, cultural and medical contexts is key to an individual's appraisal of infertility and fertility treatment (Lazarus, 1993). Often, interpersonal and sociocultural contexts are ignored in favour of intra-individual factors (Benyamini, 2009), although there has been increased attention to couples, as mentioned in the last section. Although infertility is studied as a self-contained topic, individuals and couples experience it within the context of other events and activities, against a backdrop of a particular social situation, and within a medical environment (Stanton & Dunkel-Schetter, 1991a). Qualitative research has found infertile couples' experiences to be variable and complex (Sandelowski, 1994), yet couples and individuals undergoing fertility treatment are often treated as a homogenous group, ignoring past fertility history, individual situations and experiences (Edelmann et al., 1994). Similar experiences are often assumed, for example, that infertility is unexpected and that couples suddenly discover, with shock, that they have a fertility problem (Callan & Hennessey, 1989; Peterson et al., 2008). Jones and Hunter (1996) found that individuals' accounts of infertility were complex and contradictory, and that they talked about infertility

differently in the context of time, biology, life plans, and relationships. Individuals may differ from each other, and show differences themselves during their experience.

The social and medical context influences infertility experiences. Seeing infertility as a disease amenable to medical treatment is linked to the development of ARTs, and expectations of treatment may be linked to economic and social classes who tend to rely on (and are able to make use of) medical technology (Sandelowski, 1994). Medicalisation of infertility as a disease (ASRM, 2004) validates pursuit of medical treatment, although not without criticism (Becker & Nachtigall, 1992; Greil, 2002; Sandelowski & de Lacey, 2002). Medical labels and categories have tended to be adopted within the psychological literature, even if not meaningful to people experiencing them (Greil & McQuillan, 2010).

Schmidt, Christensen and Holstein (2005) found that coping differed by social class, and suggested coping is learned from social context. Individuals may tend to express certain positions that are expected of them within a certain context, for example, whether men express less investment in having children because they are not expected to desire to have children as strongly as women do. Infertility has been described as surrounded by stigma and secrecy (Miall, 1986; Pfeffer, 1987; Whiteford & Gonzalez, 1995). Increasing knowledge and acceptance of IVF and other fertility treatments has led to less secrecy about infertility and fertility treatment, meaning that individuals' perceptions and adjustment to these issues might have changed over time (Hammarberg et al., 2001; Holter et al., 2006; Peronace et al., 2007). Additionally, the Internet has created a source of information, discussion and support for fertility patients provided formally, through clinics (Van Selm, Tuil, Verhaak, Woldringh & Kremer, 2008; Tuil, Verhaak, de Vries Robbé & Kremer, 2008), and informally, through peer-support groups (Malik & Coulson, 2008a; Porter & Bhattacharya, 2008), replacing the "books or magazines or television" that was the source of infertility information during the 1980s and early 1990s (Abbey et al., 1991a, p. 316). Infertility and fertility treatment are experienced against a changing social environment.

Recent work has broadened knowledge of infertility experiences in different cultures (Van Balen & Bos, 2004; Chang & Mu, 2008; Riessman, 2000; Todorova & Kotzeva, 2006), although tends to ignore cultural influences in familiar Western situations. With increasing focus on infertility as an experience located within a particular temporal, social and cultural context (Greil et al., 2010), ongoing and explicit attention to this issue is important.

## ***2.4 Opportunities for further research***

This section consolidates the research presented in this chapter and identifies opportunities for further work.

### **2.4.1 Specific rather than generalised experiences**

Infertility research often focuses on generalities, starting with ‘infertility’ and ‘fertility treatment’, which are broad areas for study (Hansell et al., 1998; Peterson et al., 2003). Research is often criticised for failing to distinguish between the two (Greil & McQuillan, 2010; Sandelowski, 1994; Verhaak, Smeenk, Evers, et al., 2007), but additionally both are large and complex issues (Stanton et al., 1992). It is difficult to say to what extent individuals separate the two from each other or other events in their lives. This issue has been tackled by research focusing on particular events, like a specific treatment cycle, as discussed in section 2.3.1.1. Perceptions of the difficulty of fertility treatment might differ between patients, nurses and doctors (Kopitzke, Berg, Wilson, & Owens, 1991). Kopitzke et al. found that patients rated initial interviews with a fertility physician as less stressful than nurses and physicians did, and viewed decisions about beginning adoption as helpful, compared with doctors and nurses who perceived them as stressful. Outsider classifications of the difficulties of fertility treatment may be inaccurate, even from those closely involved with the process, like doctors and nurses.

Infertility and fertility treatment are often considered stressful by definition, as they are described as uncontrollable, unexpected and carrying the threat of biological childlessness (Mendola et al., 1990). This ignores the individual appraisals that are central to the transactional model. Numerous studies (Collins et al., 1992; Litt et al., 1992) cite the finding that infertility is the most stressful event an individual can encounter (Freeman et al., 1985). However, although Freeman et al. found “most” participants thought that, it was less than 50% of their sample (“half the women and 15% of the men”, p. 48), meaning that for many, this generalisation is inaccurate. This generalisation occurs frequently and is used to define experiences across the group. Individual experiences are variable, and it may be impossible to generalise across groups (Pook & Krause, 2005). Benyamini, Gozlan & Kokia (2005) addressed the tendency to generalise, and found much variability in difficulties experienced by women undergoing fertility treatment. Infertility is often considered a “master status” (Greil et al., 1989. p. 225), to which outcomes and all life issues at the time are associated. Despite recognition of different infertility stressors, it tends to often be seen as “one objective

life event” rather than “different phenomenological events”, both to different individuals and across their experiences (Sandelowski, 1994, p. 749). In comparison, a phenomenological transactional study showed five different types of responses expressed by HIV+ men, in what might also be seen as a universally difficult stressor (Moskowitz & Wrubel, 2005), and pointed to differences between perceptions of overall outcomes and daily experiences. A generalisation of negatives as representative of all individuals gives a skewed picture of the experience of infertility (Folkman & Moskowitz, 2000). Phenomenological methods help reintroduce diverging effects and ranges of responses across a group. Despite the focus on the individual, the role of the couple is important, as they deal with infertility together. Gender should be considered without stereotyped assumptions about men and women’s experiences.

#### **2.4.2 Focus on experiences and processes rather than outcomes**

Stress, coping and infertility research has largely focused on identifying and quantifying infertility stress, and looking for links between particular coping strategies and adjustment. As mentioned in section 2.2.2, there appears to be no research into the ways that individuals weigh up, select and evaluate coping strategies, or secondary appraisal (Lazarus, 1999). Rather than identifying issues that exist, attention needs to be focused on the “content and focus” of these issues (Slade et al., 1997, p. 189). As individuals undergoing fertility treatment are generally well adjusted there is scope to investigate the other processes of interest that are occurring. This is a good opportunity to make use of Interpretative Phenomenological Analysis (IPA), which is focused on meaning.

#### **2.4.3 Moving away from focus on negative parts of experience**

Infertility research tends to attend most to negatives, difficulties and problems that individuals or couples encounter (Benyamini et al., 2005). Numerous stresses have been identified as resulting from infertility, drawing on the catastrophic role and identity issues related to not becoming a parent, and financial, marital and interpersonal issues arising during treatment. Despite a small body of work looking at positive emotional states and meaning (Folkman, 1997b), fertility treatment is often framed as inherently stressful, particularly within transactional approaches, where “every aspect of infertility lends itself to stress” (Seibel, 1997, p. 181). Qualitative work pays more attention to experiences, but there is still scope to investigate the full range of experiences occurring rather than negatives. Letherby (2002) argued that rather than childlessness being a universally desperate state, it may be so for some women some of the time. Additionally, she found that women she spoke with

placed their childlessness in context with other elements of their life and experience. Glover et al. (2009) made a similar argument for couples undergoing fertility treatment.

#### **2.4.4 Interactions**

There is a tendency to present the interactional processes of the transactional model as linear progression from stressor, through appraisal and coping to adjustment. For example, Stanton et al. (1992) found links between men's use of avoidance coping and distress during fertility treatment, which gives the implication that one causes the other, although they pointed out that the relationship as correlational. A frequent presentation of coping in this way tends to portray relationships as causal, ignoring the influence of outcome appraisals on coping. In addition, the frequent use of quantitative studies to investigate interactions leaves their authors speculating about the reasons for the relationships they identify. Qualitative studies can supplement quantitative data to answer these types of questions (Abbey & Halman, 1995).

### **2.5 Chapter summary**

The research question developed from this review was 'how do men and women experience stress and coping during the early stages of IVF, and does this change over time?' As described in section 1.4, five objectives were generated for this research:

1. To identify interpretative themes relevant to the research question and most prevalent across participants' accounts.
2. To add to psychological knowledge of men's perceptions of fertility treatment, and about how both genders make sense of their experiences as part of a couple.
3. To increase psychological knowledge and understanding about fertility treatment as a changing and dynamic experience, by identifying temporal elements of participants' accounts and the interpretative themes.
4. To extend psychological understanding of the application of stress and coping theory to fertility treatment.
5. To use the interpretative themes and theoretical observations to inform therapeutic practice for individuals and couples undergoing treatment for infertility.

There are some related studies, including concurrent studies of information seeking during treatment (Porter & Bhattacharya, 2008) and ending treatment (Daniluk, 2001a, 2001b).

There appear to be no similar qualitative studies following couples' experiences as they begin fertility treatment. One related study drew on the transactional framework to investigate couples' appraisals of their fertility problem with attention to gender and differences within the couple, although participants were at various stages of treatment and some were pregnant (Glover et al., 2009). Similar qualitative, longitudinal research has successfully been used with HIV+ men, using a transactional perspective and phenomenological approaches (Folkman, 1997a; Moskowitz & Wrubel, 2005).

The next chapter begins the presentation of the study methodology to tackle this question, starting with the phenomenological interview approach that was used.



### **3 Theoretical background of methods**

This chapter presents the theoretical background that shaped the study design. The first section explains the development of phenomenological psychology and Interpretative Phenomenological Analysis (IPA), the reasons for selecting IPA, the implications of this choice in the applications and claims of this research, and the role of bracketing and reflexivity. The next section explains the theory and execution of semi-structured interviewing in IPA, including consideration of interviewing couples, and the implications of using this data. The final section presents a set of standards for this research.

#### ***3.1 The phenomenological approach***

##### **3.1.1 Phenomenology**

Psychology is largely approached as a natural science, with research focused on objective measurement of cause and effect between variables, and with meanings determined by researchers (van Manen, 1990). This approach is criticised as being better suited to studying “regularities in physical events“ (Henwood & Pidgeon, 1992, p. 98) than the behaviour of human beings, as both researcher and participants are conscious beings who interpret and act on the world within the context of their cultural and social environment (Madill, Jordana & Shirley, 2000). An alternative approach positions psychology as a human science with a focus on individual meanings and experience as it is lived (Rennie, 2007). This perspective has gained momentum since the 1970s, when the turn to language in psychology encouraged greater attention to the meanings and uses of language (Langdrige, 2007). Numerous qualitative approaches, based on multiple epistemologies, have been developed with a common aim to understand human experience as phenomena located in particular interactions and in specific social, cultural and historical contexts (Chamberlain, 2000).

These approaches include grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990); narrative analysis (Riessman, 1993); discourse analysis (Potter & Wetherell, 1987); and descriptive (Ashworth, 2003; Giorgi, 1995) and interpretative (van Manen, 1990; Smith, Flowers & Larkin, 2009) forms of phenomenology. Selection of methodology and development of a research question are linked, as the research question and approach must be a good match to provide appropriate answers (Henwood & Pidgeon, 1992). Research into stress, coping and infertility has provided many “what” answers, but few “how” and “why” (Chamberlain, 2000, p. 290). This study aims to achieve a better understanding of *how* men

and women make sense of stress and coping during fertility treatment, focusing on meaning and individual experiences, which is the reason for the choice of a phenomenological method. Phenomenological psychology originated in the work of Edmund Husserl in the early part of the 20<sup>th</sup> Century (Langdrige, 2007). He was attempting to create a new basis for scientific research that stepped back from second order knowledge and assumptions to concentrate understanding on the underlying essential structures involved. Husserl encouraged the questioning of natural attitudes, or elements of experience that are taken for granted. The focus of phenomenological research in psychology is the investigation of the lifeworld; the world as subjectively experienced rather than as an objective, independent entity (Langdrige, 2008). Husserl's student/assistant Martin Heidegger developed his work with an existential focus, re-establishing phenomenology from the perspective of being-in-the-world (Kearney, 1994). Phenomenological psychology, drawing on phenomenological philosophy, began to emerge during the 1960s, but was given additional impetus by the turn to language in the 1970s (Langdrige, 2007).

The work of Husserl and Heidegger generated two main approaches to phenomenological psychology: descriptive and interpretative. Researchers in each tradition differ in the extent to which they believe it is justifiable to move beyond the data. Descriptive phenomenology, the focus of Husserl's earlier work, aims to describe the essential features of an experience and remains focused on the data (Ashworth, 2003; Giorgi, 1995). Interpretative approaches are based on Husserl's later work and that of others including Heidegger, Gadamer and Ricoeur (Langdrige, 2007). An interpretative phenomenological analysis (in the general sense) may move beyond meanings present in the account to place the analysis within a framework of understanding that is outside the knowledge of the giver (King et al., 2008). Various everyday and extraordinary experiences have been studied from a phenomenological perspective, including education (van Manen, 1990); mistrust (King et al., 2008); sexual identities (Langdrige & Butt, 2004); violence (Shaw, 2004), and health (King, Carroll, Newton & Dornan, 2002; Moskowitz & Wrubel, 2005; Phipps, 1993). One of the most established interpretative approaches in the field of health psychology is IPA (Smith, 1996, 2004).

### **3.1.2 Interpretative Phenomenological Analysis**

Jonathan Smith developed IPA as a particular approach to phenomenological analysis (Smith, 1996), drawing on well-established fields like hermeneutics, the interpretation of texts,

(Rapport, 2005), and idiography (Smith, 2004). IPA promotes detailed exploration of participants' personal, lived experiences to gain an understanding of how they make sense of the events they encounter (Smith, 1996, 2004). IPA acknowledges participant and researcher as social beings, experiencing a phenomenon, shaping it through their actions, and attempting to integrate and resolve (make sense of) it in their worldview (Mulveen & Hepworth, 2006). IPA focuses on the interpretative, meaning-making nature of human beings (Maggs-Rapport, 2001; Rapport, 2005). Various health experiences have been investigated using IPA including heart problems (Chapman, Parameshwar, Jenkins, Large & Tsui, 2007; Senior, Smith, Michie & Marteau, 2002; White, Hunter & Holttum, 2007); pain (Osborn & Smith, 2006; Warwick, Joseph, Cordle & Ashworth, 2004); and prosthesis use (Murray, 2004, 2005).

IPA studies focus on experiences of a small number of participants, attempting to preserve the individual in analysis even when research involves multiple participants (Smith et al., 2009). This is important in health research, where the varied nature and meaning of illness to different individuals is acknowledged (Moskowitz & Wrubel, 2005). It is a reason for not using Grounded Theory, which produces large-scale theories related to social processes (Brocki & Wearden, 2006). IPA studies have made use of case studies, which takes the focus on individual experiences to its logical conclusion (Bramley & Eatough, 2005; Eatough & Smith, 2006; Robson, 2002; de Visser & Smith, 2006). Rather than generalising experiences, convergences and divergences between participants can be noted, and related to the social context in which they took place, as well as being linked to existing theory and literature (Smith, 2004; Smith & Osborn, 2003).

IPA studies may engage a "hermeneutics of empathy" and a "hermeneutics of suspicion" (Ricoeur & Thompson, 1981, p. 6). A hermeneutic of empathy is used to develop an interpretation that attempts to grasp the understanding of the research participant (Langdrige, 2007). A hermeneutic of suspicion involves creating an interpretation that moves beyond surface meanings and digs for deeper, hidden meanings, which may disrupt or raise suspicion about the original empathic meanings (Langdrige, 2007). Smith (2004) aligns IPA with a hermeneutic of empathy, but suggests that a hermeneutics of suspicion may emerge later in the analysis, with the researcher questioning the surface meaning to produce a more complete understanding of the participant's experience. The interpretation may be one that participants would be "unlikely, unable or unwilling to see or acknowledge themselves" (Smith, 2004, p. 46).

IPA studies may draw on strategies from other qualitative approaches during the analysis process (Smith et al., 2009). Theories and concepts like social comparison, use of metaphors and linguistic markers can be used, provided the analysis stays close to the data (Smith, 2004). A common recognition of the role of language and context allows IPA studies to draw on approaches from discourse analysis that explore the conversational resources available to individuals when talking about their experiences (Smith, 1996; Smith et al., 2009). This strategy has been criticised (Willig, 2001) because discursive approaches treat discourse as independent of cognition, and instead emphasise how social, cultural, and discursive resources shape discourse available to an individual (Smith, 1996). From this perspective, language/discourse cannot be related to underlying cognitions (Willig, 2001). However, the phenomenological approach positions individuals, and their cognitions, as part of the world ('being-in-the-world'; Langdrige, 2007) not as separate functions interacting with each other. IPA recognises a link between body, cognition and discourse (Smith, 1996) and that both language and cognition are aspects of 'being-in-the-world', providing an argument for using discursive tools with IPA.

Often qualitative research has been a different way of doing research, producing accounts and themes without relating them to existing theory (Henwood & Pidgeon, 1992). Increasingly, qualitative researchers have been urged to strengthen their research, moving beyond the descriptive (as is the aim in IPA) and synthesising varied themes, linking them to existing work in the field and drawing on theoretical models (Chamberlain, 2000). IPA research aims to both give voice to participants, and to place the analysis within a psychological perspective (Larkin, Watts & Clifton, 2006). IPA has been used with theoretical models, like the Self-Regulation Model (SRM) and transactional model to guide the analysis (Etchegary, 2009; Green, Payne & Barnitt, 2004; Harman & Clare, 2006) or to further develop themes and concepts produced from the data (Senior et al., 2002; White, Hunter, & Holtum, 2007). Application of theory is valuable in infertility research, to complement and enhance the many accounts of experience that have been produced.

### **3.1.3 Bracketing and reflexivity**

Husserl originated the concept of bracketing, or epoché, to encourage focus on the essential nature of objects by setting aside the natural attitude of assumed understanding with which humans usually approach knowledge (Langdrige, 2007). Heidegger developed this concept, shifted by his existential focus, to encourage recognition of how the researcher's perspective is linked with their cultural and historical environment (Finlay, 2008). Bracketing is not a

matter of trying to be objective, but of examining and re-examining the researcher's relationship to the work, participants, developing analysis and ideas, and existing knowledge of theory, data and literature (Ahern, 1999; Smith, 2007). Hence, bracketing and reflexivity are linked as the researcher moves repeatedly between the participants' world and experience and examination of their own awareness. Pre-conceptions, assumptions, experiences and cultural expectations that might impact the research should be recognised, acknowledged and addressed throughout the course of a project (Smith, 2007). This cycle of reflection and interaction with participants will lead to changes in the researcher's knowledge structures (Smith et al., 2009).

Bracketing has several implications for work using IPA. Interactions with participants require openness to their perspective, attending closely to their meanings as they emerge. This may create tension between participants' accounts of a concept, and knowledge of how it is seen in the existing literature (de Visser & McDonald, 2007). Analysis becomes a "dance" (Finlay, 2008, p. 1) between the participant's perspective and the psychological perspective of the researcher. A reflective journal is useful to address and record this changing awareness during research (Ahern, 1999). The use of journaling during this study is described in section 4.5.

## ***3.2 Interviewing***

### **3.2.1 Semi-structured interviews and IPA**

Semi-structured interviews are the most frequently used means of generating appropriate data for IPA (Smith, 2004; Smith & Osborn, 2003). Semi-structured interviews follow a pre-determined interview schedule that includes important areas for discussion and allows sensitive questions to be introduced gradually (Smith, 1995). The interviewer may modify the order of questions, probe interesting topics, and ask the participant for clarification or elaboration. Semi-structured interviews are organised, yet flexible, allowing the interviewer to pursue interesting and unexpected avenues that may emerge. The interviewer should listen carefully, follow up answers with further, relevant questions, and be aware of how variations in tone of voice, and phrasing indicate potentially sensitive areas of discussion (Kvale & Brinkmann, 2009) to promote an open and thorough discussion of the topic at hand. Interviews are usually tape-recorded, producing a verbatim transcript. Transcription, translating interactions with verbal and non-verbal communication, like body movements, facial expressions and gestures, into a written format, requires selection of aspects of the

interaction to include. IPA concentrates on meaning, so transcription incorporates elements that provide the context of the participants' words (Smith et al., 2009). This includes self-corrections, false starts, non-speech utterances (um, err, laughter) and pauses (Smith & Osborn, 2003), and punctuation to clarify the phrasing as spoken.

Although most IPA studies have involved single interviews with each participant, there are some that have gathered data at multiple time-points through interviews (Clare, 2003; Powell, McKee & Bruce, 2009; Smith, 1999); written texts like diaries (Smith, 1999); Internet discussion forums (Chappell, Eatough, Davies & Griffiths, 2006); and focus groups (Shaw, Wallace & Bansal, 2003). Multiple interviews allow participants to elaborate on previous responses (Clare, 2003), and to observe change across time (Shaw et al., 2003; Smith, 1999). Multiple interviews provide accounts of experiences at different time points. Attention should be paid to participants' retrospective reworking of previous reported experiences, which may illuminate different factors and concerns as they reconstruct their previous experience, as Smith (1994) found when comparing contemporaneous accounts of women during pregnancy with retrospective accounts after the child's birth.

### **3.2.2 Interviewing couples together or separately**

Previous research suggests that separate interviews may be more effective when interviewing couples, especially about infertility. Tolich (2002) argued that data collected in joint interviews are rarely as informative, deep, or sensitive as those collected in individual interviews. Joint interviews may produce mutually agreed stories, highlighting the couple's "coupleness", rather than producing an account of the phenomenon under study (Seymour-Smith & Wetherell, 2006, p. 123). Individual interviews give participants a chance to produce concerns relating to their partner that they might not reveal in a joint interview, allowing a story to emerge from two different perspectives, which is a useful way to observe the effects of gender and intra-couple perspectives (Hertz, 1995).

In infertility research, Throsby and Gill (2004) observed that men appeared to try and protect their partner from their own distress, and that interviewing men alone might allow them to express themselves more fully. Glover, McLellan and Weaver (2009) noted that partners expressed minimal disagreements, despite describing differences in areas like the meaning of parenthood and need for biological connections, making it impossible to answer the question about how couples handle differences. As infertility is often considered a female issue, women might tend to speak for the couple in joint interviews (Valentine, 1999). Although a

joint interview may produce an account more similar to that given at an infertility clinic or in general interactions (Porter & Bhattacharya, 2008), this was not desired in this study, which aimed to explicitly investigate men's experiences as well as women's. Men may be reluctant to participate in fertility-related studies (Glover et al., 2009; Throsby & Gill, 2004) and less likely to participate in studies of what are perceived as sensitive health areas without their partner (Hertz, 1995), so recruiting both members of couples might enable more reliable access to men's accounts.

Interviewing people in close relationships raises additional ethical concerns with internal confidentiality. Partners may be curious about the extent to which they produce a compatible account, requiring attention to keeping their contributions confidential from each other (Tolich, 2004). Their accounts are more visible to each other than to outsiders in shared information. Tolich suggests (2002, 2004) that connected persons should be ascribed increased ethical protections, particularly in sensitive situations by, for example, asking them to clarify what information is potentially damaging and should be obscured, and to review any extracts to be used so they can ask for things they consider identifying to be removed, edited or changed.

### **3.2.3 What can be drawn from a phenomenological interview study?**

The research approach defines the nature of knowledge and the claims that can be made from particular research (Mays & Pope, 2000). The analysis is based on a particular type of data collection (interviews) and analysis (IPA). The data generated by an interview is the product of a particular interaction between the interviewer and interviewee at a particular time, place and socio-cultural context (Langdridge, 2007). Individuals tend to reproduce their individual and jointly constructed narrative that makes as much sense as possible of the experiences being related (Riessman, 2002; Sandelowski, Holditch-Davis, & Harris, 1990). The interview is a social interaction and a research activity, where both parties are trying to manage their self-presentation, particularly as the researcher may be seen as an expert or in a position of responsibility (Radley & Billig, 1996). Each participant (including the researcher) may be telling their story in certain ways to comply with culturally acceptable ways to approach the topic under discussion (Madill et al., 2000). Additionally, gathering interview data requires recruitment of participants who can talk about their experience in terms detailed enough for the analysis and may represent only certain experiences. With infertility research, this may reinforce the existing bias towards well-educated, middle class, white fertility patients (Greil,

1997). Additionally, the data reflects the interviewer's skill in conducting an interview, by creating a comfortable environment for the participant, and probing and clarifying responses. Phenomenological approaches move away from the researcher as the expert, and a search for underlying, objective "truths" (King et al., 2008, p. 81) to focus on individuals' experiences of a phenomenon (Charmaz, 1995). As mentioned above, accounts are created within a particular interactional, social, cultural, historical context, so the resulting analysis is recognised as an interpretation of individual experience within that context (van Manen, 1990). IPA involves a double hermeneutic, or interpretative element, in which the researcher makes sense of the participants making sense of their experience (Rennie, 2007). The researcher plays an active role throughout the research process, in producing the account and in making sense of the participants' account during analysis. The resulting analysis is therefore one possible interpretation of an experience (Rapport, 2005). IPA is idiographic, meaning that the individual is the focus of analysis, rather than aiming to produce generalisations across large groups. Restriction of a study to a carefully defined group means that it should be possible to say something meaningful about the experience of an issue to that group.

### ***3.3 Quality in IPA studies***

As qualitative research methodologies have developed, so have suggestions and standards for evaluating the quality of the research (Elliott, Fischer & Rennie, 1999; Mays & Pope, 2000; Meyrick, 2006; Yardley, 2000). Dixon-Woods, Shaw, Agarwal and Smith (2004) identified over 100 sets of guidelines at the time they wrote. The differing epistemological approaches informing qualitative research make it problematic to produce general guidelines, and attempts have been criticised for not being applicable across different research approaches (Elliott et al., 1999; Reicher, 2000). Yardley (2000) created four "flexible principles" that can be used to create suitable standards within many research approaches and were designed with health research in mind: Sensitivity to context; commitment and rigour; transparency and coherence; impact and importance (p. 215). The four principles recognise that quality qualitative research results from ongoing attention throughout the design, execution, analysis and presentation of research (Smith, 2011). These standards have since been endorsed as a broad and comprehensive set of guidelines for phenomenological research in general (Landridge, 2007), and IPA in particular (Smith et al., 2009). These standards are summarised here, and their application to IPA and this study is described where appropriate.



### **3.3.1 Sensitivity to context**

Research takes place within a particular intellectual and sociocultural context, and this context should be acknowledged (Yardley, 2000). A study is developed within existing theories and literature, and these should be explicitly mentioned, for example by being recognised in the design and drawn into a final report (Elliott et al., 1999). This may include a thorough review of the literature (chapter 2), and linking the analysis to existing literature and theory (see chapters 6-9). The sociocultural context is represented in selection and description of the characteristics of the participant sample, e.g. age, gender, socio-economic status (Mays & Pope, 2000). With IPA, where purposive sampling of a closely related group is used, the participant characteristics should be relevant to the research question. This allows understanding of how and where the study findings might relate to other situations (Mays & Pope, 2000), so should be clearly reported (see section 4.2). The researcher's interpretative role in producing an IPA study requires sensitivity to sociocultural issues drawn on by both parties during interactions, and the researcher during the analysis. Maintaining a reflective journal is one way to address this (see section 4.5 and 9.7).

The researcher must be sensitive and attentive to ethical issues, treating participants with respect and fulfilling all ethical obligations towards them (Elliott et al., 1999). Ethical issues should be addressed thoroughly before research begins and revisited in the light of any changes made as research progresses (Yardley, 2000). The relevant ethical considerations for this study are discussed in section 4.3.1. Carrying out ethical research requires empathy and sensitivity to participants' needs during data collection, particularly when discussing difficult topics (Smith et al., 2009).

### **3.3.2 Commitment and rigour during the process**

Research should be systematic, thorough and comprehensive, engaging in-depth with the topic at all stages of data collection, analysis and interpretation (Yardley, 2000). This begins with ensuring that the research question and strategy are well suited, and that the specific methodology of choice is the most appropriate way to investigate the problem (Dixon-Woods et al., 2004; Spencer, Ritchie, Lewis & Dillon, 2003). Data gathering and analysis are shaped by the chosen theoretical stance and research question (Mays & Pope, 2000). As Langdridge (2007) observes, good results are produced through engagement with the topic, data and analysis, rather than rigorous adherence to a particular methodological strategy.

Rigour during analysis is a key element of research quality. This may involve implementing strategies to strengthen the analysis, like checking themes against each other and the original data set, and ensuring that they are internally coherent, consistent, and distinctive (Braun & Clarke, 2006). In an IPA study, the analysis should focus on interpretation rather than description, and may draw on relevant theoretical considerations to move beyond superficial understanding of the topic (Braun & Clarke, 2006). An IPA study should reflect the participants' perspectives, and (potentially) relate to broader concerns, including practice, theory, and the existing literature (Langdrige, 2007; Yardley, 2000). In the current study, developing themes were related to existing literature and theory in the empirical chapters (6-8) and more generally to theory, and to practice in the discussion (chapter 9). Drawing on well-established strategies, like a hermeneutic interpretation of the use of metaphor, and the hermeneutic circle, that moves between the meaning of words, sentences, extracts and accounts (Smith et al., 2009), provides a broad base of established techniques to support a developing analysis.

Study participants and other researchers can help assess the credibility of the developing or final analysis. Participants may provide a "member check" of the credibility (to them) of the analysis (Mays & Pope, 2000, p. 51). This approach is inappropriate with IPA, which assumes a double hermeneutic where the analysis is a product of both researcher's and participants' sense making (Smith et al., 2009). The analysis is a possible interpretation, but not necessarily the only one (Rapport, 2005). There is a difference between an experienced event, recounted from the natural attitude, and an analysis carried out from a psychological perspective (Giorgi, 2006). An alternative credibility check in IPA is the independent audit (Smith et al., 2009), in which other researchers review the transcripts and analysis to confirm that the analysis is an appropriate interpretation of the data. Independent auditing was used in this study, and is discussed in section 4.4.2.

### **3.3.3 Reporting with transparency and coherence**

The processes applied to sampling, data collection and analysis must be described in a clearly written and well-organised report (Yardley, 2000). A research journal (see section 4.5) is a valuable tool to document the research process that can be made available or drawn on during the reporting (Rapport, 2005). The issues described in the previous two sections are included in this report to demonstrate how they were implemented throughout the research. This included addressing whether alternative methods would have been more appropriate and why the chosen strategies were pursued (Mays & Pope, 2000). The language and concepts used

should be consistent with the chosen design (Chamberlain, 2000; Yardley, 2000). The data analysis process should be described, particularly if it does not follow a pre-existing structure (Spencer et al., 2003). The data analysis procedures for this study are described in section 4.4. The analysis should present a convincing, well-organised integration of data, interpretations and conclusions (Elliott et al., 1999), clearly showing how it was developed from the data (Yardley, 2000). Spencer et al. (2003) emphasise presentation of a clear, powerful argument that makes credible, claims well founded in the data presented. Thus, the written report should include sufficient data extracts to evaluate the analysis and claims made (Dixon-Woods et al., 2004). The impact of the research process on the data and analysis should be addressed. This might include considering the effects of rendering the text from the original form into the form used for analysis (Reicher, 2000) and addressing the impact different data collection methods (Spencer et al., 2003). An area particular to qualitative research is reflexivity; that the researcher explicitly evaluates their role in the research process (Yardley, 2000).

Recent developments in IPA include standards for evaluating published research (Smith, 2011). These include ensuring that a report presents analysis, rather than multiple extracts, with illustrative extracts showing the prevalence, representativeness and variability of themes across the dataset (Smith, 2011). Prevalence relates to the occurrence of themes across the data set, representativeness means that the analysis represents all participants, rather than cherry-picking from one or two, and variability requires attention to the range of experiences within a theme. The rationale for extract selection for this study is described in section 5.1. The prevalence of themes across the data set is explained within the analysis of each, and presented within the tables of themes in each empirical chapter. Where possible, an extract for each participant is given for each theme.

### **3.3.4 Impact and importance**

As the study was initially positioned within the existing literature (chapter 2) it is equally important to relate the completed analysis back to these aspects and, where possible, suggest practical applications and development of the research (Yardley, 2000). The contribution of the research to advances in a discipline's knowledge, understanding, theory and practice should be clearly laid out (Spencer et al., 2003). This is done in chapter 9. Mays and Pope (2000) describe this as worth and relevance: that research adds to or increases confidence in

current knowledge. For phenomenological approaches, an account being persuasive/plausible to experts in the field is a key aspect of validity (Langdrige, 2007).

### ***3.4 Chapter summary***

The theoretical issues discussed here influenced the study design, execution and presentation. They formed the basis for the interview design, recruitment strategy, and data analysis, which are described in the next chapter.

## **4 Methodology**

This chapter describes the data collection and analysis procedures used to explore the research question, ‘how do men and women experience stress and coping during the early stages of in vitro fertilisation (IVF), and does this change over time?’ The interview design is discussed first, explaining the interview timing, the addition of Skype/video interviews, and creation and presentation of the interview schedule. Next, the study participants are described, starting from the development of the inclusion and exclusion criteria from the research question, examining sampling and sample size as they relate to Interpretative Phenomenological Analysis (IPA), and ending with mini biographies of the study participants. The next section explains the procedures used to gather data, beginning with an overview of the relevant ethical considerations and processes of gaining ethical approval, and continuing through recruitment, interviewing and data transcription. The last section explains the analysis process and how the established steps of IPA were applied, including how related (multiple and couple) accounts were analysed. The qualitative analysis software NVivo 8 was used for data management and analysis, so its features, advantages and disadvantages are discussed.

### **4.1 Design**

#### **4.1.1 Interview design**

The study looked at couples beginning IVF, which was a similar situation for participants with potentially different pre-IVF experiences. Beginning IVF has been suggested to be a stressful time, as it is considered the treatment of last resort for infertility (Verhaak, Smeenk, Evers, et al., 2007). Couples were interviewed separately (see section 3.2.2). Baseline interviews took place before any surgical procedures took place. Follow-up interviews occurred around six months later, to allow for some experience of treatment. A final interview after a further six months was proposed for participants still in treatment, although this did not occur, as participants were no longer undergoing treatment. One couple offered to speak again when their first treatment cycle was complete. At that point of the study, analysis suggested that failure of the first cycle was an interesting point for analysis, so this offer was accepted.

#### **4.1.2 Telephone/Skype interviews**

The option to carry out telephone or Skype™ interviews was added to the study to include potential participants who could not meet in person. Skype is Internet telephony software that allows videoconferencing when both parties have a web cam, making it closer to an in-person encounter (Slade, Emery & Lieberman, 1997). This has the advantage of allowing the non-verbal communications that can be problematic with audio telephone interviews. Skype calls can be recorded and transcribed like face-to-face interviews (Olliffe, 2010). The informed consent required participants to give specific permission to record the call to comply with applicable legal requirements (Reynolds & Prior, 2003; Turner, Barlow & Ilbery, 2002).

#### **4.1.3 The interview schedule**

The interview questions were developed from previous research on stress and coping, infertility, health, and the IPA literature (e.g. Folkman, 1997b; Lazarus, 1993; Smith & Osborn, 2003). The first question was general and open-ended to allow participants to become comfortable with the interview situation by telling a familiar story (Imeson & McMurray, 1996). Another open-ended question at the end of the interview allowed participants to raise additional thoughts. A question was included comparing the experience of infertility with other difficult situations to explore the idea that infertility is often considered the most difficult experience of people's lives (Freeman, Boxer, Rickels, Tureck & Mastroianni, 1985; Jordan & Revenson, 1999).

The terms 'stress' and 'coping' were avoided in favour of phrases like 'what bothers you' and 'what helps you', to elicit participants' own understanding and constructions of these issues (Clare, 2003). Similarly, in a study of kidney dialysis experiences, Smith and Osborn (2003, pp. 58-59) asked about the "demands" of dialysis, and how participants "deal with" it "on a day-to-day basis". The questions were phrased to address potential positive and negative actions, like 'what helps you' and 'what makes things more difficult' (Folkman, 1997b). Prompts about the impact of treatment on work, relationship, social life, etc, and mental, emotional, spiritual aspects of coping, were included to encourage participants to expand on their account. The interview schedule was structured to avoid questions that might correspond to potential themes, which risks carrying out the analysis before gathering data (Brocki & Wearden, 2006).

Three friends of friends who had received fertility treatment participated in informal, non-recorded, pilot interviews, and suggested improvements to the wording, content and structure

of the questions. Apart from the first question, all interview questions were used for the baseline and follow-up interviews:

1. Baseline interview) Could you tell me a bit about your experience of infertility?  
Follow-up interview) What has been happening since the last time we spoke?
2. In what ways is the fertility treatment affecting your life? They can be good things and bad things.
  - a. Benefits as well as negatives
  - b. What bothers you the most/least
  - c. Treatment itself/work/social life/relationship
  - d. Emotional/physical/financial
3. On a day-to-day basis, what helps you?
  - a. Mental/physical/emotional/spiritual/practical
  - b. What about what other people do? Partner, family, friends, co-workers, medical personnel.
4. Are there things you do that make life more difficult?
  - a. Mental/physical/emotional/spiritual/practical
  - b. What about things other people do? Partner, family, friends, co-workers, medical personnel.
5. How would you compare the experience of infertility with other things you've encountered in your life?
6. Is there anything else you'd like to tell me?

*Prompts are lettered: use these to encourage detail from a range of areas.*

## **4.2 Participants**

This section explains the participant selection criteria, decisions about sample size, and presents mini-biographies of the interview participants.

### **4.2.1 Inclusion and exclusion criteria**

IPA uses purposive sampling, which means identifying a specific group for whom the research question will be significant, to be able to say something meaningful about the

experience of that group (Smith & Osborn, 2003). The research design defined two broad criteria as currently childless heterosexual couples starting their first IVF cycle. Accessing the experiences of people with other sexual orientations, or single women, would be a valuable exercise, but smaller numbers of potential participants would have made this a problematic choice, particularly considering the complex issues around parenting and social context for gay and lesbian individuals and couples attempting to become parents (e.g. Clarke & Kitzinger, 2004). One practical consideration was that fertility treatment is often felt to be demanding in time and energy, which might deter potential participants from volunteering. From this perspective it was desirable to implement the least number of constraints to include as many potential participants as possible.

A list of possible participant characteristics, like socio-economic status, diagnosis, treatment history was created to evaluate how different selection criteria could answer the research question in a significant way (Silverman, 2005). These characteristics were assessed against the study objectives. Diagnosis and treatment protocol were rejected as selection criteria because they are variable and may change over time. There are many potential diagnoses for infertility, which are complicated by the tension between infertility as an individual issue, e.g. low sperm count, poor egg reserve, and as a couple who have not conceived (Greil et al., 1988; Miall, 1986). Treatment is often described as a process-like trajectory that changes over time rather than a single cure (Greil, 1997). Couples attempting to conceive using donor eggs or sperm at entry to the study, or who were experiencing secondary infertility (they already had one biological child together) were excluded, to create a homogeneous sample of couples trying to conceive their first child using their own genetic material. To focus on the experience of infertility, potential participants with serious underlying psychiatric conditions or additional chronic health conditions unrelated to infertility were excluded. Participants were required to speak and read English fluently, to understand the informed consent and participate fully in the interviews. The final criteria included aspects applicable to both individuals and as a couple, and these criteria are presented in table 1.

**Table 1 Inclusion and Exclusion Criteria**

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Heterosexual couples	Couple has child(ren) already
Prior to first IVF cycle	Third party reproduction at study entry
Speak and read English fluently	Severe underlying psychiatric conditions or additional



	chronic health conditions unrelated to infertility
	Seeking therapy or counselling

#### **4.2.2 Sample size**

IPA studies focus on depth rather than breadth of analysis, using small participant samples to retain individual perspectives in the final analysis (Smith & Osborn, 2003). Smith (2008) advises including 6 to 12 participants for this type of IPA study, but as a longitudinal study, each participant would contribute at least two interviews to the data set (Morse, 2000). Accordingly, it was decided to aim to recruit 3-4 couples, producing 12-16 interviews. This allowed divergences and convergences to emerge by gender and over time, with individual perspectives still visible, and without producing an overwhelming amount of data (Smith & Osborn, 2003). As couple 3 gave three interviews, this led to a final data set of 14 interviews. Though a large number of interviews from an IPA perspective, it is within general guidelines for qualitative analysis, where between five to twenty-five participants (interviews) is suggested as an appropriate number (Kvale & Brinkmann, 2008).

#### **4.2.3 Participant biographies**

These biographies of the three participating couples give a background of their experiences of attempting to start a family. These biographies use information given by the participants. Each participant has been assigned a pseudonym, and key details have been altered or omitted to preserve the anonymity of the participants.

##### **4.3.3.1 Natalie and Jeremy**

Natalie and Jeremy are a married European-American couple. They were in their late 30s, living in Northern California and in the first few years of their marriage when they participated in this study. They had been trying to conceive for around 13 months at their baseline interview in February 2009. Initial investigations had led to Natalie having surgery to remove a growth from her uterus, followed by two failed intrauterine insemination (IUI) attempts. Natalie had begun receiving medication for their first IVF cycle at the time of their baseline interview. This cycle failed. Between their interviews, they had another IUI cycle (which began as an IVF cycle), and had started the adoption process and another IVF cycle at their follow-up interview in July 2009. They were recruited through the IVF clinic.

#### **4.3.3.2 Judy and Matt**

Judy and Matt are a married Asian-American couple. She was in her early 30s and he was in his late 40s at the time of the interviews and they were living in Northern California. They had been married for two years and it was his second marriage: his first marriage ended in divorce because his wife did not wish to have children. They had been trying to conceive for around two years, had attempted several IUI cycles, and Judy had experienced a miscarriage a few months before the baseline interview. Their baseline interviews, in October 2009, occurred as Judy was receiving medications for their first IVF attempt, which failed. Before the follow-up interviews in March 2010, they had experienced an additional failed IVF frozen embryo transfer (FET) cycle, and were starting a second FET cycle, which would prove successful. Judy and Matt are patients at the same clinic as Natalie and Jeremy, though were recruited through the researcher's personal contacts. Judy became pregnant with twins shortly after their follow-up interview.

#### **4.3.3.3 Cathy and Chris**

Cathy and Chris are a couple living near London in the United Kingdom. Cathy was in her mid-30s and Chris was in his mid-40s and they had been together for three years. Though unmarried, it was his second committed relationship that he described as equivalent to marriage. Chris has children from his previous relationship, but he and Cathy were eager to have a child together. They had been trying to conceive for most of their relationship. Chris and Cathy were interviewed in March 2010, as they began drug treatment for their first IVF cycle, again in May 2010, after they found out that cycle had failed, and a third interview took place around the time of egg retrieval for their second cycle in August 2010. Cathy and Chris were recruited through personal contacts and were included because they were in the same stage of treatment as the first two couples and were pursuing treatment privately rather than through the National Health Service. Their second cycle also failed.

### **4.3 Procedures**

This section explains how the data gathering was implemented, including gaining ethical approvals, the recruitment processes, interviewing, and preparation for analysis.

#### **4.3.1 Ethics**

The study was designed to meet the ethical standards of the American Psychological Association (APA, 2002) and the British Psychological Society (BPS, 2004; 2006), as the research was to take place in the United States under the supervision of a British university.

The only significant difference between the codes is the APA requirement that participants consent to voice recording. The University of Derby Psychology Research Ethics Committee approved the initial study design in August 2008, which was submitted to the Palo Alto Medical Foundation (PAMF) Institutional Review Board (IRB). The PAMF IRB committee comprises doctors, lawyers and lay people (members of the community) who review all medical and non-medical research carried out at PAMF. The IRB approved the study in December 2008, subject to removal of the disclosure of the personal experience of infertility. Additional ethical approvals were obtained from both bodies in June 2009 to authorise data collection via telephone. The University of Derby committee approved a request to allow recruitment through snowball sampling. The protocol received annual renewal approval from the PAMF IRB in October 2009, August 2010, and September 2011. The ethical approval documentation is included in Appendix A. With concerns about confidentiality between couples (section 3.2.2), a line was added to the consent form requiring participants to acknowledge that their partner was being interviewed, and that both interviews are confidential between each individual and the interviewer.

#### **4.3.2 Recruitment**

Recruitment was planned to take place at an infertility clinic to enable the study to proceed under the auspices of an IRB. Requests were sent to five large clinics in Northern California that provided fertility services, explaining the study and asking about the possibility of recruiting their patients. A nurse in the PAMF Reproductive Endocrinology and Fertility clinic responded to this request and obtained the sponsorship of a physician as Principal Investigator. After receiving ethical approvals, recruitment began in January 2009. The liaising nurse was briefed on the study criteria and protocol, and distributed flyers (Appendix A) and information to eligible patients. Only one couple volunteered to participate, so further strategies were implemented, including allowing telephone interviews for patients who lived a distance from the clinic and networking through personal contacts. Networking added two further couples to the study. Potential participants completed a telephone or email screening before scheduling any interviews to review the eligibility criteria (see section 4.2.1 and Appendix A). Potential participants could address any concerns before agreeing to be interviewed.

### **4.3.3 Interviews**

A mutually convenient time and place was arranged by phone or email, and participants were encouraged to select their preferred location for the interview. Four interviews took place in the researcher's office; four at the participants' home, and all the interviews with couple 3, Cathy and Chris, took place over Skype. The involvement of the male interview participants was secured, mediated and organised by their partners, as is often mentioned with health research (Olliffe, 2010). All participants were sent the interview questions before the baseline interview.

At the baseline interview, participants were given time to read and sign the informed consent (Appendix A). Couple 3 were sent the consent in advance and returned a scanned, signed copy by email before their first interview. The key elements were reviewed verbally, including the predicted time commitment, potential risks and benefits of participating in the study, and the assurances of confidentiality, anonymity, and protection of personal data. Participants were reminded that they could choose not to answer any question at any time without needing to give a reason, and may withdraw from the study at any time. It was highlighted that the study was not providing therapy or counselling, nor was the interviewer qualified to provide it. This was emphasised during recruitment, screening and in the informed consent to encourage individuals seeking therapy to find other avenues for support. Participants were encouraged to ask questions, and were informed when audio recording was to begin. Interviews lasted between 20 and 60 minutes. After each interview, participants were offered further opportunities for questions and were given an information sheet with details about the study, avenues for support during fertility treatment, and researcher contact information (see Appendix A). All participants were given the option to receive a copy of the research or an executive summary. A commentary was made in the research journal after each interview, summarising any notable issues arising during the interviews. Before the follow-up interview, the participant's baseline interview transcript and tape was reviewed to provide a reminder of their situation and main concerns. Follow-up interviews were a balance between exploring developments to the original story and being open to new or changing topics.

### **4.3.4 Transcription**

The in-person interviews were recorded onto mini audiotapes using a Sony Microcassette-corder M-100MC. Skype calls were recorded (audio and video) using *Call Recorder for Mac*

version 2.3.8 (ecamm network: <http://www.ecamm.com/mac/callrecorder/>). The recordings were transcribed verbatim into Microsoft (MS) Word (Version 2004 for Mac), based on the criteria explained in section 3.2.1, and imported into the qualitative analysis software, QSR NVivo 8. Each transcript was line numbered to allow easy referencing. During transcription, thoughts and comments were noted, anticipating formal coding (Bramley & Eatough, 2005).

#### **4.4 Analysis**

IPA is a form of thematic analysis, where the researcher identifies experiential themes that make up the phenomenon under investigation (Langdrige, 2007). The focus remains on how the participant makes sense of their experience, rather than searching for objective truth (Brocki & Wearden, 2006; Smith, 1996). An advantage of using IPA is that there are well-established guidelines for data analysis, though flexibility and sensitivity to individual project requirements is encouraged (Smith & Osborn, 2004; Smith, Flowers & Larkin, 2009). The next sections outline how this process was carried out for this study.

##### **4.4.1 Coding individual interviews**

Consistent with the idiographic approach of IPA, the same process was used for each transcript in turn and in detail (Smith, Jarman & Osborn, 1999). Cases were coded independently to remain focused on each participant's distinct experience (Smith & Osborn, 2003). A transcript was read carefully two or three times, generating initial ideas and notes about elements that stood out, drawing on observations made post-interview and during transcription. It was then coded line-by-line, describing, summarising, making preliminary interpretations, and noting areas that seemed unusual or contradictory (Smith & Osborn, 2003).

To maintain the phenomenological perspective and focus on participants' accounts, the question 'how is this person experiencing infertility and fertility treatment?' was continually asked during coding. Increased detail was added by attending to linguistic elements like pronoun and metaphor use (Smith et al., 2009). All data was coded, not just that relating to existing concepts of stress and coping, to be open to new, unexpected or interesting dimensions in the text (Smith, 1999). Additionally, data was not coded with existing stress and coping terms, but as an interpretation of the text, to avoid imposing existing concepts on participants' unique experiences, and to be responsive to their interpretation of their experience. An example of the coding and analysis development from one interview is

presented in Appendix B. This shows an extensive coded extract from one transcript, along with an example of the written analysis developed for it, and the table of themes for that case.

Analysis involved a balance between looking at the data as a whole, line-by-line and in significant themes (Langdridge, 2007). The data was considered as a whole by attempting to identify a core storyline for each account (Sandelowski, 1995). This was a brief summary that encapsulated the main ideas and issues found during analysis. This helped group related themes together, sometimes with new super-ordinate themes, to represent the concepts that seemed most significant to each participant (Smith et al., 1999). A narrative account was produced to set “thoughts on paper” (van Manen, 1990, p. 64), illustrated with generous verbatim extracts. This entailed a process of writing, re-coding, re-organising themes, and referring to the original transcripts (Smith & Osborn, 2003). This was to make sure that the developed themes represented a balance between a focus on parts and the whole, and to reduce the chances of “idiosyncratic interpretations” that move away from the data (van Manen, 1990, p. 124). This moving focus between parts and whole is sometimes described as the hermeneutic circle (Smith et al., 2009, p. 28), which reflects an iterative process that moves between focusing at different levels of analysis, from individual words, through particular texts, projects and eventually to complete episodes and lives.

The focus was on producing a detailed, empathic account for each individual’s experience, in other words, employing a hermeneutic of understanding (Larkin, Watts & Clifton, 2006; Smith, 2004). Listing the page and line numbers for each extract helped to check whether certain extracts were used multiple times in different themes or if any parts of the interview seemed unrepresented. All relevant data was coded to the themes, including extracts that appeared contradictory, to attempt to develop as comprehensive analysis as possible.

#### **4.4.2 Analysing related accounts: Couples and multiple interviews**

The study produced related accounts: from an individual at different times, and from each member of a couple. Because time, gender and the couple were topics for study, an additional step was included in the analysis to address these. After the individual analysis and narrative was produced, each interview, set of codes, and narrative was re-read with related interviews, paying attention to convergences and divergences between accounts (Smith et al., 2009). The focus was on looking at different perspectives telling the same story rather than searching for the ‘true’ story of a couple (Hertz, 1995). Separate coding was carried out when these comparisons produced new concepts from the individual accounts, and significant areas were

written about as for the individual interviews. This approach was taken, rather than waiting until all interviews were analysed, to take advantage of fresh, detailed knowledge about the related interviews close in time to the original analysis.

Independent auditing was carried out throughout analysis. Other IPA researchers from the discussion forum founded by Jonathan Smith (<http://groups.yahoo.com/group/ipanalysis/>) reviewed three transcripts and the corresponding analysis. The study supervisors reviewed most transcripts and the individual analysis of them. Most supervision meetings while analysis was being carried out involved lengthy reviews and discussions of the developing analysis. Where concerns were identified about the developing analysis, for example, over reading certain elements of accounts, these were re-analysed.

#### **4.4.3 Integrating the analysis**

As the individual analysis progressed, it became clear that certain topics reoccurred across multiple interviews, and these ideas were noted. Moving from individual analysis to overall analysis meant identifying topics that occurred across most accounts and best illuminated the research question and these were designated as themes. First, similar sub-themes from individual interviews, often with different names, were grouped together to form group sub-themes, accounting for as many of the individual interview sub-themes as possible. Codes were excluded if they did not occur across most of the data set. For example, Cathy discussed issues that were coded as 'embodiment', but few other participants touched on this so it was omitted from the overall analysis. The sub-themes were grouped into themes that related to the research question. Top-level, or super-ordinate, themes encompassed important facets of all participants' experiences, and provided a significant or important psychological interpretation. The analysis structure is presented in more detail in chapter 5.

The themes were developed through writing, with re-coding when appropriate, and the group narrative was built from the individual narratives described in section 4.4.1. At this stage, attention was paid to checking the prevalence, representativeness and variation of themes included (section 3.3.3). These have been suggested as standards to assess published literature (Smith, 2011), but were useful concepts to incorporate during the analysis process. The prevalence of themes across interviews and the written analysis was checked using a grid, to identify underrepresented participants, gendered and temporal themes, and removal of poorly represented sub-themes. This level of analysis was linked with writing the analysis chapters, reviewing the literature, and application of the theoretical models.

#### 4.4.4 Using NVivo

The qualitative software analysis package QSR NVivo™ 8 was used in this study. Attitudes to qualitative analysis software are mixed, and two main criticisms emerge. The first is that researchers rely on automatic coding tools rather than properly engaging with the data (Langdridge, 2007). The second is that NVivo is a poor tool for IPA, because it does not allow two separate types of coding (descriptive and more interpretative), as on each side of a physical transcript (Smith et al., 2009). NVivo was used as a tool for data management and manipulation, and not a substitute for analysis (Seale, 2005). I chose to use NVivo because I prefer to work electronically, and wanted to make use of the organisational benefits of the software. There were practical limitations to using NVivo, which is only Windows compatible, via a PC emulator on a MacBook. This made the software slow to start and use. It was often necessary to produce printouts to review large quantities of data and coding.

Interview transcripts were imported into NVivo as Word documents before being coded. The NVivo annotation function was used for initial, exploratory coding. Detailed coding was done by creating 'nodes', the NVivo term for codes. Nodes were applied to text, ranging from individual words, to multiple paragraphs, coding features of the text, including thematic, linguistic, and metaphorical concepts. Text was coded at as many nodes as deemed necessary. The software was sometimes used to create automatic nodes by, for example, coding every occurrence of a particular word, which was a useful tool for exploratory coding. Nodes were arranged hierarchically to form 'coding trees' of themes and sub-themes. NVivo was used to create coding summary reports, providing overviews of the analysis, and the data coded to each theme. As analysis progressed, node names were edited, similar nodes merged, and further coding added. Separate coding trees were created for each interview to maintain the focus on the individual. As overall analysis progressed, code trees were constructed for each chapter of the report. Group level theme and sub-theme codes were added to the individual analysis codes.

The word processing capabilities of NVivo were limited so most writing was done in MS Word. NVivo does not produce tables of themes, so MS Excel was used to create table of themes with transcript references and extracts. Notes about coding, particularly during the early stages of analysis, were written up as memos in NVivo and exported to Word. A coding journal was kept in NVivo to record daily notes of analysis steps, coding, changes, and new ideas and directions. This provides traceability for the development of the analysis, supporting the rigour and reportability of the research.



#### ***4.5 Keeping research records: Research and reflective journals***

A journal has multiple purposes in phenomenological research, including capturing immediate responses to interviews to contribute to analysis (van Manen, 1990), documenting the process of research for reporting and review, and for reflections on the research process (Rapport, 2005). Separate research and reflective journals were kept during the project. Entries in the research journal were made each day. It had no formal structure, but included tasks to be completed, notes on relevant literature, developing analytical and theoretical ideas, and post-interview observations. Notes about the developing analysis here, and in the NVivo coding journal provide a record of the developing analysis. The reflective journal was kept separately to keep this information consolidated. Entries were made in response to questions arising during reading and the research process, and to reflective questions posed by Ahern (1999). This journal was kept throughout the research and formed the basis for the reflective section in the last chapter of this thesis (section 9.7).

#### ***4.6 Chapter summary***

This chapter explained the design and execution of this study from data gathering through analysis. The next chapter presents an overview of the analysis, as an introduction to the empirical chapters.

## **5 Introduction to the analysis**

This chapter introduces the analysis that is presented in the next three chapters. The first section of this chapter explains the rationale for selecting themes and extracts. The next section gives an overview of the whole analysis, explaining the central, super-ordinate themes, and how they are explored in each individual chapter, and concluding with a top-level table of themes. The final section explains the notation used in the extracts and how extracts are referenced to the transcripts.

### ***5.1 Analysis structure, theme and extract selection***

The super-ordinate chapter themes were chosen because they provided the most comprehensive analysis and interpretation of the data in terms of the research question, important theoretical and psychological concepts, and participants' accounts. Each chapter contains one to three themes, which themselves are divided into sub-themes, showing dimensions of the theme. These are summarised in table 2. Time and gender were of particular interest, and some sub-themes were largely confined to men or women's accounts. This meant that a sub-theme occurred multiple times across one gender's account, with few (one or two) or no occurrences in the other gender's. Though some sub-themes relate to one gender's experiences, extracts from participants of the other gender are used if they develop the analysis. Sub-themes demonstrated temporal change or continuity, and this is described in the analysis. Changes in sub-themes occurring in baseline and follow-up interviews across most participants are described within the theme. Sub-themes specific to a particular time point are treated as separate sub-themes. This occurs in chapter 8, which deals most explicitly with temporal aspects.

Each empirical chapter contains the analysis for each theme with its sub-themes, followed by a discussion section linking the analysis to the relevant literature. Discussion is mostly kept separate from the analysis, as suggested by Smith, Flowers and Larkin (2009), with minor exceptions when reference was made to relevant literature to support points that were not further developed in the discussion. Extracts were selected to show the prevalence, representativeness and variability of themes and sub-themes across the data set (Smith, 2011). The tables of themes and analysis show extracts from all participants represented in each sub-theme. Each participant is represented in the analysis, with the aim being to provide a similar number of extracts from each, to maintain the representativeness of the analysis. Extracts were selected that best illustrated the particular theme or sub-theme, or provided an

opportunity for rich analysis. Though presented separately, there were interrelationships between themes and sub-themes. This is mentioned in the analysis. Concepts like control occurred in multiple super-ordinate themes (chapters) so are addressed where appropriate in sub-themes and in the general discussion. Some extracts were equally relevant to two sub-themes. Extracts that were applicable in more than one sub-theme were used where they provided the most interesting and informative analysis, and to balance the representation of participants.

## ***5.2 Doing it the best way that we can: Super-ordinate themes***

This section provides context for the analysis, and gives a summary of the three super-ordinate chapter themes. Three main issues shaped this analysis. First, that having a child was important to participants, hence their decision to pursue treatment. Participants at different stages of the study made remarks like:

*It isn't to curtail my emotions about the process or the desire to want to have a child but it's to protect the validation of the life that I have which I think is a good one (Natalie 1; 3.9-11)*

*Everything else seems to have some degree of reversibility about it. Fertility doesn't. You know, in one way, if you have kids you're stuck with them for your rest of your life, if you don't have kids you're stuck with that for the rest of your life. You know, there's no going back either way. (Cathy 1; 13.7-10)*

*I mean, it's going to be all worth it if, you know, we start a family. Get a little, little child out of this, it's all worth it, so. (Matt 2; 13.11-13)*

*I actually um love seeing kids and, you know, playing with them, and and and I just think they're so cute and I, you know, I can't wait to have my own, so I think it's just a bigger appreciation. (Judy 1; 3.22-25)*

*We've got a really good relationship, and I think it would ahh, having a baby would be the icing on the cake (Chris 3; 6.21-22)*

This contrasted with the idea that infertile couples (and women, particularly) are desperate to produce a child at any cost, as often portrayed in the literature (see Letherby, 2002 for a review and critique). The second issue was that participants wished to act and respond in a way allowing them to attain parenthood in the best way possible across multiple dimensions,

including emotional, financial and marital well-being. This became the central organising theme of the analysis and is represented by the thesis title 'doing it the best way that we can'.

The final point was that explicit expressions of stress in relation to fertility treatment and infertility as a whole were rare, and participants were more likely to deny that either was generally stressful. The strongest remarks included:

*Well this is it, this is what I was thinking when I read those questions. I feel positive, and actually I almost felt a bit strange when I was reading those questions, it was almost like I should be really worried and scared and and, but I don't. (Chris 1; 12.17-19)*

*I don't look at it [infertility] as one of the most difficult things. (Judy 2; 10.27)*

*I don't see infertility as being difficult; probably not a word that I ever have at least to date associated with the process, it just is. (Natalie 1; 11.13-14)*

Other participants suggested that infertility was difficult or stressful, though instances of this were less than emphatic. Cathy placed 'stress' in the past and future, but passed over it at the moment:

*I know it's been very stressful extremely stressful in the last year or so, um when we realised actually this wasn't going to happen as a pleasant accident, a little bit more effort was needed. (Cathy 1; 1.12-14)*

*So yeah, I feel, I feel quite positive. Um. Interested in seeing what this is going to be like and how it does effect us. And then bracing myself for the stress a bit later on, I think it will be stressful, but I don't know what way yet. (Cathy 1; 8.28-9.2)*

Matt acknowledged but downplayed the stress of infertility, describing it as 'frustrating':

*When we started trying, this is actually now two years of trying, eh, it gets, I guess it's a little frustrating. (Matt 1; 1.7-8)*

The first set of extracts, particularly, challenged a strategy of interpreting the data only within a model of infertility and fertility treatment as stressful experiences. Participants described specific issues as being difficult, and these are pointed out in the analysis. Shaw (2011) found similar differences between unequivocal position statements, and variable lived experiences in her study of women's voluntary childlessness. The lack of explicit and general acknowledgement of infertility and fertility treatment related stress meant it was impossible to broadly apply transactional stress and coping theory to understanding or interpreting most of the data. This required the assumption that infertility and fertility experiences were

generally stressful, despite participants' general positions about the stress of these issues, and the focus on specific difficult issues in their accounts. Retaining the transactional model as an organising theory for this research would mean interpreting the data in terms of the theory, rather than developing an analysis that remained close to the data while being informed by psychological knowledge (Smith, 2004). This contradiction, along with the identified central theme, prompted broadening the study's theoretical framework from the transactional model to a self-regulatory perspective.

The three themes identified are: shaping emotional representations of fertility treatment; solving the problem of infertility; and changing perspectives on treatment. The first super-ordinate theme, *shaping emotional representations of fertility treatment*, explores the most prevalent emotional perspectives that participants raised in their interviews, focusing on choice and control to achieve the best responses. This theme includes gendered sub-themes, exploring women's comparisons with other (poorly responding) fertility patients and men's focus on their experiences as a couple, and relative to the demands on their partner. This theme explores how participants' emotional perspectives on treatment were not responses to events, but were actively shaped by variable social perspectives. The second super-ordinate theme is *solving the problem of infertility*. The theme explores participants' focus on making correct, careful decisions and taking action to change their situation. This chapter includes themes relating to participants' focus on fertility treatment as a couple activity, and how divergences between partners' individual narratives of their joint experience highlighted areas of difficulty for individuals. The final super-ordinate theme is *changing perspectives of treatment*, and is the most temporal chapter. These themes show how perceptions of medical expertise, and luck and fate, and their own familiarity with treatment processes developed as cycles were carried out. Failure of the first treatment cycle appeared important in participants' adjustments of their treatment expectation. This chapter looks at the variable temporal perspectives taken by participants during their interviews, and how these were chosen to be most helpful at particular times.

**Table 2 Top-level Table of Themes**

<p><b>Chapter 6</b></p> <p><b>‘It doesn’t help to worry’: Shaping emotional representations of fertility treatment</b></p>	<p><b>Chapter 7</b></p> <p><b>‘We decided to get aggressive with it’: Solving the problem of infertility</b></p>	<p><b>Chapter 8</b></p> <p><b>‘It’s a matter of when, not a matter of it’: Changing perspectives on treatment</b></p>
<p>Choosing and controlling emotional responses</p> <ul style="list-style-type: none"> <li>• ‘Stress is never good for these things’:</li> </ul> <p>Evaluating the best reactions</p> <ul style="list-style-type: none"> <li>• ‘We try to keep sane’: Working at desired responses</li> </ul>	<p>Making decisions and taking action</p> <ul style="list-style-type: none"> <li>• ‘It’s such a conscious decision’: Making the right choices</li> <li>• ‘It’s expensive’: Managing financial issues</li> <li>• ‘Let’s get on the fast track’: Taking action</li> </ul>	<p>Time and treatment</p> <ul style="list-style-type: none"> <li>• ‘It’s a third party process’: Pursuing expert solutions</li> <li>• ‘It’s what you’re supposed to do’:</li> </ul> <p>Invoking luck and fate</p> <ul style="list-style-type: none"> <li>• ‘The injections are nothing now’:</li> </ul> <p>Treatment processes get easier with experience</p> <ul style="list-style-type: none"> <li>• ‘There’s no logic to it’: Making sense of signs and outcomes</li> <li>• ‘I’m trying to be in the moment’:</li> </ul> <p>Shifting temporal perspectives</p>

<b>Chapter 6</b> <b>‘It doesn’t help to worry’: Shaping emotional representations of fertility treatment</b>	<b>Chapter 7</b> <b>‘We decided to get aggressive with it’: Solving the problem of infertility</b>	<b>Chapter 8</b> <b>‘It’s a matter of when, not a matter of it’: Changing perspectives on treatment</b>
Comparing with other patients <ul style="list-style-type: none"> <li>• ‘I’m fairly positive compared to a lot of other women’: Coping better</li> <li>• ‘You pick up on people’s anxieties’: Learning about stress</li> </ul>	IVF as a mutual endeavour <ul style="list-style-type: none"> <li>• ‘We’re doing it together’: Fertility treatment as a joint project</li> <li>• ‘Is this the right thing for both of us?’: Diverging accounts and stress</li> </ul>	
Men’s perspectives within the couple <ul style="list-style-type: none"> <li>• ‘You see how hard it is on her’: Focusing on the woman</li> <li>• ‘I’m going to help her with the injections’: Being part of it</li> <li>• ‘I need to support her in the now’: Dealing with things the female way</li> </ul>		

### 5.3 Guide to extracts

A simple transcription scheme was used, focusing on the meaning of accounts (Smith, Flowers and Larkin, 2009). The notation is presented in table 3.

**Table 3 Transcription Guide**

Non-verbal utterances, or comments on noticeable changes in tone of voice	<i>[laugh]</i>
Clarifying comments	[clarifying]
Omitted words or unclear from the recording	<unclear>
Short pauses	(.)
Longer pauses	(duration in seconds)
Correct spellings are used, except when participants used an audibly different form of a word, for example 'cos' for 'because'.	
Emphasised speech	<u>Underlined</u>
Interjections	=interjection=

Extracts are identified with the participant's name, interview number, and page and line number on the interview transcript. For example, Matt (2; 5.10-15) refers to Matt's follow-up (second) interview, page 5, lines 10 to 15. Information is omitted if apparent from context, for example, if the text describes 'Matt's follow-up interview', the extract would be labelled with the page and line-number only. Extracts are italicised, and those of more than 5-10 words are paragraphed separately; shorter extracts used within the sentence structure are written continuously with the text.



## **6 ‘It doesn’t help to worry’: Shaping emotional representations of fertility treatment**

This chapter explores the different ways that participants talked about stress and emotion, not as an outcome of their experiences, but as ‘best’ responses that were chosen and managed, even though that might be difficult and require effort. The meaning of emotion about infertility and fertility treatment was shaped by multiple contexts: the impact of stress on fertility, differences between the couple, in comparison with other patients, and against social perceptions of correct behaviour. This chapter contains three main themes, which are presented in table 4. The first was drawn from all participants’ representations of the emotional aspects related to treatment, drawing on the perceived impact of stress on fertility, a desire to ‘stay positive’, and the work required to meet these objectives over time. The second discusses the emotional representations drawn from their interactions with other fertility patients. Though men made a few comparisons, women made far more, so this chapter focuses on how the women positioned themselves favourably compared with other patients. The third theme focuses on men’s perspectives on the couple, rather than external others. Men seemed constrained in their emotional expression by their smaller physical burden of treatment, despite their physical participation in giving their partner regular and multiple injections. Throughout, participants perceived right and wrong ways to behave, which could be chosen and worked towards. Emotional views of treatment were not simply responses to events but were shaped by perspectives drawn from participants’ social environment.

(Title extract from Matt 1; 3.1-2)

**Table 4 Table of Themes: Shaping Emotional Representations**

<b>Theme</b>	<b>Sub-theme</b>	<b>Extracts</b>	<b>Participants in sub-theme data</b>
<b>Choosing and controlling emotional responses</b>	‘Stress is never good for these things’: Evaluating the best reactions	Stress is never good for these things (Cathy 2) infertility; that sounds so bad (Natalie 1) I don’t think that [mental pressure] helps (Cathy 3) I figured just to relax (Judy 1) it becomes all-consuming, and that doesn’t seem like a good way to go (Jeremy 2) it doesn’t help to worry (Matt 1) the stress... doesn’t help the whole process (Chris 3)	Jeremy (1,2), Natalie (1), Judy (1,2), Matt (1,2), Cathy (1,2,3), Chris (1,2,3)
	‘We try to keep sane’: Working at desired responses	We try to keep sane (Jeremy 1) I can control my attitude, I might as well focus my energies on that (Natalie 1) Other things I’ve been trying to use as coping (Judy 1) What are we trying to gain? (Matt 1) Managing your way through it (Cathy 1) I want to try and stay positive (Chris 3)	Jeremy (1), Natalie (1,2), Judy (1), Matt (1,2), Cathy (1,2,3), Chris (1,3)

Theme	Sub-theme	Extracts	Participants in sub-theme data
Comparing with other patients	'I'm fairly positive compared to a lot of other women': Coping better	<p>I'm fairly positive compared to a lot of other women (Judy 1)</p> <p>People get so caught up into the 'we have to have one' (Jeremy 2)</p> <p>They're so used to having the obsessive kind (Natalie 1)</p> <p>Other women feel that way (Judy 2)</p> <p>They were in very very different positions (Cathy 2)</p> <p>Some of the other couples we've met they've been holding on to every time (Chris 3)</p>	Jeremy (2), Natalie (1, 2), Judy (1,2), Cathy (1,2,3), Chris (1,2,3)
	'You pick up on people's anxieties': Learning about stress	<p>You pick up on peoples' anxieties (Natalie 2)</p> <p>I wonder if they'll bring me down (Judy 1)</p> <p>My older sister just gave birth, so, there's hope (Matt 2)</p> <p>It just spread anxiety (Cathy 2)</p> <p>Other people's baggage (Chris 2)</p>	Natalie (2), Judy (1), Matt (2), Cathy (2), Chris (2,3)

<b>Theme</b>	<b>Sub-theme</b>	<b>Extracts</b>	<b>Participants in sub-theme data</b>
<b>Men's perspectives within the couple</b>	'You see how hard it is on her': Focusing on the woman	You see how hard it is on her (Jeremy 2) It affects Natalie more than me (Jeremy 1) Trying to support Judy (Matt 1) I don't like her to go through this (Chris 1) I wanted to cocoon her away from the stress (Chris 3) My moods contribute a big stress to my husband (Judy 1)	Jeremy (1,2), Matt (1,2), Chris (1,2,3) And Judy (1,2)
	'I'm going to help her with the injections': Being part of it	I'm going to help her with the injections (Chris 1) She's getting six shots a day and I'm giving them to her (Jeremy 1) I don't want to hurt her (Matt 1) The first time was a little bit strange, stabbing my girlfriend in the stomach (Chris 2) I'm not a fan of the needles (Natalie 1)	Jeremy (1,2), Matt (1,2), Chris (1,2) And Natalie (1)
	'I need to support her in the now': Dealing with things the female way	I need to support her in the now (Matt 1) I have to acknowledge her hurt or her emotions (Matt 2) Cathy would rather not tell loads of people, so I've honoured that (Chris 1) He's learned that he needs to try not to "fix" the situation (Judy 1)	Matt (1,2), Chris (1,2) And Judy (1,2)

## **6.1 Choosing and controlling emotional responses**

This theme explores participants' perspectives on the emotional experience of in vitro fertilisation (IVF), and particularly of emotions and stress as chosen and controlled. Emotions were not an unavoidable consequence of experiences, but were good or bad choices that could be selected and carried out. The first sub-theme explores the range of emotional responses, from the negative impact of being stressed and distressed, to the desire to remain positive and stay 'sane'. The second sub-theme investigates participants' efforts to achieve the emotional goals they had established as desirable. The final part of this section relates the analysis to the relevant literature.

### **6.1.1 'Stress is never good for these things': Evaluating the best reactions**

Participants described good and bad emotional responses to infertility. Several participants suggested a link between stress and fertility. Chris wondered whether his partner, Cathy, might conceive '*naturally*' now she was, he believed, experiencing less stress:

*But you know the crazy thing is that for the last year and half, of the two years that we've been trying, Cathy's been doing this doctorate, and you never know, she might end up having one naturally in-between, you hear crazy things like that, do you know what I mean? It's just, now she's not stressed, now, going through this process, um, takes the pressure in a way off of trying to conceive. (Chris 2; 7.11-15)*

Her work and the '*pressure*' to conceive were stresses that might have impeded conception. From this perspective, rather than being a stressor, fertility treatment became a way of reducing stress. Stress was a potential impediment to conception whether it arose from infertility or other issues, like Cathy's doctorate. Cathy also mentioned stress being unhelpful:

*I'm trying not to put too much mental pressure on myself. Because I don't think that helps. Or stress. (Cathy 3; 3.19-20)*

Judy described delaying a job search because '*I figured just to relax and take time off*' (1; 2.12-13), avoiding stress she felt would arise when starting a new job, and gaining time to '*relax*'.

Both Chris, in the earlier extract, and Matt pointed to potential physiological effects of stress for their partner. Chris was more concerned about the effects of stress on Cathy, though the

fertility impairment was his (a failed vasectomy reversal). Matt mentioned negative effects for his wife, Judy:

*There's not much for us to be able to worry about. Stressing over it is not going to help anything, because that just affects her body and stresses it out, is negative towards that, you know (Matt 2; 17.3-5)*

Though they might both have worries, and he used 'us' to suggest mutual concern, 'stressing over it' only appears an issue for Judy, with an impact on her body. Stress was perhaps perceived as more important for the woman because her body was central to both conception and fertility treatment. Jeremy described how getting 'tense' and 'panicking' would 'hurt':

*Accepting of the process might be better way of putting it. That panicking over the process, or - isn't going to help, it's actually going to hurt to get tense. (Jeremy 1; 5.24-26)*

He suggested that stress would impact the process and their chances of conception. Based on this, he aimed to be 'accepting of the process', which seemed to mean remaining calm, methodical and unemotional. Jeremy's accounts generally emphasised the practical aspects of IVF (see chapter 7). He talked little about emotions and contributed little data to emotion-related themes, but the split in his accounts between emotional and practical informed the structure of the super-ordinate themes.

Stress might also hinder the ability to take appropriate action. Natalie explained that getting 'mired down in the difficulty of it' a poor way to cope with 'life challenges':

*I've had life challenges um I'm acutely dyslexic but you just kind of find a way and then you do it, it's not, I mean if I got mired down in the difficulty of it I probably wouldn't be able to achieve it. So for me it's a choice and I don't I see it I see it as a to do, not as a difficulty it's just something that has to be done (Natalie 1; 12.1-4)*

Her approach to infertility was a choice based on what she saw as effective ways to tackle a situation. Seeing it as 'difficult' did not produce helpful action. She refocused from a negative response of being 'mired down in the difficulty' to a practical one of 'just something that has to be done'. The response to infertility is a 'choice', as she stated here. Similarly, Cathy referred to her response to their infertility as 'a mindset', and the mentioned importance of avoiding getting 'worked up' and 'anxious' (2; 8.10-11). Matt also expressed stress and worry as unhelpful:

*I come from the background of the thinking is, it doesn't help to worry about something because it's not going to help, it's not going to add any minutes, or hours to your life.*  
(Matt 1; 3.1-3)

For Matt, being positive about their infertility was an extension of his characteristic outlook. He described himself as an optimistic person who *'always tr[ies] to see the positive in things'* (Matt 2; 15.21). These participants all linked worry as a poor way to achieve desired results. Stress and worry had two consequences. First, they had a negative perceived effect by impeding fertility. Second, *'being stressed'* produced no useful outcome and inhibited better responses, like taking action.

Conversely, participants aspired to being positive and emotionally *'healthy'*. Matt and Chris, particularly, highlighted the encouraging aspects of their situation and endorsed a positive attitude. Matt showed this emphasis when summing up at the end of his baseline interview:

*No, like I say, everything has been positive. Even though we had the ups and downs we're moving forward, be good!* (Matt 1; 11.19-20)

He made two entirely positive evaluations, how *'everything has been positive'* and *'we're moving forward'*, with an acknowledgement of *'ups and downs'* almost lost between the two upbeat statements. Chris downplayed the potential stress of fertility treatment in favour of his positive feelings about the process, because the desired outcome was *'a positive thing'*:

*I'm not seeing it as I've, I've, I'm inadequate in some way, I'm, it's almost like it's a journey to get a baby. Which is a positive thing, isn't it? I'm not seeing it as "Oh my god, I'm inadequate, oh dear, I can't (.) produce (.) this, and I can't give that,"?* (Chris 1; 11.19-21)

He turned the situation from a failure into a positive experience, a *'journey'*, with a desired outcome at the end. Chris denied personal inadequacy, and was able to explain the situation to remove potential responsibility from him, as infertility is often linked to lack of virility for men (Meerabeau, 1991). This approach reframed the situation as a gain rather than a loss. Cathy similarly described staying positive as the best response to her situation after her first cycle failed, reflecting Chris's positive approach during his interviews. She chose the best way to look at her situation by focusing on eventual success over three cycles, explaining that *'I think that's the best way to try and thinking about it, and to try and keep positive'* (Cathy 2; 5.30). Again, this shows a participant selecting the most helpful response, and the perceived value of staying positive. A *'positive'* attitude was more common among the men than the

women. Men might find it harder to express negative feelings if they endorse the importance of 'thinking positive', and needing to be positive may reduce the extent to which stress was an acceptable response (see section 6.3).

Learning was another positive outcome of the experience, rather than focusing on losses or disappointment, that Matt mentioned:

*So, in a sense with the infertility, it is a struggle, but I think it's something that we learn more about each other, and figure out what our likes and dislikes, and you know, what our, I guess, frustration levels are and stuff like that. (Matt 1; 1.19-22)*

This extract reiterates comments earlier in his interview about 'struggle' and the lengthy, 'frustrating' process of fertility treatment (1; 1.7-8). Here, he combined positives and negatives, acknowledging the difficulties but focusing on the gains, learning about each other, and later how he will be able to provide support for others having similar experiences. Despite looking at the gains from their experiences, one of the things they are learning is about their 'frustration levels', which appears negative. The gains Chris described also focused on his relationship with his partner:

*But our relationship, I think, as far as I'm concerned has got stronger through this. And there's been times when I've needed to step up, and we both seem to be able to fill the void when the other one's lacking. Which you only find at times of stress and upset, don't you? (Chris 2; 8.28-31)*

Both men, despite giving accounts including negatives of 'struggles', and 'stress and upset' looked at the gains, and learning opportunities they had had, where Jeremy did not:

*I guess you do learn about each other but I don't know if I wouldn't say it's a good thing (Jeremy 1; 1.26-27)*

Jeremy reluctantly acknowledged learning 'about each other', but did not find this gain valuable. This suggests that there might be a difference between attempting to respond in an acceptable way, by not being distressed, and positively reframing a situation as a gain.

Natalie referred to staying emotionally healthy:

*I think then it could easily you know cross that thin red line and it could become all-consuming and if we don't have a child life still goes on if you know we're still married and we still have lives and lots of interests those things don't get halted because we don't have a biological child. (Natalie 1; 2.8-12)*



Using the phrase ‘*thin red line*’ suggested a short step between emotional health and fertility becoming ‘*all-consuming*’, which she felt was emotionally unhealthy. She balanced the desire to have a child with maintaining the rest of her life. Belief in the importance of a positive attitude and remaining in control emotionally occurred through participants’ baseline and follow-up interviews and was mostly seen as a good response.

Over time, the subject of positive evaluation changed for some participants, moving from general optimism to specific reasons to be hopeful about treatment outcomes. At his third interview, which took place the day of egg retrieval for their second IVF cycle, Chris explained the basis for his positive mindset at the time:

*Yeah, well we had seven eggs this morning; that was very positive! And my little sperm were very, were up for the job as well, very good, very positive. That’s two positive things today! And also, mine and Cathy’s relationship every time, you know, much as I said all that before, when we come to times like this I just realise what a cool relationship we’ve got... So that’s a really positive thing at the moment. (Chris 3; 7.21-28)*

He still valued being positive, but focused on specific signs. He drew on medical factors and aspects of his relationship with Cathy. This may be a function of a process step (egg retrieval) that provided tangible and quantitative evidence of success.

Participants defended themselves against the implication that their perspective might not be seen as realistic, reinforcing that they wished to be seen as reacting the best way possible. They touched on psychological concepts, suggesting that they were aware that some behaviours and emotions are considered maladaptive. Chris mentioned what he described as uncharacteristic optimism about the treatment outcome:

*I’ve always had a gut feeling that it’s going to be alright. Whether that’s complete denial I’m not sure [laugh] (Chris 1; 2.23-25)*

Being positive may be seen in a good light, with social demands to do so, but his ‘*gut feeling*’ may be accused of being unrealistic. Judy defended herself from the accusation of coping wrongly:

*All of a sudden my schedule is heavier. I think that helps me so much more to distract me, and I know that maybe that’s just kind of escaping the problem but, yeah, it helps me just to think about other things. (Judy 1; 6.5-7)*

Though she found being busy helpful, escaping the problem was potentially an unsatisfactory way to behave. She described both ‘*escape*’ and ‘*denial*’ (10.9) as negative behaviours. Perceptions drawn from psychological knowledge about the ‘right’ ways to cope may shape the ‘best’ way to respond.

Participants talked about emotional responses as a choice, with good and bad ways to respond. Being positive was seen as good, and being stressed as bad, particularly with suggested links between stress and infertility. These perceptions were unchanged over time, though attaining the desired state appeared to become more difficult, and this is discussed in the next sub-theme.

### 6.1.2 ‘We try to keep sane’: Working at desired responses

While participants identified the ‘right’ ways to respond, doing so required effort, but emotional responses were seen as being under individual control. Natalie differentiated between control of ‘*the process*’ of medical treatment and her ‘*attitude*’:

*I can't control the process but I can control my attitude so I might as well just focus my energies on that. (Natalie 1; 6.4-5)*

Her ‘*attitude*’ of staying emotionally healthy is a choice, requiring work, or to ‘*focus my energies*’, to achieve. Her separation of ‘*process*’ and ‘*attitude*’ placed her emotional response alongside the practical part of treatment, rather than as a response.

Several participants described ‘trying’ to achieve a desired response, suggesting effort was required. Chris wanted ‘*to try and stay positive*’ (3; 7.18). Judy chose ‘*things I've been trying to use as coping mechanisms*’ (1; 6.15-16). Jeremy described how ‘*we try to keep sane*’ (1; 6.6). All these show effort and a particular emotional goal: staying positive, coping, keeping sane. Jeremy described balancing his depression with Natalie's emotional responses to the fertility medications:

*Jeremy: One of the other things is that I fight depression, so when Natalie has a bad day and gets upset with me, and then sometimes that makes for a long days for me. But, I mean, it's just the balancing act, everything, so*

*Elly: between your mental health and her?*

*Jeremy: ahhh, so and she's very aware of it and she works very hard to make sure, I mean, she tries not to dump everything on me (Jeremy 1; 6.9-14)*

They were both actively pursuing what they believed was the right way to act: he '*fights depression*' while she '*works hard*' to avoid burdening him on her '*bad days*'. Fertility treatment made these issues harder, because the medication affected Natalie's mood from his perspective. He mentioned her awareness of her moods, that emotions and stress are something that can be monitored and managed.

Matt attempted to balance the urgency of his desire to have a child with his faith in '*God's timing*' and that God would, eventually, '*bless us with a family*' (1; 1.9):

*I think, you know, the timing itself for me, is. It's it's God's timing. So. You know, I can't argue with that, even though it's been long and stuff like that. (Matt 1; 1.14-16)*

Matt struggled with a wish to accept God's will, saying '*I can't argue with that (God's timing)*' when '*it's been long*'. He cannot argue with it, but his acceptance seemed harder to maintain after the time they had spent unsuccessfully pursuing this goal.

Achieving the desired positive responses appeared more difficult at follow-up interviews, which could be related to time in treatment, and treatment failure, particularly. In Matt's follow-up interview, the repeated cycle failures seem to have taken their toll and he described himself as feeling '*a little drained*':

*I have to admit this last one; I think emotionally I felt a little drained. I mean before it would be OK, let's well, we'll try again. But this time, for some reason this time I just felt, I think I felt more down than she did in that sense, so, it was different. (Matt 2; 1.15-18)*

Matt's statements here is negative overall, compared with the extract in section 6.1.1, where a negative statement is bounded with positive ones. His weariness emerged as he talked about feeling '*down*' and '*drained*', though he minimised the impact with terms like '*a little*', '*just*', '*in that sense*'. Time and repeated failure seemed to be wearing on him, making it harder to maintain his desired positive attitude. Despite this, later in the interview he downplayed that things were becoming more difficult:

*I don't know if I'd say it's a tad harder, but no, I think it's about the same. (Matt 2; 3.23-24)*

He moved from suggesting it was '*a tad harder*' to '*about the same*' and seemed reluctant to define his situation as difficult, or getting worse. The contrast between the two extracts suggests differences when talking in general about an experience rather than a particular event. In the second extract, Matt minimised his difficulties in general. In the previous

extract, he talked about a specific experience, the failure of their second cycle, which allowed difficulties to emerge.

Cathy experienced an unexpected physical response to the medication during her second IVF cycle, and found it harder to ‘*keep positive*’:

*I think it's hard to keep positive. It was so great last time. I mean the procedure; it was so eventless and hitch-free that it was so easy to keep positive. It's a bit harder this time. I feel. (Cathy 3; 2.2-4)*

The smooth process and low impact of her first treatment cycle, even though it failed, reinforced her positive attitude when approaching the second, creating expectations for her second cycle. The unforeseen difficulties she experienced challenged those expectations, increasing her emotional difficulties and making it harder for her to stay positive. Matt had struggled with a cycle failure but unanticipated side-effects were difficult for Cathy. Cathy responded by focusing on the practicalities of treatment:

*And ah, this time it's been harder to commit emotionally and it's just kind of more of a process that I'm going through. (Cathy 3; 7.20-21)*

The emotional investment is, as she said, ‘*getting my hopes up and really believing that this might happen*’ (Cathy 3; 7.23). She appeared to see emotional responses as something separable from the actions, or process, of IVF. Focusing on the ‘*process*’ seemed to help manage a potentially difficult situation where her hopes were raised then dashed (see chapter 7). Additionally, the approach she saw as best changed in response to her experiences.

Emotional responses were seen as controllable, though requiring work to achieve the required reaction. More work was required with time and when encountering failure or disruption to expectations created by previous experience. Strategies could be changed to maintain the desired outcome of emotional control.

### **6.1.3 Section discussion**

Participants discussed emotions as a choice, and one element of fertility treatment that was clearly under their own control. Participants attempted to manage their emotions and behaviour towards what they saw as the best way to behave, though this could get harder over time. Stress and emotion were not a response to participants’ experiences, but were evaluated themselves alongside perceptions of infertility and treatment, reflecting the Self-Regulation

Model (SRM) concept of emotional representations of an illness and management towards those goals (Leventhal, Brissette & Leventhal, 2003).

An important underlying factor of emotional representations seemed to be the perceptions of the negative impact of stress on fertility. This reflects an association that appears to remain strong in popular perception (Lampman & Dowling-Guyer, 1995). Lord & Robertson (2005) found that 46% of their sample attributed their infertility to stress, though empirical support for a connection is weak and equivocal (Anderheim, Holter, Bergh & Möller, 2005; Boivin, Griffiths & Venetis, 2011). Perceived links between stress and physiological health have been identified in other areas like heart disease (Senior, Smith, Michie & Marteau, 2002). Acknowledging stress might mean accepting responsibility for treatment failure, in that efforts to control stress have been unsuccessful. Infertility related stress might be harder to acknowledge if it is seen as impeding financially and emotionally costly treatment (Edelmann, Connolly & Bartlett, 1994).

In addition to avoiding negative effects of stress, participants tried to ‘stay sane’ and ‘stay positive’. The latter may reflect a general growth in positive thinking in the popular (Ehrenreich, 2009) and psychological literature (Folkman & Moskowitz, 2000; Snyder & López, 2002). Frank (1998) suggested that stories of gains or growth occurring during a health challenge are expected or desired by others, to mitigate the impact of the health threat. Infertility research has identified gains such as improvements in the marital relationship, or spiritual growth (Abbey & Halman, 1995; Lee, Hoi Chic, Chan, Chan & Ng, 2009; Repokari et al., 2007), but less on positive thinking. Callan and Hennessey (1988) found that adopting a positive attitude was the major strategy adopted by the IVF patients in their sample. While stress might be a neutral term in psychological research, acknowledging emotion and stress was meaningful for participants. Some responses were seen as more desirable than others. The current research suggests that ‘stress’ might have negative connotations for people undergoing fertility treatment. Though the meaning of infertility has received attention (Friese, Becker & Nachtigall, 2006; Glover, McLellan & Weaver, 2009; Silva & Machado, 2008), the meaning of stress to people encountering infertility has not. The implications of a desire to appear positive might be a valuable area for research, too.

This theme examined how participants talked about choice and control of emotions during fertility treatment, and linked it with the concept of emotional representations from the SRM. The next theme explores how participants’ drew emotional understandings of fertility treatment from their social environment.

## 6.2 Comparing with other patients

Participants made observations of the emotional responses of other fertility patients, shaping their perceptions of the right ways to behave. Though the men in this study made comparisons, the women made many more, so the first sub-theme focuses on the women's comparisons of their treatment responses with other patients'. The second sub-theme concentrates on two perceptions of learning about stress from others, firstly, how the women suggested that the difficulties of fertility treatment were acquired from interactions with others, and secondly how men used others' difficulties to normalise their own. The analysis is related to relevant literature at the end of this section.

### 6.2.1 'I'm fairly positive compared to a lot of other women': Coping better

Accounts of friends, family, and other clinic patients pursuing treatment generated largely negative stereotypes of them being stressed, anxious, and obsessive about treatment. These acted as a warning about how not to behave, and allowed participants to compare themselves favourably with others. Judy described being unable to '*relate*' (1; 9.29) to the problems a friend encountered during treatment, despite going through similar experiences:

*In fact, it was funny because my friend who went through infertility and who went through IVF, she kind of warned me that, you know, IVF would be so much more intense than IUI [intrauterine insemination] and for me, I was more worried about the physical aspect, like how many shots I had to receive and all of that. (Judy 1; 5.12-15)*

Judy contrasted her worries about the physical aspects of IVF with other's more emotional concerns about how '*intense*' the process was. She implied that she had little in common on an emotional front with her friend, though she gained '*so much information*' (Judy 1; 5.2) on practical aspects from their interactions. Natalie set herself apart from a negative '*template*' of IVF patients:

*I do have a friend who's going through it now and who just got pregnant via IVF and she was sort of the template of what I didn't want to be, she was way too invested. (Natalie 1; 8.10-12)*

She saw the emotional '*investment*' of her friend as harmful, to be avoided, and producing a potential for stress. Her mention of a '*template*' reinforces the earlier point about forming emotional representations independently of response to treatment. Natalie contrasted others '*tremendous anxiety*' with her own pressing physiological reason for treatment; her age:

*I think it's also the benefit of age. I mean granted they're dealing with a range of people, but I'm little towards the higher end at 39, you know, lots of 31 year olds walking in there with tremendous anxiety um and, as I say, you know I'm at the front of the line, right? He who's closest to errr to menopause goes first! (Natalie 1; 5.28-6.1)*

Her age has two advantages. She is closer to menopause, suggesting the presence of physical impediments to conception and establishing a physiological claim to treatment, which can be difficult, as infertility has no obvious symptoms. Second, her age makes her more resilient to anxiety that occurs with younger women. She suggested that distress (or anxiety) might be used as a claim for treatment attention, rather than a response to objective medical requirements. She distanced herself from involvement in the situation by referring to 'he' who is closest to menopause, rather than herself. Humour has been found to be a way of distancing oneself from potentially threatening, emotional health situations (Francis, Monahan, & Berger, 1999).

Contact with other patients seemed to build a picture of undesirable responses. Cathy's experience contrasted with Judy's and Natalie's because at her baseline interview she had not '*really spoken to anybody who has had any experience of it [treatment]*' (Cathy 1; 8.21-22). Allan (2007) suggested that fertility patients in the United Kingdom seem more isolated than those portrayed in the literature originating from the United States, though this seemed to be largely due to Cathy and Chris receiving treatment overseas, not at a local clinic, rather than inherent cultural differences. After attending the clinic for her first cycle and meeting other patients staying at the same hotel, she referred to others' experiences:

*Because it was their third go, for both of them, the women were in, you know, their forties, they had, you know, serious problems, umm, things that were wrong, whilst I'm not in that position, which I'm thankful for, but at the same time it was devastating to see them have to got through that, and obviously I know that for them it didn't work out this third time, either, and it's really sad, in a way. So it's kind of that in the back of my mind that I hope I don't end up like that. (Cathy 2; 6.10-11)*

The other women were older and had '*serious problem*', which differed from Cathy's situation. She still saw them as a negative example of a potential future self, which seemed, for all the women, to contribute to a desire to remain emotionally healthy.

Natalie described herself as dealing with infertility well, and described her difference from the negative ‘*template*’ she attributed to others. During this account of undergoing acupuncture she emphasised that ‘*of course*’ she was different to other patients:

*I guess he [acupuncturist], you know, you know based on his account by the time people go see him, he is the man of last resort, as it were. And, of course, I didn't fit the profile of people who walk through the door (Natalie 2; 11.4-6)*

Though she tried acupuncture as she suggested many other patients do, she described this as her best effort to ‘*pull out all the stops*’ during her final treatment cycle (Natalie 2; 11.21) rather than exhausting the ‘*last resort*’ as other patients do. She differentiated herself from other patients based on the acupuncturist’s account, rather than her own, suggesting that others, especially expert, professional others, see her the way she does. At the end of the interview, she apologised for being ‘*atypical*’ (14.3) again reinforcing how she distanced herself from others.

Judy described successfully coping with experiences suggested to be difficult for infertile individuals, like being around children (Collins, Freeman, Boxer & Tureck, 1992; Stanton, Tennen, Affleck & Mendola, 1992):

*So I think it's given me a certain freedom of like where other IVF patients feel like they can't deal with [it]. (Judy 2; 16.2-3)*

Others ‘*can't deal with it*’, which limited them, but she was free, able to pursue her interests and activities. The perception of others comes from her own experience, as well as reflecting descriptions in the literature, although she describes herself as differing from these.

Disassociating themselves from an infertile identity seemed a way to avoid unwanted sympathy, particularly with treatment failure:

*The more people we have to tell that um, you know, it didn't go well. And then the more sympathy and I can't bear it, really [laugh]. (Cathy 2; 10.23-24)*

Others knowing that they were receiving treatment created an obligation to pass on updates. Sympathy reinforced her sense of failure, and being continually distressed might encourage continual unwanted sympathy. Natalie seemed to avoid sympathy by using humorous descriptions, like ‘*we shower every day we shoot up every day*’ (Natalie 1; 1.27), referring to treatment as ‘*Project Weeble*’ (1; 6.28), and her husband’s unsuccessful attempt to give an injection as like ‘*harpooning a whale*’ (14.22). Humour has been found in male accounts of



illness to dispel tension and be treated as normal (Hilton, Emslie, Hunt, Chapple & Ziebland, 2009). Natalie used humour frequently, which might be a way of influencing the way others respond to her and reducing expressions of sympathy (see Francis et al., 1999).

Cathy and Natalie described themselves as outsiders, observing their own responses objectively, rather than being like other infertility patients and immersed in the process:

*Interested in seeing what this is going to be like and how it does affect us. (Cathy 1; 8.29)*

Rather than the prospect of treatment being worrying, Cathy formulated it as interesting. Their responses, how it ‘*does affect*’ them is unknown, not unavoidable difficulty. Natalie called her experience a ‘*discovery tour*’ (1; 8.23). The objective terminology distanced them from poorly coping others and perhaps their own potential worries. Natalie emphasised her distance from other patients, describing her perceptions of the clinic waiting room as a ridiculous ‘*parody*’:

*I found the waiting room to be a parody, I mean I really thought it was, you know, shits and giggles central because it was just. It was like “Oh my god, if someone at 30,000 feet was filming this they’d be like [in a whisper] what are you doing? What are you people doing?” (Natalie 2; 8.6-9)*

She described the situation as humorous, ‘*shits and giggles central*’, rather than stressful. The outsider perspective of ‘*someone at 30,000 feet*’ seeing the situation objectively reinforced her own objective position. She appeared to be using ‘*you*’ to refer to others, rather than including herself, focusing on others’ emotional reactions rather than the action of pursuing fertility treatment itself, which includes her.

The women portrayed other fertility patients unfavourably, based on their own observations, emphasising others’ desperation, investment and ‘*poor*’ emotional reactions. These comparisons seemed to shape several ways of regulating the women’s experiences. First, they provided desired ways to respond to fertility treatment, contributing to emotional representations of what fertility treatment meant. Second, they highlighted their own better coping through social and temporal comparisons. Third, they appeared to regulate their identity, with poor emotional responses strengthening negative perceptions of what it meant to be infertile, and their self-described better responses allowing a more positive, and perhaps ‘*less infertile*’ identity.

## 6.2.2 'You pick up on people's anxieties': Learning about stress

Participants learned from others about stress in two different ways. First, that stress about treatment could be learned from others. Second, others' difficulties were a way of normalising what might otherwise be seen as difficulties. The former tended to be a female perspective and the latter, a male view. Natalie described the possibility of 'pick[ing] up' anxieties from other patients:

*You sort of pick up on people's anxieties in the waiting room or in other situations with friends. Wow, should I worry about that, like. Oh my God, it never occurred to me.*

*(Natalie 2; 9.20-22)*

Natalie wondered whether she 'should...worry about that', implying that potential worries about fertility treatment were learned, rather than being an unavoidable consequence of fertility treatment. This reinforced her assertions that 'I don't see infertility as being difficult' (1; 11.13) or 'I don't think there was a lot of stress' (2; 5.22). She switched pronouns from 'you' when talking about picking up anxiety, and potentially being anxious, to 'I' when taking actions, wondering whether to 'worry about that'. Malone (1997, p. 46) suggested that 'you' could be an ambiguous substitute for 'we', or 'I' because it is unclear whether the speaker was included. The use of 'you' at the beginning of the extract makes it unclear whether she is suggesting that she did pick up other's anxieties, and thus become anxious herself, or that it is a possibility. Cathy described picking up anxiety from the other patients they met at the hotel near their clinic.

*I think their anxiety started to transfer over to me a little bit, and Chris for that matter, I don't know about Chris, but I started to feel a bit anxious. (Cathy 2; 11.4-5)*

Cathy described advantages of meeting others in a similar situation, like company and shared experiences, but also increase in anxiety, which arose from comparisons with others further on in treatment and facing potential failure. Anxiety about the process was partly shaped by the concerns (and situation) of others. Chris described 'picking up' on others' stress:

*Because it's all the people are talking about, is the process, and it just builds up pressure, builds up stress, d'you know what I mean? And you end up picking up on their stress.*

*(Chris 2; 4.28-30)*

Chris may have had more contact with other patients than the other men did, perhaps because he and Cathy were in closer proximity, and of longer duration, than other participants were,

as they stayed in a hotel near the clinic. Judy resisted joining an infertility support group describing concerns about the impact of interacting with other fertility patients:

*I feel like I'm fairly positive compared to a lot of other women. And so I almost wonder if they'll bring me down [laughing], um so um or or the other thing is I'm not sure whether I'd have that much compassion on them. (Judy 1; 9.24-27)*

Judy's generally positive attitude might be affected by interacting with others who are less positive, and might 'bring her down'. These extracts support the argument that emotional responses can be seen not as a response or outcome of the process, but arrived at in their own right, in this case being learned from other patients.

The men used others' situations to normalise what might otherwise be seen as difficulties. Matt worried that he was going to become an older father than he had planned (see section 7.1.1). He drew on the example of his sister, who had recently had a baby, to reduce the impact of this concern:

*You know, she's older than me, and I figure, well if they can do it, I guess I can do it, too. Because her husband is going to be (.) sixty, so. (Matt 2; 5.22-24)*

The comparison provided reassurance that he was not too old to be a father. A concrete example helped, perhaps more so because his brother-in-law was significantly older than Matt, who was in his mid-40s, which provided a stronger comparison than if there was only a few years between them. Though Chris generally suggested that he did not find fertility treatment difficult, during his second follow-up interview, he had started to worry about the possibility of treatment not working. He downplayed his concerns by suggested they were normal:

*But I'm sure most people have, most people in the back of their heads have the same worries, I suppose. It's a very ahh very emotive and highly-strung situation, isn't it? (Chris 3; 6.28-30)*

He enhanced the comparison by including 'most people', and by expressing it as 'very emotive' and 'highly-strung'. This contrasts with extracts in section 6.1.1 where Chris defended himself against being seen as unrealistically optimistic during his baseline interview. His concerns about overall treatment failure increased as they experienced failure. He moved from justifying his optimism to justifying his concerns, and comparisons with others justified his worries as normal in an extreme situation.

These two sections showed participants making a variety of comparisons. Women portrayed themselves as coping better than others did, without the distress, investment and anxiety that others' experienced. They suggested that it was possible to learn anxiety from others. Men used others' difficulties to downplay their own concerns as normal.

### **6.2.3 Section discussion**

Infertility research often observes how infertile individuals compare themselves with fertile norms, identifying issues like role failure and stigma (Gonzalez, 2000; Miall, 1986). Here, the women, particularly, made many comparisons with other fertility patients rather than fertile others. Downward comparison has been found to mitigate the perceived threat of a diagnosis, by comparing with worse off others, in health areas including heart disease risk (Senior et al., 2002), vitiligo (Thompson, Kent & Smith, 2002), osteoarthritis (Turner, Barlow & Ilbery, 2002). Though the women in this study compared their physical situation favourably with other patients', they were more attentive to how they were managing their emotions better than others were. Stanton (1992) found that infertile women avoided downward comparisons, speculating that they related to their 'shared fate' and avoided unfavourable comparisons, whereas women with breast cancer were found to favour them, even against women who were coping well (Stanton, Danoff-Burg, Cameron, Snider, & Kirk, 1999).

The women differentiated themselves from concepts common in the literature, for example, avoiding children or pregnant women (Daniluk, 1997; Glover et al., 2009) and being consumed or obsessed by treatment (Greil & McQuillan, 2004). This might have been to distance themselves from being labelled with infertility stereotypes and generalisations (Sandelowski, 1994), and being "desperate and helpless" is a pervasive stereotype in the literature (Earle & Letherby, 2007, p. 234). Letherby (1999) highlighted alternative perspectives of women's experiences, like lack of distress, and the "multi-dimensionality" (p. 364) of their lives. Though generalisations about particular conditions may be useful, it might be more accurate to search for different types of responses. Moskowitz and Wrubel (2005) interviewed HIV+ men, but instead of producing a single type of response to their situation, they identified five different categories, which were partly based on how these men responded to other HIV+ men. A similar classification might be useful for fertility patients, to identify potential ranges and types of response.

Comparisons contribute to identity formation (Tajfel, 1978). In the SRM, identity is related to illness symptoms, which are often minimal with infertility. For these participants, an infertile identity was linked to struggling emotionally, which shaped their emotional representations of fertility treatment, and their own behaviour. Sandelowski (1994) mentioned that acting as if infertile (pursuing treatment) does not necessarily mean accepting oneself as infertile. Radley and Billig (1996) argued that an ill person must display a certain amount of normality to be worthy of receiving treatment. Work in infertility has suggested that patients must appear 'sick' enough to require treatment, which is problematic if there are no obvious physical symptoms, and yet healthy enough to be parents, for example, that their relationship has not suffered from their difficulties in conceiving (Jones & Hunter, 1996). Some patients may draw on emotional distress to validate treatment, whereas others may draw on a physical problem, like age, or a particular condition, though the latter becomes difficult with unexplained infertility.

The women made temporal comparisons, looking forward to others further along in the treatment process (Aspinwall, 1997). Studies investigating self-regulation tend to focus on individuals attempting to regulate themselves back to a previously preferred state. Temporal comparisons with past-selves have frequently been studied in older adults (Suls, Marco, Tobin, 1991), but also in younger adults with health problems like back pain (Osborn & Smith, 1998) and schizophrenia (Dinos, Lyons, & Finlay, 2005) and identified as ways of establishing a favourable identity in the present. Affleck and Tennen (1991) found that women tended to feel that over time they had learned to cope better with infertility. With infertility, the previous state is not the desired one as individuals and couples wish to attain pregnancy and parenthood. Individuals further ahead on the temporal trajectory of treatment are those for whom treatment has not worked, which is also an undesired state. Individuals undergoing fertility treatment may therefore lack positive temporal comparisons, and references to an "anticipated future" (Davies, 1996, p. 581) drawn from comparisons with others perceived as further on in the process may tend to be negative, being those facing financial or emotional challenges, or treatment failure.

Downward comparisons with others further on in treatment might aid current adaptation (Tennen, McKee, Affleck, 2000), and provide a warning of future situations to avoid from others' experiences. This suggests that participants were pro-actively coping, to avoid stressful situations occurring (Coyne & Gottlieb, 1996), but could be viewed in an SRM context as controlling themselves to achieve preferred goals (financial and emotional health,

for example). Anticipatory coping provided another future focus, in preparing for a reoccurrence of personal experiences, like miscarriage (Aspinwall & Taylor, 1997), which has been found in other studies of infertility experiences, with men on an online discussion forum (Malik & Coulson, 2008b). The men in this study barely mentioned other patients, though when asked, men were found to be almost twice as likely as women to feel that they are coping better than same-sex others (Stanton, 1992). The lack of explicit attention to comparisons when men are allowed to talk about the experiences that are important to them suggests that comparison may be less relevant to (these) men. Their experiences of IVF focused on their partner, and this is explored in the next theme.

### ***6.3 Men's perspectives within the couple***

Men's accounts were focused on their experiences as part of a couple, and the greater demands they perceived on their partner creating constraints on how they expressed themselves. The first sub-theme explores how the men tried to balance their own difficulties against their partners' experience. The second sub-theme discusses men's experiences of giving injections, which stood out as a unique and significant experience when men's IVF experiences are usually described as second-hand through their partner. The third sub-theme explains how men attempted to shape their responses to the female favoured approaches.

#### **6.3.1 'You see how hard it is on her': Focusing on the woman**

Men expressed strong emotions about their experiences, but minimised them in relation to their partners' greater physical and emotional burdens of appointments, receiving injections and experiencing hormonally induced mood swings. Matt downplayed his difficulties compared with Judy being in a 'down mood', and the physical impacts of her being 'in pain' and 'dizzy or nauseous':

*(3) Well... I, I mean, I would have to say seeing her go through the struggles is what bothers me the most, in the sense of, not in some cases not being able to either comfort her, or not knowing how to comfort her, when she either if she's in a down mood, or she's in pain, or she's feeling dizzy or nauseous, you know, I'll try to say "what can I do, what can I do?" and you feel a little bit out of control at that point. (Matt 1; 4.19-23)*

His distress is apparent, indicated by the three-second pause before he spoke, along with his repetition of 'what can I do, what can I do?' He mentioned 'feeling ... out of control', though the switch from 'I' to 'you' distanced him somewhat from his emotional response (Malone, 1997). His account suggested that he found the situation frustrating, a struggle, and he hated

seeing his wife suffer while feeling helpless to stop it. His own feelings and '*struggles*' were lessened as he concentrated on '*comfort(ing) her*' and working out what support to give. He used '*bothers*' for himself but '*struggles*' for her, which imply a disproportionate burden. Her needs seemed extreme when he described himself as '*not being able to comfort her*', but also that he was running out of strategies to provide comfort. He qualified his sense of loss of control with '*a little bit*'. It may have been hard for Matt to express negatives without compromising his positive identity (section 6.1.1).

The other men expressed distress in response to their partner's difficulties. Jeremy explained that '*it's hard because you see how hard it is on her*' (2; 1.24) despite Natalie, in her interviews, downplaying the impact of the process on her. As Matt did, Jeremy used 'you' when talking about his response to Natalie's difficulties, distancing himself from expression of emotion. Chris defined his role during IVF as '*keep(ing) her calm*', which sounded overwhelming as he described Cathy's stress becoming '*bigger and bigger and massive and massive*':

*I'm frightened of Cathy getting err; I'm a bit wary of Cathy getting really upset and then that causing problems in itself. Do you know what I mean? Like she gets stressed out and it becomes a bigger and bigger and massive and massive thing, and I'm trying to keep her calm and, and just generally that's where I am. (Chris 2; 1.18-21)*

Chris used a strong term - '*I'm frightened*' - but quickly changed this to '*I'm a bit wary*', which is much less strong. Like Matt, he focused on his partner and her needs rather than expressing his own. Chris was the protector, an established male role (Clare, 2001). He described himself as responsible for Cathy's well-being, and that of other patients he met during their first IVF cycle, explaining that he '*felt quite (3) felt quite protective over them, in a way*' (Chris 2; 9.12). During his last interview, he explained that he wanted to '*cocoon her [Cathy] away from the stress*' (3; 3.15). Being responsible for keeping others calm provided him a clear role unrelated to his own potential distress.

An exception to men downplaying their own distress relative to their partners occurred during Matt's follow-up interview, when he described himself as feeling '*more down than she did*' after a recent treatment failure:

*But this time, for some reason this time I just felt, I think I felt more down than she did in that sense, so, it was different. (Matt 2; 1.15-18)*

He acknowledged difficulties, though they were limited to ‘*this time*’ rather than being general. Judy also mentioned this reaction, describing it as ‘*unusual*’:

*I think the last time it seemed to affect my husband a little more than me, um, which is unusual.* (Judy 2; 4.25-26)

Both seemed to expect her distress to be generally greater, though it was unusual for one of the women to comment on their partner’s emotional response, perhaps because the women tended to focus on the social rather than the couple. Judy was the only woman who reflected on the impact her experience had on her husband.

The disparities of treatment demands were a difference in experience that the men acknowledged, as Jeremy did in his baseline interview:

*With the I- the appointments it affects Natalie more than me, the number of appointments she has to go to.* (Jeremy 1; 2.16-18)

The woman is required to fulfil most of the medical tasks, whereas the demands on the man were negotiable: they can choose whether to attend appointments. Matt chose to attend Judy’s appointments:

*And a lot of our friends are kind of amazed it’s like he was able to. A lot of them have gone through the fertility treatment. “He was able to go to all your appointments? He was able to be here and here and there?” They were just kind of amazed because husbands may or may not have to go.* (Matt 1; 8.25-28)

His involvement was positioned favourably against other husbands’, and marked out as remarkable. Chris emphasised the physical burden on Cathy:

*I think this next ten days is going to be a bit more, with the injections and stuff like that I think, um think she’s going, it’s going to be a lot harder on her than it would be for me to just have a little bit drawn away.* (Chris 1; 6.22-24)

Despite needing to undergo surgical sperm retrieval, he evaluated the process as more difficult for Cathy, perhaps due to the longer duration of intervention for her. He valued physical resilience in himself, one of the factors associated with a masculine identity (Gough, 2006).

With the central role the women had during treatment, the men mentioned other elements of their experience that might often be overlooked, like bearing the brunt of their partners’ mood



swings. The perceived effects of the hormonal fertility medications on mood were a tangible, physical difference between the couple. Jeremy mentioned this several times:

*Jeremy: It does effect Natalie's mood, she is has much more swings of emotion, which is interesting to deal with. I mean you know why she's not feeling good, why she's temperamental, but umm there's not much she can do to change it, so*

*Elly: Is that hard for you just?*

*Jeremy: Yeah, a little, but um I mean you know why it is, so that makes it easier, so. She's not really that upset with you; it's just the drugs. (Jeremy 1; 1.18-23)*

Again, he downplayed the difficulty of the situation, describing it as 'a little' hard, though it was significant enough for him to mention when he tended to generally talk about practical matters. He suggested here that as Natalie's moods were outside her control, '*there's not much she can do*', and he was left to '*deal with*' it, though being able to attribute Natalie's moods to '*the drugs*' seemed to ease the situation. His use of '*you*' here downplays potential impact on him, distancing himself from Natalie's '*upset*'. Matt described similar experiences:

*But even with those times or when she gets really moody and things, I have, I always tell myself "things will work out", umm, it's not, she's not angry at me, she's not pointing fingers at me. (Matt 2; 7.2-4)*

Matt explained that they both '*attribute*' Judy's mood swings to '*the meds that she's taking, the hormones*' (Matt 1; 2.18-19). Like Jeremy, identifying a reason for their partner's '*temperamental*' behaviour (that was not due to him) seemed comforting.

### **6.3.2 'I'm going to help her with the injections': Being part of it**

Another unique experience for the men was giving injections to their partner, as IVF involves multiple injections of hormonal medications. All participants described their medication and injection experiences; it was the most significant medical aspect during the interviews. It was especially so for the men, as they tried to carry out this unfamiliar task correctly, with minimal discomfort to their partner. Jeremy's tone of voice changed while talking about the injections, indicating them as an important part of his experience (Smith, Flowers & Larkin, 2009). His voice was mostly measured and unemotional, but he used a more natural, faster paced tone when talking about the injections, and gave an extensive (for him) account:

*Once again, Natalie does not like needles, so she's getting six shots a day, and I'm giving them to her. So, I'm trying to make sure I give 'em to her with the least amount of*

*discomfort and there's one in particular, I'm not good with drug names, but um that it is a lot of drug, and it's a fairly big needle and I that one in particular she gets very uncomfortable with. So, and sometimes I feel bad, because like, one time I did something wrong that there's been a bruise now at the injection side for the last couple of days, and that happens, I mean, it's a normal adverse effect, but... (Jeremy 1; 3.3-10)*

He drew attention to Natalie's dislike of needles and the scope of the injections 'six shots a day', 'a lot of drug', 'fairly big needle'. Not only was Natalie experiencing something she found uncomfortable and distressing, but he was responsible for doing it. Despite his best efforts, he did 'something wrong' and caused her pain and a long-lasting bruise. The emotional evaluation of 'I did something wrong' contrasts with a more analytical analysis 'it's a normal adverse effect'. Despite that analytic evaluation, the incident was significant enough for him to remember and recount, perhaps because he was trying to 'give 'em to her with the least amount of discomfort' and failed. Jeremy's expression of emotion about this topic contrasts with the rather detached, objective way he generally talked about their infertility experiences.

Jeremy talked again about injections during his follow-up interview, though their treatment was almost over:

*A lot of needles, a lot of shots, and Natalie really doesn't like shots. And it was very frustrating to give her shots because you knew it made her very uncomfortable. So you try to do the best you can. There are a lot of shots. <unclear> Then after the procedure you give her a shot of progesterone, which was almost worse because the progesterone is a very thick shot and means you need a bigger needle, you have to be much more careful. Ah, I mean it's a visibly thicker needle. (Jeremy 2; 1.12-20)*

He repeated 'a lot' and Natalie's dislike of injections, underscoring the significance. He explicitly expressed emotion, saying 'it was very frustrating', which was unusual in his account. The visual description in the last sentence provides emphasis. He found this an unpleasant experience, but it seemed difficult for him to acknowledge this too openly because she was the one receiving 'lots of shots', 'thick shot', 'bigger needle' and he was simply giving the shots. This was noticeable in his use of the second person throughout the extract: 'you knew', 'you have to be much more careful'. His concern contrasts with Natalie's light-hearted account:

*Sometimes he forgets his own strength and he bruised me the other day; he was like "I*

*could tell I was bearing down a little too hard" and I'm like "you forget your own size" [laughing]. I'm no shrinking violet, but sometimes so, you know, and those are the moments of levity when I'm like "Hi, I'm not a whale and you're not harpooning me, OK?" (Natalie 1; 14.19-23)*

Her humorous account of ‘*a moment of levity*’ and the whale-harpooning metaphor contrast with his bleak ‘*getting it wrong*’. He was ‘*trying*’ to get it right and yet she suggested he ‘*forgets his own strength*’, which is not getting it right. If Natalie’s light-hearted version was the main story, it might be harder for him to express his uncomfortable experience. The divergence between their accounts, and Jeremy’s more explicitly individual focus underscored this as an area he found stressful, reinforcing the benefits of carrying out individual interviews.

Chris talked about injections, too, explaining that he had never ‘*stabbed*’ his partner before.

*And um we're starting the injections tonight, so I'm going to have to help her with the injections and err. You know, hold this space I don't know. It might be very emotional for me, I don't know, I've never I've never stabbed my partner before [laughing] with a needle, so we'll see! (Chris 1; 4.24-27)*

‘*Stabbing*’ implies assault and inflicting pain. No matter how he felt, ‘*it needs to be done, doesn't it?*’ (Chris 1; 9.3); in this case, he needed to minimise his own concerns to do so. In his follow-up interview, Chris mentioned relief after his concern that Cathy would get ‘*all bruised*’ from the injections was not fulfilled (Chris 2; 11.17). Matt mentioned the ‘*little bruises*’ that Judy acquired from the injections:

*But it's sad to see her belly's got the little bruises on either side. So. I say "ugh I'm sorry, I'm sorry", and she yells "I know you can't help it", it's like, "OK, I feel bad". (Matt 1; 7.23-25)*

Matt’s mention of ‘*I feel bad*’ and apologies to Judy touched on similar concerns to Jeremy and Chris about responsibility and causing harm. Mentioning her ‘*little bruises*’ and the way she ‘*yells*’ at him, tie strong reactions to her that seemed more justified, as she has physical consequences, than his feelings about ‘*it's sad*’ and ‘*I feel bad*’. Neither Judy nor Cathy appeared to find the injections as difficult as Natalie did, and suffered few side-effects, which perhaps explains why they were more significant for Jeremy than the other men.

Giving the injections was an available active role for the man when most of the treatment and appointments focus on the woman. Matt valued this opportunity and worked hard at it, not going to just one class but doing ‘refresher courses’:

*I don't want to hurt her, I want to make sure I do it right, so, going through class that they taught, ah, one class, and then going through some of the refresher courses. But you know, basically I try to be on the positive, and say this is what we need to do, try to reassure her that, OK, this is what I'm doing, this is why I'm doing it, and everything else. (Matt 1; 7.11-15)*

Like Jeremy, he was concerned with ‘do[ing] it right’. Though the injections themselves might be quick and only be needed for a few weeks, the men described thinking about them more often, developing the ‘best’ way to do it, worrying about the effects of causing pain or bruising. Natalie described Jeremy saying ‘he's like “I have a new technique” and he'll talk about his new technique’ (1; 14.25-26). Giving injections was a difficult experience, but it was something that needs to be done and a role available for the man, considering that his partner must fulfil most of the medical tasks. Because their partner bears the physical impact of the injections, men’s experiences can appear relatively unimportant.

### **6.3.3 ‘I need to support her in the now’: Dealing with things the female way**

Men described their attempts to conform with their partners’ desired approaches, though they did not suggest that their partners should reciprocate this attention. Matt highlighted how he has learned, through reading and therapy during his divorce, to overcome the ‘wrong’ ways that men behave:

*So, see, that's something I'm learning too. Again, not just with guys have a tendency to want to fix things, to do this, but to sit here and be a listener, and to be able to understand where she's coming from and and acknowledge that OK, you are feeling this and it is real, you know, how do I support you? (Matt 1; 3.11-14)*

Matt emphasised how he has learned to change the way he dealt with the situation and their responses. He diminished men’s ways of responding, where they ‘just’ want to ‘fix things’, which portrayed ‘guys’ as having a mechanical or practical response. Instead, he learned to focus on her feelings and ask her how she wants to be supported, which is a more typical female focus. Chris emphasised his sensitivity to Cathy’s wishes:

*I tend to be a sort of person that will tell people what it is, but Cathy's more in the way of I don't want too many people to know what is happening. A couple of times I made a few*

*mistakes of telling too many, the odd people she didn't want to hear. From that point on I said, 'that's it, I'm not saying another word'. (Chris 2; 6.6-10)*

He prioritised her need for privacy over his own inclination to 'tell people'. He classified his normal approach as a 'mistake', and complied with her wishes. He seemed to value knowing and understanding Cathy, reinforcing his protector role. This contrasts with general representations of male/female communications where women tend to share with their social circle more widely than men (Hjelmstedt et al., 1999), which may reflect generalisations that do not apply to every man or woman. Chris prioritised Cathy's needs and way of responding over his own.

The men seemed to endorse 'female' ways of dealing with important issues, even that it would enable them to become an improved person, as Matt suggested. It has been argued in the literature that female ways of coping are often taken as the norm or standard, and men are assessed by how much they measure up to these (Jones & Hunter, 1996). Attention to their partner's needs was a way to be sensitive and supportive to their partner. Doing so might mean minimising their own needs, like for support from the wider community.

#### **6.3.4 Section discussion**

The couple was the most important relationship in the men's accounts, reflecting the established picture of gender and relationships where women resolve issues through discussion with their social network, and men confide largely in their wife (Hjelmstedt et al., 1999; Jordan & Revenson, 1999). The couple focus emphasised the disparity in individual experiences between the woman, who attended multiple appointments, received injections, medications and underwent surgical procedures, and the man, who largely observed and supported. Research frequently suggests that infertility is less distressing for men (Abbey et al., 1991a), and that they avoid expressing emotional responses (Peterson, Gold & Feingold, 2007; Thompson, 1997). Here, the men expressed strong emotions, like feeling 'out of control' or 'frightened', and the desire to have children. The stereotype that men do not find infertility distressing or parenthood desirable has been challenged in other recent research (Fisher, Baker & Hammarberg, 2010). Malik and Coulson (2008b) studied men's interactions on an infertility discussion board and found that, as well as seeking information, which is often regarded as male support, men vented about their experiences and expressed grief.

The men in this study did not avoid expressing their emotion, but downplayed and minimised it in comparison with their partner's more identifiable difficulties. Men's fertility treatment

experiences appeared less significant in comparison with women's, which has been found in other infertility research (Jones & Hunter, 1996; Robson, 2002; Webb & Daniluk, 1999). Robson (2002) illustrated this in a case study of a man whose wife had undergone a foetal termination, and described how he found it difficult to express his distress in light of her greater physical involvement with the pregnancy and termination process. Assumptions about relative distress may be reinforced in social settings. Malik and Coulson (2008b) found that men felt family and medical staff expected them to take bad news 'on the chin' (p. 24). Thompson (1997) draws on the concept of 'disenfranchised grief' (p. 78): grief that is not recognised or legitimated. Infertility and fertility treatment could generate a similar disenfranchisement in men.

Men experienced unique issues during treatment: difficulties in identifying useful ways to help their partner, dealing with their partner's (medically induced) moods, and giving injections. These seem easily overlooked in research as unique experiences, despite appearing central to the man's experience of treatment, as attention to the process and experience in terms of the woman's body are prioritised (Throsby & Gill, 2004). The men in this study spent time and effort on getting the injections 'right', and were keenly aware of making mistakes and causing pain and bruising. Some research has identified these unique male experiences, and others like the potentially embarrassing experience of producing sperm (Carmeli & Birembaum-Carmeli, 1994; Throsby & Gill, 2004); and teasing from friends (Throsby & Gill, 2004). Chang and Mu (2008) found men with their wife hospitalised for ovarian hyper stimulation syndrome, though apparently in a less severe position than their partner, experienced multiple stressors, like being worried about their wife, while taking on multiple caring roles for her, their children and home, and visiting her. Men may bear additional financial burdens if their partner stops working to focus on fertility treatment (Carmeli & Birenbaum-Carmeli, 1994).

Men's distress is often focused around their partner's suffering (Abbey et al., 1991a; Greil, Leitko & Porter, 1988) and their need to support their partner (Greil et al., 1988; Malik & Coulson, 2008b). The men tried to be responsive to their partner's wishes and needs, but often found it difficult to find the best ways to do so. When interacting with their partner, these men tried to act on the 'best' ways of responding. In summary, men seemed to have limited scope to express their situation and concerns, and their expressions of emotion about treatment. The contextual constraints on women's coping have been noted (Benyamini,

2009). Men are constrained, during fertility treatment, by the disparate physical burden of treatment on their partner, who is frequently their closest confidante.

#### ***6.4 Chapter Summary***

This chapter explored emotional representations about fertility treatment, and how they were shaped by gender, and individual and social contexts. Men and women endorsed the desirability of working to retain good emotional health and ‘be positive’, while stress and anxiety were perceived to have negative effects on fertility. Emotions were not seen as an unavoidable response to infertility or treatment, but something to be controlled to achieve the best response. Men and women’s emotional representations seemed shaped in relation to different social contexts. Women positioned themselves in comparison with other fertility patients that they saw, as they felt, responding poorly. Men focused on their partner, and seemed limited in their expressions of emotion due to the relatively larger burden on their partner.

The SRM proposes that individuals develop an emotional representation of their illness, which contributes to regulation of emotional outcomes (Benyamini, 2009). Emotional representations are often ignored, as they are difficult to separate from emotional outcomes, which have been the focus of infertility research (Benyamini et al., 2004). Despite the controlled and contextual emotional representations that minimised stress and emotion, participants still valued the goal of having a child and were taking steps to do so (having IVF). Others have found that individuals may simultaneously minimise an emotional threat while implementing behaviours to moderate it (Senior et al., 2002). The next chapter explores how participants went on to tackle infertility as a problem, with IVF as the solution.

## **7 ‘We decided to get aggressive with it’: Solving the problem of infertility**

The theme of this chapter is how in vitro fertilisation (IVF) was approached as a practical solution to infertility, with the objective of making the best decisions to reach the desired goal of a baby. This chapter explores two themes. The first theme explores participants’ focus on objective decision-making and their preference for action, and specific concerns about wasting time and money. The second theme looks at how participants emphasised planning and acting together to achieve a mutually desired goal, and where emergence of an individual focus in accounts indicated differences of opinion and experience, and stress. Table 5 gives an overview of the themes and sub-themes in this chapter. The themes in this chapter mostly show temporal continuity rather than change over time, with examples of specific stressful events at particular time points.

(Title extract Jeremy 1; 1.9)



**Table 5 Table of Themes: Solving the Problem of Infertility**

<b>Theme</b>	<b>Sub-themes</b>	<b>Extracts</b>	<b>Participants in sub-theme data</b>
<b>Making decisions and taking action</b>	<b>'It's such a conscious decision': Making the right choices</b>	<p>It's such a conscious decision (Chris 2)</p> <p>This is how we have to do it (Jeremy 1)</p> <p>You just kind of find a way and then you do it (Natalie 1)</p> <p>Being uncertain of whether or not we're wasting our time (Judy 1)</p> <p>The timing isn't perfect, but it's good enough (Cathy 1)</p> <p>I have to get from A to B and everything I do is like that (Chris 1)</p>	<p>Jeremy (1,2), Natalie (1, 2), Judy (1), Matt (1), Cathy (1,2,3), Chris (1,2,3)</p>
	<b>'It's expensive': Managing financial issues</b>	<p>There's financial issues with it, too. It's expensive (Jeremy 1)</p> <p>A tremendous amount of money (Natalie 2)</p> <p>We've been spending so much money (Judy 1)</p> <p>Finances have been OK, we haven't been struggling (Matt 2)</p> <p>It just creates a lot of pressure to consider. Money. (Cathy 1)</p> <p>The money would have gone. (Chris 3)</p>	<p>Jeremy (1), Natalie (1,2), Judy (1,2), Matt (2), Cathy (1,2,3), Chris (1,2,3)</p>
	<b>'Let's get on the fast track': Taking action</b>	<p>Let's get on the fast track (Natalie 1)</p> <p>We were going to try to attack the problem (Jeremy 1)</p> <p>I like keeping myself busy (Judy 2)</p> <p>What will we do next? (Matt 2)</p> <p>We're moving forward (Cathy 1)</p> <p>Just carry on with the process (Chris 2)</p>	<p>Jeremy (1), Natalie (1,2), Judy (1,2), Matt (1,2), Cathy (1,2,3), Chris (1,2,3)</p>

Theme	Sub-themes	Extracts	Participants in sub-theme data
IVF as a mutual endeavour	<p>'We're doing it together': Fertility treatment as a joint project</p>	<p>We're doing it together (Jeremy 2)  We're accepting that there needs to be a line (Natalie 1)  It's been a huge learning experience for us (Judy 1)  We'll get through this (Matt 2)  We've got each other (Cathy 1)  I just realise what a cool relationship we've got (Chris 3)</p>	<p>Jeremy (1,2),  Natalie (1,2),  Judy (1,2), Matt (1,2), Cathy (1,2,3), Chris (1,2,3)</p>
	<p>'Is this the right thing for both of us?': Diverging accounts and stress</p>	<p>Is this the right thing for both of us? (Cathy 1)  You hear people breaking up over this sort of process (Chris 1)  Natalie really wanted to finish this cycle, I was more along the lines of let's not (Jeremy 2)  We just decided why not? (Natalie 2)  I did have a miscarriage early this year, so that's what was tough for me (Judy 1)  It was hard for her when she had the miscarriage (Matt 1)</p>	<p>Jeremy (2),  Natalie (2), Judy (1, 2), Matt (1),  Cathy (1,2,3),  Chris (1,3)</p>

## **7.1 Making decisions and taking action**

Participants wished to have a child, but wanted to do so by making the best decisions. The first sub-theme explores participants' careful and practical (rather than emotional) decision-making, shaped by concerns about wasting time and money, and uncertainty about establishing the best choices. The second sub-theme focuses on the significance of the financial investment in IVF, particularly to the women. The final sub-theme looks at participants' preference for taking action, and how they preferred to be busy and occupied.

### **7.1.1 'It's such a conscious decision': Making the right choices**

Participants wanted to make the right choices, based on objective, rather than emotional, factors. They emphasised the need for logical thinking, but worried about whether they were making the right decisions. Natalie emphasised that '*you have to sort of think objectively*' (1; 1.23) when considering alternatives to IVF:

*I think we were very practical, and by the time we had finished the second IVF attempt, it was like "OK, we need to come up with option B". (Natalie 2; 7.14-15)*

Natalie did not mention disappointment about the outcome, but how the failure spurred a new approach, '*option B*'. She used '*we*', emphasising mutual decision-making discussed further in section 7.2.1. Jeremy described their plans for IVF in objective terms:

*You do the protocols and see what comes out and then you see if it doesn't work you decide are we going to try it again or are we going to try something else? We've also talked about if at some point we decide IVF is not going to work we've talked about things like adoption. This isn't the our only hope there's other things we can do so (Jeremy 1; 5.26-30)*

His described a cyclical problem-solving process, where one step was tried, the outcome examined, leading to the next choice. The consequence of failure was to try another approach. During his follow-up interview, he disparaged others making choices for more emotional reasons:

*You see people get so caught up into the "we have to have one" and that just doesn't seem like a healthy way to approach it. (Jeremy 2; 3.22-23)*

Jeremy drew on the emotional stereotypes mentioned in the last chapter, where others were carried away or '*caught up*' in the goal of having a baby without considering other issues. He identified these as poor, unhealthy choices.

Chris mentioned that the deliberate thought and action involved in IVF made conception more special than conceiving after a quick '*fumble in the dark*' (3; 7.30):

*In fact, it probably would have been better than doing it naturally. Because it's so conscious, it is such a conscious decision. You're consciously getting on the plane to go away to have a baby (Chris 2; 1.3-5)*

Rather than infertility being a negative and fertility treatment an embarrassment or a last resort, he emphasised its advantage in achieving something important in a mindful way. Doing IVF meant that they had to think about their decision and take deliberate action: it is '*conscious*'.

Decision-making was not always straightforward despite attempts to weigh up the issues. Deciding whether to do IVF was difficult for some participants. For Cathy, this meant balancing the expensive, time-consuming process with Chris already having children from a previous relationship. The decision-making was made harder because the questions could be asked many times:

*And because Chris has children from before, and so I was really questioning him to are you sure you want to do this again? Are you really certain that this is what you want to do? And, I guess at the same time I was asking myself those questions for me. (Cathy 1; 5.10-13)*

Cathy considered repeatedly whether to attempt IVF. If they had become pregnant easily, there would not be a need to question Chris's desire to have another child, but as it is, they can change their mind at any point, adding to the uncertainty. Making the decision to do IVF was a difficult one for Cathy (and Chris), as it potentially influenced the future of their relationship. This is discussed further in section 7.2.2. She later suggested that life was easier when things happened accidentally: it was done and there is not as much to think about. Similarly, Natalie mentioned the advantages of being unexpectedly presented with their adoption situation, thus avoiding '*planning*':

*Very exciting, very unexpected, umm not for everyone [laugh], I think. You know. It was just kind of like; in some ways it's a blessing because there is no planning, so you can't get caught up in sort of that rigmarole, which for us I think is nice. (Natalie 2; 3.2-5)*

Though Natalie valued objective decision-making, excessive thought and planning could become a '*rigmarole*'. As in the previous chapter, she highlighted her difference from others, who may not so easily cope with unexpected events. Natalie's response, distancing herself

from positive and negative emotions, reflects Moskowitz and Wrubel's (2005) description of the 'detached' group in their study of HIV/AIDS patients. Moskowitz and Wrubel found that this strategy worked well for these patients, as it appeared to for Natalie.

Unexpected events like miscarriage were unpleasant consequences of an initially logical and objective choice. Judy and Natalie experienced miscarriages, Natalie between the two interviews. Where Natalie dismissed them as a '*frustration*' (2; 5.15), Jeremy's account suggested he was more affected:

*I mean it's hard having the miscarriages, I mean. Um, I - this last round Natalie really wanted to, once she found out about the adoption, she really wanted to finish this cycle and I was more along the lines of (2) let's not, or, that I mean, same reason I don't see what we're changing (1) that would make it better or different. (Jeremy 2; 5.9-13)*

The emotional impact of miscarriage was '*hard*', and Jeremy wanted to avoid another one, without apparent options to do so. Miscarriage needed to be experienced before being considered. Though patients are presumably aware of the possibility of miscarriage, it was not included in early decision-making, perhaps because as couples generally overestimate their chances of success (Slade, Emery & Lieberman, 1997) they overlook the possibility of conceiving then miscarrying. The impact of miscarriage added an emotional weight to decisions to continue treatment. Events like miscarriage stood out as difficult against general experiences of treatment.

Where Cathy had an easy physical experience with her first IVF cycle, the second cycle caused an uncomfortable rash:

*Cathy: Yeah, although to be honest with you, after this cycle here, the thought of a third one really doesn't appeal very much. Umm. But, you know, needs must.*

*Elly: Is that because of the physical reaction or just the hassle and?*

*Cathy: Ummm. It's, yeah, it, yeah. The phy- <breaks up> all cos react quite badly to these drugs and I was so positive last time that I didn't have any kind of reaction, and now I have, it just means like oh what else could happen, you know? (Cathy 3; 3.25-30)*

Uncertainty and change, once experienced, become possibilities for future attempts. What was once an objective decision became more complicated by the awareness that unpleasant experiences could result. Participants did not appear to choose IVF because they were

desperate for a baby, but after weighing up issues they considered important, including the consequences of failing (miscarriage) as time progressed.

Participants' desire to make the best decisions centred on two topics: minimising the temporal and financial investment in treatment, and how and when to choose between IVF and adoption. These decisions were difficult because there was no objective indicator of the correct choice. Judy and Matt particularly struggled with uncertainty about which was the right choice, and the decision to do IVF appeared a difficult one for them. Even before beginning IVF, both considered adoption as an alternative. Judy mentioned being '*open to adoption*' (1; 2.8) and Matt considered whether to '*go directly into adoption*' (1; 10.15). They both found making a choice between the two difficult, as Matt explained:

*Then it was kind of like how long do we try? How many times do we go through the IUI [intrauterine insemination], and, you know, we've gotten to a point where it was hard for her when she had the miscarriage, and then, now going through, debating whether to do IVF or not? You know, are we, should we go that route or should we go directly into um into adoption? (Matt 1; 10.11-15)*

Though he later described IVF as '*the next step*' (1; 10.24) he seemed undecided about whether it was the best option. The right time or choice is neither clear nor externally validated. As mentioned before, Judy's miscarriage indicated a negative potential consequence of attempting to get pregnant again. His account was phrased as questions, suggesting a search for answers. Judy expressed uncertainty about when they would succeed, how long their finances would last, and when they should stop trying to conceive and pursue adoption:

*So it's that whole thing of, you know, are we just wasting our time and our money. You know, like you know when we should just be doing adoption instead. (Judy 1; 3.16-18)*

Judy seemed uncertain that the choice to do IVF was the best one, particularly if they were '*wasting*' more time and money, delaying parenthood and risking funds needed to adopt. They had undergone IUIs as fertility treatment for eighteen months before beginning IVF and the time and money they had already invested contributed to this concern. Like Cathy, Matt and Judy found the decision to do IVF a difficult one.

Worries about wasting time in the past were mirrored by attempts to make the best use of time in the future. Natalie attempted optimised their use of time by pursuing adoption and IVF simultaneously, getting a '*head start*' on adoption:

*And so it seemed like if it was going to take another few months to do the last round of IVF by the time we started and did all- everything, to um start adoption so at least we burnt through 3 or 4 months of that and we kind of gave ourselves a head start so it's like OK, now we're really only wait going to wait 10 months which with the gestation period of the baby would be the equivalent. So I think when we mapped it out that way more or less it would have been same time frame. Of course, that went right out the window, in a good way. (Natalie 2; 7.16-22)*

By careful planning, she tried to minimise the time they might wait for an adoption. Her reference was the gestation time for a pregnancy, which appeared a significant reference for time. Compared with the uncertainty about time that Judy expressed about IVF, Natalie seemed to have a firm timeline of 'going to wait 10 months', perhaps making the adoption process appear more certain.

Cathy expressed difficulties with balancing the right time for IVF with the pressure of finishing her PhD thesis:

*I've been doing this doctorate for the last four five years and there's that part of me that wants to wait until that's done but then another part of me that screaming don't wait just get on with it. (Cathy 1; 3.23-25)*

She has two competing pressures: completing the doctorate in which she has already invested 'four five years' and attempting IVF, with her biological clock ticking and 'screaming don't wait'. The stress was not specific to undergoing IVF, but in balancing two important issues. Though she worried whether she has made the right choice, 'have I set myself up to, for a massive treatment when something else huge is going on?' (Cathy 1; 7.8-10), she made a choice.

Worries about the right time and best use of time added to concerns about passing time and the biological clock. The impact of participants' age and that of their partner on fertility and potentially adoption were important issues. For two couples, Matt and Judy, and Cathy and Chris, the issue was complicated by discrepancies in age, as Matt and Chris are around 15 years older than their partners. Judy was relieved that she was still young for an IVF patient, improving her chances of conception, but worried that Matt was older, limiting their opportunities for adoption:

*I think time is still OK, I mean, um. You know, cos I'm 33 and so I well I'm I know I am aging a little bit but not as much as like some other IVF patients where you know, they're*

*in their late 30s and there's more risk, so I think um I think the age thing is not as much of a pressure, my husband is like 47, so he's getting up there and there's some restrictions as far as adoption. (Judy 2; 3.10-14)*

It was more favourable for Judy to pursue IVF immediately, but as time passed, she was 'aging a little bit' and the more restrictions she perceived with adoption due to Matt's age. In age terms, now was the best time to do both IVF and adoption, but pursuing IVF and eventually failing might limit their chances of adoption in the future.

The obvious impact of increasing age was on the biological clock. While Cathy focused on the practicalities of IVF, the infertility remained difficult:

*So with every attempt, or with every, more time in between, it just feels like um yeah, time is passing. And it feels like it's going really quickly. And, that biological clock is ticking louder and louder. So um, that creates a stress in one way (Cathy 3; 3.7-10)*

Passing time increases Cathy's stress about not having a child yet, particularly as their treatment options are unsuccessfully exhausted. The biological clock has been found to be more stressful for women than for men (Hjelmstedt et al., 1999) though Matt struggled with it:

*Even though with men the biological clock is not, you know, not an issue, but as, I keep looking at it and looking and saying that, by the time we have, if she gets pregnant this time, then by the time the kids are 10 years old, I'll be in my late 50s, and when she gets, you know, then when they, that's only at 10 years old, so when they get into college I'll be in my, you know, my what 60s close to 70s. And, you know, it's always my dream to be able to be there when my kids get married and have kids, to see grandchildren, but, you know, it may be getting to that borderline where I may not, so, that's something that I just have to realise and accept. (Matt 2; 8.27-9.5)*

Matt focused on parenting, whether he might be too old to be a father, and not live to see his children grow up. The right choice about when is acceptable to become a father is arbitrary, with no external authority to establish what was correct. The decision to conceive now eclipsed worries about longer-term consequences. This conflict between long and short term decisions is further explored in section 7.1.3, which looks at how pursuing a treatment cycle as a way of managing disappointment may distract from longer-term decision-making. Concerns about age became more urgent at follow-up interviews. Judy mentioned in an earlier extract how she was 'aging a little bit', where Matt mentioned age more at his follow-



up interview. The passage of six months appeared to put more pressure on him at 47 than on Judy at 33.

Perhaps because of the uncertainty about the right choice participants who appeared most committed to IVF (Judy and Matt, Cathy and Chris) emphasised the positive aspects of their decisions and the negatives of other options. The perceived negatives of adoption, particularly a long wait, provided impetus to try IVF for Judy and Matt:

*It's just such a long wait period and stuff, and so I think that would be hard. I think that's why I'm pushing it off, like the decision and all of that. So I think that that would actually be harder than the IVF process. I don't know if other people feel that way, but. And then just waiting for it. Because we have some friends, one friend waited like four years or something. Um, and so that would be gut-wrenching, to have to face that option. (Judy 2; 13.26-30)*

Compared with the quick results (even if negative) obtained in weeks with IVF, adoption entailed a 'long wait period', potentially 'years', reinforcing the decision to do IVF. She mentioned doing a 'quick search on line as far as restrictions' for adoption (Judy 2; 3.15-20), focusing on the rejected option's constraints. Both Judy and Matt drew on friends' negative experiences with adoption, and medical expertise with IVF. Matt mentioned that the cost of adoption and IVF were similar and focused on the time advantages of the latter:

*We went in for, you know, the consultation, they said OK we've got to take this med this med this med, for you know, x number of weeks and blah blah blah. And then we'll retrieve the eggs, and then we'll transplant the, you know, transfer the eggs in and we'll know in two weeks whether she's pregnant. (Matt 1; 11.1-5)*

The IVF process is clear and well defined, in the steps involved and the timeframe. Adopting would mean stepping away from the guidance of their doctors. Cathy referred to the poor performance and reputation of UK fertility clinics to explain her decision to pursue IVF abroad:

*Well when you [laugh] in the hotel you come across other people and you can't help but talk about what people's experiences were. And there are some really awful stories out there, actually. (Cathy 2; 7.19-21)*

The negative (though second hand) evaluation of UK clinics bolstered her decision to pursue treatment overseas, along with positive perceptions of her chosen clinic. In contrast, Natalie emphasised the negatives of IVF:

*We're not willing to crumble our marriage, we're not willing to create a financial crisis, we're just not willing to do that. Because then we're broken, and I mean putting any child biological or otherwise into that situation is not healthy. (Natalie 1; 4.16-24)*

Natalie saw IVF as having multiple, negative consequences in her marriage, their finances, and the possible, yet unknown, long-term effects on her body, like being '*taxing on my liver*' (1; 4.11). She considered the implications of putting a future child into that environment, rather than solely affecting her and Jeremy. Natalie perceived more disadvantages to IVF than other participants did, and she and Jeremy were in the process of adopting during their follow-up interview.

Participants wanted to make the best choice to achieve their goal of parenthood with the minimum investment of time and money. This was difficult because there was not always a clear indication of the optimum choice. Highlighting the advantages of the chosen option and the disadvantages of alternatives like adoption provided reassurance and confirmation of otherwise uncertain choices.

### **7.1.2 'It's expensive': Managing financial issues**

All participants were concerned about finances, as they were all paying for their treatment. Money was a big concern to the women. Natalie repeatedly mentioned finances, as IVF was '*very expensive*' (1; 4.13) and she wished to avoid a '*financial crisis*' (1; 4.20). She prioritised financial implications over emotional ones:

*You know, it's a financial investment, I mean it's an emotional investment, clearly, but there is a financial component to it. And it's all cash, so you have to sort of think objectively, I think. (Natalie 1; 1.21-23)*

Natalie glossed over the '*emotional investment*' as self-evident ('*clearly*') to concentrate on the financial aspects. Finances could be tackled '*objectively*', and Natalie emphasised the importance of doing so. She explained the consequences for themselves and their potential child, if '*we'll have little junior but little junior can never go to camp [laugh] no birthday party for you! Just kidding*' (4.14-15). As in the previous section, Natalie considered the impact of their decisions in the future. This contrasts with Matt, who focused on attempting to conceive now rather than worrying about not living to see his child grow up in the future.

Judy's financial concerns were exacerbated because she was not working and felt she was not contributing financially, meaning she felt like a '*dead weight in the family*' (Judy 1; 3.7). Though she has reasons for not working, like avoiding trying to balance a new job with

fertility treatment, they are traded-off against the financial implications, which caused her stress. For Judy, *'the biggest thing is the cost, but um so that is like the stress'* (Judy 1; 5.17-18), and finances were the only aspect she explicitly described as stressful.

Finances influenced decision-making during treatment. Natalie described weighing up costs of treatment with her physical response and their chances of success, changing the process to a *'numbers game'*, rather than an emotionally charged decision:

*Ah, the reason for the switch up [from IVF to IUI] was because I simply didn't produce enough eggs to warrant the additional 8500 dollars to go for it, so it came down to a numbers game. (Natalie 2; 3.13-15)*

Finances reinforced the practical facet of decision-making, most significantly in ending treatment. Judy described that decision as largely financial, *'I mean again, that's where the finances come in'* (2; 12.28). She and Matt still struggled to decide when this point should be.

Making the wrong decisions meant wasting money, and this occurred from the level of pursuing a whole treatment cycle to smaller decisions and actions. Cathy expressed frustration that the flights to their clinic cost more than anticipated through her error:

*Other than my brain went fuzzy and um for the flights and everything and that cost us a lot of money, actually. Whether that's one of the side effect I don't know, I don't usually make mistakes, and my brain did go to mush. (Cathy 2; 2.20-23)*

Failing was a difficult issue for Cathy. She did not see herself as a person who usually failed, and was frustrated about making mistakes that she does not *'usually make'*. This was exacerbated by the cycle failure. She made a mistake, it *'cost a lot of money'*, and that potentially has an impact on their future pursuit of IVF.

The men acknowledged the expense of fertility treatment, too. Jeremy stated that *'there's financial issues with it, too, it's expensive'* (1; 2.14-15). The men expressed fewer concerns about the couples' ability to cope with the financial demands. This contrasts with findings by Abbey, Halman and Andrews (1992) that money was a bigger stress to men than women were. Matt made a positive assessment of their financial situation, saying that *'finances have been OK'*: they are not *'struggling'*, *'living paycheck-to-paycheck'* and are *'even able to help out other people'* (Matt 2; 7.29-8.1). The men mentioned other potential uses for the money:

*The kind of a joke always saying every time we go through the IVF process is like buying a little economy car or something, 's like oh, we could have bought several cars, you*

*know, by now, but I think the transfer, the IVF where they do the egg retrievals are a little more expensive, but now going through the frozen embryos is a little less, maybe half the cost of a small economy car, but. (Matt 2; 8.5-8)*

The comparison with the cost of buying a car emphasises the expense of IVF. Matt expressed confidence in their ability to cope financially, but mentioned significant alternative uses for the money. He described their ‘*kind of a joke*’, jarring with the actual comparison. Chris mentioned regret over money that could be used elsewhere:

*I don't want it to go to the third one. Because this money we could be spending on a new baby, it's money we could be spending on lots of other things to make our life very nice, but we worked it out that we've got enough money to do the three cycles, so money isn't a big problem. (Chris 3; 10.8-11)*

Like Matt, he emphasised having ‘*enough money*’ for the treatment they hoped to undergo. Where women worried about money, men emphasised having ‘*enough*’, reflecting stereotypes of men as providers, wanting to appear financially secure (Dyke & Murphy, 2006). Finances were a limiting factor on treatment that, while clear in principle, was not necessarily clear in practice. Awareness of financial limits was apparent early in treatment, not as financial resources were being exhausted:

*Financially, we've set aside money for this and I've been saving. So, it at the moment it isn't a pressure, because I know we're OK for money, but if it goes into cycle two or three then I might start feeling differently about that. But we can at least afford two, so. (Cathy 1; 12.7-10)*

Though it ‘*isn't a pressure*’ right now, Cathy was aware that might become so in the future. There was a mismatch between her suggestion that they can ‘*afford two*’ and that it might go into ‘*cycle two or three*’, when they might have already exceeded their financial limits. During Chris’s third interview, in the middle of their second treatment cycle, he talked about finding money for further cycles:

*Because then we'll have to then weigh up what we want to do, in other words, because we'd have to then look at finances and things like that, what we can afford to get rid of and what we can't to make it happen again, because the money would have gone. (Chris 3; 10.15-18)*

Initially clear limits, like available funds, become less definite as failure occurred with no other option open, unlike Judy and Matt who wanted to ensure they had enough money still

available for adoption. The women took responsibility for monitoring the couples' spending. Judy described 'tracking down' and 'trend(ing)' their expenditures, and worried about the depletion of their savings:

*I've been like looking at our finances like so closely and like tracking down every single expense that we have. And trying to kind of trend our monthly expenses and so. I mean, I think we've been OK so far but the yeah the fertility there are huge chunks when IVF is involved, whereas before I was just doing Clomid cycles and um IUIs so it was fine, I mean, we were fine with that, but with the bigger bigger chunks of IVF payments, like yeah, it's digging deeper into our savings. (Judy 2; 2.23-29)*

Finances could be monitored and controlled by Judy, contrasting with uncontrollable medical aspects of treatment. Matt mentioned reporting his spending to Judy and having a budget for eating out each month (Matt 2; 8.10-18). Cathy described managing their money, finding cheap flights, and arranging to walk or bike to the clinic rather than taking an expensive taxi. However, Chris 'laid the law down' (3; 4.8) when Cathy attempted to save money by biking to the clinic for embryo transfer. Throsby and Gill (2004) described men issuing a "rational veto" (p. 343) when making decisions to end treatment, reflecting gender stereotypes of men as rational and women as emotional. Here, both Cathy and Chris were being rational about particular aspects, Cathy focusing on conserving their financial resources, and Chris about Cathy's health and the potential impact on the treatment cycle.

Financial concerns were important to all participants, and particularly to the women, who took the lead in monitoring and managing the couples' spending on treatment. The men tended to emphasise alternative uses for the money spent. Participants had less difficulty acknowledging financial concerns in comparison with their unwillingness to talk about the emotional demands of treatment (chapter 6). Participants were aware of potential financial limits when beginning IVF, not just as resources were exhausted.

### **7.1.3 'Let's get on the fast track': Taking action**

The decision to do IVF was difficult for some participants, but once this decision was made, taking action and being busy were favoured over worrying and being unoccupied:

*That was hard to get to that decision, but now it's made and we're getting on with it I feel ok, I feel much relieved. (Cathy 1; 4.17-18)*

Despite the difficulties Cathy experienced in deciding to do IVF, taking action was a positive step and provided relief. Where Cathy struggled with the decision to do IVF, Jeremy minimised the ‘*introspection*’ involved and focused on taking action to ‘*attack*’ the problem:

*We figured out how we were going to try to attack the problem, I don't think there was a big introspection piece there. It was just, ok, this is just reality, that if we want to have a child naturally, this is how we have to do it. (Jeremy 1; 2.5-8)*

The decision to pursue fertility treatment was the only option to have a biological child, thus making the decision straightforward. Infertility was a problem to be ‘*attack[ed]*’, emphasising action. Earlier, he described that ‘*we decided to get aggressive with it*’ (Jeremy 1; 1.9).

Coveney, Nerlich and Martin (2009) argue that war metaphors in health and disease discourses act as a strong focus for a story, bringing a “moral imperative” to validate intervention (p. 490). Medical treatment is a valid response to infertility. Attacking language suggests IVF as a short, sharp solution, and taking aggressive action suggested quick results, as Natalie described them as getting ‘*on the fast track*’ (1; 1.18). Matt used movement metaphors, like ‘*going towards that goal*’ (1; 3.3-4), ‘*moving forward*’ (1.11.20), that they are making progress to resolve their fertility problem. In her follow-up interview Natalie described herself as ‘*kicking back into gear*’ (1.9), emphasising action and movement.

Taking action appeared a way of coping with treatment failure by refocusing on the next action, as Chris explained shortly after their first cycle failed:

*I want to get on with it; I want to get onto the next stage. I want her to hurry up and have her next cycle! It's been very inconvenient having to wait 28 days in between each one [laughing]! I want her to finish up her cycle so we can move onto the next one. (Chris 2; 10.20-23)*

A failure was disappointing, but there are more opportunities ahead offering potential success. Matt described his response to failure and uncertainty about the next step:

*I wouldn't say bothers, it's just a question of (1) what will we do next? (Matt 2; 7.24)*

He focused his attention away from his emotional response, whether he was ‘*bother[ed]*’ by the failure to the practical decision of ‘*what will we do next?*’ Sometimes, no action may be available, like between cycles, as Chris mentioned in the extract above. Judy described the time between embryo transfer and pregnancy test as a difficult ‘*waiting period*’:

*Elly: Is that [embryo transfer] the time you find the hardest?*

*Judy: I don't know if it's that or if it's actually the waiting period um of the two weeks. I mean, again, I try my hardest to keep myself busy. But it's probably more like you know, counting down the days up until the um test. You know, so. Yeah, that's probably the harder part. (Judy 2; 7.4-11)*

No action is available at these times, even planning further treatment. Judy described other ways to keep busy, compensating for the lack of treatment related activity. She described herself as doing *'a good job of keeping myself busy, so that I don't dwell on it'* (Judy 2; 6.10-11), suggesting that being busy was better than worrying, and was a choice requiring effort as discussed in the previous chapter. Judy generally described herself as dealing well with treatment (chapter 6), but highlighted waiting for the pregnancy test (and embryo transfer, but less so) as a specific difficult time. These difficulties have been found in other fertility treatment research (Boivin et al., 1998; Callan & Hennessey, 1988). The difficulty of this time has been attributed to the lack of expert support, as patients do not attend the clinic during this time (Lancastle and Boivin, 2008). Judy seemed to find the lack of available action during this time difficult, and tried to find other ways to occupy herself productively. Despite this, she was *'counting down the days'* to take the pregnancy test, so keeping busy was both effortful and not always successful.

For Cathy, other activities and obligations distracted her as she waited to take the pregnancy test after her first IVF cycle:

*And um I was doing my thesis as well, so I had other things to think about so I wasn't constantly having that churning around in my head. So I was getting on with things, living life as I normally do. (Cathy 2; 3.18-20)*

She avoided thinking excessively about the progress of treatment, having it *'churning around in my head'* as she got on with *'living life'* as normal. The general busy-ness of life, with other demands on his time, distracted Chris from thinking about infertility *'as much as in your quiet moments you're thinking about it'* (3; 3.12-13). There was a balance between *'avoiding'* infertility and not dwelling on things unnecessarily. Fertility treatment is not the only thing going on, while life was continuing, and it seemed a poor coping strategy to invest all time and attention in one activity. Being busy can distract from potential emotional impact. Chris described the clinic closing for the summer as *'frustrating'*, but that keeping busy with other things distracted from that:

*So that was a bit frustrating, but um, but, we both got quite busy lives, and especially the*

*last few months that this has really been the first probably time we could ahh come out without there being additional stresses to do with our other life, you know, our life around it. (Chris 3; 3.1-4)*

He used 'frustration', downplaying the impact, particularly where he added 'but'. Balancing the treatment with their 'other life', it actually worked out for the best. Assuming that patients' lives revolve around infertility is stereotypical, as they can actually be equally pursuing important projects, like Cathy's PhD, in which she has invested a lot of time.

Cathy mentioned advice from other patients to stay in bed between embryo transfer and pregnancy test.

*There's all these things that, they're saying oh well, you can't walk upstairs, and I said "what do you mean I can't walk upstairs for two weeks, I can't sleep in my sitting room!" (Cathy 2; 9.1-3)*

This was a form of action (through inaction): a task that might influence the cycle outcome. External constraints limited the ability to take action: waiting time for a pregnancy test, between cycles, or the clinic schedule. Though action appears an effective coping strategy, fertility treatment focused action may not always be available. Judy, Cathy and Chris endorsed staying busy, which stopped them from the negative obsessing they attributed to other fertility patients; as Judy said 'it's they just like have a hard time getting it off their mind, it would just come up over and over again' (Judy 2; 6.12-13). Staying busy was socially and culturally appropriate within the Protestant work ethic where not working equals not worth (Blood, 1969).

While immediate action was attractive to participants, it diverted attention from longer-term planning. Judy found that beginning another treatment cycle overcame the disappointment of a failed cycle, but that comfort seemed to overcome thinking about alternative options:

*I think we keep pushing it back and pushing it back, you know. Oh maybe this, maybe after this next time, you know, we should, you know, maybe I should get a job, or maybe we should start the adoption route, or maybe we should do this or that. But we do kind of keep almost pushing it back, like, oh no it's another failed one what do we do now. And so I think we do kind of wait to that point, like, we do try to take it one step at a time, you know, so it's like OK, we're in this trial now, so I think we'll wait for the pregnancy test to decide. (2; 12.29-13.6)*



Ending treatment removes that encouragement and certainty, requiring other action that would be more difficult: investing time and energy finding out information about adoption. Repeated treatment continued the wasted time and money that worried her, but focusing on small steps obscured passing time.

Being able to take action was favoured over dwelling on negative situations. Once decisions were made, there was relief associated with being able to 'get on with it'. When failure happened, action was a way of coping, by focusing on the next available steps. Alternative actions might be substituted for unavailable treatment procedures, by keeping busy with other activities and finding actions that might contribute to the treatment success, like going on bed-rest.

#### **7.1.4 Section discussion**

Fertility treatment was a solution to the problem of infertility. This places IVF as a strategy for regulating participants' situation to the desired goal of pregnancy and gaining a family, rather than a stressful activity itself. Participants focused on making good decisions, and favoured taking action. Both have been identified as favoured strategies to deal with infertility (Lord & Robertson, 2005). Despite being seen as adaptive coping, these strategies generated difficulties for participants as the right decisions were not always clear, and participants tried to minimise their outlay of time and money to achieve the desired goal. Where successful IVF patients, looking back, see the investment of time and money as worthwhile (Redshaw, Hockley & Davidson, 2007), for the participants in the current study who were beginning treatment and looking forward, they are an investment with uncertain outcomes.

Infertility is an unusual health problem in that treatment is not required for physiological well-being, but to achieve the social objective of parenthood. The decision of whether to undergo fertility treatment has received less attention (Verhaak, Smeenk, Evers, et al., 2007) than making decisions during treatment, choosing (or not) procedures (Frank, 1990; Redshaw et al., 2007), planning (Redshaw et al., 2007) and ending treatment (Peddie, van Teijlingen & Bhattacharya, 2005). During baseline interviews, which took place during the early stages of IVF, participants reflected on their decision to undergo IVF, and this was a difficult time for some. The required investment of time and money was a particular concern, as was making a choice between IVF and adoption. Deciding to do IVF may not be easy, representing a specific issue that is stressful for some.

Participants attempted to be rational and make the best decisions, contrasting with IVF as a choice of desperation (Glover, McLellan, & Weaver, 2009). Smith, Michie, Stephenson and Quarrell (2002) found a similar desire to make rational choices in individuals deciding whether to be tested for Huntington's Disease. More generally in health research, Frank (1997) described the concept of moral agency, where ill people wish to be seen to make the right decision so their actions are morally accountable. Making the moral choice is difficult when the right decision is unclear, and the uncertainty associated with IVF may make decision-making more difficult (Malik & Coulson, 2008a; Sundby, 1999; Zucker, 1999). Participants were aware that alternatives like adoption might provide more reliable outcomes than IVF, undermining their certainty about treatment. They overcame their uncertainty by highlighting the positive aspects of the choices they made and the negatives of alternatives. This confirmation bias may provide helpful reassurance (Nickerson, 1998), but changing chosen actions may become more difficult, as deciding to end IVF, for example, means overcoming the negative perceptions associated with the alternatives. Verhaak, Smeenk, Evers et al. (2007) suggest that ending treatment might require changing from an "active, treatment-focused" coping style to a cognitive coping style, to adjust life goals and make this shift (p. 33). Decision-making re-occurred, as each failed cycle was a chance to continue or end treatment. Other research has identified recurrent decision-making, for example when telling donor offspring of their genetic heritage (Daniels, Lewis, & Gillett, 1995).

Existing research highlights the lure of new treatment options to stay in treatment (Wilson & Kopitzke, 2002). This research adds the possibility of the attraction of action and familiarity over uncertainty in selecting IVF rather than adoption. Action was preferred over inaction and worrying about infertility or treatment, consistent with the negative connotations of distress and stress discussed in chapter 6. Active-avoidance coping, or turning to outside activities to keep one's mind off infertility, is seen as maladaptive, along with avoiding pregnant women and keeping infertility-related thoughts to oneself (Peterson, Pirritano, Christensen, & Schmidt, 2008). When no relevant actions are possible, like between cycles, this might actually be helpful. Tuil, van Selm, Verhaak, de Vries Robbé and Kremer (2009) found that patients tended to use online support more at this point, when there was no action to be undertaken with the fertility clinic. Porter and Bhattacharya (2008) found that participants found ways to be proactive, even when they had no hope of conceiving by themselves. Participants saw being worried and obsessing over infertility as unhelpful and retaining diverse interests and activities as positive, showing how adaptive coping responses

may not be clear-cut (Sommerfield & McCrae, 2000) and multiple purposes for which a strategy may be used (Danoff-Burg, Ayala, & Revenson, 2000).

Doing fertility treatment provides action that contributes to progress towards the desired goal, and can be a way of coping with failure by embarking on new treatment. Taking action to resolve a situation has been found to relate to greater well-being (Connolly, Edelman, Cooke, & Robson, 1992). Other research has suggested that (particularly retrospectively) ex-patients see treatment as a whirlwind of activity that did not give them time to think (Glover et al., 2009). The action of treatment appeared helpful in the short-term, but distracted from long-term planning. The focus on making decisions and taking action outlined in this theme is consistent with a self-regulatory approach as participants attempted to find a way to regulate infertility and gain the desired state of parenthood. In this theme, particular events were identified that could be described as difficult or stressful, particularly miscarriage, making the decision to do IVF, and the wait for pregnancy test, which add to those found in other infertility research, like those associated with failed attempts at conception (Kopitzke, Berg, Wilson, & Owens, 1991).

The next theme turns to participants' emphasis on the mutual and joint nature of decision-making.

## ***7.2 IVF as a mutual endeavour***

Participants described IVF as a joint project with their partner. Doing fertility treatment together aligned the hoped for artificial conception with natural conception, and allowed both members of the couple to draw on it as a shared experience. Against this backdrop, individual accounts sometimes diverged from the joint perspective, reflecting difficult issues for one individual or between the couple.

### **7.2.1 'We're doing it together': Fertility treatment as a joint project**

Fertility treatment was described as a mutual endeavour where the couple worked together towards a shared goal. Most participants referred to the sense of being 'in it together' as the best part of their situation. Jeremy expressed the importance of both practical and emotional support from Natalie:

*Just Natalie. I mean just, that we're doing it together, trying to plan it out, talking to each other when one of us is down or frustrated or kind of (Jeremy 2; 6.9-10)*

Jeremy described jointly undertaking IVF as a project, working and ‘*plan[ning]...out*’ together, and being united as a couple to achieve parenthood. Despite how Jeremy and Natalie downplayed the emotional elements in the previous chapter, they are a source of support to each other when they are ‘*down or frustrated*’. Other participants expressed the importance of togetherness during treatment:

*And then Judy just being here, regardless if she's in a good mood or not, she's there and that helps, too. (Matt 2; 10.9-10)*

The presence of his wife helps Matt, even if she is not ‘in a good mood’ or providing him with support. Both ‘doing it together’ and ‘being here’ were important.

*And Chris is very supportive, and I know that he'll be there, and be as supportive as he can be. So. We've got each other, in that sense. (Cathy 1; 9.9-10)*

The experience is less lonely because they have ‘*got each other*’. Fertility treatment was explicitly a mutual endeavour, where participants felt ‘best’ about it as a couple. Chris, after reiterating their doctors’ confidence, focused on the strength of his relationship with Cathy:

*We're both there for each other when each of us are feeling down in whatever way in life. There's times when I don't show that I'm down about other stuff, and she picks up on it and she holds a space for me, and I hold a space for her when she needs, so we have a good relationship. (Chris 1; 12.22-25)*

Throughout his interviews he referred to their loving and supportive relationship as a basis for raising a child, which would be the ‘*cream on top of the cake*’ (Chris 1; 2.15). Their togetherness is reflective of their life, not an unusual aspect limited to infertility.

Judy’s baseline interview provided a contradictory account, framed more as ‘*I*’ than ‘*we*’, like mentioning that ‘*I've been doing IUIs*’ (1.10), rather than ‘*we've been*’. The implication was that her husband was not involved, which does not seem to be the case. Her use of ‘*I*’ might reflect her feeling responsibility for their infertility, with her diagnosis of PCOS. If she was responsible for the infertility, she may feel more responsible for fixing it, exacerbated by her financial concerns with not working and spending money on fertility treatment.

The shared experience was highlighted by participants drawing on similar ideas, even while talking as individuals. Natalie’s and Jeremy’s baseline interviews reflected similar approaches to fertility treatment, both focusing on making objective decisions. Both presented IVF as a possible path to parenthood with adoption as an alternative if IVF failed:

*So if you do the protocols and see what comes out and then you see if it doesn't work you decide are we going to try it again or are we going to try something else? We've also talked about if at some point we decide IVF is not going to work we've talked about things like adoption. (Jeremy 1; 5.26-29)*

*If we don't have a child life still goes on if, you know, we're still married and we still have lives and lots of interests those things don't get halted because we don't have a biological child, and then we'll just shift gears and adopt a child. (Natalie 1; 2.9-12)*

Their individual accounts appeared to reflect joint narratives created outside the interview situation, as the couple narrate their experiences elsewhere. These joint elements indicate that not everything in an infertile couple's life is about infertility (Sandelowski, 1994). Though Natalie and Jeremy have not been married long, they intend to be together for a long-time, and the mutual perception of the course of infertility is situated within their wider relationship. Couple's expressions of unity reflect their being in a long-term relationship, where the future path depends partly on their actions now.

Joint involvement reflected 'natural' conception during the 'artificial' process of IVF, where the presence of both partners is not always needed. Matt made great efforts to attend appointments, to 'be a support to Judy', and so both were present at the (hopefully) conception of their child:

*And my thinking was always that I wanted to be at the appointments, so if the kids were ever to ask, you know, about the birds and the bees, it's kind of like yeah mom and dad were together when we conceived you. You know. Instead of, no dad was way over here, and mom was over here and you guys were in a little Petri dish. (Matt 1; 8.26-9.2)*

The desire to 'be there for things as it happens' allowed a future joint narrative about their child(ren)'s conception based on Matt's experience, not just Judy's account. Throsby and Gill (2004) suggested that men see ART as an enhancement of nature, but the natural element could be enhanced by the chosen actions. Natalie emphasised shared experience:

*If I just did it all by myself I could relay it to him, but it's not an actionable for him. And I think that those memories, if it turns out for the good or if it doesn't turn out, and we choose another path, it's still there, there's still that commonality of experience that will inform our decision-making. (Natalie 1; 13.24-27)*

Mutual action produced 'commonality of experience', which Natalie saw as important for future choices. Participants emphasised that they were not undertaking fertility treatment

alone, and valued the presence and involvement of their partner. This included reciprocal support and mutual decision-making. Common experiences during treatment reflected natural conception and provided a basis for future decision-making.

### 7.2.2 'Is this the right thing for both of us?': Diverging accounts and stress

Despite participants' emphasis on joint experience and decisions, explicitly individual perspectives occasionally emerged in their accounts, reflecting differences between the couple. These divergences were temporal, and arose, disappeared or re-occurred rather than occurring continually. Diverging accounts appeared to indicate areas of stress, which again were linked to specific issues. Jeremy described his difference of opinion with Natalie over their final IVF cycle while they pursued the adoption of the baby they nicknamed 'Squirt' during his follow-up interview:

*Insanity is doing the same thing over and over and expecting a different result. Nobody can tell me what we're changing or what is different that is going to make the outcome different. So. That, I mean I mean it's hard having the miscarriages, I mean. Um, I - this last round Natalie really wanted to, once she found out about the adoption, she really wanted to finish this cycle and I was more along the lines of (2) let's not, or, that I mean, same same reason I don't see what we're changing (1) that would make it better or different. (Jeremy 2; 5.7-13)*

In this extract, Jeremy expressed himself using 'I', rather than 'we' or 'you' as he did usually, expressing an underlying difference in their approach to this issue. He worried about their chance of success and the futility of repeating the previously unsuccessful actions. His use of 'nobody' included Natalie, making him appear isolated against a majority sweeping him along. Doing the 'same thing' again was pointless despite the time they had invested in the cycle, whereas Natalie wanted to continue because they 'were halfway' (through) and it 'was worth finishing' (Jeremy 2; 5.21-22).

In contrast, Natalie's account presents their decision-making as straightforward, and mutual:

*So, we just took the weekend ... and just decided why not? So we'll pursue them both at the same time ... Um, so we decided to adopt Squirt who as of, as of this moment is now ah just over 6 weeks old and um to do fertility as well because literally that decision and fertility were happening within the same week. (Natalie 2; 2.20-27)*

In Natalie's account this was a straightforward, mutual decision. Jeremy's version suggested not, and that this bothered him enough to mention it. His ambivalence about their final IVF

cycle was possibly unimportant in a longer-term perspective, because they were not pursuing further treatment. This disparity may not have emerged in a joint interview, or if only one person was interviewed with their perspective taken as the couples' experience.

Matt and Judy share a religious perspective, with faith in the eventual reward of a child from God, and the importance they perceive in the support of prayer from their Church community. Matt and Judy's experience diverged after Judy miscarried following a successful IUI, which both described as harder for Judy. Judy's faith was impacted, leading to her withdrawing from Church activities:

*Um, and well, I guess, oh oh a big thing was going to church. It was very difficult for me to worship. It had a big impact on my ah spiritual life, and so so I withdraw from that. I was worship leading and I withdrew from that and I was I. There were so many things I withdrew from um due to the miscarriage. And it was mostly like, yeah, it was mostly like church related stuff. (Judy 1; 4.8-12)*

Despite withdrawing from institutional religious activities, on a personal, social level (e.g. her women's group, prayer) her religion was more helpful. This may not be a particularly religious issue: she mentioned that after the miscarriage she generally withdrew from social events, as she met a lack of sympathy that made coping with her miscarriage difficult. It may have been easier to manage social interactions on a personal level, where individuals would be more sensitive. The miscarriage appeared more difficult for Judy than for Matt, and religious coping was less helpful for her. By Judy's follow-up interview she and Matt both drew on religious elements:

*I just I keep trying to, you know, to depend on my faith, you know, and just that you know, God has his timing, and whatever and so, yeah, so I just have to wait. (Judy 2; 5.8-9)*

*I think, just realizing that, you know, for me, being a Christian that it's in God's hands. And just hearing another couple, or another one of our friends telling us that yeah, God knows what he's doing, and that He knows what egg and what sperm to put together to make the child that he wants you to have. (Matt 2; 3.10-13)*

Judy's spiritual difficulties at the baseline interview reflected her greater struggle in dealing with her miscarriage. At the follow-up interview, the miscarriage appeared less difficult and the religious emphasis in their interviews was similar.

Underlying Cathy's and Chris's baseline interviews was the potential for their relationship to end, if they could not have a baby. At this time, Cathy focused on the differences in their individual need for a child:

*I mean this kind of goes into um relationship issues as well. And. Um. We're, Chris and I and how our relationship was being affected. And. And because Chris has children from before, and so I was really questioning him to are you sure you want to do this again. Are you really certain that this is what you want to do? And, I guess at the same time I was asking myself those questions for me. And so I think, in a way we were processing that. Um. You know, is this the right thing for both of us? In each of our circumstances. (Cathy 1; 5.9-165*

During these portions of her account, Cathy moves to a much more individual perspective on their experience, considering 'each of our circumstances'. She questioned Chris's desire to have another child, and put time, money and energy into IVF. As the infertility was his (he had had a vasectomy and two attempts at reversal failed) Cathy might be able to have children naturally with someone else, so both were invested in the process: he to acquire something he already had, and she to gain what she could possibly gain more easily with another partner. She was making a decision for herself as an individual and for them as a couple. Chris had children who are 'part of their lives' (3.3.5-6), and adoption was not an option for them (Chris 3; 7.3-6). Chris expressed concern about their relationship, which was unlikely to be resolved soon:

*There's also a chance that it will cause a lot of if we didn't that it would cause a lot of stress between me and Cathy in our relationship, and umm and we'd have to see how that effected. You never know do you? You hear people breaking up over these over this sort of process, and I can't see that happening, but I'm not going to sit here and say that oh it's definitely not going to 100%. (Chris 1; 11.31-12.4)*

His worries about the future of their relationship contrasted with the importance he placed on it as a place of strength for them to tackle future situations. The relationship uncertainty was reduced when they began pursuing fertility treatment, but returned as the first cycle failed and the second cycle progressed and overall failure became a possibility. Stress appeared as Cathy tried to reconcile mutual support with the individual decision about the relationship. These examples show (marital) stress arising in specific situations at particular times.



### 7.2.3 Section discussion

The couple relationship is a primary source of reciprocated support (Abbey, Andrews & Halman, 1991b), particularly the husband supporting his wife (Chang & Mu, 2008), emphasising fertility treatment as an individual experience focused on the woman. Instead, participants talked about it as mutual endeavour, enhanced as they framed their accounts using 'we', rather than 'I'. Steuber and Solomon (2008) suggested that this demonstrates a strengthened relational identity developed during a difficult situation, though differences still emerged between couples in their study. Couples mentioned similar topics, presumably reproducing perspectives of their experience made sense of together outside the interview. The involvement of both partners during the treatment process allowed support, creation of mutually shared experiences, and attempted to mirror 'natural' conception processes.

Studies of infertility highlight differences between men and women, like the desire for parenthood, and involvement in treatment. Greil, Leitko and Porter (1988) found no common areas of meaning-making about infertility between the couples in their study. Gender stereotypes (Coates, 2003) and infertility research distinguish between men as generally rational and women as emotional (Throsby & Gill, 2004). Here, couples mostly expressed similar perspectives on their decision-making, showing that general gender differences related to fertility may be more significant than variations between particular couples (Jordan & Revenson, 1999). Couples who were disagreeing might not participate in this kind of study. Couple decision-making in other areas shows wide ranges from complete agreement to complete disagreement, for example, whether to tell children about their status as donor offspring (Daniels, Lewis, Gillett, 1995).

Use of mutual language reflects that fertility treatment occurs within a couple's relationship as a joint experience (for these participants). It seemed to arise from a desire for the process and decisions involved in fertility treatment (or adoption) to be mutual because having a child is done together. A common story may be especially desirable with IVF, to reflect natural conception. Cathy, particularly, struggled with the difference between staying together, doing IVF and being parents, and splitting up over not being able to have a child. For some participants, the mutuality of IVF recreated the process of natural conception in a medical environment where being together is not actually necessary.

Glover et al. (2009) encountered difficulties clarifying individual and joint perspectives during interviews with couples, but even with individual interviews, it was not always clear

which was being used. Participants appeared to use a more individual perspective when talking about issues that were problematic between the couple. Research suggests that this relates to mismatches in the extent to which couples both want a child, or are seen to take an active enough role in treatment activities (Steuber & Solomon, 2008), though the former was the case for only one couple in this study. These issues varied over time, emerging, resolving or reoccurring as decisions were made or events unfolded and changed. Schmidt, Holstein, Christensen and Boivin (2005a) found that difficult marital communication was linked to high marital stress. In the current study, potentially difficult communication appeared linked to some events rather than being generally the case.

### ***7.3 Chapter summary***

This chapter presented two themes related to decision-making. The first was how the decision to do IVF was a solution to a problem, which resulted in action that was perceived as helpful by the participants. These sub-themes showed temporal continuity: the focus on making good decisions was similar throughout the study. However, the timeline element of the Self-Regulation Model (SRM) illness perceptions was important in these themes. Participants tried to minimise their temporal investment, and compared the timelines for IVF with the potential alternative of adoption. The second related decision-making to the couple relationship as they tackled infertility together, though certain parts of accounts diverged and became more individual, indicating stress or difficulty. These sub-themes were temporal, showing the difficulties limited to particular times. The next chapter looks at the experience of treatment itself, particularly as it developed over time.

## **8 ‘It’s a matter of when, not a matter of if’: Changing perspectives on treatment**

This chapter presents one theme exploring temporal perspectives of in vitro fertilisation (IVF). This theme comprises five sub-themes focusing on changing treatment perceptions. The first two sub-themes explore changing perceptions of IVF from a process controlled by expert doctors to one explained by luck and fate. The third sub-theme examines how experience made participants’ own role more familiar and routine, but sometimes more wearing. The fourth sub-theme looks at participants’ attempts to understand unexplained treatment failure, reconciling good signs during treatment with poor outcomes. The last sub-theme investigates the way participants used different temporal perspectives in their interviews, taking the perspective that appeared most helpful or comforting. The theme and sub-themes in this chapter are summarised in table 6.

(Title extract from Cathy 3; 6.21)

**Table 6 Table of Themes: Time and Treatment**

<b>Theme</b>	<b>Sub-Themes</b>	<b>Extracts</b>	<b>Participants in sub-theme data</b>
<b>Time and treatment</b>	'It's a third party process': Pursuing expert solutions	It's a third party process (Natalie 1) They obviously know what they're doing (Jeremy 1) They always answer my questions (Judy 1) The doctor says... (Matt 1) They had considered everything (Cathy 2) But when you spoke to the doctors... (Chris 2)	Jeremy (1), Natalie (1,2), Judy (1,2), Matt (1,2), Cathy (1, 2,3), Chris (1,2)
	'It's what you're supposed to do': Invoking luck and fate	It's what you're supposed to do (Jeremy 2) It's meant to be (Natalie 2) God has his timing (Judy 2) Everything has a kind of plan (Matt 1) You've got to play the odds (Cathy 2) It's with the gods (Chris 3)	Jeremy (2), Natalie (2), Judy (2), Matt (1,2), Cathy (1,2), Chris (1,2,3)
	'The injections are nothing now': Treatment processes become easier with experience	The injections are nothing now (Judy 2) The IUI was a warm up to it (Jeremy 1) I had no expectations (Natalie 1) I don't know whether we're more relaxed (Matt 2) I know it's not going to be painful or difficult (Cathy 2) Knowing the process, it seemed a lot easier (Chris 3)	Jeremy (1,2), Natalie (1), Judy (1,2), Matt (2), Cathy (2,3), Chris (1,2,3)

Theme	Sub-Themes	Extracts	Participants in sub-theme data
	<p>'There's no logic to it': Making sense of signs and outcomes</p>	<p>There's no logic to it (Matt 2)</p> <p>It'll probably be positive, but that doesn't mean anything (Natalie 2)</p> <p>If they knew all of it, the percentages would be a lot higher (Jeremy 2)</p> <p>She had PCOS as well, yet she had four kids (Judy 1)</p> <p>It's positive in the sense that she can get pregnant (Matt 1)</p> <p>It all went quite well, so it's disappointing to get that result (Cathy 2)</p> <p>Everything was perfect all the way down the line, the egg never stuck (Chris 2)</p>	<p>Jeremy (1,2), Natalie (1,2), Judy (1,2), Matt (1,2), Cathy (2,3), Chris (1,2,3)</p>
	<p>'I'm trying to be in the moment': Shifting temporal perspectives</p>	<p>I'm trying to be in the moment (Cathy 2)</p> <p>We were expecting 12-18 months and 30 days later, he calls us (Jeremy 2)</p> <p>I live in these 72 hour intervals (Natalie 1)</p> <p>I try not to think past the next pregnancy test (Judy 1)</p> <p>Look at it as treatment over three cycles (Cathy 1)</p> <p>It's part of three stages (Chris 3)</p>	<p>Jeremy (2), Natalie (1), Judy (1,2), Cathy (1,2,3), Chris (1,2,3)</p>

## **8.1 Time and treatment**

The participants in this study were all undergoing IVF, meaning that they had all chosen medical treatment as the appropriate way to fulfil their desire to become parents. This theme explores their changing relationship with medical solutions as their treatment progressed. Time and treatment failure were linked together, as more time in treatment occurred due to failure. Key sub-themes are changing perceptions of control, certainty about the diagnosis of the problem, acceptance of medical expertise, and the impact of participants' accumulating experience as fertility patients.

### **8.1.1 'It's a third party process': Pursuing expert solutions**

During baseline interviews, participants emphasised the medical expertise and knowledge represented by the IVF process. Starting IVF meant relinquishing control of reproduction to the attending doctors. The relinquishment of control in this area contrasts with the expressions of personal control in previous chapters, particularly of choice and control of emotional responses (section 6.1), and of overall course of action (section 7.1). Loss of control in this area was not seen as negative, as experts were seen to provide the optimum chance for achieving pregnancy:

*It's like being in an airplane at 30,000 feet: you have absolutely no control of anything, so you either submit and enjoy, or you try to control something that's beyond reach, like obsess about the email you need to send, or a phone call you need to make. And it I equate it to be the same: that the minute you realise that you effectively have no control day in, day out the better off everybody's going to be. (Natalie 1; 5.4-9)*

Though Natalie herself had no control in either situation, the metaphor of '*being in an airplane*' links fertility treatment to other situations where a highly trained expert has control. Later in the interview, she explained that:

*I don't have to do the planning because that's why I have a medical team I mean I guess I could take over the planning and be the least qualified person to do it so I' (1; 10.22-24).*

This was a task requiring expert knowledge, and being the '*least qualified person*' to take it on, relinquishing control to the medical team is the best action, to accept, '*submit and enjoy*'. Again, Natalie drew on understandings of the 'best' way to respond. Cathy expressed similar sentiments, that '*you don't worry so much about things that you can't really control, anyway*' (Cathy 1; 8.24-25). Lack of control did not appear to be intrinsically distressing.

Confidence in the expert doctors who '*know what they're doing*' (Jeremy 1; 4.28) and IVF as an advanced medical technique eased relinquishing control. Participants were initially confident that their fertility problems were identified and solvable, reinforcing optimistic perceptions of success early in the treatment process. Providing a solution to clearly identified problems seemed straightforward:

*We're going to have the operation in Europe, and um they're more like, well, we don't know any other way to make people pregnant, really. You know? They're sort of, very 'we don't bother doing reversals, we inject, we take the sperm out, and we do it, and no need for a reversal'. So it's completely <unclear>, maybe that's given me confidence to go through low points every now and then, where I worry about the future; if I start, if I think about it not being successful. (Chris 1; 2.2-8)*

For Chris, the situation appeared well defined and manageable with the techniques available: the only problem to be solved was how to '*take the sperm out*'. He draws on reports of the doctors' assurances about the process: they appear certain and he draws confidence from this. In this extract he mentioned going '*though low points every now and then*', contrasting with other statements about his lack of stress and positive outlook. This highlights a difference between a global view of a problem (where Chris defined himself as unstressed) and talking about it in more detail (when he found areas of difficulty).

The identified details and precise timed steps of IVF reinforced the perception of it as a precise technique. Cathy had confidence in the medical solution because it was specific to their situation, being '*tailor made for us. It wasn't one size fit all*':

*That's why I was so pleased with this clinic, because they do try and tailor everything to how, you know, all the data they have from this cycle they'll take into consideration when they prescribe for the next one. Umm, so and you know, they have meetings with everybody and look at the quality of the egg and quality of the sperm. (Cathy 2; 7.10-14)*

The doctors rely on '*all the data*' and '*meetings with everybody*', reinforcing precision, knowledge and expertise of the medical team. This information can be used to '*tailor*' the process and improve their prognosis. Matt and Judy cited their doctors as authorities, who might '*restrict my activities*' (Judy 1; 8.7), or be available to '*always answer my questions*' (Judy 1; 8.25). Matt explained that undergoing IVF meant:

*That the doctors says, is that now that the egg and the sperm are outside the body, they can see why things didn't work. (Matt 1; 6.4-5)*

Matt's description suggests that once the experts can see everything, they can give answers. The doctors are experts, who provide definitive answers and solutions, and request that Matt and Judy limit their routine if medically necessary. The defined routine and processes of treatment contributed to confidence in IVF:

*It's pretty (2) you know you go in you get your ultrasound it's pretty routine =yeah= um so I don't think it's off-putting I mean I just sort of figure that you're just a social security number at the end of the day right? There were thousands of women before me there'll be of thousands women after me. (Natalie 1; 7.10-13)*

The process is 'routine' and well established. Thousands of women have experienced it already, making it pedestrian, minimising her situation as being difficult or unusual. The precise routine suggested that adherence to the routine contributed to success:

*I was surprised how sad I was. I don't know why I was surprised, but I, it really, it hit me quite a lot, 'cos I think I was just going through the technical things and then. I was so certain that she was going to have it that, when we did find out it failed, it was; I was really surprised by how much it affected me. (Chris 2; 1.13-16)*

Chris's use of the term 'technical things' presents IVF as an expert process, with a predictable relationship between inputs and outcome: fulfil the required actions and the outcome occurs. Both the focus on getting these things right, and confidence about the outcome seemed to prevent him from anticipating potential failure.

At the baseline interview, only Jeremy tried to reconcile the precise routines and 'level of medical care' with the low success rates from IVF:

*The level of medical care and the fact that they obviously know what they're doing, and it's a-. They prepare you that this will happen, this will happen, this will happen, and they have the timing down so well, that it makes you feel confident that they know what they're doing. Ummm, the downside is that it amazes me what the percent- how low the percentages are, umm, which it seemed like with how accurate they know all the timing that the percentages were so so low, and I don't, that doesn't make sense to me. (Jeremy 1; 4.25-5.1)*

The detailed, precise timings and clearly laid out process reinforced IVF as a scientific, well-established, well-understood process, but this appeared inconsistent to Jeremy in light of the resulting success rates. Informed by his education and experience in statistics and chemistry, he questioned the poor outcomes from IVF when '*all it is, is a chemistry experiment*'



suggesting a predictable and repeatable outcome arising from mixing 'substance A with substance B' (Jeremy 1; 5.7-16). Knowing 'the timing' suggested that exact timing was an important factor in producing a successful outcome, and yet so many other factors were unknown. He tried to balance between acceptance of the knowledge and skill of the medical staff and his own understanding and interpretation based on his pre-existing knowledge. In comparison, the other participants highlighted the expertise and knowledge of the doctors without relating this to the chances of any particular outcomes.

Perhaps because of the initial confidence, failure of the first IVF cycle was significant. This was illustrated by Cathy's and Chris's interviews, the only participants interviewed at this point. Cathy described her focus on the practicalities of the first cycle, particularly with the decision to go abroad, resulted in the emotional impact of failure taking her by surprise:

*Yeah, I was more concerned about the physical side of it, actually. Umm, but actually it's more the emotional side that's harder, I think, for me. (Cathy 2; 13.14-15)*

Before the first cycle, participants were focused on the practicalities of getting through the process correctly, as the details were new and unfamiliar (see section 8.1.3). This failure seemed to represent a turning point from perception of the process as something physical or practical to something with potential emotional consequences. It crystallised the possibility of overall treatment failure. During Chris's baseline interview, he expressed a 'gut feeling' that IVF would work out for them (2.23-24). After the cycle failed, he described a change from being 'so definite' that treatment would succeed to a 'realisation' that it 'might not succeed':

*Now it's failed once, I have a realisation that there is a chance that it might not succeed, we might not succeed with this, and err so I have a more fuller picture, because of what we've been through and the doctors that we've spoken to. Which I suppose is healthy, but (3) yeah, so my mind has changed a little bit. Cos I was just so definite, I thought we was just going to go over there, bang the operation away and suddenly we'd be having a little baby. (Chris 2; 6.22-27)*

The experience of failure made Chris acknowledge the possibility that the process as a whole might not succeed. Though he had described it being a process of three cycles during his baseline interview, he did not seem to expect that they might all fail. Despite the potential disappointment associated with the prospect of failure, he described his new knowledge as an advantage, as now he has a 'fuller picture', and that it 'is healthy', again focusing on a positive perspective (section 6.1.1).

Before treatment began, most participants associated IVF with scientific clarity and certainty, with little consideration of chances of failure, with exception of Jeremy. This, along with confidence in the expert solution chosen is suggestive of a confidence that IVF will be successful (for them). Failure turned fertility treatment from a short-term, acute, situation into something to be repeated many times (chronic), raising more awareness of future attempts and the chance of overall failure. Failure reduced the perception of the level of control doctors had over the process, and instead, participants relied on luck and fate as explanation of control, which is dealt with in the next section.

### **8.1.2 'It's what you're supposed to do': Invoking luck and fate**

Unexplained (and unexplainable) treatment failure reduced confidence in the control the doctors had over infertility, and this emerged increasingly during later interviews.

Participants relied less on perceptions of physician control over IVF, to explaining outcomes as luck or fate. After Chris and Cathy's first IVF cycle failed, Chris recognised parts of the process outside their or their doctor's control, like '*the egg*' failing to implant:

*So. I think it's just potluck, isn't it? And I know it sounds terrible to say that about a baby, it seemed to be (3) it's like a lottery isn't it? Cos everything was perfect all the way down the line, and just for some reason, the egg never stuck or grabbed hold of or whatever it does. (Chris 2; 1.10-13)*

The cycle failed, which Chris can only put down to luck, as they had such good signs along the way. His comment about '*it sounds terrible to say that about a baby*', suggested that baby making was something that should be above chance. An attribution to luck deflected potential suggestions that they (or their doctor) could have done more.

Natalie used game metaphors repeatedly during her follow-up interview referring to process and decisions as '*a card game*' (4.20), '*a money game*' (3.14-15), and '*a numbers game*' (11.30-31). This metaphor draws on luck and makes it objective, that it is out of control of anyone involved. Participants varied on the extent to which they were willing to continue treatment with only luck determining the outcome. Some were willing to '*play the odds*', like Cathy:

*There's nothing wrong, there's nothing, other than luck, I think, and you've got to play the odds. And I think that helps to just keep reminding myself that it, there's no reason why it shouldn't work. (Cathy 2; 8.19-21)*

There was no reason for the cycle to fail; there was '*nothing wrong*' with her or what they did, as Chris also suggested. Being to blame for failure has been associated with distress (Litt, Tennen, Affleck & Klock, 1992). Luck became a useful factor because they can '*play the odds*' and repetition might bring success: if failure was random, so is success. This leads to the possibility of engaging in multiple cycles in the hope that something will eventually happen to change the outcome, which might not be the case if there was a clear reason for failure. Cathy's willingness to undergo multiple attempts might arise because IVF is her last option for having a child. Relinquishment of control to luck might be helpful in minimising blame for treatment failure, moving it beyond the fault of the doctor, which might undermine confidence in the chosen path, or actions of the couple.

Where luck appeared an element of chance, some outcomes were attributed to fate, guided by an outside power or force. For Matt and Judy, devout Christians, fate was expressed in terms of God:

*I just have to, you know, know that ah there is a plan, God has a plan and that sooner or later, whether it be adoption or through natural, I guess, in a sense natural, or IVF it'll happen. (Matt 2; 3.19-21)*

Fate relieved the pressure of whether they would be parents because according to God's plan, the outcome was already decided and Matt had faith that '*it'll happen*'. This removed some responsibility from him; instead he needed to endure and remain faithful to God's plan. Matt mentioned in his baseline interview that they needed to '*stay the course*' and '*it'll happen when it is supposed to happen*' (1; 2.12-13) emphasising persistence and suggesting a predetermined outcome. Though based in his religious understanding, it also reflects cultural expectations of (eventual) reward for persistence in pursuit of a desired goal (Sandelowski, 1991). Giving up means accepting that it is not '*supposed to happen*' after all, or that they either misunderstood God's plan, or he did not want to reward them after all. Though this kind of religious fatalism might have helped him avoid feeling responsible for tasks not correctly fulfilled, like not giving the injections at the correct times (section 8.1.3), it might provide an alternative sense of control, that they are required to complete other tasks before being '*allowed*' to succeed with fertility treatment:

*Like sometimes I question like I said, you know if I actually need time, you know, to sort through my own stuff before I have a family. So I mean, I guess it's kind of dependent on God, you know, and just I'm just kind of trusting that he's allowing me to go through*

*what I need to do before I get a family. (Judy 2; 5.21-24)*

This provides meaning and work while waiting, and relinquishes responsibility to God for deciding when things happen, but there is an expectation that the family will happen. It might be negative if she has worked hard and ends up not being rewarded. Of all the participants, Matt and Judy particularly struggled to define a limit for treatment, and to decide when was the right time to stop (section 7.1.1). This might result from their deeply held conviction that God, and neither they nor their doctors, is in control of the outcome and has already decided the outcome. Elsewhere, religion has found to be less helpful in making sense of infertility as it happened, and tended to be drawn on once a child was in the home (Greil, Porter, Leitko and Riscilli, 1989). For Matt and Judy, religious explanations generally helped validate their decisions during treatment, which perhaps reflected their strong religious faith. Judy's withdrawal from church-based activities after her miscarriage was an exception to this (section 7.2.2) and highlights the significance of specific stressful events for an individual, rather than general experiences.

In contrast to Matt and Judy's strong Christian beliefs, other participants expressed a more general spiritual attitude:

*I sort of feel like the universe guides you, anyway. (Natalie 2; 7.4)*

Again, rather than being luck, there is the right outcome and an external force guiding her to that point. Introducing fate moved control away from individuals or their doctors, but still provided a sense of control in an outside force that 'desires' the same outcome as participants.

Especially in hindsight, there was a perception that events were meant to turn out the way they did. Attributing outcomes to fate retrospectively validated the decisions that were made, especially when a satisfactory end point had been reached:

*I think trying the fertility was a good thing, because it kind of makes you sure about the adoption decision. And that it's what you're supposed to do, so, if that makes sense.  
(Jeremy 2; 6.19-21)*

With the concerns about the expense and time with IVF, these were seen in retrospect as checking out every path, rather than as a waste. During the process, smooth progress was interpreted as a sign that the correct choices were being made:

*The whole thing seemed to be clicking into place really nicely, like it's meant to be.*

*(Chris 1; 9.15-16)*

This might be particularly reassuring when there was uncertainty about making the decisions initially. A retrospective confirmation that *'it's meant to be'* helped alleviate remaining concerns. Fate provided an explanation for failure, which occurred because a particular situation was not *'meant to be'*:

*And that's what she said with the two kids that they have, you know, is that if there were any other egg and sperm, it wouldn't be, you know, little Jane, or little Ian so you know, look at that one, yeah, so the ones that we've had in the past they weren't the right ones.*

*(Matt 2; 3.13-17)*

Again, Matt referred to a pre-determined eventual outcome, with intermediate failures may occur until the correct situation arose. All participants drew on luck and fate more as time progressed. An increasing perception of the lack of control that they or their doctors had over the process seemed to lead to a greater reliance on external forces controlling their situation to reach the desired outcome. Fate was a way of making sense of the way events had unfolded. If things went smoothly or produced a favourable outcome that was a sign that the right choices had been made. As time progressed, medical procedures became more familiar, and this is the subject of the next sub-theme.

### **8.1.3 'The injections are nothing now': Treatment processes become easier with experience**

While the perceived effectiveness of the medical interventions reduced over time, participants became increasingly familiar with the processes and procedures of treatment. Initially, IVF was new and unknown for both partners and concerns about carrying out the processes properly were raised during baseline interviews. For men, giving the injections was a significant experience (section 6.3.2). The women described obtaining factual information about what would happen, while the physical experience of the process remained unknown:

*Because I know two women who have gone through it they give me heads up on everything I should expect, and so um, nothing's really been that much of a surprise because I have so much information. (Judy 1; 4.29-5.2)*

Though Judy generally suggested that she could not relate to the emotional problems described by other infertile women (see Chapter 6), she gained practically from their interactions, which provided her with *'so much information'*. Her mention of women *'who have gone through it'* suggested that experiential information from peers was valuable,

perhaps more than information from medical sources. Worries about what IVF will actually be like to experience were important to the women at this time:

*I was more worried about the physical aspect, like how many shots I had to receive and all of that. (Judy 1; 5.12-15)*

Again, Judy focused on physical aspects rather than emotional ones, but worried about ‘*all the shots*’, so there was a difference between having information and having first hand experience of what IVF was like. Cathy had no experiential information to draw on:

*I'm kind of going into this in the unknown. No idea really what to expect. And as I said I haven't really spoken to anybody who has had any experience of it. So. I don't know. (Cathy 1; 8.20-22)*

Going into ‘*the unknown*’ sounded frightening, and reinforced a line between factual knowledge and experiential knowledge from other people. Before the first cycle, information is helpful, but there is a difference between factual information and knowledge of what IVF is like to experience. Others with similar experiences were a favoured choice for information, but that does not help the women know what IVF will be like for them. Natalie also ‘*had no expectations*’ of what treatment would be like (1; 7.7-8) and would be finding out as it happened:

*I just try to think like an anthropologist, that I'm on this discovery tour of myself, and creationism, or whatever you want to call it. (Natalie 1; 8.23-24)*

Positioning herself as an ‘*anthropologist*’ suggested a more distant, objective perspective where she was observing rather than participating, consistent with her resistance to becoming like other fertility patients (section 6.2.1). Where Judy and Cathy appeared somewhat worried about what treatment might be like, Natalie’s ‘*discovery tour*’ made this concern more distant and less personal, shifting her from living infertility to observing and gaining knowledge, from subjective to objective experience.

Patients are responsible for carrying out some parts of the process, most significantly the hormonal injections at home. The initial focus was on correctly executing the required steps, ‘*going through the technical things*’ (Chris 2; 1.14-15), like injections and appointment scheduling, which were new and unfamiliar. The defined timing and routine of the medical reinforced the importance of carrying out the required tasks correctly, and worries about what might happen if it was done wrongly:

*I've missed two sprays, and I'm thinking oh gosh, is that bad? Is that going to, what effect will that have? I'm a little bit on tenterhooks in trying to get it right. And I think that getting it right might mean that if I get in wrong in some way maybe it won't work, and that adds a bit of pressure. (Cathy 1; 8.12-17)*

At this stage she was focused on getting the new processes right. With the emphasis on specific timings mentioned earlier, the impact of mistakes was uncertain, but could be devastating, and might mean 'it won't work'. Fitting in the required activities, particularly injections, involved disruption to regular schedules, or constraints on activities:

*Just the scheduling of the doctors appointments the giving of the shots especially with IVF having to basically every 12 hours give 3 shots ummm and Natalie does not like shots anyway so that's a lot of shots it's you have to kind of plan your day around. The morning ones don't tend to be a problem the evening ones it seems like we're always trying to rush home to get them (Jeremy 1; 1.13-16)*

The requirements for the injections, particularly, are an intrusion into their regular routine, particularly considering Natalie's dislike of them. Yet, the disruption appeared transient at this point:

*Then the other part of it, it really is only a couple of weeks of the shots and with the I- the appointments it affects Natalie more than me, the number of appointments she has to go to. Ummm, but it just it becomes your routine. (Jeremy 1; 2.16-18)*

The main burden was on Natalie, but Jeremy suggested that IVF, despite the potential inconvenience, becomes a new routine to be incorporated into everyday life. The burden seemed less significant as it appeared to last only 'a couple of weeks' so, at this point, inconveniences appeared time limited.

With practice and time, new skills and procedures required become familiar and more easily executed. The process of carrying out the second or third cycles appeared much less difficult. One reason was personal experience, allowing more knowledgeable anticipation of feelings of treatment:

*I've felt quite relaxed really, with this second attempt. Thinking that I knew what I was letting myself in for and it wasn't a bad experience last time, so, yeah. (Cathy 3; 1.18-19)*

Cathy's previous experience added to the practical information she had before her first cycle and informed her expectations. Particularly that it was not a 'bad experience' eased her

worries. Chris explained a similar confidence during their second cycle. The previous experience meant that he '*definitely felt more confident going through it this time, cos we sort of know the process*' (3; 2.27-28). Having expectations from previous personal experience seemed most valuable to participants. Others explained that experience reduced the attention required to execute the required steps:

*I think we're accustomed to it. I think maybe, in the first, in the beginning trying to, the first time round with more of the medications and more of the scheduling, it was like OK, when do we have to do this, we've got to schedule it, we can't go to this outing or we can't go here because of that, but now maybe because we're forgetting what it's supposed to be, it's easier, it's not an inconvenience or it's not a hindrance, it's not something that's negative. Just do it, you know. (Matt 2; 13.17-22)*

Matt (and Judy) emphasised familiarity with the process to the extent that they forgot to take the medications on time. Judy described forgetting to take the medications to highlight how busy she was and how little time she spent worrying about IVF:

*I think we're keeping ourselves busy enough that we actually forget to take it [medications], and it's kind of like something we have to remember, so it's good. (Judy 2; 3.29-4.1)*

Maintaining the routine of injections no longer required explicit attention, reflecting familiarity with the process and perhaps less worries about receiving injections, which Judy had mentioned as a concern before her first IVF cycle.

Changing experiences were influenced by the couples' exact course of treatment. Matt and Judy found the second and third cycles easier because they were doing a frozen embryo transfer (FET) cycle, involving fewer medications and procedures (ASRM, 2008). Their subjective perceptions reflect the objective differences between fresh and frozen cycles. Having undergone multiple cycles allowed participants to compare within their own experiences, rather than having no experience or relying on second-hand knowledge from friends. Though the practicalities of treatment became easier with time, the experience of treatment varied between cycles. Cathy's first cycle was smooth, but her second required additional medications and resulted in uncomfortable side effects:

*I think I'm probably a bit disappointed that it isn't going as well. I went to, um for a scan on Monday and my body hadn't responded as well as it did last time, either. So they had to give me extra drugs and more time. Umm. I don't know, I just have a weird feeling*



*about that. It just feels, it feels very different, and I feel a bit sad about it, to be honest with you. (Cathy 3; 1.19-24)*

The difference was in her physical response, both the visible effect of the uncomfortable rash, and the unseen poor response to the medication. Her new expectations of IVF after having experienced one cycle were violated by her latest experience: *'there's a lot of things going wrong that I didn't expect'* (1.27-29). This created uncertainty about potential future cycles, too.

Though familiarity led to more confidence and ease of the IVF procedures, and a new routine, for some the IVF processes shifted over time from a temporary inconvenience to being burdensome from repetition and multiple implications. For Jeremy, the disruption stemmed from many small demands on him:

*I don't know if it's any one thing, it's just, (1) there's always something. There's dealing with the drugs, there's mood swings, there's um all the doctors appointments, there's all the adoption things there's. So I don't think it's necessarily that any one wouldn't be a big deal but it's all of them. (Jeremy 2; 6.4-7)*

Whereas in his baseline interview he described these tasks as being *'routine'* (2.15), now they seemed more wearing, not by any one stressful element, but that *'there's always something'*. His situation might be more demanding than many, as he and Natalie were pursuing IVF and adoption simultaneously. His irritation might stem from his desire to *'go get him [their son]'* and that he wanted to end their current IVF cycle. Natalie described having to *'psych'* herself up to repeat IVF after a miscarriage

*But, it was just like OK, batter up, you know, having to kind of psych yourself up to do it again, it's very time consuming, it's, you know, a tremendous amount of money, because you know it's not covered by insurance for us. (Natalie 2; 5.17-20)*

In contrast with Natalie's usual emphasis on the unemotional nature of IVF, the phrase *'psych yourself up'* suggested emotional weight to the decision to do IVF again. She emphasised the investment of time and the financial implications as the burdensome components of repeated treatment. Jeremy found the multiple tasks difficult and Natalie seemed to find the further drain of money and investment of time hard.

Initially, participants were attentive to getting the steps of the process right and, for the women, there were worries about what IVF would be like to experience. Executing the practicalities of treatment, like managing injections and timing, were challenging. Focus on

the required action, and perceived links between doing the process right and a successful outcome, might have left little time to prepare for potential failure or to worry about the cycle outcome. Carrying out the processes required less attention as treatment progressed. The increased familiarity and ease of the processes as treatment progressed might allow emotional responses to assume more significance. Though tasks became easier with time, the practical demands may become wearing with repetition. Events disrupting the expected familiarity of the treatment process caused difficulties, and the next theme explores this.

#### **8.1.4 'There's no logic to it': Making sense of signs and outcomes**

Throughout the interviews, participants searched for signs and indications indicating positive outcomes. During baseline interviews, a good response to treatment was seen as a good sign. Judy gained confidence from her response to the medications:

*And, like I said, it's been helping just to know that I do respond to medications. I think that if my body didn't respond, or if I only had a few eggs developing ... I'd definitely get depressed. So I know that my body's working. (Judy 1; 8.19-22)*

Positive signs gave her confidence that treatment would succeed, but made the idea of success fuzzier because IVF was being successful in that eggs were developing and her body was 'working', though she was not getting pregnant. She reinforced these signs with a similar prognosis from her doctor, who was 'hopeful' (2.23) because Judy responded well to the medication. Judy's mother also suffered from polycystic ovarian syndrome (PCOS) and yet went on to have four children. Judy drew on multiple indicators: her body's response, her doctor's confidence and her mother's experience, all of which gave encouragement for an eventually positive outcome. Natalie suggested that because 'follics have grown' she did not need to think of herself as infertile and that there was 'no reason you can't get pregnant now' (1; 11.15-16). For Matt, Judy's miscarriage, though negative for her, identified the positive sign that 'she can get pregnant':

*Because of the miscarriage it was kind of, you know, it was hard on her, but it's positive in the sense that she can get pregnant. (Matt 1; 10.20-21)*

Achieving pregnancy validated the potential of fertility treatment to work for them, meaning it can happen again. The line between fertility and infertility appeared blurred by successful steps in treatment. This was less so at Natalie's follow-up interview, where good signs were not indicative of a good outcome:

*My sister this morning was like "oh you're going to do a pregnancy test?" and I said*

*"it'll probably be positive but, that doesn't mean anything."* (Natalie 2; 10.4-6)

Where during her first cycle, the presence of *'follics'* was a good sign, now even a positive pregnancy test is not any indication of a good outcome. When treatment failed, participants attempted to reconcile the good signs they saw with the poor outcome to make sense of the implications for future attempts. Cathy described her optimism between embryo transfer and pregnancy test before finding out that the cycle had failed:

*And then, yeah, they got put back, and then the two weeks waiting, I was fine throughout because I felt so positive. And I started to get quite excited because it had just gone so well and they were so perfect.* (Cathy 2; 3.15-18)

Cathy linked cycle progression to the outcome, particularly because it had *'gone so well'* and produced *'perfect'* embryos. This reflects work with daily diaries, suggesting that optimism peaks after embryo transfer (Boivin and Takefman, 1996). She reinforced this by reporting that her consultant was *'pleased'* (7.1) with her response to the medication; like Judy, drawing expert perceptions to reinforce her own. Against this background, it was hard to understand why the cycle failed, but it reduced her certainty about the future, if IVF failed when it had *'gone so well'* and the embryos were *'so perfect'*, future success appears less likely. Perhaps this was why during her next cycle, she focused on her underlying advantages of age and fertility health rather than the treatment process:

*But at the same time I'm just trying to stay with what I know is positive for me, which is I've got my age on my side and the fact that there's nothing wrong with me.* (Cathy 2; 6.11-13)

Her refocusing appeared effortful, as she was *'trying to'* focus on the positive elements. The positive indicators changed and she focused onto the areas offering the most reassurance.

Experiences were compared with others as an attempt to indicate future success. Chris had friends who had tried IVF, successfully and unsuccessfully:

*My friend went through this process about 12 years ago, and they weren't successful, they did it about three or four times and they weren't successful. But it was pretty much when it first started, so I think it wasn't as honed in then.* (Chris 2; 11.17-20)

Unsuccessful experience might be discouraging, but as it was some time ago, he can reassure himself because the process *'wasn't as honed in then'*. Chris and Cathy's easier experience with injections further distanced them from his friends' experiences: the poor process they

experienced led to a poor outcome, which gave more encouragement to the thought that good processes – well, led to poor outcomes in this case, but might easily not. He simultaneously looked at his friend's experience as both a good sign and an irrelevant one.

At follow-up interviews, unexplained treatment failure had dimmed confidence in the scientific certainty of the IVF process as the cure for infertility, particularly for men, as they tried to reconcile apparently optimal solutions with failure:

*I thought wow, you can't get much better than, more help than that, you know, you're transferring the embryos into the uterus, you've given them a little hole to come out of, and they can grasp on. (Matt 2; 1.25-27)*

The steps taken appear to improve their chances: the embryo was given a 'little hole to come out of' and put right in the uterus. All it needs to do was 'grasp on', and yet the cycle failed. It was problematic when doctors and other medical staff did not take what appeared to be the best or logical course of action. Matt wondered why their embryos were frozen together irrespective of their quality, which appeared to fail to exploit their best chances by using the best embryos:

*We started wondering wait a minute, we had some 7 cell ones that were done by ICSI, why weren't they transf-, you know, wouldn't they have a better chan-. I don't know if they have a better chance, but thinking, you know, kind of in that logic, wouldn't they have had a better chance? (Matt 2; 2.7-11)*

What seemed like a logical way to maximise their chance of conception was not taken. He avoided outright criticism of the medical team, correcting himself from stating what would be the 'best' option to asking it as a question. He expressed frustration that they 'wasted' money in transferring lower quality embryos that may have had less chance of being successful. Tension occurred when the medical process seemed insensitive to factors that were important to him, like saving money by not doing unnecessary cycles, apart from not giving them the best chance of pregnancy.

Jeremy questioned the value of engaging in further cycles as the line between problem and solution became less clear: 'nobody can tell me what we're changing or what is different that is going to make the outcome different' (2; 5.12-13). He saw no value in repeating previously failed actions: either change to better adapt to the situation or stop. Chris was less worried about unexplained failure than the other men, though his initial certainty that it would all go forward 'as a matter of course' (1; 6.17) changed to 'it's a good process and all that, but...'

(3; 6.4). Matt and Jeremy had done one more IVF cycle at a similar time point, Chris was focusing on success 'over three cycles', and had confidence, as Cathy did, in the doctors 'tweaking' the procedure each time and finding the best solution.

Matt, Chris and Jeremy tried to make sense of a clear, logical, scientific process that led to unknowns, uncertainty and failure. The situation seemed clear-cut until failure was encountered and the certainty of the medical solution appeared less over time. Jeremy moved from a position of IVF being a science to IVF being more like an art between his interviews, after experiencing treatment and treatment failure. While they were pursuing treatment, the men strove for acceptance: to put themselves in the hands of the expert doctors though this became more difficult as failures occurred. Other research suggests that men tend to have faith that medical technology will work eventually (Glover, McLellan, & Weaver, 2009). These men had less faith over time, particularly as doctors were unable to explain why treatment failed.

Perhaps because outcomes of IVF are so uncertain and unknowable, participants attempted to find ways to predict them. This drew a mix of sources: expert prognosis, lay perceptions linking smooth process and good signs with potential success, and others' experiences. Malik and Coulson (2008b) found that IVF patients found it hard to make sense of symptoms and potential outcomes. Unless participants believed there was a chance of success, they would abandon treatment.

### **8.1.5 'I'm trying to be in the moment': Shifting temporal perspectives**

Perceptions of treatment changed over time, but different perceptions of time were used during the interviews. Varying temporal perspectives were taken up in apparent attempts to find the most helpful outlook. During the early stages of treatment, participants felt their situation was under control, but were aware of the potential for that to change in the future:

*I think that we're dealing with it OK, I mean, Chris and I are communicating well, and we're quite comfortable with what we're doing. I don't feel, at this stage that it's a crisis or anything. I still feel slightly anxious but quite positive and that we're going to just try again and um, so therefore I don't feel like I need anything more than what I already have. (Cathy 2; 12.20-25)*

Though Cathy wished to be pregnant, therefore was not at her desired state, she was doing everything feasible to obtain that. The perception that everything possible was being done appeared reassuring. There was potential for it to become a crisis but her focus was on this

point in time, 'at this stage'. Chris emphasised the currently favourable situation, while looking forward to a future that might not be so good:

*So, stay positive while we can and if it does turn negative and then we'll deal with that.*  
(Chris 1; 13.5-6)

Chris emphasised developing changing responses to a changing situation. Participants anticipated the potential for future difficulties, like financial constraints as discussed in the last chapter. Natalie drew on perceptions of the long-term course of treatment, and presumably observations of other patients, to project a potential future that she wished to avoid:

*And my assumption, I mean we're talking about a trail I haven't blazed, is that you become more emotionally invested with each turn of the dial. So you know, now we're at the early stages of IVF; if we're having this conversation 6, 7 months down the line, and we were choosing to continue with IVF, I think that the emotional strain may be heightened.* (Natalie 1; 2.27-3.1)

She already foresaw a potentially increasing emotional 'investment' and 'strain' with repeated IVF attempts. Her reference to the 'turn of the dial' suggested a process that becomes cumulatively more difficult. Comparisons with others' situations provided a warning about the potential future:

*Cathy: But, you know, we're OK financially. But it is a worry. And again, you know, people's stories at the hotel, they're selling their cars and selling their homes and it's all a bit depressing really, what some people go through.*

*Elly: Kind of a warning like you wouldn't go that far?*

*Cathy: I guess I just don't want to think about that, I must say. You know, at what point do you stop? (2) I mean I can't even go there right now. I don't know what when that would be for us. I mean I think we'd have to talk seriously about that. But we're not there yet, so I'm not, I refuse in a way to think about that. I'll deal with that when it comes along.* (Cathy 2; 15.7-16)

Seeing others further on in the process led to caution about negative potential consequences ahead. She separated herself from the others, as they're 'not there yet', but it's depressing because it is a choice they might end up making. As others' experiences were a warning about what might lie ahead, participants attempted to minimise potential future problems,

engaging in anticipatory coping. They began to anticipate the re-occurrence of previously experienced failures that they had not perhaps been aware of initially, like failure or miscarriage. Jeremy had little confidence in the potential for a better outcome from their final cycle:

*You have to kind of. I mean, it's almost like adoption you have to hope for the best and expect the worst, you know, it's just how it goes. (Jeremy 2; 3.47-8)*

Compared with his baseline interview, where he described an objective process of 'doing the protocols and seeing what comes out' (Jeremy 1; 5.26), now he prepared himself for potential failure. As in section 8.1.4, he tried to explain the failure they had encountered, describing it as the 'art side of medicine'. He was cautious in regard to their ongoing adoption, which has not yet failed or had any indication of failing, suggesting that the experiences with IVF may have informed his general approach to having a child.

As well as anticipatory coping, participants engaged in temporal reframing, where they took the time perspective that was most helpful in a particular context. Temporal reframing helped Cathy to reduce her sense of failure after her first cycle failed:

*Umm, and to just kind of, you know, look at it all as one process instead of failing and that sort of thing, it's not a failure, yet. (Cathy 2; 5.28-29)*

Seeing this cycle in the overall context of three treatments, as their doctors had told them, mitigated the disappointment of failure. The three-cycle perspective appeared helpful to both Cathy and Chris in allowing them to refocus on eventual success rather than success of a particular cycle. The potential for overall failure is present, indicated by Cathy ending her sentence with 'yet'. Cathy struggled with IVF failure reflecting on her personally, as someone who does not usually fail or 'make mistakes' (2; 2.22). For Cathy, the longer-term future offered hope of success to overcome disappointment and avoids her concerns about failure. In contrast, Judy, at her follow-up interview found a short-term perspective more comforting:

*I guess I'm almost afraid to look forward. Umm, you know, cos sometimes I'm like, oh it'd be so cool to start buying all these maternity clothes [laugh] in preparation, or all these baby clothes, or you know like, if I see coupons like for Babies'R'Us, I'm like oh I should buy something. But I get freaked out, you know, cos I'm probably jumping too forward. Um, so yeah, I try not to because I think it's a little bit scary, because, you know, just because it's unknown or because of the disappointment involved. So yeah, so I guess I try to focus more on what I can be doing in the meantime. (Judy 2; 12.16-22).*

The future is unknown and potentially disappointing, if they continue to fail with IVF. Action right now is comforting as something can be done about this, without risking adding to her disappointment. Keeping busy might help her avoid looking forward.

Cathy, Natalie, and Judy all mentioned focusing on the present, which to them meant '*staying real*' (Cathy 2; 8.22), rather than worrying about abstract concerns that might not occur, or just '*focus[ing] on the next step*' (Judy 1; 8.15-16), with a short-term focus. While Natalie mentioned her concerns about the long-term impact of fertility treatment on her health, she focused on short-term practicalities and immediately available actions, and '*living in the now*':

*I very much think like Buddha, you know, I live in the now, and the now is, you know, get the drugs in, develop the follicles aka 'Project Weeble', you know. Next step would be embryology, but I really don't think more than probably three days ahead of what things will be, and make sure there's enough what I call baby crack, the drugs in the refrigerator and that's it (Natalie 1; 10.5-9)*

Natalie distinguished between control over her actions right now and the lack of control over those far in the future: '*I could think of a hundred years out right not much of it I could probably impact right now*' (1; 10.11-12). Again, this highlights differing levels of control over events and the significance of being able to take action regarding any of them. There are multiple temporal perspectives that can be selected, depending on which was most useful. There is, as Cathy put it, little point worrying about the future that cannot be controlled, whereas action now might change that future and attention can be focused on that.

Short-term perspectives were significant when there was an opportunity for change to occur. Being actively engaged in a cycle of IVF raised the possibility that pregnancy might be attained in a matter of a few weeks, minimising the impact of longer-term worries.

*I don't know, I'll have to see how it goes over the next couple of days, especially tomorrow is a big day, see how my body has performed, again! (Cathy 3; 7.23-25)*

Her previous failure, particularly after the cycle went so '*swimmingly well*' (7.19), made her cautious about anticipating success. She downplayed her hopes that it might work this time with concerns about her body's (poor) performance to the medications. Despite this, she brought her focus back to the immediate future, waiting to see what would unfold over '*the next couple of days*'. If things went well, concerns about the future would be irrelevant.



Section 8.1.1 suggested that couples saw fertility treatment as something short-term during the first cycle, with expectations that IVF will work for them, and failure turned this into a longer-term view, with the possibility that treatment might fail overall. While actively engaged in a treatment cycle, a short-term view of the future might again emerge because change (pregnancy) could occur.

### **8.1.6 Section discussion**

Participants tried to make sense of, and retain confidence in, fertility treatment as the best course of action to tackle their infertility. This theme explored how perceptions of fertility treatment changed with time and experience of treatment. Views of control and time-line, two illness representations from the Self-Regulation Model (SRM; Leventhal Leventhal, & Contrada, 1998), were important throughout this chapter. Embarking on IVF meant handing control to the medical team, contrasting with the emphasis on personal control seen in previous chapters (sections 6.1 and 7.1). Relinquishing control here was seen as a positive step, in contrast to being a loss of control as suggested in other work (Greil, 2002; Litt et al., 1992). Participants' perceptions at this point appeared incompatible with a transactional definition of stress. Rather than their resources being exceeded and well-being being endangered (Lazarus & Folkman, 1984), undertaking IVF relieved their stress as an ideal tool to achieve their desired goal.

Other research has supported the evaluation that fertility patients have no control over treatment processes and outcomes, and thus experience low control (Glover et al., 2009; Verhaak, Smeenk, Evers, et al., 2007; Webb & Daniluk, 1999). However, these studies are largely retrospective, whereas in the current study, participants were interviewed concurrently with treatment. Attention to personal control of treatment outcomes was negligible compared with the perception that their doctors had control of the situation. This is vicarious control, a form of secondary control (Mendola, Tennen, Affleck, McCann, & Fitzgerald, 1990). Mendola et al. found that vicarious control was the only form of secondary control positively correlated with primary control for their group of women undergoing fertility treatment. However, Abbey and Halman (1995) found that the women in their study tended to have negative evaluations of their doctors, focusing on their mistakes and financial gain, though it is unclear how long they had been receiving treatment. Vicarious control may be most helpful at the beginning of treatment, when confidence in the medical solution and professionals appears highest.

Perceptions of control shifted as unexplained treatment failure occurred. Participants placed less emphasis on their doctors' skill and knowledge, and were more likely to relate outcomes to luck and fate. Drawing on fate appeared to retain a sense of control by implying a role for an outside power, either God or 'the universe' depending on the religious orientation of the individual. Random outcomes have been linked with poor adjustment, for example, Abbey and Halman (1995) found that individuals who attributed their infertility to chance were more poorly adjusted than those who found a reason for it. However, they suggested that some people might see themselves as lucky, and therefore see chance as 'a benevolent factor' (p. 288). These individuals may be more willing to 'play the odds' than those who favour a strong sense of control (either theirs or their doctors) over the outcomes of IVF. A link between perceptions of luck and vicarious control might be a factor in ending treatment while medical options are available.

The men in this study expected that certain treatment produced predictable outcomes. Treatment failure challenged this perception, particularly when doctors had no explanation for the failure. Inexplicable treatment failure contrasted with straightforward explanations for the cause of infertility, like polycystic ovarian syndrome (PCOS), age, or failed vasectomy reversal. Though unexplained infertility has been found to be difficult for individuals (Daniluk & Tench, 2007), unexplained failure also appeared challenging, particularly for men, who have been found to have greater faith in technological solutions (Glover et al., 2009). This reflects two perspectives of the causal element of the SRM, incorporating both illness and treatment representations (Leventhal et al., 2004). These participants had little difficulty explaining the causal element of their infertility, but struggled to extend this perception to further factors that might explain treatment failure.

Failure has been found to be one of the most difficult aspects of fertility treatment (Boivin & Takefman, 1996; Holter et al., 2006). Personal encounters with failure crystallise it as a possibility that can reoccur, as Malik and Coulson (2008b) found, rather than an abstract, and perhaps overlooked, possibility. In this way, past experiences are integrated with the present situation to clarify understanding of the present and determine future expectations (Sandelowski, Holditch-Davis & Harris, 1990). Failure of the first cycle was particularly important.

Participants' perceptions of their treatment time-line changed. Fertility treatment is often described as open-ended and long-term, based on retrospective accounts where this had been participants' experience (Greil et al., 1989) and low overall success rates (CDC, 2010).

Couples beginning treatment may have a different perception, tending to believe that IVF will work for them and anticipating a quick resolution of their infertility. Other research has found that individuals embarking on fertility treatment tend to overestimate their chances of success (Beaurepaire, Jones, Thiering & Saunders, 1994; Becker & Nachtigall, 1992; Callan & Hennessey, 1988; Imeson & McMurray, 1996). Callan and Hennessey found that with subsequent attempts, no women rated their chances of success that highly. This suggests that the first treatment cycle is an important time for reforming perceptions of IVF that may be less changed during subsequent cycles. Perceptions of a short time-line reflected participants' initial confidence in their diagnosis, and the treatment they were to receive.

Participants' viewed the start of treatment positively, as it meant taking action to tackle infertility, which aligns this with research identifying this as a time of hope (Collins et al., 1992; Slade et al., 1997) rather than stress (Cousineau & Domar, 2007). However, the women had concerns as they lacked personal experience of what undergoing treatment would be like for them, and how they, as an individual, would feel and react. Other research has identified the need for information at this time (Markestad, Montgomery, & Bartsch, 1998), and that its lack can lead to stress (Slade et al., 1997). For these women, practical information seemed easily acquired, but experiential knowledge was limited because it is not possible to fully share what another has experienced. This highlights stress occurring related to a closely defined issue that is limited in time.

The impact of failure of the first treatment cycle seemed important. Lord and Robertson (2005) similarly found significant differences in illness representations between individuals undergoing first and subsequent cycles of fertility treatment. Failure of the first cycle causes distress (Holter, Anderheim, Bergh, & Möller, 2006), which is understandable and not unexpected (Edelmann, Connolly, & Bartlett, 1994). The current study suggests that lack of experience with IVF procedures may divert attention to managing those aspects rather than preparing for a potentially negative outcome, which comes as a shock (Glover et al., 2009). Participants tended to gain hope from good signs, which is consistent with previous research that reaching milestones like embryo transfer reinforces expectations of success (Boivin & Takefman, 1996). Those for whom treatment fails might have been better off if prepared for that possibility (Verhaak, Smeenk, Evers, et al., 2007), perhaps after embryo transfer when the burst of optimism occurs (Boivin & Takefman, 1996), but which signs might or might not indicate a positive outcome. There is a potential contradiction between reducing stress and anxiety, and giving patients a balanced prognosis to reduce disappointment after a cycle.

After the first cycle, perceptions of IVF shifted from an acute event, a single cycle, to a longer term, chronic process involving potentially multiple cycles after the first cycle failed. Berg and Wilson (1991) found a similar pattern of initial acute stress during early stages of treatment, changing to chronic stress after several years in treatment. Leventhal, Easterling, Coons, Luchterhand and Love (1986) found a similar change in temporal perceptions in women undergoing chemotherapy for breast cancer. Changes in perceived timeline were linked to experienced time and multiple treatment, not medical judgments of the cancer as acute or chronic. In the present study, perceptions of the treatment timeline varied with treatment experience. Engaging in a treatment cycle appeared to return to a short-term view as there was a possibility of pregnancy.

## ***8.2 Chapter summary***

This chapter examined changing perspectives of treatment over time, particularly views of treatment control, time-line, and causes, reflecting three elements of illness representations described by the Self-Regulation Model (Benyamini, 2009). In this chapter, perceptions of control, cause and timeline were important and changed, particularly with treatment failure. It appeared that fertility treatment might replace infertility as the 'illness' being represented.

## 9 Discussion

This final chapter discusses what was attempted and achieved during this research, draws together the themes, and assesses their implications within the related empirical, theoretical and therapeutic literature. The first section restates the study objectives, and explains where each is discussed further in this chapter. The second section summarises the study themes. The third and fourth sections relate the analysis to the relevant infertility literature and theoretical models respectively. The fifth section assesses the implications of this research for therapy and support of fertility patients. The next section evaluates the scope and limitations of the research, and how to develop this work further. The chapter ends with a reflective section exploring the personal interaction between researcher and research, and the impact on the process and outcome of this research, and a conclusion.

### 9.1 Review of study objectives

This study investigated men's and women's experiences of fertility treatment starting at the beginning of their first in vitro fertilisation (IVF) cycle, as this is often considered one of the most stressful points in fertility treatment. As the existing literature suggested that infertility experiences are diverse, Interpretative Phenomenological Analysis (IPA; Smith, 1996) was chosen to preserve individual perspectives in the final analysis. The study was designed to make use of the transactional stress and coping framework (Lazarus & Folkman, 1984), which is widely established in infertility research. The research was guided by the question 'how do men and women experience stress and coping during the early stages of in-vitro fertilisation (IVF), and does this change over time?' The research question generated five objectives:

1. To identify interpretative themes relevant to the research question and most prevalent across participants' accounts. *The themes are summarised and discussed in section 9.2.*
2. To add to psychological knowledge of men's perceptions of fertility treatment, and about how both genders make sense of their experiences as part of a couple. *This is discussed in section 9.2 and 9.3.*
3. To increase psychological knowledge and understanding about fertility treatment as a changing and dynamic experience, by identifying temporal elements of participants' accounts and the interpretative themes. *This is discussed in section 9.2 and 9.3.*

4. To extend psychological understanding of the application of stress and coping theory to fertility treatment. *The theoretical implications of this research are explored in section 9.4.*
5. To use the interpretative themes and theoretical observations to inform therapeutic practice for individuals and couples undergoing treatment for infertility. *Therapeutic suggestions based on this study are presented in section 9.5.*

The next section summarises the thesis themes, and how these answer the study objectives.

## **9.2 Summary of main themes**

This analysis focused on themes that were well represented through the data set. The analysis represents one particular interpretation of these participants' experience, but is selective of the data presented, because it looks at themes that were prevalent among this group of participants. The overarching thesis theme is participants' efforts to tackle infertility and fertility treatment in what they perceived to be the best way possible. While they strongly desired parenthood, as others have found (Imeson & McMurray, 1996), they wished to remain emotionally healthy, with a strong relationship, and to reach their goal with the minimum investment of time and money. Participants worked to identify the optimum course of action, make decisions, and shape their behaviour to achieve the identified goals. This overarching theme was explored as three super-ordinate themes (chapters 6, 7 and 8).

Chapter 6 examined how participants shaped emotional representations of infertility and fertility treatment. Participants drew on different explanations and contexts to address the meaning of stress and emotion during fertility treatment. Both genders drew on perceptions that stress is bad for fertility and valued the importance of positive thinking. Gender effects emerged, particularly the social context shaping emotional perceptions of treatment. Women used social comparisons with other fertility patients, tending to perceive others as coping more poorly with treatment than they did. Men were focused on the couple and their spouse, which made it harder for them to express their emotions about treatment unequivocally, as they balanced their own distress with their partner's.

Chapter 7 focused on participants' framing of fertility treatment as a solution to the problem of infertility. Emphasis was placed on careful, objective decision-making, and attempting to make the best use of time and money. Finances were a major concern to all participants and especially to the women, who appeared to become the couples' financial manager. Action was prized over worrying and being unoccupied, and participants kept busy with both

treatment and non-treatment related tasks, as these were available. The couple was an important reference in accounts, with participants' individual narratives describing joint decision-making and action. Divergences in individual accounts appeared to highlight areas of stress, but these were temporally specific.

Chapter 8 explored participants' changing perceptions of fertility treatment over time. Participants initially had great confidence in the knowledge and expertise of their doctors, which supported their decision to pursue treatment. Treatment failure reduced their perception of this expertise and they began attributing treatment outcomes to luck and fate instead. Participants struggled to reconcile good signs during treatment with poor outcomes, and lack of predictability about future events, and men tended to search for logical patterns of cause and effect. While faith in medical expertise reduced over time, participants' familiarity with the treatment processes, particularly those they were required to carry out themselves, increased. Participants drew on different time-frames as they were most helpful at any time. The next section looks at these themes in relation to existing infertility research.

### ***9.3 Connections with other infertility research***

An attempt to reach the goal of parenthood in the best way possible contrasts with the idea of parenthood at any price, as is often presented in the literature (Becker & Nachtigall, 1994). Though participants expressed distress, stress, and difficulties, they focused on achieving goals, including maintaining emotional well-being. This contrasts with previous findings that qualitative research emphasises distress more than quantitative does (Greil, 1997; Stanton and Dunkel-Schetter, 1991) and that individuals are more willing to express negative emotions in an interview situation, which is more transient than a written questionnaire (Anderheim, Holter, Berg, & Möller, 2005). These findings reflect what others have found: that fertility patients generally deal well with treatment (Beaurepaire, Jones, Thiering, & Saunders, 1994; Greil, 1997; Lord & Robertson, 2005; Slade, Emery & Lieberman, 1997). Participants' emphasis on decision-making and action reflects that active and problem-focused coping have been found to be the most used strategies (Lord & Robertson, 2005). Other topics emerged in the themes that were not related to the main objectives. Control reoccurred across themes. Infertility and fertility treatment are often described as uncontrollable stressors, but a more complex picture emerged, fitting with an observation that control is unclear in fertility treatment and may be multi-dimensional and variable (Glover, McLellan, & Weaver, 2009; McQueeney, Stanton & Sigmon, 1997). Control was less related

to objective measures of outcome than is often described (Schmidt, 2010; Verhaak, Smeenk, Evers, et al., 2007), and was divided between the couples and their doctors. Participants retained control of their choices to do, continue and end treatment, and control of finances was an area of particular concern, in avoiding a financial crisis and getting maximum benefit from the investment in IVF. The sense of control may be related to the times at which the interviews took place, when decisions were made and action being taken, and the start of fertility treatment has been identified as a point at which control of infertility is regained by deciding to pursue treatment (Glover et al., 2009). Though participants relinquished control of their reproductive processes to their doctors, this was not necessarily perceived as negative; in fact, this was (initially especially) seen as positive in gaining expert intervention, previously described as attaining vicarious control (Abbey & Halman, 1995). Perceptions of physician control diminished over time with treatment failure, though, particularly as medical teams were seen as having no answers for why failure occurred.

Experiences were shaped by comparisons with other fertility patients, particularly at fertility clinics, rather than fertile others as is often assumed (Miall, 1986). There is little research into social comparisons during fertility treatment (Stanton, 1992), and this focuses on the extent of comparisons rather than their meaning and implications. This research showed participants making (usually unfavourable) temporal comparisons with patients further on in the process. This differs from other health research showing patients making temporal comparisons with past selves, who were in a better state of health (e.g. Osborn & Smith, 1998; Turner, Barlow, & Ilbery, 2002). For fertility patients, the old self is undesired (not pregnant or a parent), and an available comparison with other patients is of those who are unsuccessful. Temporal comparisons have received little attention in infertility studies, though previous research has shown that fertility patients tend to favourably compare their current coping with earlier coping skills (Affleck & Tennen, 1991). The role of temporal comparisons against other, longer-standing patients, who are by definition unsuccessful in treatment, is an area of potential interest for future research.

#### ***9.4 Relationship to theoretical models***

The study was intended to relate the developed themes to the transactional stress and coping framework of Lazarus and Folkman (1984). This was insufficient to address the data for three reasons. First, participants themselves rejected the classification of infertility or fertility treatment as a general stressor. Second, the accounts contained elements that could be considered stressful, but this was tied to closely defined events, which were generally time



limited. Third, participants' accounts showed their attempts to manage their behaviour, actions and emotions to best meet their goal of parenthood. The developing analysis, participants' explicit and implicit expressions of stress, and the importance of setting and achieving goals and objectives, pointed to a better fit between the data, themes and Leventhal's Self-Regulation Model of health (SRM; Leventhal, Leventhal & Contrada, 1998). The themes of the empirical chapters here reflect the dual focus on the SRM on individuals' emotional (chapter 6) and physical (7 and 8) understandings of their illness. The use of IPA, an inductive, participant-centred methodology, allowed the research to move outside the pre-conceived theoretical framework imposed and to develop along a line sensitive to the actual data obtained. Smith (2007) described a similar flexibility when calling on theoretical frameworks for his study of role change during new motherhood, from an individual experience to a socially influenced process.

Stress, though a neutral term in research, had negative connotations for participants. This difference between formal and informal uses of terms has been noted elsewhere. Abbey, Andrews and Halman (1991a, p. 311) referred to participants' 'fertility problems' rather than 'infertility' as that the latter term was found to carry a sense of finality that was distressing to participants, despite being the medically defined term for their condition (ASRM, 2004). Others have identified the more varied interpretations individuals and couples make of infertility (Greil & McQuillan, 2010; Sandelowski, Holditch-Davis, Harris, 1990). Here, being stressed carried negative connotations, by linking individuals with stereotypes of distressed, obsessed fertility patients, because stress was seen as bad for fertility, and because emotional outcomes were perceived as something that could and should be controlled. Acknowledging difficulties with practical elements, like finances, appeared less problematic and did not appear to be seen as reflecting badly on the individuals' choices or control. The meaning and significance of 'stress' in different contexts therefore varied, suggesting that explicit exploration of this issue would be valuable in understanding the meaning to individuals generally and in the context of infertility.

Infertility and fertility treatment are considered generally stressful and most research reinforces the picture that infertility is a problem (Lloyd, 1996). This reflects an identified problem in stress and coping research where researchers decide in advance what stress and coping constitutes in the situation (Lazarus, 1993). The approach taken here was harder, because participants did not necessarily describe issues 'supposed' to be stressful as such. Stressful elements were situationally and contextually dependent, varying with couples'

particular experiences. This suggests that fertility treatment is not necessarily a general stressor (Berghuis & Stanton, 2002) or continually stressful, but is something that is stressful at times, and within individual's context. There is a difference between looking at day-to-day experiences of fertility treatment and asking for opinions on it as a whole. Though the transactional model emphasises the individual and contextually specific nature of stressors (Lazarus, 2000) it appears difficult to conceptually implement this rather than focus on a more general issue, like fertility treatment, or a treatment cycle.

Participants identified specific events as difficult, some of which have been identified in previous research like waiting for pregnancy test (Boivin et al., 1998; Callan & Hennessey, 1988), or miscarriage (Kopitzke, Berg, Wilson, & Owens, 1991). Some issues were difficult at specific times and did not necessarily reoccur, like relationship threat, gaining awareness of infertility, and perceptions of non-biological parenthood. At other times, stress emerged while participants were mostly positive about their situation, like at the beginning of the first treatment cycle. Participants were optimistic about their chances of success and excited to be taking action to tackle their infertility, while (for the women) anticipation of the experience of treatment was worrying, and both partners had to expend effort to become familiar with treatment processes, and the men had to learn to give injections.

Some infertility literature has pointed out how variable individual experiences may be of fertility treatment, even though it appears the same for all (Benyamini, Gozlan & Kokia, 2005; Dunkel-Schetter & Lobel, 1991). Benyamini and colleagues have also questioned the assumption that infertility and fertility treatment are wholly and inherently stressful and can be completely theorised within that perspective (Benyamini, 2009; Benyamini, Gozlan & Kokia, 2004). As Jones and Hunter (1996) argued: infertility should be viewed as 'a stressor for some of those people some of the time' (p. 105). Other health research has tackled the tendency to group all sufferers of a certain condition in one group. Extensive research was carried out by Susan Folkman and colleagues into stress and coping experiences in men who were HIV+. Moskowitz and Wrubel (2005) identified five types of illness appraisals, with groups showing distinct differences in the meaning they assigned to their apparently similar situation and, consequently, different types of coping strategy. A similar approach, identifying groups or trends of stress and coping responses might also be useful in studying infertility.

These problematic issues around the concept of stress, combined with participants' focus on achieving goals, led to inclusion of the SRM in this study. Two important perspectives

emerged. First, as the SRM conceptualises (Leventhal, Brissette & Leventhal, 2003), participants discussed both the physical aspects of treatment for their condition, and emotional representations of how they believed they 'should' act. Participants had clear opinions about desirable emotional behaviour and that this was within their control, which contrasts with existing infertility literature that focuses on emotional reactions as automatic consequences of an experience (e.g. Newton, Sherrard & Glavac, 1997; Slade et al., 1997; Verhaak, Smeenk, Nahuis, Kremer & Braat, 2007). What were seen as desirable emotional responses remained constant as treatment progressed, but participants described it as harder to maintain control of their emotions. Interpreting within the SRM model allows a more detailed picture of individuals' illness representations, or perceptions of their condition. This is important, as illness representations have been found to be important and independent (of coping) moderators of adjustment (Lord & Robertson, 2005). Participants described various aspects of control, for example their control over their emotions, versus the control of their medical team over the treatment, which reduced over time. Investigation of the SRM illness representation concept allows more exploration of how individuals perceive infertility and fertility treatment, providing more detail about this aspect than the transactional model, which classifies situations as a loss, threat, challenge or unstressful (Lazarus & Folkman, 1984).

The second perspective that emerged here was description of multiple clear goals that participants tried to balance. The desire for pregnancy or biological parenthood is often considered the most important factor in those undergoing fertility treatment, reflecting biological parenthood as a central life goal (Stanton & Dunkel-Schetter, 1991a). This is reflected in previous work examining goal adjustment when fertility treatment fails (Daniluk & Tench, 2007; Kraaij, Garnefski & Schroevers, 2009), and the assumption that other life goals, such as career, hobbies and relationships are adversely impacted as fertility patients pour their resources into treatment (Benyamini et al., 2008; Cousineau & Domar, 2007; Kraaij, Garnefski, Schroevers, Weijmer & Helmerhorst, 2010). Participants described a desire for biological parenthood, but also emphasised their efforts to maintain their relationship, and remain financially secure. For some, achieving parenthood, whether biological or social, was the primary goal. Multiple goals are compatible with a self-regulation approach. Scheier and Carver (2003) presented a model with hierarchical goals, with multiple sub-goals contributing to an overarching goal, and this has potential to present a more detailed picture of fertility goals made up of multiple sub-goals. Additionally,

research often constructs a sequential process from treatment, to adjusting to treatment failure (and biological childlessness) and potentially readjusting goals to consider alternative parenting options (Goldberg, Downing & Richardson, 2009; Hammarberg, Astbury & Baker, 2001). This research suggests that consideration of alternative family building approaches may occur alongside treatment, as for Natalie and Jeremy. Similarly, Daniluk and Tench (2007) found that 15% of the couples in their study on transitioning to biological parenthood terminated treatment because they had adopted. The present research suggests that goal setting is more complex and varied than has been assumed so far.

Participants not only identified desired emotional states and multiple goals, but also played an active role in evaluating and appraising their situation and responses. Attention to this element of appraisal has often been neglected in the realm of women's health (Benyamini, 2009). Further, this research provides information about how and why participants selected particular strategies as being appropriate and correct. There is little other research that shows how and why individuals do so. As research in other areas has shown (Danoff-Burg, Ayala & Revenson, 2000), there were differences between psychological and lay perceptions and conceptualisation of coping strategies. Participants endorsed the importance of being busy with treatment or other life tasks, which is considered avoidance and a negative coping strategy (Berghuis & Stanton, 2002; Peterson, Newton, Rosen, & Skaggs, 2006a, 2006b). Avoidance in the form of keeping busy might be a good coping strategy when no treatment-related actions are possible, like between treatment cycles, which is consistent with the transactional model, where coping strategies are situationally dependent (Lazarus, 1999). Cultural expectations shape perceptions of appropriate actions, like keeping busy or being positive. Lazarus (1993) pointed out that Western values favour problem-focused approaches over emotional ones, which was seen here where participants favoured active, decision-making approaches over emotional responses.

An objective of this study was to extend psychological understanding of the application of stress and coping theory to fertility treatment. The analysis, themes and discussion here suggest that the SRM provides a broader applicable framework for exploring general fertility treatment experiences. Patients' own perceptions of fertility treatment can be explored, rather than it being assumed to be stressful. This perspective encompasses positive and negative aspects, and may focus on what were, to participants here important, efforts to restore normality or gain a desired state. According to the original definition of stress (Lazarus & Folkman, 1984) given in chapter 2, stress occurs when a situation exceeds an individual's

resources or threatens their well-being. It was unclear that these participants perceived infertility or treatment as exceeding their resources at this time, or threatening their well-being. Additionally, the SRM presents separate processes related to problem solving and emotions, making it possible to identify both (Senior, Smith, Michie, & Marteau, 2002). This reflects recent calls to integrate the transactional model more generally into a self-regulation framework (Carver, Scheier & Fulford, 2008; Kraaij et al., 2010; Leventhal, Halm, Horowitz, Leventhal & Ozakinci, 2004).

### ***9.5 Implications for therapy and support***

The final objective for this study was to inform therapeutic work with individuals undergoing fertility treatment. Therapy and support for fertility patients frequently focuses on alleviating distress (Cousineau et al., 2008), managing stress (Schmidt, Tjørnhøj-Thomsen, Boivin, & Andersen, 2005) and improving resilience (Ridenour et al., 2009) to endure through treatment. This perspective appears linked the emphasis on medical solutions for infertility, with the presumption that couples should be assisted to continue in treatment until their medical and financial resources are exhausted (Domar, 2004). Despite the extent to which patients endorse a desire for counselling and support, frequently the uptake of these options is low (Boivin, 1997; Boivin, Scanlan & Walker, 1999). This study provides four main points regarding support for couples undergoing treatment.

First is the extent to which counselling for distress is useful to patients in fertility treatment. Boivin (1997) suggested that support is more tailored to clinically distressed patients, neglecting the needs of those without such strong emotional responses. Sandelowski and de Lacey (2002) go further and argue that infertile individuals and couples are framed as emotionally distressed to legitimise the work of the professionals engaged in providing emotional support. The negative associations the women made between other fertility patients and distress might make 'support' an unfavourable option, if it was perceived to place them in that category, or introduce more negative ideas to worry about. Individuals who disassociated themselves from distress and stress might find there is not any kind of support available to them.

Second, the problem-solving approach to fertility treatment described here suggests that informational and decision-making support, particularly about limiting treatment (how, when, alternatives), might be more helpful. The issue of ending treatment arose indirectly here, but has been raised more explicitly. Participants in other studies have expressed a desire for end

of treatment decisions to be addressed through counselling (Hammarberg et al., 2001) and for a realistic appraisal from doctors about a prognosis (Peddie et al., 2005). This highlights a conflict between a medical objective to attain pregnancy (Greil, Leitko & Porter, 1988) and social objectives focused on becoming a parent, which could include other routes like adoption (Greil, Slauson-Blevins, & McQuillan, 2010). The medical perspective prioritises a cure, and aims to retain patients in treatment, and assist them with psychological endurance, to minimise treatment drop-out (Malcolm, 2004; Verberg et al., 2008). Doctors and nurses have been found to place emphasis on successful treatment, with adoption seen as failure, where patients see adoption as an alternative route to parenthood (Kopitzke, Berg, Wilson, & Owens, 1991). Recognising the potentially differing priorities of medical staff and patients suggests that clinical personnel recognise the need to set limits on treatment, assist patients in considering adoption, or childfree living as a choice and not a failure (Daniluk, 2001a; Seibel, 1997; Wilson & Kopitzke, 2002), though some individuals may find it hard to consider treatment ending unsuccessfully (Glover et al., 2009). The three couples interviewed for this study displayed different perspectives on end of treatment, highlighting potentially different needs.

Thirdly, therapy is sometimes proposed to encourage helpful coping strategies (McQueeney, Stanton & Sigmon, 1997; Stanton, Lobel, Sears & DeLuca, 2002). However, these participants felt that they were already dealing with the situation in the best way they could. Like Moskowitz and Wrubel (2005) suggested developing a range of interventions for HIV+ men to respond to the range of appraisals they made, some fertility patients might need no support, others support related to reducing distress, others to making decisions. Recent research has begun to look at different types of support, but work to identify who might benefit from it would be useful.

Finally, it would be valuable to acknowledge the unique experiences that men have during treatment, even though these may appear less significant than their partners'. Men might find support from other men going through similar experiences (Malik & Coulson, 2008b) and benefit from having easier access to these experiences. Men seem to attempt to adapt to socially approved, feminine approaches to managing in situations (Robson, 2002), but should not be pathologised for expressing masculine responses (Thompson, 1997).

## **9.6 *Evaluating and developing this research***

This section evaluates the study design and execution. It begins by assessing the change to the theoretical approach used, before discussing the characteristics of the participant sample, the interview design, and opportunities to include more variety of data sources in infertility research. The final sub-section explores specific ways in which this study could be extended to future work.

### **9.6.1 *Changing theoretical approach***

There is no published qualitative research using the Self Regulation Model (SRM) to study infertility or fertility treatment, and very little quantitative work (Benyamini et al., 2004; Benyamini, Gozlan & Kokia, 2009; Kraaij et al., 2010; Lord & Robertson, 2005). The SRM is a good fit with IPA as it focuses on the subjective experience of the person with the illness or condition (Leventhal et al., 1998). The present study has taken a novel approach by conceptualising infertility experiences in relation to this model, focusing on (changing) perceptions of the condition of infertility (illness representations) and emotions related to it (emotional representations). Particularly significant is highlighting how participants described multiple goals during treatment, and discussed emotions in terms of maintaining what were described as ‘healthy’ and desirable responses. Identifying multiple goals of those undergoing fertility treatment may elucidate issues that have perplexed researchers, such as the contradiction between the perceived difficulty of infertility and the lack of general psychopathology (Lord & Robertson, 2005; Verhaak, Smeenk, Nahuis et al., 2007), or couples who drop out of treatment before exhausting medical or financial resources (Olivius, 2004; Verberg et al., 2008). Understanding emotional representations during treatment (rather than evaluating emotional responses) may explain why emotional responses to fertility treatment appear to vary so widely (Greil et al., 2010). Similarly, identifying different goals and their varying importance between couples may clarify why couples terminate treatment ‘prematurely’.

These points suggest avenues for future research. One is to explore all these elements in more detail, to understand the various goals that couples in treatment are attempting to balance, how they represent the emotions of treatment, and their perceptions of infertility or fertility treatment as an illness. Chapter 8 explored changing views of treatment over time, for example in terms of control, as well as varying perspectives of time depending on the situation, which provide knowledge of those elements of the SRM illness representations.

Another possibility is to use the SRM, particularly with IPA, to gain access to internal views of fertility patients rather than relying on external definitions, for example of 'stress', or 'control', which are not necessarily good representations of the perspective of those being studied. An additional perspective is to use the knowledge gained from a self-regulation perspective to explore some of the issues that have been problematic in infertility research, as mentioned in the previous paragraph. Recognition of a range of perspectives may create a more flexible and detailed model that is able to include the breadth of responses that have been identified to date.

### **9.6.2 Participant characteristics**

This is an idiographic study into the experiences of a small number of participants engaged in a similar endeavour: beginning IVF. The participating couples were a small subset of patients beginning IVF, perhaps those feeling able to talk about their experiences, or feeling well adjusted as a couple. Edelman, Connolly, and Bartlett (1994) argued that finding that couples in IVF are well-adjusted might result from self-selection of individuals/couples willing to take part in studies. The experiences of this group potentially differ markedly from couples unwilling to participate.

Recruitment was a challenge. A more personal role in recruitment may have improved participation. Drawing on the analysis, non-participating couples might have anticipated a quick resolution to their fertility issues or been more challenged by the prospect of treatment, and wished to focus on successfully managing their first cycle. Recruiting through wider channels resulted in the addition of a British couple to the two US couples, introducing potential cultural differences. This was not apparent in the data and the themes were similar across the dataset. The major divergence was that the couple in the UK, Cathy and Chris, were not attending a local clinic but were travelling overseas for treatment.

The study was designed to focus on currently childless couples starting IVF. There were differences in participants' previous treatment and diagnosis. These were rejected as selection criteria because treatment and diagnosis might change during the study anyway. One participant had children from another marriage (Chris), though the status of the couple allowed them to be included. Added to this were unexpected differences that produced variability in themes, particularly willingness to pursue adoption. Previous treatment experiences appeared more important than expected. The beginning of IVF might not be the leveller of experience that it is sometimes suggested as a final treatment opportunity



(Verhaak, Smeenk, Evers, et al., 2007), due to the impact of previous time and treatment experiences, and the acceptability of alternatives of non-biological parenthood.

### **9.6.3 Interview design**

Two particular aspects of the interview design need consideration: the timing and the decision to interview couples separately. The study design was to carry out a baseline interview before the first IVF cycle and a follow-up interview six months later. The six-month interval was flexible, to cater to scheduling constraints, but the follow-up interview took place as all participants were beginning an IVF cycle, the third for Natalie, Jeremy, Matt and Judy and the second for Cathy and Chris. Though there seemed to be differences between the first and subsequent IVF cycles, it was unclear from the interview timings if there were potentially differences between the second and third cycles.

Because almost all interviews were during time periods when participants were engaged in an IVF cycle, and taking medications or undergoing surgical procedures, the identified practical and action-focus of the themes might reflect this specific time points, rather than being more general to the entirety of the IVF process. Anderheim et al. (2005) commented that the level of optimism displayed by their participants might have reflected their similar situation to the participants at the beginning of this study (beginning a first IVF cycle), reflecting that they are finally taking action with associated high hopes for success. Different interview timing might elucidate differences between cycles, and the temporal specificity of themes at different points in the same cycle. The longitudinal design of this study allowed subsequent interviews to clarify previous ones (Clare, 2003), for example in changes between concurrent accounts, and how participants reconstructed their previous account retrospectively at the follow-up interview (Smith, 1994). The design allowed a larger timeframe of IVF experiences to be studied using data produced relatively concurrent with those experiences.

Interviewing couples separately allowed each partner a chance to express their side of the story (Hertz, 1995; Valentine, 1999), particularly considering observations made by Glover et al. (2009) that joint interviewing of couples seemed to produce a mutually agreed version of events, downplaying differences. This study supports the value of separate interviewing, particularly as men appeared to try to conform to their partners' perspective and wishes. The individual accounts frequently drew on mutual and similar ideas, and it was not always clear when and whether there was a line between individual and joint experiences. This design allowed identification of differences, when participants' accounts changed to a more

explicitly individual focus. For example, Jeremy talked about disagreements over decision-making that Natalie did not mention and, in fact, referred to as mutual and straightforward decisions. The dual perspective allowed each account to inform analysis of the other.

#### **9.6.4 Adding variety to data sources in infertility research**

This was another interview study on infertility, of which there are many. Interview data is created within and shaped by a particular interaction, social and cultural context, and the reliance on interview data in qualitative research has been criticised for this reason (Atkinson & Silverman, 1997). Other sources of data can provide additional perspectives and develop the observations made here. Internet Mediated Research (IMR) is one possibility for exploring alternative data sources. Use of IMR is increasing generally, and is particularly relevant in health research as the Internet is an important and growing source of health information and mutual support between patients. Infertility research has drawn on Internet data from discussion forum posts (Malik & Coulson, 2008a, 2008b; Steuber & Solomon, 2008), chat room exchanges (van Selm et al., 2008), and Internet journals, or blogs (Steuber & Solomon, 2008). The significance of other patients' experiences in shaping participants' perceptions of fertility treatment meanings and reactions could be investigated this way, though it is possible that particular groups of individuals make use of these forums.

Participants seemed to draw on, if not endorse, a 'culture of infertility'. Thirty years ago (Menning, 1980), fertility patients may have been isolated, fertility treatment was less understood, and stigma might have been significant as most comparisons took place against fertile groups. The growth of the Internet as a source of information and meeting others, combined with knowledge about fertility treatment may enable today's infertility patient to feel part of a normalised larger group. They may correspondingly be able to place themselves related to that group rather than related to fertile individuals. It seem like research is in its infancy about meanings of infertility, and particularly in how these might be generated by groups.

#### **9.6.5 Further Research**

These lead to a number of suggestions for developing future research from this study. First is for continuing use of the SRM in qualitative infertility research, particularly to further examine fertility patients' emotional representations, rather than emotional/distress outcomes. Further research should investigate the extent to which the themes developed here are generalisable to other individuals undergoing fertility treatment, and establishing the

variation existing within these themes, including the gender trends identified here. This research suggests that factors like attitudes to adoption and previous time in treatment might be important in shaping patients' response to treatment, and are suggested as future criteria for study sampling. The timing of interviews appears important, within individual cycles and between cycles. Further studies could investigate participants at different times of their treatment cycle, rather than during the active, medicated stages included here. Further understanding of differences between first, second and further cycles could be clarified. Participants' relationship with the wider infertility community seemed important, and has not been greatly studied how this might influence fertility patients' understandings and shaping of their experience.

### ***9.7 Reflection: Insider or outsider?***

A vital aspect of qualitative research, and particularly IPA, with 'people researching people', is explicit reflection on the role of the researcher during the research process (Shaw, 2010). Keeping a reflective journal from the beginning of this project allowed me to record my thoughts about my relationship to the topic, particularly through interactions with participants and the developing analysis (Smith, Flowers, & Larkin, 2009). Like others, my choice to investigate infertility was triggered by personal experience (Greil, 1991; Sundby, 1999). Though it was not apparent to me at the time, my orientation to the project was three-fold: researcher, learner, and fertility patient. Hence, the key question discussed here is how and when I was an insider or an outsider to the research (Kanuha, 2000).

At the early stage of the project, my ideas about infertility were largely based on my perceptions to the topic as an insider (Clare, 2002). I was critical of the infertility literature portraying a one-dimensional picture of fertility patients desperate, depressed, and stigmatised (Letherby, 1999). At this stage, I saw myself with my potential participants, seeing infertility 'from their side', and hoping to produce research outside this stereotype (Letherby, 2002; Pfeffer, 1987). Despite this, my perception of what I expected to find out about infertility was influenced by the attention in the psychological literature to maladjustment, distress and stress, and I expected to see participants expressing stress. As a novice researcher, I noticed that my understanding of experiential and psychological concepts developed through the research.

My position as an insider shifted soon after the study began when my husband and I adopted our son, Ciaran, at birth in January 2008. From longing to be a parent, I was suddenly a

mother. This had several identifiable consequences. Infertility as a topic no longer seemed so personal or immediate, contributing to a shift in position to an outsider compared with potential participants. I saw adoption as an alternative to fertility treatment, which I became aware, influenced my perspective on ending treatment. I felt insensitive that I was constrained by child-care issues when arranging interviews. I noticed that I was endorsing one of the assumptions I criticised: that couples having fertility troubles would not wish to have contact with children. My adoption experience made me notice participants' perspectives on ending treatment and adoption. Adoption seems easier once you have done it, and I had to consciously put myself in participants' shoes to be aware of their different perspective on the matter.

As a novice interviewer, I was nervous about enquiring deeply into others experiences, particularly when I had been obliged to remove the disclosure of my experience. In hindsight, I think the disclosure reflected my wish to validate my position as an outsider by demonstrating my insider 'qualifications'. Instead, it was necessary to build rapport as an outsider, a researcher, rather than relying on personal experience to be entitled to ask questions. I began to feel that I could be more respectful of and attentive to participants' experiences by excluding my own. It was surprisingly easier to probe sensitive issues from the position of an outsider, where insider status tended to carry (for me) connotations of friendship with associated boundaries. I became aware that participants were viewing me as a researcher who was entitled to ask those questions. I realised that all the participating couples had willingly volunteered for the study and answer the questions. In the event, Natalie, Jeremy and Cathy asked about my own infertility experience, and I answered their questions honestly, but I did not perceive any differences between cases where I did and did not disclose.

I hoped that my familiarity with IVF facilitated the interviews (Greil, 1991), though in hindsight it may have lead to making assumptions about participants' meanings and explanations, and as I became more aware of my dual insider/outsider status I tried to pay more attention to where my assumptions might be emerging. Though I initially prioritised common infertility experience as the key dimension during interactions with participants, an unexpected difference arose between Matt and Judy, who are devout Christians, and me as an atheist. Their religion was an important element of their meaning making and they drew on it frequently during the interviews. There was no reason to disclose this difference and I focused on being empathic and uncritical towards their religious meaning making, even

though I did not share it and tended to feel critical of it. This inspired further reflection on the potential impact of gender and national origin on the interviews (as a British woman interviewing American men and women). I am personally comfortable in male-dominated environments, having worked in engineering for several years, and have lived for nearly a decade in the USA. This does not mean that participants were not sensitive to these issues; though they gave no indication of this.

I continued to pay attention to these issues during analysis. A phenomenological perspective helped place my focus on each individual's perspective, rather than on my own assumptions and experience. An emotional response or a difficulty in coding often occurred when there was a conflict between the data and my assumptions or expectations, which helped me look more carefully at these areas to understand what was happening. This was especially noticeable during early phases of analysis when looking at Natalie and Jeremy's interviews, as they produced accounts that seemed wildly different from what I'd anticipated. The decision to use software during data analysis was a somewhat contentious one in the IPA world. I decided to do so as I am personally more comfortable working electronically than on paper. The ease of coding and recoding required attention to actually carrying out analysis rather than just manipulating codes. This was one reason for developing a written analysis of each case, rather than relying on the coding.

Over the course of the project, I became aware of the multiple roles I took. My understanding of my preconceptions and subjectivity increased as I learned to divide my own experiences from the research: to more clearly (to myself) separate or be aware of the insider and outsider positions. As a novice research, investigating a topic with explicitly personal relevance seems to have been a valuable experience, to tackle these issues within an environment focused on learning and to acquire lessons that can be reapplied elsewhere. Perhaps my distance from infertility experiences lets me see this as one of many things that I've experienced and may (hopefully) come to study in the future. My experience forms part of my natural attitude, but so does the clearer and deeper understanding I've learned of being a researcher.

## **9.8 Conclusion**

Fertility treatment is undertaken as a couple attempts to overcome the problem of infertility and achieve the desired goal of parenthood, while remaining emotionally, financially and morally healthy. Active attention to selecting and managing all these goals linked the data more closely to a self-regulation perspective than to a transactional framework. Placing

fertility treatment within this context recognises that those choosing treatment play an active role in shaping their experience, as they choose and take action to managing their actions and behaviour to the best options identified. The self-regulation perspective offers considerable possibilities for understanding these experiences, further developing the few recent studies carried out. Developing knowledge of individual and couples' active and problem-solving role during treatment adds nuance to the study of an experience that is often reduced to a set of negative assumptions and generalisations.

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## **APPENDIX A: Study design materials**

A.1 Recruitment flyer

A.2 Screening form

A.3 Informed consent

A.4 Debriefing information

A.5 Ethical approvals from the University of Derby and the Palo Alto Medical Foundation (original full approval from December 2008)

# PhD Research Study Stress and Coping During Fertility Treatment

Researcher: Elly Phillips, BSc  
Health Psychology Research Group  
University of Derby, United Kingdom



If you are a man or woman in or about to start fertility treatment you may be able to take part in this study

#### ABOUT THE STUDY:

This is a research study into the experiences of men and women who are having fertility treatment. If you are willing to take part, you will be asked to take part in two, 1-hour interviews 6 months apart, with an optional third interview after a further 6 months. The interviews will involve talking about the stresses and positive experiences you have in your life while undergoing treatment and the things that help you deal with them (or not).

The study focuses on the perspective and experience of the people having fertility treatment. It aims to provide information that will help other people undergoing treatment, particularly to see how their need for support may change over time. It will also add to the psychological literature about infertility experiences, and stress and coping during treatment.

If you are interested in taking part, or would like more information, please contact:

**Elly Phillips**  
**650 224-9773**  
**e.phillips@derby.ac.uk**

University of Derby, Kedleston Road, Derby, DE22 1GB, United Kingdom. Telephone: +44 (0) 1332 591703  
[www.derby.ac.uk](http://www.derby.ac.uk)

Health Psychology Research Group: [psychology.derby.ac.uk/centre/page\\_04.htm](http://psychology.derby.ac.uk/centre/page_04.htm)

***A.2 Screening Form***

**Study of Stress and Coping during Fertility Treatment**

**Study of Stress  
and Coping  
during Fertility  
Treatment**

**10**

**Date:**

**Name:**

**Address:**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Year of Birth:**

\_\_\_\_\_

**Gender:**

\_\_\_\_\_

\_\_\_\_\_

**Phone:**

**E-mail:**

**How would you describe your racial origin or ethnicity?**

\_\_\_\_\_

**Inclusion Criteria:**

\_\_\_\_\_ Pre or during first treatment cycle

Start date: \_\_\_\_\_

\_\_\_\_\_ Speaks and reads English

**Exclusion Criteria:**

\_\_\_\_\_ Not a substitute for counseling or therapy

\_\_\_\_\_ Other chronic illness

\_\_\_\_\_ Psychiatric condition not related to infertility?

Screening took place on: \_\_\_\_\_

\_\_\_\_\_

**Other issues:**

**Review:** \_\_\_\_\_ Interview questions

\_\_\_\_\_ Interview scheduling

\_\_\_\_\_ Consent form

Date consent signed: \_\_\_\_\_

\_\_\_\_\_

Date of first interview: \_\_\_\_\_

Date of second interview: \_\_\_\_\_

Date of third interview (if applicable): \_\_\_\_\_

**Notes:**

***A.3 Informed Consent***

**PALO ALTO MEDICAL FOUNDATION RESEARCH  
INSTITUTE**

**WRITTEN INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY**

**Stress and Coping during Fertility Treatment**

**FOR QUESTIONS INVOLVING THE RESEARCH STUDY OR A RESEARCH-RELATED INJURY, CONTACT THE PRINCIPAL INVESTIGATOR:**

FULL NAME: Salli Tazuke, MD

ADDRESS: Palo Alto Medical Foundation, Fremont Center

3200 Kearney Street

Fremont, CA 94538

510-499-2890

**OTHER PHYSICIAN(S) INVOLVED IN THE STUDY:**

FULL NAME

ADDRESS

CITY

STATE

ZIP

PHONE

**FOR QUESTIONS RELATED TO SUBJECTS' RIGHTS, OR COMPLAINTS ABOUT THE CONDUCT OF THE STUDY, CONTACT THE OMBUDSPERSON:**

FULL NAME Office of the Ombudsperson

ADDRESS: Palo Alto Medical Foundation, 795 El Camino Real

CITY: Palo Alto, CA 94301

PHONE: 650-853-4817

# PALO ALTO MEDICAL FOUNDATION RESEARCH INSTITUTE

## INFORMED CONSENT

Are you participating in any other research studies?  Yes  No

You are invited to participate in a study of stress and coping during fertility treatment. You will be asked about the stresses and positive events that you experience while you are undergoing treatment and the ways you deal with them. The interviews will be tape recorded and then written out word-for-word for analysis. If the interview is conducted over the phone, it will also be tape recorded. The analysis will look for stresses that occur for different participants at different times, and the ways people find to deal with those events. You were selected as a possible participant in this study because you are about to begin IVF treatment.

Your decision whether or not to participate will not prejudice you or your medical care. If you wish to participate in this study, you must sign this form. If you decide to participate, you are free to withdraw your consent, including your authorization regarding the use and disclosure of your health information, and to discontinue participation at any time without prejudice to you or effect on your medical care. If you decide to terminate your participation in this study, or revoke your authorization regarding the use and disclosure of your health information, you should notify Elly Phillips at (650) 224-9773, or [ellyphillips@gmail.com](mailto:ellyphillips@gmail.com).

The University of Derby, UK (Centre for Psychological Research) is providing support for this study.

If you decide to participate, we will arrange two interviews with you. The first will take place before (or just as) you begin treatment and will take approximately one hour. The second interview will take place six months after that. If you are willing, then there is also an option to take part in a further one-hour interview, six months after that. The total time commitment for this study is estimated at 2-4 hours. The interviews will be tape recorded and then written out word for word to be analyzed.

There are risks, discomforts, and inconveniences associated with any research study. These deserve careful thought. You should talk with the researcher if you have any questions. This study involves talking about a sensitive subject (infertility), and some people may feel uncomfortable sharing their experiences with someone they do not know. It may be stressful to you to take part in this study while undergoing treatment. You may benefit from talking

about your experiences with another person. The data gathered by this study may enable more or better support to be provided in the future for other people undergoing fertility treatment.

**WE CANNOT AND DO NOT GUARANTEE OR PROMISE THAT YOU WILL RECEIVE ANY BENEFITS FROM THIS STUDY.**

You will be told if any new information is learned which may affect your condition or influence your willingness to continue participation in this study.

You may choose whether or not to take part in this study. There is no alternative procedure if you do not wish to participate in the interviews.

Your identity will be kept confidential and you will not be identified by name, social security number, address, telephone number, or any other direct personal identifier. If your research records are disclosed, you will be identified **only** by a unique code number or pseudonym. Information about the code and pseudonym will be kept in a secure location and access limited to research study personnel.

The results of this research study will be submitted for award of a PhD, and may be presented at scientific meetings or published in scientific journals. The researcher's supervisors and examiners may review tapes and transcripts for academic award purposes only. Tapes will be retained for the duration of the program of study then may be returned to you or destroyed as you choose. Your identity will not be disclosed in any published or written materials by name or other identifying information.

Patient information may be provided to federal and regulatory agencies, as required.

The Food and Drug Administration, for example, may inspect research records and learn your identity if this study falls within its jurisdiction. Under normal circumstances, the FDA does not access patient names. However, in order to verify the accuracy of data submitted to them, it may be necessary for them to examine your unaltered medical record and learn your name as a result. Every effort will be made to maintain patient record confidentiality, but complete confidentiality cannot be guaranteed when such disclosures are required by law or regulation.

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**USE AND DISCLOSURE OF YOUR MEDICAL INFORMATION**

By signing this form, you are authorizing the use and disclosure of your health information relevant to your participation in this research study. Your information will only be used in accordance with the provisions of this consent form and applicable law. If you decide to



terminate your participation in the study, or if you are removed from the study by the protocol director, you may revoke your authorization, except to the extent that the law allows us to continue using your information.

Your health information related to this study, relevant to infertility related diagnoses and treatment, may be used or disclosed in connection with this research study.

The following party is authorized to use and/or disclose your health information in connection with this research study:

- The Principal Investigator, Salli Tazuke, MD.
- The co-investigator, Elly Phillips, BSc MEng

The parties listed in the preceding paragraph may disclose your health information to the following persons and organizations for their use in connection with this research study:

- The Office for Human Research Protections in the U.S. Department of Health and Human Services.
- Dr Jane Montague and Prof James Elander at the University of Derby, UK.

Your information may be disclosed if the recipients described above are not required by law to protect the privacy of the information.

Your authorization for the use and/or disclosure of your health information will be in effect until Dec 31, 2015.

Signature of participant: \_\_\_\_\_ Date: \_\_\_\_\_

Print Name: \_\_\_\_\_

---

*No payment will be provided for participation in this project.*

*There is no cost to you to participate in this study.*

At the discretion of the principal investigator, subjects may be taken out of this study due to unanticipated circumstances.

Some possible reasons for withdrawing a subject from the study may include:

- Failure to follow instructions,
- The investigator decides that continuation could be harmful to you,

- The study is canceled,
- Other administrative reasons.

If you have any additional questions regarding withdrawing a subject, please contact the IRB office at (650) 853-4825 or email [irb@pamfri.org](mailto:irb@pamfri.org).

You do not waive any liability rights for personal injury by signing this form. If you are not satisfied with the manner in which this study is being conducted, please call the Ombudsperson at (650) 321-4121, or address a letter to 795 El Camino Real, Palo Alto, California 94301. For further information, please call (650) 853-4825 , email the IRB office at [irb@pamfri.org](mailto:irb@pamfri.org), or contact the IRB Administrator, Research Institute, 795 El Camino Real, Ames Building, Palo Alto, CA. 94301.

### **PATIENT BILL OF RIGHTS:**

As a human subject, you have the following rights. These rights include but are not limited to the subject's right to:

1. Be informed of the nature and purpose of the experiment.
2. Be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized.
3. Be given a description of any attendant discomforts and risks reasonably to be expected.
4. Be given an explanation of any benefits to the subject reasonably to be expected from the experiment, if applicable.
5. Be given a disclosure of any appropriate alternatives, drugs or devices that might be advantageous to the subject, their relative risks and benefits.
6. Be informed of the avenues of medical treatment, if any available to the subject after the experiment if complications should arise.
7. Be given an opportunity to ask questions concerning the experiment or the procedures involved.
8. Be instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation without prejudice.
9. Be given a copy of the signed and dated consent form.

10. Be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion or undue influence on the subject's decision.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT YOU HAVE DISCUSSED THIS STUDY WITH THE PERSON OBTAINING CONSENT, THAT YOU HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED AND THAT A COPY OF THIS FORM HAS BEEN GIVEN TO YOU.

---

Signature of Participant

---

Date

*Person Obtaining Consent/Assent*

I attest that the participant has been provided with the Experimental Subject's Bill of Rights, that I have discussed the research project with the participant and explained to him or her in nontechnical terms all of the information contained in this Informed Consent/Assent form, including any risks and adverse reactions that may reasonably be expected to occur. I further certify that I encouraged the participant to ask questions and that all questions asked were answered.

---

Signature of Person Obtaining Consent/Assent

---

Date

## ***A.4 Debriefing information***

Please keep your copy of the consent form. It contains important information about your rights as a participant in this study. If you have further questions, would like more information, or decide to withdraw from the study, please contact me, Elly Phillips, on (650) 224 9773 or [ellyphillips@gmail.com](mailto:ellyphillips@gmail.com).

### **Support Resources**

If you feel that you would benefit from emotional support, there are a number of groups and organizations that might be of interest to you.

#### **Organizations**

- American Fertility Association: [www.theafa.org](http://www.theafa.org). Provide information about conception, infertility, adoption and other fertility related issues.
- The International Council on Infertility Information Dissemination: [www.inciid.org](http://www.inciid.org). The website also provides information about fertility related issues, and there are discussion boards for these topics.
- Resolve (National Infertility Association): [www.resolve.org](http://www.resolve.org), with a chapter in San Francisco (312 Sutter St #405), phone 415-788-6772, [www.resolvenc.org](http://www.resolvenc.org), email [resolvenc@aol.com](mailto:resolvenc@aol.com). They have a number of different groups for infertility, adoption surrogacy and general support.

#### **Online Forums**

- IVF Connections: [www.ivfconnections.com/bulletinboards.htm](http://www.ivfconnections.com/bulletinboards.htm).
- Babycenter has a number of infertility related boards: [www.babycenter.com](http://www.babycenter.com).
- Fertility Friend: [www.fertilityfriend.com](http://www.fertilityfriend.com).

#### **Therapy and Support Groups**

Stanford REI Clinic has a psychologist who specializes in fertility issues, Penny Donnelly. She has a private practice, for those who are not Stanford patients. Through the clinic, she offers a variety of support groups for a small initial fee. Contact Penny by email at [pdonnelly@stanfordmed.org](mailto:pdonnelly@stanfordmed.org) or call 650-723-6408.

#### **Outcome and Findings of the Study**

Please let me know if you would like to receive information about the findings of the study. I am happy to provide a summary of these if you are interested.

Thank you very much for being willing to participate in my research. I appreciate your time and willingness to share your experience. I look forward to speaking with you again in the next part of the study.

***A.5 Ethical approvals***

**Ethics Application  
Response Form**

**Application:**

Approved ✓

Rejected

Further information requested

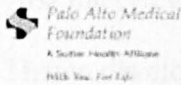
Name of applicant	Elly Phillips
Title of study	Men and women's experience of stress and coping during fertility treatment: An interpretative phenomenological analysis
Ethics Application number	007/08/EP

**ETHICS COMMITTEE FEEDBACK**

The committee felt that all ethical issues had been well addressed and no further clarification was needed. Ethical approval has been granted.

**Checklist of further documentation required:**

None.



**Palo Alto Medical Foundation Research Institute  
Institutional Review Board**

795 El Camino Real, Ames Building  
Palo Alto, CA 94301  
[irb@pamfri.org](mailto:irb@pamfri.org)

**New Protocol Approval  
(IRB #30)**

**To:** Salli Tazuke M.D., Principal Investigator  
**From:** Rita French, Ph.D., Chair, Institutional Review Board *Rita deS French, PhD*  
**Cc:** Barbara Anderson, Clinical Research Manager  
**Date:** December 12, 2008  
**Re:** **Protocol #08-58:** "Stress and coping during fertility treatment."

The full Committee reviewed and approved the initial submission of the above referenced protocol at its meeting on **December 11, 2008**. This protocol and the informed consent(s), and if applicable, questionnaires or other attachments, have been approved for a period of 12 months.

**Conditions of approval:** *Delete the 'Personal Disclosure' from the Interview Script.*  
**Expiration Date of approval:** *December 10, 2009*  
**Sponsor/ Funding Agency:** *No external sponsor*

If this proposal is used in conjunction with any other human experimentation, or if it is modified in any way, it must be re-approved for these special circumstances. **Note that the following should be reported to the IRB:** 1) *all serious adverse events occurring here or at other institutions, regardless of whether or not the events are thought to be study related;* 2) *any unanticipated problems;* and/or 3) *any injuries to subjects enrolled here.*

All continuing projects and activities must be reviewed and reapproved at least annually by the Committee. If this project is to continue beyond the expiration date, the investigator must submit a renewal request for approval by the Committee prior to the expiration date. **In any event, no new patients may be enrolled in a study for which the approval date has expired. At the completion of the project or study, a termination report must be filed with the Committee, in order to comply with FDA regulations.**

## **APPENDIX B: Example of analysis development**

Natalie's baseline interview is used to illustrate the development of coding and themes. This was the first interview carried out. This appendix presents:

B.1 Theme development table

B.2 Complete table of themes

B.3 Extract from analysis account of social comparisons, a theme which appeared in the final analysis (section 6.2)



### ***B.1 Extract from Natalie's baseline interview***

This is the middle third of Natalie's first interview (transcript reference 6.4 – 11.29). The coded transcript, nodes and annotations were exported from NVivo and pasted into IPA three column tabular form. Annotations are numbered in NVivo and the numbering is retained here. The emergent themes represent the final form the themes took at the individual analysis stage. The highlighting in the central column is produced when text is coded in NVivo.

<b>NVivo Annotations (Exploratory comments)</b>	<b>Coded Transcript</b>	<b>Emergent Themes</b>
<p>59 control. Attitude controlled, not giving into emotion like she said before</p>	<p>Natalie: yeah cos its the only one I can control &lt;yeah&gt; right I can't control the process but I can control my attitude so I might as well just focus my energies on that<sup>59</sup></p>	<p>We try to keep sane: choosing your attitude control</p>
<p>60 I feel like the future path is unclear. Like they have ideas about what they will or won't do, but at the same time there's an ambiguity about how to know when to call it a day, the potential for the emotional investment to ramp up and overtake the financial constraints or physical demands. The one step at a time thing also comes up when she is talking about the</p>	<p>Elly: its an interesting mix of control though because its like you can control how many treatments you have but then you can't actually control the detail of what happens necessarily</p> <p>Natalie: right and you can't you know when is it one treatment too many? I guess it depends on your emotions on your money on your um on your general view of you know creating a life you know<sup>60,61</sup> if and there's no sure bet you're not going to get the perfect kid I mean that's I think that's another thing is to go into it and not to think you're going to get the uber-child you know I'll satisfy I'll take average I'm all for average you know I mean you might it doesn't take out all the horrible factors that can happen birth defects um the</p>	<p>There needs to be a line/Financial investment</p> <p>Looking ahead vs focused on the next step</p> <p>Your general view of creating a life</p> <p>Expectations of treatment</p>

process of treatment and potentially getting pregnant.

<sup>61</sup> money yet again

<sup>62</sup> others are out for the 'uber-kid'? She wants a child yet would send it back?

<sup>63</sup> injections obviously a big deal for her. Something she admits bothers her

<sup>64</sup> her implication that others are more informed (although she could become so). The 'normal person' - she's not like other infertile women?

inevitable tragedies those still exist and to some extent they are statistically enhanced because of the process so I think that sometimes people view it as "but this is the way to get the uber-kid" right? and I don't see it that way <yeah> I would be disappointed if they were an uber-kid I wouldn't know what to do with one send it back<sup>62</sup>

Elly: its like reality vs. err practicality

Natalie: right right exactly

Elly: yeah. So what's um what bothers you the most I guess the needle bit

Natalie: I'm not a fan of the needles although I'd say I do fairly well.<sup>63</sup> What bothers me? I think probably just that I'm going at times assumption that you understand all the next steps you know the jargonesque of getting through everything and its sort of like sometimes I'll say to the doctor pull the handbrake speak to the

normal person<sup>64</sup> you know don't assume that I've been living with you know a map of my uterus on my wall since I was 15 OK break it down for me um and I try to do that by you know now my doctor Dr Smith sort of speaks Natalie speak like we refer to it as Project Weeble like lets lets not talk about follicles lets not you know what are we doing here which adds a little bit of levity and at the same time

Humour

Interactions with medical personnel

We try to keep sane: choosing your attitude

Humour

65 more humour. Seems like a trivial issue in some ways - injections obviously are a big deal to her (fainting), but her other 'hang up' is terminology?

66 seems like this might be important in some ways

67 weighing up good or bad. There are judgments about things like this? In her mind or others? Mine?

68 the idea of investment again. Why isn't she invested in the process? Draws to the idea of finances, or chance of words? Investment implies gain or benefit?

69 routine, ordinary, doesn't stand out (despite

clarity<sup>65</sup> in terms of what we're doing um so that's probably terminology is probably my only hang up

Elly: yeah, and then is there anything that doesn't bother you that you thought might have done before you started

Natalie: that

Elly: that you thought might have bothered you that perhaps doesn't

Natalie: No. And yeah the only reason I can't answer that question is because I had no expectations<sup>66</sup> <laughs> so I don't know if that's a good thing or bad thing<sup>67</sup> I'm sure that something would have if I would have invested more in the process but it doesn't only<sup>68</sup> because I can't I mean you know its pretty (2) you know you go in you get your ultrasound its pretty routine <yeah> um so I don't think its off-putting I mean I just sort of figure that you're just a social security number at the end of the day right? There were 1000s of women before me there'll be of 1000s women after me I don't sort of look at it like 'they're going to remember ME cos I'm such a great patient', you know I don't you know I know that they just want to impregnate me and send me two doors down to the OBGYN <yeah> that's the goal, the goal is not to see me in 9 more months<sup>69</sup> um so I

Expectations of treatment

Investment

Routine not difficult

Interactions with medical personnel

how she talks about the 'project weeble' stuff earlier, like she is funny and different).

don't think there there is anything that really bothers me or ( ) expected

Elly: do you um feel the need for much support or do you get support

Natalie: emotional support?

Elly: or any other support

Natalie: um yes, I do get support I mean my parents are very supportive my sister and her husband they're going through it they're supportive um my in-laws are supportive within their emotional range <laugh> you know in terms of its not a familiar thing to them but they intellectually understand it and you know they enquire its not like they're just going to pretend this isn't happening, which I appreciate. Um. So I think there's support I don't tend just as a general rule to tell people you know I haven't told any of my coworkers know I've told a few friends but I'm also very open about it<sup>71</sup> like if someone people naturally say you know 'why don't you have children' you know and I'll say 'oh I just I had fertility issues and we're working on it'<sup>70</sup> and I think at first people that jars them "wow, ok awkward moment, sorry I asked, wow feel like a jerk" um and then they're refreshed by it you know the people a surprising number of people that I say that to will say "so did I, I can't believe

Managing identity through disclosure

control

<sup>71</sup> seems a bit contradictory in telling/not telling being open

<sup>70</sup> Slides from 'support' into disclosing and sharing with other people. Rather like earlier slide from patience to control to interactions with medical personnel (I think I got the order

right).

<sup>72</sup> this is quite a dramatic contrast to other stuff about 'not caring'. Strong rejection of the group

<sup>73</sup> She uses the term investing several times (here emotionally invested vs financially)

<sup>75</sup> privacy, IVF makes choices potentially public?

<sup>74</sup> She earlier remarked about being 'open'. But to be honest, I think there are two different issues. The first is having fertility treatment at all, the second is about (as she says) the choices they might make.

you're so open about it" then they just sort of want to spill their story or other people are like "good luck, sorry I mentioned" or um "oh really, what are you what are you doing" I mean just they're interested they don't know anyone its its kind of an educational moment um so I'm not hiding it but I don't go advertising it either

Elly: yeah you don't feel the need to sort of get involved in like groups or anything like that

Natalie: no good god no no no no, no group thing I can barely manage within my own mind I don't need to be in other people's<sup>72</sup> um and I think you can I do have a friend who's going through it now and who just got err pregnant via IVF and she was sort of the template of what I didn't want to be she was way too invested<sup>73</sup> I don't want to kumbayah with people about the process its just not for me um because I can only manage my own issues around it not Susie's and John's and everybody else's um and its private<sup>75</sup> and people can get judgmental they can they can just you know "oh you're going to transplant three what if you got pregnant with three would you have" you know we don't need to advertise to the world the choices that we would make<sup>74</sup>

Elly: yeah ( ) things about the choices

No group thing

Comparisons with other patients

Investment

Managing identity through disclosure

<sup>77</sup> discovery tour plus journey earlier.

Travelling? Making progress?

<sup>76</sup> very objective, scientific

<sup>78</sup> in contrast to 'very open' earlier

Natalie: right its sort of like when you're pregnant and I'll see people who are pregnant and they'll share what they're going to name the child and I'm always amazed at people's visceral reactions "Joe, why would you name it Joe oh my god" you know its like cos they want to and that's their right um and I think people just don't catch themselves <yeah> um and I just try to think like an anthropologist that I'm on this discovery tour<sup>77</sup> of myself and creationism or whatever you want to call it.<sup>76</sup> Um and that's just how I view it so sometimes to be shared and sometimes not<sup>78</sup>

Elly: yeah I think people kind of expect that they have ownership in pregnancy and like random people can come up comment things to do with pregnancy and small children <right> why do people feel entitled to comment?

Natalie: right why do they I mean entitled to comment or somehow a semi-stranger's opinion weighs or factors into your thinking its just its on some level its endearing that people care enough to lift the veil of their personality that way and then at some point its also annoying as well. For me it's a strange combination of glad you care wish you'd shut up <laughs>. Um so that's yeah that that

Elly: Have you come across any kind of odd views or is it just something you just=

Managing identity through disclosure

Staying an outsider

Managing identity through disclosure

<sup>79</sup> money, again!

<sup>80</sup> compare with what she said earlier about not talking about it much, she's 'always telling' him re finances. (Also that little emotional impact vs a lot of financial impact)

<sup>81</sup> I wish I'd've 'unpacked' support, and some of the other ideas around here, e.g. impact earlier, why adoption is a delicate subject

Natalie: =on IVF?

Elly: Yeah.

Natalie: Um. Odd opinions. No I think that people are especially in the state of California where it isn't covered by insurance so for instance my sister lives in Mass its covered by state law so she pays a \$10 co-pay. Every ultrasound costs me 300 dollar and seventeen \$317 so I think people have an opinion in so far as money um that they're surprised how costly it is they're surprised its not covered by insurance<sup>79</sup> um I'm always telling my husband you know there's this err there's this current of interest that if somebody would actually leverage it you know you could change the law ahh because people don't really realise the impact.<sup>80</sup> Um you know I think people express themselves "oh would you consider adopting". That can sometimes be a delicate subject for people um if they've been adopted or know someone that has been um you know this country doesn't in general make that an easy goal to achieve sometimes so people have opinions on that too I that's a thing I've discovered but I haven't gone through that process that's ( )

Elly: yeah so is there any other support<sup>81</sup> you would think of apart from emotional support pretty much it practical or spiritual sort of person or

Financial investment

Natalie: I wouldn't say a spiritual person prac- I mean you know people are dropping babies in the bush in Africa all day long all the time and they're turning out to be perfectly healthy and fine and running around in bare feet and the world is a happy place um I don't think ah I don't think I could screw it up like that's I've just liberated myself of that possibility whether it is a biological or a not biological child I think it would be fine so I guess I don't seek support in certain realms where perhaps others might because I'm I just you know we'll figure it out and I'm sure that there'll be moments throughout that course of figuring it out where I do seek support but not right now I mean I haven't there's nothing in me it hasn't been born I haven't even created and or met so I don't you know I'm seeking ideas about support about a personality I hope to know but I don't know

Elly: so you're kind of very much compartmentalising, but you know keeping a focus on what's now rather than

Natalie: Yeah, I very much think like Buddha you know I live in the now and the now is you know get the drugs in develop the follicles aka Project Weeble you know next step would be embryology but I really don't think more than probably three days ahead of what things will be and make sure there's enough what I call baby crack

Anticipating the future

There needs to be a line

Being responsible for defined tasks

Looking ahead vs focusing on the



82 limited future focus. Concentrating on having drugs, that's it. Knows the next step. Not daring to think of it? Way of coping?

83 idea of pregnancy perhaps quite close, could be in a few days (or weeks).

84 This is separate? She behaves differently?

85 again, not really clear if she's talking about planning treatment itself, or planning about having a child. Maybe that treatment is a step to having a child, not an end in itself?

the drugs in the refrigerator and and that's it<sup>82</sup> and then if I get pregnant well that will be a whole other set of issues discoveries and then once the child is born if the child is born you know a whole other layer of things when you're thinking of a human life I could think of a hundred years out right not much of it I could probably impact right now<sup>83</sup>

Elly: yeah so is that kind of focus something you do anyway or is it particularly specific

Natalie: I'm actually very much a planner in my other life um you know sort of planning vacations a year out that kind of thing<sup>84</sup> um but not with this because again its a personality and an identity that I don't know I mean that even if I were to be pregnant it was in my womb I mean I might think 'oh they'll be like this' then they'll come out and they're a holy terror and they're running round then the whole game plan has to change so we'll see. But I am generally a planner; <yeah> this would be a semi exception to the rule<sup>85</sup>

Elly: yeah sort of like a situation specific

Natalie: Well, I feel I enjoy it because I don't have to do the planning because that's why I have a medical team I mean I guess I could take over the planning and be the least qualified person to do it so I <laughs> if we want to get it right I wouldn't self nominate to be in

next step

control

Anticipating the future

Patience vs control

Control

<sup>86</sup> letting the medical experts get on with it. Decisions that they are better off taking. Like there's a boundary of medical vs non-medical and she doesn't try to cross it?

<sup>87</sup> short time scale. Could get it wrong. Comforting to have little gaps. She makes it sound like she isn't very capable, just in this area?

<sup>88</sup> comparisons again, others find it hard, she finds it easy. Others overthink?

charge of the planning probably best to let the MDs and the RNs take care of that<sup>86</sup> and you know they're very nice about scripting things out and on Tuesday you do this come and come see us on Monday that one thing I do like about the process actually going back to an earlier question is that I do the intervals of things so that is to say that when you're going through IVF you know you're basically seeing someone every 3 or 4 days so its dummy proof I mean you know if there's only a 72 hour gap between me seeing you once vers- and twice well I mean I could probably manage not to screw it up in 72 hours, right <laughs>? If you gave me you know a week and a half two weeks, there's some added variables in there but 72 hours I'm fairly confident I could I could not goof it so that's another reason that one really have to plan or in my case I don't feel that I need to because I live in these 72 hour intervals<sup>87</sup> which some people find annoying or they've expressed to me that they do because its sort of this nag nag nag feeling for them but for me its liberating because excellent so I'm going to wait until Wednesday at 8:15 in the morning and then they'll tell me about the next chapter and the next chapter takes me like bunny hopping over 72 hour time intervals <yeah> so I love that I feel like I don't have to think<sup>88</sup>

Elly: so how would you compare infertility with any other difficult situations you've encountered in your life?

Being responsible for defined tasks  
Comparisons with other fertility patients

<sup>89</sup> Hmm, it's NOT difficult? Accepting?

<sup>90</sup> identity as fertile vs infertile. Some part of fertility works therefore not infertile?

<sup>91</sup> had other choices and control

Natalie: I don't see infertility as being difficult probably not a word that I ever have at least to date associated with the process, it just is.<sup>89</sup> Um and it's interesting because I don't think of myself as infertile, um perhaps wrongly but you know I mean follicles have grown you know there's quote there's no reason you can't get pregnant now of course that leaves many many factors unanswered um but I don't think of myself as infertile I just sort of think it as this is my life<sup>90</sup> right I mean I made other choices for not to have children earlier which because of the worm probably wouldn't have been the case. But I don't I don't regret all the other the decisions I made to get me to this point you know I mean I'm glad I went to grad school I'm glad I have and have had a good career you know regretting anything related to that which I think again is liberating in the sense that if a baby were to come along biological or not for that matter then that's done that's satisfied that need within myself at least for that part is satisfied I will never feel like I didn't take care of me first <ah huh> and I think that will allow me to get more invested with the child because I won't ever try to be moving in too many directions at once. Hopefully.<sup>91</sup>

Elly: so you wouldn't describe it as difficult it is just

Natalie: it is

We try to keep sane: choosing your attitude

Valuing current life and past choices

Investment

## ***B.2 Table of themes for Natalie's baseline interview***

<b>Themes</b>	<b>Page/line</b>	<b>Illustrative phrases</b>
<b><i>Anticipating the future</i></b>	3.20	If I started heading down that road
slippery slope	3.20	I know my own weakness
increasing emotional investment	2.28/29	a trail I haven't blazed yet
	2.9	more emotionally invested with each turn of the dial
what can be influenced now vs what can't		
<b><i>Social comparison</i></b>	3.17	We see our counterparts
no group thing	8.9	I can barely manage within my own mind, I don't need to be in other people's
staying an outsider	8.23	I try to think like an anthropologist
negative comparisons	5.16	the obsessive kind
	5.30	more people err to the side of high anxiety
<b><i>Limit setting</i></b>	2.26	that is not a sustainable route for me
	4.7	there needs to be a line
need for biological connections	6.10/11	your general view of creating a life
value of life and decisions	4.19	not willing to crumble our marriage
	11.20	I don't regret all the other decisions I made to get me to this point
financial	1.13	cash and carry process

	1.21	it's a financial investment
potential physical effects over longer term	4.11	taxing on my liver
	3.2	ain't nothing natural going on here
<b><i>Engaging with fertility treatment</i></b>		
letting doctors be in control	11.5	I live in these 72 hour intervals
	10.23/4	I guess I could take over the planning and be the least qualified person to do it
humour	12.25/26	We're just like Project Weeble, that's what we do, that's how the nurses refer to it
Evaluation	2.1	give me the raw breakdown of what the statistical chances are
being responsible for a small portion	10.8	make sure there's enough baby crack in the refrigerator
	2.1	tell me what the advanced protocol is and set me loose
knowledge and being informed	2.4	done cursory research, but other than that...
	1.28	haven't Googled one thing

### ***B.3 Making social comparisons: We see our counterparts***

One thing that emerges from this interview that doesn't from Jeremy's is that Natalie seems more conscious of (or at least talks about) external influences and perceptions of fertility treatment. She talks about, for example, her awareness of fellow patients and their sources of information (books, Google, Wikipedia) and compares herself with other patients, friends and relatives receiving fertility treatment:

*I do have a friend who's going through it now and who just got pregnant via IVF and she was sort of the template of what I didn't want to be, she was way too invested.*

And:

*We see our counterparts, sort of in the waiting room, who are, you know, coming with pamphlets and books and, you know, IVF for Dummies and all that kind of stuff, which is - I'm not passing judgment on it as much as I sort of look at it and go 'I know my own weaknesses', so if I started heading down that road it would become all-consuming.*

Two issues seem particularly significant to her: anxiety and the level of knowledge or information people acquire about the treatment process.

*I mean granted they're dealing with a range of people, but I'm little towards the higher end at 39, you know, lots of 31 year olds walking in there with tremendous anxiety um and, as I say, you know I'm at the front of the line, right? He who's closest to errr to menopause goes first!*

She relates her need to be treated to a practical reason (age) rather than an emotional reason (anxiety). She doesn't refer to her own anxiety directly, but suggests that she differs from other patients in that dimension. She compares her own knowledge about fertility treatment to the high level of information she feels others have. She says she considers herself 'generally informed' but describes her perception of other patients who make particular efforts to find out more through reading, Internet searches etc.

As mentioned in the last section, it seems like part of her comparisons are to some extent an effort of anticipatory coping. She sees how others seem to behave and the consequences for them, and bases her own behaviour on avoiding the negative outcomes. She presents herself as an outsider who observes and remains objective:

*I just try to think like an anthropologist, that I'm on this discovery tour of myself, and creationism, or whatever you want to call it*

These comparisons seem to fill a number of functions. She manages her identity, perhaps by rejecting the stigmatising label of 'infertile' although, as mentioned in the introduction, she doesn't suggest that she considers infertility stigmatising per se. By being unlike the stereotypical infertility patient she distances herself from being included with them. If they are anxious and depressed they need sympathy and support and she doesn't. Additionally, Hilton, Emslie, Hunt, Chapple, & Ziebland (2009) suggest that humour is a way of pre-empting sympathy. Natalie uses humour frequently in her account, which might be a way of influencing the way others respond to her and reducing expressions of sympathy. Natalie seems to create a strong, positive identity for herself by comparing to other infertile women/couples and suggesting that she isn't falling into the anxiety that they experience or becoming over invested.

So on the one hand, it seems like she makes comparisons to set herself apart and highlight that she is different from other fertility patients. On the other hand, in this extract about support from others suggests that the distancing is partly a strategy to avoid being exposed to issues that might lead her to suffer negative emotional consequences:

*Elly: You don't feel the need to, sort of, get involved in, like, groups, or anything like that?*

*Natalie: No! Good God, no no no no! No group thing. I can barely manage within my own mind; I don't need to be in other people's. [left out a sentence]. I don't want to kumbayah with people about the process, it's just not for me, um because I can only manage my own issues around it, not Susie's and John's and everybody else's.'*

So as well as implying that she was not as invested in the process as others, she seems to resist behaviour that she feels would be unhealthy for her. So even though she talks about the 'tremendous anxiety' that other patients show, she also seems to suggest that getting over-involved in other's situations might tip her over the edge? Comparisons with others firstly allow her to position herself more favourably within the group of 'infertile people', but also act as a warning about the risks of emotional trauma. There is also a contradiction between her statements that she doesn't find infertility difficult to cope with and here where she says 'I can barely manage within my own mind'.