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Counselling Psychology of Infertility

Joanne Marie Perkins

Thesis submitted in fulfilment of requirements for the degree
Doctor of Psychology

City University, London
Psychology Department
March 2006

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Declaration

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SECTION A: PREFACE

Overview

The central theme of this thesis is infertility. It links different areas of my work as a chartered counselling psychologist working with clients experiencing difficulties conceiving. I currently work in private practice specialising in this area. Previously I worked as an IVF counsellor at the Assisted Conception Unit of the Lister Hospital in London.

Although the term 'infertility' is commonly used, being 'infertile' means a total absence of reproductive function and this condition is rare (HFEA, 1999). The majority of people presenting with difficulties in conceiving actually have 'sub-fertility', where one or more parts of the reproductive system are impaired. Throughout this thesis the term 'infertility' is used to refer to both infertility and sub-fertility.

I initially became interested in the psychological impact of infertility when a number of close friends started having difficulties conceiving. I observed that whilst there was a wealth of medical support available, psychological and emotional support was somewhat lacking. This led me to reflect on the counselling psychology of infertility.

After conducting a review of the infertility literature it became apparent that research contributions from counselling psychologists were somewhat scant. The main body of literature is comprised of contributions from nurses, medical practitioners, clinical psychologists and counsellors working in the field. Part of my motivation in undertaking this degree was to establish the role that counselling psychology can play in the field of infertility. Linked to this, was the motivation to make a difference and raise the profile of infertility within the field of counselling psychology.

The thesis focuses on three different areas of infertility that are all linked to the practice of counselling psychology with this client group. Firstly there is an exploratory piece of research. It focuses on the psychological and emotional impact of the infertility experience and the role of counselling. Secondly there is a case study. This is reflexive

exploration which focuses on some of the challenging issues that I encountered in my clinical work with an infertile female client. Finally there is critical review of the literature that explores infertility and counselling from a historical perspective. The review places infertility in a historical context so that the complex psychological aspects of the infertility experience today can be more fully understood and appreciated. An overview of each section is now provided.

1.1 SECTION B: RESEARCH

The research section is comprised of three studies. Study 1 was conducted in response to a gap identified in the literature. Prior to conducting this research there did not appear to be an overall coherent account of the issues that might be experienced at different stages of the infertility process by the male, the female or the couple. The study set out to explore male and female infertility experiences from the point at which difficulties conceiving are encountered through to post treatment. The aim was to gain an understanding of the overall male and female experiences and how these individual experiences impact on the couple relationship.

Study 2 was conducted in response to findings from Study 1 and my clinical experience. It set out to explore the differing male, female and couple experiences and perceptions of counselling in general and specifically for infertility. This was with a view to understanding the factors involved in the decision making process about whether to have counselling for infertility or not. It was anticipated that findings could be used to inform the development and delivery of appropriate psychological services to those experiencing infertility.

As far as I am aware there is currently no psycho-educational tool that is widely available to those experiencing infertility. Yet my clinical experience suggested that there is a demand for one. The aim of Study 3 was to develop a user friendly psycho-educational tool for this client group, based on findings from Studies 1 and 2. The intention was to gain feedback regarding the relevance of the tool with a view to updating it beyond the present research.

The aim of all three studies was to:-

- Gain a broader understanding of the differing experiences and counselling needs of males, females and couples from this growing client group.
- Generate findings that can inform the development and delivery of appropriate psychological services for them.
- Develop a pilot psycho-educational tool for those experiencing infertility.

1.2 SECTION C: PROFESSIONAL PRACTICE

In this section I have presented a case study that focuses on the work I did with an infertile female client. I chose to present this particular case because I found it a key learning experience from both a personal and a professional perspective. Moreover the case highlights an important point at which some clients could benefit enormously from psychological and emotional support. The client was a 49 year old, single female who was pregnant with twins following IVF treatment with donor sperm and donor egg. This case was my first experience of working with a pregnant client following IVF treatment as I normally see clients prior to treatment and/or when treatment fails. I found the case challenging for a host of reasons and these are explored in the case study.

1.3 SECTION D: CRITICAL REVIEW OF LITERATURE

The aim of the review was to explore infertility from a historical perspective so that the psychological impact of current infertility issues and experiences could be understood within a frame of reference (Marsh & Ronner, 1996). Literature from the 20th century to the present day was reviewed. The review highlights the extent to which females have traditionally been the focus of infertility investigations whilst males have largely been ignored and sidelined. It explores social, political and psychological influences over this period. It considers the impact of these on the collective psyche and how this in turn has fed into current perceptions of the infertile.

1.4 Summary and conclusion

I have found the process of conducting research, reviewing the literature and reflecting on my client work hugely beneficial in terms of my personal and professional development.

The process has provided me with insight and understanding into this topic and client group in numerous ways. My perspective is now much broader as a direct result of this thesis. I feel that this has impacted positively on my clinical practice.

It has compounded my resolve to raise the profile of infertility within the field of counselling psychology. I have already started to share the findings with colleagues through lectures and I fully intend to expand on this via conferences and publication. I am also going to work towards promoting the benefits of counselling to those experiencing infertility by building relationships with and disseminating relevant information to doctors, assisted conception units and other practitioners working with this client group.

SECTION B: RESEARCH

COUNSELLING PSYCHOLOGY OF INFERTILITY:

An Exploration of Male, Female and Couple Experiences, Perceptions and Counselling Needs.

Abstract

Background: Infertility affects over 80 million people worldwide (World Health Organisation, 2003). There are a number of issues involved for the individual/couple experiencing infertility and the emotional and psychological impact can be immense. **Aims:** Study1) To explore the process of the infertility experience for females and males and how these individual experiences impact on the couple unit. Study 2) To explore counselling experiences and perceptions of females, males and couples. To identify potential counselling and support needs throughout the infertility experience for each group respectively. Study 3) To develop a pilot psycho-educational tool for those experiencing infertility. **Methods:** Data was collected from eleven couples who met the criteria for infertility. A grounded theory approach was employed. Semi-structured interviews were conducted first with couples then with individuals. **Findings:** Study 1) Three distinct models of the infertility experience were developed for the female, the male and the couple respectively. This resulted in a fourth model depicting the overall infertility experience. A stage theory of infertility was proposed. Study 2) Distinct counselling and support needs were identified for females, males and couples respectively. Perceptions and experiences of counselling were identified for each group. Study 3) Based on findings from studies 1 and 2 a psycho-educational video was developed including a female, a male and a couple scene. Feedback provided support for the video. Suggestions for improvement were made. **Conclusions:** Findings can inform the practice and provision of psychological counselling services for these three client groups, at each stage of the infertility experience. Counselling needs to be made accessible from the point difficulties conceiving are encountered, preferably via GPs. Counselling suggestions/referrals need to be accompanied with information about what it is and potential benefits need to be highlighted. The value of developing a series of psycho-educational films for those experiencing infertility was identified.

CHAPTER 1

Introduction to research

1.1 Infertility – a definition

A widely held expectation is that those who choose to have children will be able to. This assumption is not challenged until a time when prolonged difficulties in conceiving are experienced. 'Infertility' is defined as the failure to conceive after one year of engaging in regular sexual intercourse without contraception (Mosher & Pratt, 1982).

1.2 Infertility – facts and figures

Infertility affects over 80 million people worldwide (World Health Organisation, 2003). According to The Human Fertilisation and Embryology Authority (HFEA, 1999) 1 in 6 couples experience fertility problems. Amongst these couples, female infertility accounts for 40% of all cases with 30% being accounted for by male infertility. The remaining 30% of infertility is due to infertility in both partners and unexplained infertility (HFEA, 1999).

Infertility is not a new problem. It has been prevalent through the ages, though traditionally it has been a taboo subject (Marsh & Ronner 1996; Pfeffer, 1993). Statistics confirm that the incidence of infertility has not increased over time but that the number of people presenting with fertility issues have increased (Read, 1995). This is largely due to medical and technical advances during the last 30 years which have meant that the possibilities available to the individual/couple experiencing infertility have grown considerably. Moreover, social and economic change over this time has made advances in technology such as in vitro fertilization (IVF) more accessible to a wider range of people. These possibilities have recently been extended to a broader population, with guidelines from the National Institute for Clinical Excellence (NICE, 2004) stating that the NHS will provide 1 free cycle of IVF for all females aged between 23 and 39 who meet certain clinical criteria from April 2005.

2004 saw the 25th anniversary of the birth of the first baby through IVF. Since then, more than 68,000 children have been born through IVF in Britain. Over 8,000 of these babies were born in the 12-month period between 1st April 2000 and 31st March 2001. This figure makes up 12% of the total number of babies born through IVF in the last 25 years. Whilst the number of babies born through this method is increasing, the success (live birth) rate for patients of all ages is still only 22% (HFEA, 1999).

1.3 The infertility experience

For many couples infertility is psychologically distressing and can be a major life crisis (Leiblum & Greenfield, 1997; Burns & Covington, 1999). The experience is a multi-layered and complex phenomenon. A number of issues are involved for the individual/couple experiencing infertility, e.g. biological, emotional, physical, relational, social, financial and psychological. The pain and loss that they face can be immense. Gibson & Myers (2000) found that the infertility experience can cause serious emotional, psychological & social distress. The experience can also have a significant negative impact on marital and sexual relationships (Leiblum, Aviv & Hamer, 1998).

Greil (1997) reviewed the literature on the social psychological impact of infertility, with particular reference to the relationship between gender and the infertility experience. The findings from this review suggest that the infertility experience is more emotionally distressing for the female than for the male. The review also found that the relationship between gender and infertility distress is not affected by which member of the couple has the impairment. Greil (1997) concluded that more attention needs to be paid to the way in which social factors condition the experience of infertility. It was also argued that ways of accounting for the process of the infertility experience need to be developed.

In addition to coming to terms with the idea that they may not be able to conceive naturally, couples also face decisions about what to do about it. Options include whether to have treatment e.g. IVF, using a sperm/egg/embryo donor, finding a surrogate mother, trying to adopt/foster a child and/or not having treatment and face a future without children.

Couples who proceed with IVF are then confronted with the medical and biological factors involved in this process. IVF treatment can be physically invasive and exhausting, financially demanding as well as time consuming. As a result IVF treatment can be anxiety provoking and exert extreme stress on the relationship (Salvatore, Gariboldi, Offidani, Coppola, Amore & Maggini, 2001; Levin & Sher, 2000; Greil, 1997; Ow, Kumar & Leo, 2003).

Given the success rate of IVF (22%) many couples are faced with a decision about whether to 'try again' and have a second cycle. If there are egg/sperm or embryo donors involved, this raises even more issues for consideration. In this instance they need to consider the implications for them as a couple and for the potential child. There are a host of implications arising from gamete donation. These include the issue of whether to tell the child about their conception and if so, how (Murray & Golombok, 2003; Klock & Greenfield, 2004), whether to tell others (Klock & Greenfiled, 2004), whether to use known or anonymous donors [1](Baetens, Devroey, Camus, Steirteghen & Ponjaert-Kristoffersen, 2000), the potential impact of them not being the child's genetic parent/s (HFEA, 2003) and in the case of using a donated embryo the possibility of the existence of full genetic siblings to their own child or children (HFEA, 2003).

There are also issues for donor-conceived children. These include identity issues (Hewitt, 2002; Turner & Coyle, 2000), the possibility of there being other children genetically related to the donor conceived individual (HFEA, 2003), the way in which they hear the news about their conception and the impact of this on them (Turner & Coyle, 2000), amongst others.

A number of other factors contribute to the individual/couple's infertility related distress. For example pressure from family, friends and work colleagues can contribute to feelings of inadequacy and loss. This pressure can contribute to secrecy around the infertility issue (Bor & Scher, 1995) which can lead to couples withdrawing from friends and families further adding to feelings of isolation (Dunkel-Schetter & Lobel, 1991).

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[1] HFEA Regulations introduced on the 1st April 2005 state that all donors must be identifiable to donor-conceived children once they reach the age of 18 (HFEA, 2004). However anonymous donation is still permitted in other countries.

1.4 Infertility and counselling

Given the distressing experience of infertility many infertile couples have expressed a desire to receive more psychosocial support (Laffont & Edelman, 1994; Sundby, Olsen & Schei 1994). Despite this research suggests that less than 25% of infertility patients take up psychological services (Sundby *et al.*, 1994; Hernon, Harris, Elstein, Russell & Seif, 1995) or have the intention to use these services (Schmidt, Holstein, Boivin, Sangren, Tjornhoj-Thomsen, Blaabjerg, Hald, Nyboe Anderson & Rasmussen 2003).

A number of psychosocial interventions have been developed for infertile couples although only a few of the interventions reported are empirically supported (Boivin, 2003). These interventions include cognitive behavioural therapy (Tuschen-Caffer, Florin, Krause & Pook, 1999), couple therapy (Stammer, Wischmann & Verres, 2002), psychological and sexual counselling (Sarrel & DeCherney, 1985), supportive group interventions (Ferber, 1995) and mind-body therapy (Domar, Zuttermeister, Seibel & Benson (1992). Couples experiencing infertility that do take up services such as counselling and support groups tend to be experiencing more social, personal and/or marital distress, and consequently experience more marital benefits, than those that do not attend counselling or support groups (Berg & Wilson, 1991; Laffont & Edelman, 1994; Schmidt *et al.*, 2003).

1.5 Infertility counselling

In light of the complexities surrounding infertility, outlined above, the HFEA state in their Code of Practice (1993) that three distinct types of counselling must be available at licensed treatment centres. These include "implications counselling", "support counselling" and "therapeutic counselling". However, the HFEA Code of Practice also states that 'no-one is obliged to accept counselling' (p. 28, HFEA, 1999). These three types of counselling are briefly outlined below.

Implications counselling is concerned with enabling clients to consider the implications of treatment for themselves, their families and any children born as a result of treatment. This form of counselling is obligatory for all patients who go for egg, sperm or embryo donation.

Support counselling focuses on providing emotional support at particularly stressful times, such as when treatment fails.

Therapeutic counselling aims to help people cope with the consequences of infertility and treatment. It aims to help the couple/individual work towards a resolution of the problems incurred as a result of infertility and treatment. It also helps the couple come to terms with their situation and adjust their expectations for their future (p.29, HFEA, 1999).

The Code of Practice states that centres "must" (HFEA 1999, p.29) make "implications counselling" available to everyone. It also states that treatment centres should provide "support" or "therapeutic" counselling in appropriate cases, or refer individuals on to those with specialised training outside centres. The emphasis placed on the provision of "implications" counselling by the HFEA, ties in with the HFEA Guide description of infertility counselling, which is defined as counselling that relates specifically to the infertility issue (HFEA, 1999).

It is important to bear in mind that many couples experiencing infertility will only be offered counselling once they embark on treatment. Even then only one session may be offered. Furthermore, whilst many clients are offered counselling for issues involved in the treatment and support for failed attempts, they may not be offered any therapeutic counselling. It cannot be assumed that because counselling is offered, it will be taken up.

1.6 The research

1.6.1 Study 1:

Male and Female experiences of Infertility: How individual experiences impact on couples as a unit.

Whilst different aspects of the infertility experience have been the subject of much research (e.g. Leiblum & Greenfield, 1997; Leiblum *et al.*, 1997; Greil, 1997; Burns & Covington, 1999; Gibson & Myers, 2000; Salvatore *et al.*, 2001; Ow *et al.*, 2003; Hewitt, 2002) there appears to be a gap in the body of literature. There does not appear to be an overall coherent account of the issues that might be experienced at different stages of the infertility process by the male, the female or the couple. The aim is to address this gap

in the literature, by looking at the whole process of infertility for the individual male, the individual female and the couple as a unit.

1.6.2 Study 2:

Counselling and the Infertility Experience:

- **An exploration of counselling perceptions and experiences**
- **Identification of potential counselling needs of the male, female and couple respectively.**

The intention is to explore perceptions and experiences of counselling in general and specifically for the infertility experience. This is with a view to gaining an understanding of the factors involved in whether an individual/couple decide to go for counselling for infertility or not. A second aim is to identify counselling and support needs of those going through the infertility experience. This is with a view to informing professionals in the field so that counselling programmes tailored to this client group can be developed. It is anticipated that findings will facilitate and inform the promotion of counselling to this client group. Finally the findings will be used to check the validity of findings from Study 1.

1.6.3 Study 3

Development of a pilot psycho-educational tool:

- **Develop a psycho-educational tool for those experiencing difficulties conceiving.**
- **Gain feedback regarding the pilot tool.**

The aim is to develop a pilot tool for those experiencing infertility. It will focus on the psychological and emotional impact of the infertility experience. The tool will be developed in conjunction with findings from Studies 1 and 2. Feedback regarding the relevance of the tool will be sought and analysed. Study 3 findings will be used to check the validity of findings from Studies 1 and 2.

1.7 Professional Justification

Having conducted a review of the infertility literature it is clear that infertility research contributions from counselling psychologists are somewhat scant. A systematic review dating back to 1997 of the Counselling Psychologist and the British Psychological

Society's (BPS) journal, Counselling Psychology Review, revealed that no infertility related studies have been published during this period. The main body of infertility literature is comprised of contributions from nurses, medical practitioners and counsellors working in the field.

Given that the role of counselling psychologists is to work 'therapeutically with clients with a variety of problems, difficulties and life issues and crises' (BPS Division of Counselling Psychology, 2002), they need to be able to work therapeutically with this growing client group and their specific needs. Furthermore, given that there is a focus on the wide range of 'human psychological functioning across the lifespan' (BPS Training Committee in Counselling Psychology, 2003. p.3) within counselling psychology, it is necessary to understand how psychological functioning can be affected by issues encountered during the pivotal childbearing period.

In addition to the justification for this research as a counselling psychologist my work as an IVF counsellor at an Assisted Conception Unit and in private practice raised some issues for consideration. I have observed that the majority of patients/clients tend to take up the offer of counselling only when they hit a 'crisis' point or when it is 'obligatory'. What constitutes a crisis point can differ between individuals and hence couples. An example is a series of failed IVF cycles or a miscarriage resulting in a crisis that brings the couple into counselling. Counselling is obligatory for all egg, sperm or embryo donors and recipients to discuss the social, legal and ethical implications involved (HFEA, 1999). These issues are generally explored and discussed in one session with the unit counsellor.

For many this 'obligatory' or 'crisis intervention' counselling session is a point at which the individual or couple can express themselves. In my experience many clients will use the opportunity to talk about how 'traumatic' and 'isolating' the experience has been for them. In the majority of cases they talk about the 'pressure' that the experience has put on their relationships with each other (if a couple) and with friends and family. Levels of emotion in these sessions can be high, i.e. particularly in crisis intervention sessions and when egg, sperm or embryo recipients have only recently been made aware that this is their best option if they are to have a chance of having a baby.

As a counselling psychologist working in this field these observations led me to wonder whether people were being offered counselling at any stage before they reach a crisis or whether they are offered counselling but decline. I was interested in establishing at what point counselling is offered, if at all, and by whom. I wanted to understand what people experiencing infertility think counselling is and whether they believe it can help with the infertility experience, and if so in what ways. I was also keen to identify potential 'crisis' points, with a view to helping couples prepare for them in advance either through the provision of appropriate counselling services and/or providing these couples and individuals with relevant information.

1.8 Personal Justification

A number of people close to me have experienced infertility. I have witnessed the profound effect on both of the individuals within that couple and on the couple as a unit, not to mention their families, social and professional circles. The process is not a static one and it would seem that feelings and issues experienced differ as a function of where the couple / individual is in terms of the process e.g. whether they are just discovering they are experiencing difficulties in conceiving or are at the stage of receiving treatment.

I have noticed that in instances where professional support has been offered, it tends to be medical in nature. Perhaps more importantly, the 'support' offered seems to be primarily focused on finding a 'solution' to the problem e.g. medical intervention 'ideally' resulting in the birth of a healthy baby. In my experience it would appear that the psychological and emotional needs of those going through the infertility process are often overlooked, at what could be argued as perhaps one of the most stressful times in their lives.

Arguably appropriate psychological services need to be developed for, and offered to, this client group alongside medical interventions. In order to achieve this it is essential to first establish what the different emotional and psychological needs might be at any given stage of the infertility process. Once these needs have been identified the process of meeting them can be addressed.

1.9 Research Aims

Study 1

- To gain an understanding of the different emotional and psychological needs that might arise at any given point during the infertility experience.
- To explore how infertility is experienced by males and females and how these individual experiences impact on the couple as a unit.

Study 2

- To explore perceptions, beliefs and experiences of counselling in order to understand the factors involved in the decision making process concerning the decision to embark on counselling for infertility.
- To identify potential counselling and support needs of the male, female and couple respectively.
- To check the validity of findings from Study 1.

Study 3

- To develop a pilot psycho–educational tool providing information and support to those going through the infertility experience.
- To gain feedback regarding the relevance of the tool.
- To check the validity of findings from Studies 1 and 2.

CHAPTER 2

Methodology employed in the research

2.1 Rationale for adopting a qualitative research paradigm

A qualitative approach utilising semi-structured interviews was deemed the most appropriate fit with the exploratory nature of the research aims (McLeod, 1996; Strauss & Corbin, 1998; Pidgeon & Henwood, 1998). The aims of the present study were 1) to build a picture of what the emotional and psychological needs of this client group might be at any given stage of the infertility process 2) to explore perceptions, beliefs and experiences of counselling in order to understand the factors involved in the decision making process around whether to have counselling for infertility 3) to identify potential counselling and support needs throughout the infertility experience of the male, female and couple respectively 4) to gain feedback regarding the relevance of the psycho-educational tool developed. In order to meet these aims thoughts, feelings, perceptions and behaviours of those who have experienced or were experiencing infertility were explored.

Research that employs a quantitative paradigm tends to be concerned with testing grand theories or universal laws. Quantitative methods are less conducive to conducting an in depth exploration of an area about which relatively little is known. As such it does not lend itself as readily to the generation of new theory (Henwood & Pidgeon, 1995), which was the purpose of the present study.

2.2. Philosophical assumptions underpinning qualitative research

A general definition of qualitative research is that it is mostly built around accounts or stories that individuals provide about their personal experience (McLeod, 1996). Qualitative research is mostly based on a 'social constructivist' perspective on knowledge (Gergen, 1985). In contrast with a quantitative approach, the implication of this

philosophical perspective is that the qualitative researcher does not seek a 'universal truth'. Instead the fundamental aim of qualitative research is to search for and clarify the meaning that surrounds or is attached to biological, social and psychological issues. It is the researcher's job to translate different versions of an individual's unique reality. Thus it is an interpretive line of research.

2.3 An emic (insider) approach with etic (outsider) coding

A fundamental observation in the qualitative literature is that multiple interpretations can be applied to human experience, thoughts, feelings and behaviour when viewed in context and in their full complexity (Pidgeon & Henwood, 1998). In short experience is always interpreted and constructed according to an individual's unique position and frame of reference.

According to Pike (1954) there are two perspectives that can be adopted when studying a society's cultural system. These are an "insider" or "emic" perspective and an "outsider" or "etic" perspective. The emic perspective focuses on the intrinsic, cultural distinctions that have meaning for members of a given population. The "etic" perspective relates to the extrinsic concepts and themes that have meaning for scientific observers outside the population's cultural and social world. In short it attempts to find universal explanations.

Thus if a researcher is to gain privileged insider or emic knowledge of the way the world is viewed and constructed by a given population they need to closely engage with that population. This essentially means embarking on an in depth exploration of how the world is perceived through the eyes of the participants from their social and cultural location, in this instance - infertile. At the same time it is important that the researcher keeps sufficient distance from their participants' worlds in order that they are able to translate the inherent emic constructs into extrinsic etic constructs, so that they have meaning for those 'outside' of the infertility experience.

A benefit of adopting a qualitative approach to data collection and analysis in the present research is that it permits the researcher to gain emic knowledge and translate this into etic knowledge for a wider population e.g. counselling psychologists and medical professionals.

2.4 Compatibility of qualitative methodology with counselling psychology

In addition to the compatibility of a qualitative paradigm with the aims of the research, the epistemological assumptions underlying qualitative research outlined in the previous section, have many parallels with the theory and practice of counselling psychology. These parallels will now be briefly outlined.

Psychology and therefore counselling psychology is a human science. The German philosopher, William Dilthey, linked the notion of human science to a theory of understanding. He played an influential role in the development of researching into human consciousness, culture, meaning and subjective experiencing (Strawbridge & Woolfe, 1996). Methods and tools employed within a qualitative research paradigm permit the exploration of the diversity both within and between these areas, all of which are at the core of counselling psychology. Furthermore, central to the practice of counselling psychology is its humanistic value base (Duffy, 1990). This value base emphasises that each human being is separate and that their subjective experience, feelings and meanings are unique (Woolfe, 1996). This highlights the value of adopting a research strategy that reflects this value base as it permits the search for meanings constructed by individuals about their unique experience of infertility. Qualitative methods are appropriate for data that cannot be easily or fully explained by numbers e.g. feelings, perceptions and experience – issues all central to the practice of counselling psychology. Once an understanding of the feelings, perceptions and experience is reached using this approach, quantitative methods can then be employed to elaborate on and substantiate initial findings in future studies.

A further strength of utilising a qualitative approach in this research is that it is similar to the process of therapy in that a skilled qualitative researcher uses empathy, genuineness

and acceptance in the development of the relationship with informants (Mearns & McLeod, 1984). These ingredients were considered especially valuable given the sensitive nature of the topic under investigation. The reflective skills used in my role as a counselling psychologist also provided a firm base to work from in the interview process.

Thus for reasons outlined above employing a qualitative research strategy for exploring an issue such as infertility, relevant to counselling psychology, has distinct advantages over using a quantitative one.

2.5 Rationale for adopting a Grounded Theory approach

There are a number of different approaches to the analysis of qualitative data e.g. grounded theory analysis, phenomenological methods and narrative analysis (McLeod, 1996). Following discussion with my research supervisor a grounded theory approach was considered the best fit with the aims of the present research (see Chapter 1). It was anticipated that a grounded theory approach would facilitate the identification of key categories and the relationship between these categories leading to a model or theory of understanding of the infertility experience that is grounded in the localised accounts and experience of the participants being studied. Consequently it was expected that this would provide the most 'realistic' account of the infertility experience.

In addition to the good fit with the research aim, grounded theory is considered an appropriate approach for newcomers to qualitative research because it provides a better description of techniques that aid analysis than other forms of qualitative methodology (Pidgeon & Henwood, 1998). Data analysis was conducted by following the steps set out by Strauss & Corbin (1998). This particular approach was chosen because whilst it is an interpretive line of research it utilises a systematic approach to data collection and analysis. The step by step guide also permits flexibility providing that the researcher makes it explicit what steps were followed and when during analysis.

2.6 Overview of Grounded Theory methodology

Grounded theory was developed by Glaser and Strauss (1967). It has become one of the most widely used frameworks for analysing qualitative data (Bryman, 2001). The methodology has evolved over time and the originators subsequently went on to debate

the methodology between them. In its original and highly inductive form the grounded theorist aims to embark on a path of study without a preconceived theory in mind (unless the purpose is to elaborate an existing theory) (Strauss & Corbin, 1998). Instead they start with an area or a phenomenon that they wish to understand more about and allow the theory to emerge from the rich data source. Theory development is one of two central features of grounded theory. The other central feature is the iterative process. The researcher continually moves between data collection and analysis whilst developing the theory. So "in this method data collection, analysis and emergent theory stand in close relationship with each other" (Strauss & Corbin, 1998, p.12). The epistemology of grounded theory has become a topic of lively debate over the years. A brief overview highlighting just some of these debates follows.

Firstly there is the debate between Glaser (1992) and Strauss and Corbin (1990, 1998) and their differing stand points. Whilst key methods are common to both e.g. constant comparative analysis, memos and theoretical sampling there are differences in the approaches. Strauss and Corbin, (1990, 1998) argue that reality needs to be interpreted and description is basic to theorising. They emphasise the systematic nature of collection and analysis of data in theory development. Glaser (1992) criticises Strauss and Corbin (1990) for being too prescriptive and concerned with description and conceptualisation. Glaser (1992, 2002) places emphasis on the 'emergence' of theory. He argues that data is there to be 'discovered' and should not be 'forced' into categories. He argues that his version of grounded theory is about abstraction not 'accurate description' (2002).

Grounded theory is clearly a qualitative approach and hence arguably it is an interpretive line of research. However it has been questioned whether it is based on a positivist (or post positivist) epistemology and as a consequence at odds with a qualitative philosophy (e.g. Pidgeon & Henwood, 1998; Charmaz, 2000; Urquhart, 2002; Bryant, 2002). Urquhart, (2002) argues that the paradoxical nature of grounded theory e.g. a systematic method for analysing qualitative data that permits theory generation, leaves it open to the positivist vs. interpretive debate. Klein and Myers (1999) argue that there is little benefit in considering a method as either positivist or interpretive since quantitative methods have been used in interpretive research and vice versa. Instead, they suggest that researchers need to state their philosophical position. This is a key point as grounded

theory has been criticised for neglecting the role of the researcher in the development of the emergent theory (e.g. Charmaz, 1990, 2000; Bryant, 2002).

Charmaz (1990, 2000) a constructivist grounded theorist, highlights the importance for researchers to make explicit what values, ideas and assumptions they bring to the study and the part they play in the developing theory as this will undoubtedly influence the interpretation of findings. The grounded theory assumption that theory is waiting to be 'discovered' has received criticism. This assumption suggests that a social reality exists objectively in the world and that this reality can be found in the constructs pertaining to a given phenomenon. The implication being that these constructs should mean the same thing to anybody that has access to them and are not open to the researcher's unique subjective interpretation. An interesting study challenges this premise. Madill, Jordan & Shirley (2000) gave two researchers the same set of data to analyse using grounded theory methods. The resulting categories were different. They found that researcher training and research interests influence choice of codes and categories. They too highlight the importance of the researcher making their philosophical position explicit to the reader.

Madill *et al.,* (2000) argue that philosophical position in respect to grounded theory depends on the extent to which the researcher believes findings are to be either discovered in the data, a view they attribute to Glaser (1992) or whether findings are the result of constructing relationships between concepts, a view they attribute to Strauss and Corbin (1990). My philosophical position is compatible with Strauss and Corbin (1990). I am aware that my personal and professional background is likely to influence my interpretation and description of the data. Hence I comment on my process, ideas and views in relation to the research where appropriate.

2.7 Research Objectives

- To interview a range of participants located at different stages of the infertility continuum.
- To conduct interviews with the couple as a unit.
- To conduct interviews with both individuals within the couple.

CHAPTER 3

STUDY 1

Male and Female experiences of Infertility: How individual experiences impact on couples as a unit.

Study 1 - Research Method and Design

Aims

- To gain an understanding of the different emotional and psychological needs that might arise at any given point throughout the infertility experience.
- To explore how infertility is experienced by males and females and how these individual experiences impact on the couple as a unit.

3.1 Purposive sampling

Purposive sampling (Silverman, 2000) requires choosing a selection of participants who illustrate the processes under research. A diverse sample was taken in order to capture the process of the infertility experience. Minimum criteria for selection were that couples had to meet the Mosher & Pratt (1982) definition of 'infertility' - 12 months trying to conceive naturally, and to have experienced sufficient difficulties conceiving to have led them to seek medical advice/treatment, either currently or in the past. To access experience at different stages of the infertility continuum three couples with biological children and three without biological children were interviewed.

3.2 Characteristics of sample

Six volunteer couples were interviewed. The age range was 28 to 43 years. Five couples had female factor infertility. One couple had unexplained infertility. At time of interviewing two couples had no children, one couple had two children via adoption and three couples had biological children (two couples via IVF and one couple conceived naturally after eleven years of treatment). Each couple was at a different stage of the

infertility continuum ranging from trying to conceive naturally for 2 years, to having made a decision to stop treatment after 10 years and face a future without children. Given the sensitive nature of the topic demographic details are not provided for purposes of confidentiality (Lee, 1993).

3.3 Recruitment

Three couples were friends of the researcher. Three couples were not known by the researcher. Couples did not know each other. Initial approach differed slightly on this basis. Couples known by the researcher were initially approached with a telephone call, the purpose and nature of the study was outlined and any questions answered. Known couples were made aware of the potential obligation they may feel in agreeing to participate on the basis of their relationship with the researcher. To minimise this, they were given time to consider the decision to take part. A follow up information sheet also outlined the dual relationship in place and potential issues relating to this (see Appendix 1).

Couples were invited to contact the researcher if they decided to take part. They were told that no contact would be made if they decided not to take part and no explanation required.

Couples not known by the researcher were initially approached by a mutual friend. They were provided with a brief, verbal outline of the study (provided to each friend by the researcher). A letter of introduction (see Appendix 2) and an information sheet (Appendix 3) was then sent by the researcher. Contact was made a few days later and questions were answered. Couples were invited to contact the researcher should they decide to take part. They were told that if they decided not to, no further contact would be made and no explanation required.

3.4 Theoretical Sampling

When using a grounded theory approach data collection is driven by emerging concepts. Theoretical sampling (Silverman, 2000) means that the choice of participants to interview next is informed by the emerging concepts. The aim of initial data collection was to

interview participants that would provide the richest data (Pidgeon & Henwood, 1998). Data collection became more focused in line with emergent themes.

To build a broad framework of the infertility experience interviews with two couples who had been through the 'whole' infertility experience and had children biologically were conducted first. The rationale being that these 2 rich sources of data would yield a broad range of emergent themes for the couple, the male and the female that could be compared for similarities and differences. These themes would then guide the next stage of data collection (Strauss & Corbin, 1998).

A number of emergent themes, for example 'distance within the couple relationship' for couples, 'pragmatic ambivalence' in males and 'sense of isolation' experienced by females (see chapters 5, 6 and 7) suggested that it would be pertinent to next interview a couple at the earlier stages of the infertility process. The couple who had been experiencing difficulties conceiving for 2 years were interviewed next.

3.5 Ethical Considerations

The topic of infertility is a sensitive one. I was aware that this may have been the first time that the individuals/couples taking part have spoken to each other and/or to anyone outside their relationship about their experience. Talking about their experience could evoke new or underlying unexplored feelings for each of the individuals and between both as a couple. There was also a possibility that they may disclose more than they intended to, especially couples known by the researcher. It was my responsibility to be transparent and manage participants' expectations. I needed to ensure that participants were made aware of the potential issues before they agreed to take part. All couples were informed that they could withdraw from the study at any point.

These issues were addressed in the information sheet (Appendix 1 and 3) they received following the initial conversation. The sheet acknowledges that feelings may be evoked either during and/or following the interview. It states that the interview is not the appropriate place or time to deal with these feelings. To prepare participants, it explicitly states that if it was felt that the interview was drifting into the realms of counselling then

the focus would be shifted back to the interview. This was carried out with respect and sensitivity. The purpose of adhering to the interview format was to reduce the risk of participants disclosing more than they had planned to.

I had an ethical responsibility to manage boundaries and maintain an awareness of interviewees' feelings at all times and to monitor my own. This was particularly relevant given my position in the role of interviewer, which was different to my role as a counselling psychologist.

Participants received a contact sheet (Appendix 4) with details of different organisations offering counselling and support with the introduction letter. This was to cater for the event that participants may wish to explore issues arising in the interviews therapeutically, either now or in the future.

3.6 Confidentiality and consent

Before signing consent forms (Appendix 5) participants were made aware of the following points:-

- All data would be treated in the strictest confidence.
- Participation would not be disclosed to third parties.
- Material discussed in the individual interviews is treated confidentially and not disclosed to their partner.
- The interviews would be stored in a locked filing cabinet.
- Participants were shown the labelling system for the interviews, protecting confidentiality.
- Comments used in the study would be presented anonymously.

Consent forms were signed by all participants and me prior to commencement of interviews.

3.7 Preparation

Prior to the first interviews I did not have experience working with couples. Hence it was considered appropriate to conduct pilot interviews. The rationale was to orient myself to working with the dynamic and discourse particular to couples, which is distinct from that of individuals. I was aware of a potential danger of focusing on one member of the

couple, for example the most vocal member of the couple or the one considered to have the issue. This can lead to the other member disengaging from the process (Hooper & Dryden, 1991). Not only would this not meet the objectives of the study, it is likely to be replicating the dynamic that these couples experience at clinics and the GP, which may negatively influence the way the couple talk to me. Conducting pilot interviews helped me anticipate potential issues. The topic chosen was 'favourite foods' as it was considered to be relatively non-emotive in the negative sense. Three couples were interviewed in total, for approximately 45 minutes each.

The exercise highlighted the need to stay in control of the interview and to manage the dynamics of the couple. For example, within each couple one individual emerged as the dominant speaker, resulting in limited input from the other. It revealed how a seemingly non-emotive topic such as food could give rise to strong emotions, discourse and potential conflict. It demonstrated potential reactions that couples may go through if they are discussing things for first time with each other. The following is a quote from one of the interviews "I can't believe you feel like that [about the weekly shop] why haven't you told me that before, I feel really stupid now!". This emphasised the need to be aware of boundaries and sensitivity in the infertility interviews.

The exercise also highlighted the centrality of reflecting on my role in the interview process and how this impacted on the responses given and the direction of the interview. For example, I needed to ask myself what the effects of my being there were, what dynamics were created between the couple and myself and how were these exerting their effects on the interview and how this may impact on the data (Lee, 1993).

3.8 Equipment

Interviews were recorded on a Sony portable MiniDisc Recorder (model MZ-R50) with a Sony Electret Condenser Stereo Microphone (model ECM-MS907), using Sony Mini Discs (80 minutes duration).

3.9 Data collection

Eighteen interviews were conducted in total. Couples were interviewed together first, then individually. This way the story of their infertility experience could be told in the

presence of each other. It was anticipated that it would help couples feel more comfortable with the process. It was important that trust was established and separating couples initially could create difficulties such as forming an allegiance with the first member I interviewed or create feelings of anxiety in the individual (Lee, 1993). All couples were interviewed in their homes.

Interviews lasted between 45 and 60 minutes. Before interviewing participants were thanked for participating. They were reminded of their right to withdraw from the study at any time without explanation. They were informed that they did not have to answer any questions they did not want to. They were shown how to turn off the recorder so that they had a sense of control and could exercise choice without having to ask the researcher.

All interviews were semi-structured with the initial couple and individual interviews being the least structured with the aim of yielding a rich data set. The focus of the interviews became more specific as the theory emerged. The initial and final questions remained the same for each interview and these are provided in the following section.

3.10 Couple interview

To ensure participation from both members of the couple, couple interviews opened with the following question -

"Who normally does the talking when you are at the doctors or the hospital?"

Their answer was followed by the next statement –

"Well for my purposes, it may be that I ask 'X' specific questions, will that be alright?"

A list of questions/areas to be covered used in the first interview is listed in Appendix 6 (couples with children) and Appendix 7 (couples without children).

All couples were asked the following question –

"When did you first realise that you were experiencing difficulties conceiving naturally?"

Everybody had unique experiences so some aspects may not have been captured during the interview. In order to account for the possibility that some essential or interesting information may not have been discussed, each interview ended with the following question -

"I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or are there any questions that you are surprised I have not asked and would like to discuss?"

Finally, all couples were thanked for sharing their experience with me and were asked whether they had any questions.

3.11 Individual interview

To establish how the participants were finding the experience of talking about such a sensitive issue and how this may impact on the process and in which ways (Lee,1993) the following question was asked at the beginning of individual interviews -

"How did you find talking to me previously about your experience?"

It was explained to each participant that although they have gone through the infertility process as a couple, the purpose of the individual interview was to access their own unique, personal experience throughout the process. They were once again assured of confidentiality.

The next question was –
"How has your experience of infertility/difficulty conceiving affected you?"

Questions/areas to be covered used in the first interview can be found in Appendix 8 (for individuals with children) and Appendix 9 (for individuals without children).
As with the couple interviews each individual interview ended with the following question –

"I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or are there any questions that you are surprised I have not asked and would like to discuss?"

Finally, participants were thanked and were asked if they had any questions.

CHAPTER 4

Data Analysis

Overview

A step by step guide of the analysis process is presented in this chapter, using an example from the 'female' data set. The analysis outlined was carried out on each data set - male, female and couple. The process is described in 'stages' for purposes of illustration however it was not a linear process as different stages of analysis were operating in tandem. There was a constant interplay between data analysis, collection and the developing model. An example of the analysis process taken from the female data set can be found in Appendix 10.

4.1 Stage 1 – Open coding

Given the volume of interviews being conducted - 18 in total I decided to use the actual recordings as my permanent record and I initially analysed directly from them. This technique results in less data reduction and decontextualisation of speech, such as occurs when working from solely written transcripts (Pidgeon & Henwood, 1998). A key advantage of using digital recording equipment such as mini discs is the opportunity to place electronic markers at key places on the recording rind to be able to rapidly and repeatedly return to the same section to replay it.

Analysis began immediately after the first interviews (Strauss & Corbin, 1998). I listened to the male, female and couple interviews once without making any notes. At this stage I was interested in getting an overall sense of the data, observing what tone was used and when, comparing interviews with notes taken during interviews regarding observed body language that accompanied comments and what impact my questions had on participant responses.

On second listening I started open coding of the data (Strauss & Corbin, 1998). I stopped the disc every few seconds and considered what the participant was saying then 'coded' it. Each interview had a record which included the location (time) on the disc of the

comment being coded, the participant interview code and the label code. An example is provided in the following, data codes are shown in bold:-

9-8.34 (Code = participant 9, location on disc- 8 minutes 34 seconds)

I understand the processes of grieving **[grieving process]**, I mean I was very fortunate that I did have a pregnancy **[fortunate to have been pregnant]** that I could point to and that I could grieve about **[pregnancy as focus for grief]** and acknowledge **[significance of pregnancy]** and all sorts of things **[pregnancy means many different things]** that is more than many people have **[pregnancy not taken for granted]**. I mean I suppose for me...

9-8.49

...I think the clinic that I was at were **[sense of dealing with 'clinic' not individual people]** just fantastic **[positive experience at clinic]** going above and beyond to **[a concerted effort]** make you feel like a person **[feel like a person]** and I think that made a huge difference **[clinic reaction influences patient experience]**. And they never let you feel **[others ability to influence how you feel]** as if you had failed **[failure]**, never ever, they were very good **[positive experience]**.

4.2 Memos and diagrams

Memos and diagrams were kept throughout the analysis and formed a key part of the process (Strauss & Corbin, 1998). They served a number of functions. In brief they provided a record for ideas and hunches, represented relationships between concepts, guided theoretical sampling and helped to organise the vast amount of data. Storyline memos formed the basis for writing the storyline when it came to integrating the final categories (Strauss & Corbin, 1998). All memos and diagrams were dated, noted participant and disc location codes, given a title and any other relevant information.

The following is an example of 2 memos written for the data coded 9-8.34:-

MEMO – 9-8.36, 12/2/04. 'FEMALE'

GRIEF – related concepts = failure, pregnancy, communication.

It seems that miscarriage provides a focus which allows grief to be expressed.

There is a suggestion that a miscarriage legitimises the feelings of grief that were present in response to the infertility prior to falling pregnant. What do females who do not become pregnant do with these feelings of grief? Based on the other female interviews it seems that the feelings are not shared readily with others. How does this relate to the concept 'failure' – do females that have a pregnancy 'to point to' feel they have more of a right to grieve or that are they more comfortable because they have 'been pregnant'?

MEMO – 9-8.36, 12/2/04. 'FEMALE'

PREGNANCY - related concepts = failure, feeling grateful, isolation, hope

It seems that the experience of pregnancy is highly valued and not an experience that the infertile female has the luxury of taking for granted. This seems linked to the theme of 'being grateful'. There is also a suggestion that a pregnancy means a number of different things. What might these unsaid things be?

- Feeling like a 'woman'
- Experiencing the symptoms of pregnancy 'like other females'?
- Evidence that body is not a 'failure'
- Hope that they will fall pregnant again
- Acceptance
- Inclusion

NB - Need to consider these ideas further

4.3 Stage 2– Development of categories and subcategories

Initial analysis of the 'female' data (first 2 interviews) yielded 41 concepts. Constant comparative analysis was used to examine the similarities and differences of codes and concepts both within and between the 2 cases. Comparisons were also made with the couple and male data. 11 tentative categories were generated. At this stage all data feeding into developing categories were transcribed. File cards with tentative category labels were created, these were - failure, grief, hope, communication with partner, communication with others, isolation, loneliness, pain, anger, not feeling understood and need for a child. The variation across line codes within each category led to formation of

subcategories. For example the concept of 'failure' repeatedly appeared in both interviews. However, 'failure' was talked about in similar and different ways.

For example:-

The comment below led to the subcategory **'Failure as a female'.**

1.24.05 *"There's an expectation that as a woman that is what you do (have babies) and for some reason I couldn't."*

The comment below led to the subcategory **'Body as failure'.**

1-11.23 *"I needed to know why my body was failing me"*

The comment below led to the subcategory **'Failure as a person'.**

3.4-7.25 *"I was not used to failing, I took it as a personal failure (not falling pregnant)".*

Comparisons with new data resulted in development of additional subcategories.
For example:-

The comment below led to the subcategory **'Failing others'.**

6-21.01 *"I really hate to let people down, and this (not falling pregnant) is part of that".*

4.4 Stage 3 – Axial coding

Axial coding is the process of relating categories to subcategories along the lines of their properties and dimensions (Strauss & Corbin, 1998). At this point each tentative category title was laid out on a clear surface along with the relevant subcategory labels. All codes were manually allocated to subcategories. This process led to the act of collapsing the 11 tentative categories into 8 categories and promoted the development of more subcategories. Data was collected and coded until categories were 'saturated' (Glaser & Strauss, 1967). Saturation is reached when the coding of data does not yield any new properties or dimensions that add variability to categories. No new categories emerged after the initial 4 sets of interviews. As interviews had already been arranged

with the 2 final couples I continued with data collection and analysis until categories were saturated.

4.5 Stage 4 – Selective coding

This stage is characterised by the process of integrating and refining the model (Strauss & Corbin, 1998). The aim was to build a model that accounted for the male and female experience and how this impacted on the couple. Only categories that specifically related to the overall model were included.

A core concept had emerged which had more codes and subcategories than any other category. The core category for females was **'SENSE OF ISOLATION'**. At this stage the other categories were organised in terms of their relationship with the core category. 3 of the female categories were directly related to the core category – **sense of failure, overwhelming desire for a child** and **emotional response.** The female model of the infertility experience demonstrating the relationship between categories is presented and discussed in chapter 5.

4.6 Credibility of current research

The criteria by which qualitative research is assessed in terms of reliability and validity differ from those used to assess quantitative research. The assumption underlying quantitative research is that there is an objective reality and scientific methods can lead to accurate models of that reality (McLeod, 1996). In contrast qualitative research is based on subjective individual, unique accounts regarding the object of study. A number of researchers (e.g. Strauss & Corbin, 1990, 1998; Henwood & Pidgeon, 1992; McLeod, 1996) recommend that to demonstrate reliability and validity of a piece of qualitative research procedures followed in data collection and analysis need to be clearly outlined and explained. This is in addition to the role of researcher reflexivity (McLeod, 1996). As discussed previously (Chapter 2) I comment on my role and what I bring to the research process at appropriate points throughout.

Steps were taken both during and following the analysis process to demonstrate the credibility of the research. This was done in the following ways:-

- *Respondent validation*

During data collection as concepts and categories were being developed their validity was checked with participants. This involved going back to participants to clarify their previous account and/or to ask specific questions relating to concepts. I also checked out how developing concepts fit with their personal experience. Future participants were asked about their experience in relation to emerging categories.

- *Independent judgement*

Once the model had been developed an independent judge (a counselling psychologist colleague who is not familiar with the field of infertility) was invited to allocate codes to the subcategories of each of the final categories. The aim of this was to rectify instances where there may have been bias and to ensure that codes were allocated appropriately.

- *Documentation*

A record of what was done, when it was done and why it was done has been presented in this chapter. In addition a list of all categories and subcategories developed for the male experience, female experience, impact on the couple, overall infertility experience can be found in Appendices 10-13. A definition of each category based on how it was arrived at is provided. All statements pertaining to each subcategory are included. This permits traceability of themes back to the data source.

- *Transferability*

Following analysis I spoke with two new couples experiencing difficulties conceiving. The infertility experience as described by these couples seemed to fit well with the model. Furthermore on seeing the model they reflected that it accurately mirrored their overall experience. This suggests that the findings of the present study are relevant and applicable to others going through the experience of infertility beyond the present sample.

STUDY 1: FINDINGS & DISCUSSION

Overview

The findings and discussion section for Study 1 is comprised of five chapters:-

- Chapter 5 – The female infertility experience.
- Chapter 6 – The male infertility experience.
- Chapter 7 – Male and female experience of infertility: impact on the couple.
- Chapter 8 – The overall infertility experience.
- Chapter 9 – General discussion and conclusion.

Chapters 5, 6, 7 and 8 include the following:-

- A figure of the model under discussion.
- A section on category development.
- Comments taken from the actual interviews pertaining to the core category.
- A summary of the infertility experience under discussion e.g. female experience.
- Critical reflection and discussion.

Chapter 9 includes:-

- A general discussion and conclusion of Study 1.

All research categories developed in relation to each experience are briefly outlined in the relevant chapter. Data from interviews are used to illustrate core categories. Full descriptions of all categories and their subcategories complete with comments taken from the interviews can be found in Appendices 10-13.

CHAPTER 5

FINDINGS & DISCUSSION 1: The Female Infertility Experience

Overview

This chapter comprises the following sections:-

- Model of the female infertility experience (see Fig. 1).
- Category development – female infertility experience.
- Summary of the female experience of infertility.
- Critical reflection and discussion.

Figure 1. The Female Infertility Experience

PRE-ACTIVE INFERTILITY

'Wanting a baby'

- Desire to have a child
- Actively trying to conceive
- Not falling pregnant - visit GP

ACTIVE INFERTILITY STAGE

The psychological and emotional impact

Overwhelming desire for a child

Sense of failure

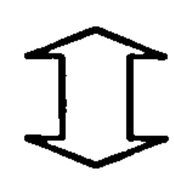
- Failure as a female
- Body as failure
- Failure as a person
- Failing others

Emotions

- Grief
- Pain
- Anger

SENSE OF ISOLATION

- Not feeling understood/supported by partner
- Not feeling understood/supported by others
- Awareness of male's ambivalence
- Loneliness
- Isolation when friends/family have children



IMPACT ON COUPLE RELATIONSHIP = DISTANCE

POST-ACTIVE INFERTILITY

'Moving on'

Becoming a mother

- Happy
- Complete
- Normal

Facing future without children

- Process of acceptance
- Consider new direction for future
- Grieving

Perkins, J. (2006)

5.1 Category development: The Female infertility experience

No females interviewed were located in the Pre-Active Infertility Stage thus none of the categories developed for females were assigned to this stage. Six categories relating to the psychological and emotional impact of the female infertility experience were developed. Four were assigned to the Active Infertility Stage. Two were assigned to the Post-Active Infertility Stage. Full descriptions of all categories and their subcategories complete with comments taken from the interviews for the female infertility experience are listed in Appendix 11 and are outlined below. Comments are identified as to whether they were made by a male or female.

ACTIVE INFERTILITY STAGE

CORE CATEGORY: SENSE OF ISOLATION

A key theme that emerged was how 'alone' females felt going through the infertility experience. The female experience is characterised by an intense state of isolation from her partner, friends and family. The core category for females 'sense of isolation' was formed. Overall, females feel unsupported and misunderstood. Five subcategories demonstrate the way in which this sense of isolation is contributed to by different people and situations in their lives. Subcategories are presented below:-

Subcategory of 'Sense of Isolation':- Not feeling understood or supported by partner

Throughout the experience there is strong sense that the female feels that her partner does not understand the pain she is feeling or her need to have a child. This results in her feeling unsupported within the relationship.

Interviewee Comments:-

7.8-49.01 *I am not feeling understood by x, I need support to deal with this (accepting that they are not going be have children) (Female)*

1-29.05 *I wanted sympathy from him, I needed hugs and for him to just listen to*

how I felt, I didn't get that. (Female)

Subcategory of 'Sense of Isolation':- Not feeling understood or supported by others

The female goes through the infertility experience with the sense that no-one understands what she is going through. The focus extends from partner to general 'others'. As a result the female can feel unsupported on every level and as if she is going through the experience alone.

Interviewee Comments:-

1.2-47.04 *No-one really understood, so I really felt like I went through it without support (Female)*

9-23.31 *Family all of a sudden stop asking you what is happening and you feel all at sea (Female)*

6-45.13 *People don't ask you what's happening but you want them to, you want to talk to them about what is happening they need to understand (Female)*

Subcategory of 'Sense of Isolation':- Isolation when others have children

Feelings of isolation can be compounded when friends and family have children. Once friends have children the dynamic between them changes. Discussions about the experience of labour and having children coupled with changing social situations can feel excluding. In the absence of the motherhood experience a divide is created which further isolates the childless female.

Interviewee Comments:-

9-17.42 *It's very isolating, there are things you can't join in on, for example pregnancy and labour stories. You can't contribute, that feels awful. (Female)*

7-35.13 *You can't join in when your girlfriends are talking about labour and being mums. (Female)*

Subcategory of 'Sense of Isolation':- Awareness of male pragmatic ambivalence

The female has a strong sense that her desire for children is not matched by her partner. Although it may not have been discussed the female is acutely aware of the male pragmatic ambivalence towards children and as a result IVF treatment. This further contributes to the sense of going through the experience seemingly alone and often feeling misunderstood.

Interviewee Comments:-

9-52.34 *I felt that he could live without children (Female)*

1.2-39.33 *I felt he couldn't give a toss about the IVF or having a baby. (Female)*

7-37.23 *His need has never been as strong as mine, at times it was like he didn't even want children. (Female)*

Subcategory of 'Sense of Isolation':- Loneliness

The female infertility experience is on the whole a lonely one. Not feeling understood, feeling unsupported and being infertile when combined contribute to a sense of aloneness.

Interviewee Comments:-

6-25.43 *I've felt so alone at times it's unbearable (Female)*

1.2-46.30 *I didn't feel like I had any support at all, it was very lonely. (Female)*

The next three categories presented all link to the core category 'sense of isolation'.

CATEGORY: AN OVERWHELMING DESIRE FOR A CHILD

Females talked passionately about their need or desire for a child. The way that the females talked about this need or desire suggests that it can be overwhelming and pervasive. Over time the goal of having a child becomes the total focus for the female. The need/desire seems to increase as the chances of having a child reduce. This led to the formation of the category 'overwhelming desire for a child'.

CATEGORY: A SENSE OF FAILURE

Female discourse, regardless of location on the infertility continuum e.g. trying for two years or after ten years of treatment, contained references to 'failure'. The fact that all females made reference to feeling like a failure suggests that the sense of failure is present throughout the whole infertility experience. This led to the formation of the category 'sense of failure'. The sense of failure is multi-layered. It is both global and specific. The following four subcategories were developed from analysis of this category:-

- **Failure as a female** A widely held assumption is that a female should be able to have a child biologically. This assumption seems to gives rise to a belief held by females experiencing infertility that if a female can not have a child then she is a 'failure'.
- **Failure as a person:** The infertility experience impacts on the sense of self. This sense of failure as a person is acknowledged by the female as being largely generated by herself rather than imposed by others.
- **Failing others:** The female feels that she has failed others by not providing a child. Those that she feels she has failed extends to partner, family and other people close to the female.
- **Body as failure:** The female feels let down by her own body. Just as she feels that she is a failure as a female, a person and that she has failed others, she feels that her body is failing her in her quest to bear a child.

CATEGORY: EMOTIONAL RESPONSE

A range of emotion was expressed in response to the infertility experience. This led to the formation of the category 'emotional response'. Three responses were repeatedly expressed. This led to the formation of the following three subcategories:-

- **Anger:** Anger experienced in relation to the issue of infertility tends to be expressed in a general sense e.g. irritability with others, general bad mood.
- **Pain:** The infertility experience is talked about as a painful one for the female. This emotional pain can be so intense it can manifest physically at times.
- **Grief:** The experience of not having a child can induce a grief reaction. The feelings experienced in response to not falling pregnant / having a baby are

characteristic of feelings related to bereavement. The expression of this grief is facilitated when there is an actual pregnancy resulting in miscarriage to focus on.

POST-ACTIVE INFERTILITY STAGE

Two categories signify the end of the Active Infertility Stage. One is 'becoming a mother' either by falling pregnant or via adoption / surrogacy. The other is 'facing a future without children'.

CATEGORY: BECOMING A MOTHER

Females that became mothers talked about how this had brought about a change in their emotional state. There were three key ways in which females talked about how becoming a mother made them feel leading to the following subcategories:-

- **Feeling happy** The female that has a child/children talks about feeling happier since becoming a mother.
- **Feeling complete:** The female that has a child/children talks about feeling complete since becoming a mother.
- **Feeling normal:** Females expressed feeling normal since becoming mothers.

CATEGORY: FACING A FUTURE WITHOUT CHILDREN

When fertility treatment stops and has been unsuccessful the female faces a future without children and the reality of that she is not going to become a mother. A female in the sample had reached this particular point. Three subcategories were developed:-

- **Process of acceptance:** At this stage the female facing the future without children talks about starting the process of accepting that she is not going to have a child or be a mother. This suggests that until the point at which it becomes clear she is not going to have children she does not give up hope of having a child.
- **Grieving:** For the female facing the future without children, the process of accepting that they are not going to be a mother, feeds into the grieving process that starts during the active infertility stage.

- **Looking for a new direction in life:** In the face of a future without children the female talks about wanting to find a new direction in life now she is not going to be a mother that will fulfil her emotionally.

5.2 Summary of the female infertility experience

Based on those females that took part, females have a desire for a child which increases as the possibility of having a child reduces. This desire can become overwhelming. Not becoming pregnant can evoke a sense of failure and feelings of anger are experienced along with pain and grief. Overall females feel an intense sense of isolation from their partners and others. The female that did not become a mother following treatment had embarked on a process of acceptance and was continuing with the grieving process that started in the Active Infertility Stage. She was also looking for a new direction for the future. Females that did become mothers felt complete, happy and normal.

5.3 Critical reflection and discussion

The difference between the emotional states of females who became mothers and those who had not was apparent during interviews. The most emotionally charged interviews were with females who did not have children, both of whom expressed extreme emotion and were tearful. The pain in the room was palpable. It was difficult to obtain an in depth verbal account of how the females felt about the prospect of not having children, given the pain they were experiencing. I did not feel it was appropriate or ethical to pursue the issue further than I did e.g. by asking how they felt about the prospect that they may not become a mother. It was apparent in the emotion conveyed and the account of their experience of the infertility process that the prospect/reality of not having children was devastating.

In contrast females who became mothers were less emotional when recalling how it had felt for them at each stage of the infertility process. The emotion was readily accessible and clearly not forgotten. The arrival of a child either biologically or via adoption had healed a lot of the pain experienced throughout the infertility process. Overall females reported feeling happier since becoming mothers. Leiblum *et al.*, (1998) also found the contrast identified in the present study between females who have children with those who have not. For example, Leiblum *et al.*, (1998) carried out a long-term investigation

of marital and sexual function with 75 infertile females and found that females who became biological mothers through IVF were significantly more satisfied with their lives than females who were unsuccessful in IVF and remained childless. Findings from this study indicate that becoming a mother regardless of the method may contribute to increased life satisfaction. More research is required to establish this and whether there is a difference between those females who become biological mothers and those that become mothers via an alternative method e.g. via surrogacy or via adoption.

Grief as an emotional response is recognised as being one of the key emotions for females experiencing infertility issues (Crawshaw, 1995; Read, 1995). Models of grief counselling e.g. Kubler-Ross (1973) and Worden (1991) can provide a counselling framework when working with those going through the infertility experience (Read, 1995). It is often a loss which precipitates the counselling process (Crawshaw, 1995). This was the case for females interviewed who received counselling. However, not all females have a miscarriage or another bereavement that can 'legitimise' or provide a 'focus' for their feelings of grief relating to the infertility experience. Consequently they may not feel that their needs 'justify' counselling. Counselling perceptions and experiences are addressed in Study 2.

The majority of females interviewed were professionals with careers. They were used to achieving what they set out to do and getting what they wanted during the course of their careers. This was a key factor that heightened their sense of failure throughout the infertility experience. Interestingly, the only female that did not have a career and was the youngest in the sample (28 years) was the only one that did not report feeling like a failure in any way. She had a close family whom she saw regularly, spoke openly with and felt supported by. The female's sense of failure as the 'infertile' member of the couple is acknowledged in the literature (e.g. Read 1995; Crawshaw, 1995). This sense of failure is also reportedly experienced by 'infertile' males (Mason, 1993; Read 1995; Pengally, 1995).

Career females were in their thirties when they started trying for children. Prior to trying to conceive, being part of the ingroup 'career woman' was considered a positive social identity by each of them (Tajfel & Turner, 1986). It was found that when they reached

their early thirties, membership of the alternative group e.g. the outgroup 'mothers' started being considered more positively than membership with the ingroup 'career woman'. For many females there is likely to be an assumption that they can either 'choose' to trade in their current 'membership' or add to their current membership and join the group 'mothers', as a function of biological makeup. Significantly for those females going through the infertility experience, this is not the case and as a result their positive self-image can be negatively affected. For example, Miall (1985) found that those females who are mothers often treat females who are 'disqualified', as a function of infertility (either theirs or their partners), from the ingroup 'mothers' as second-class citizens who cannot contribute to conversations about children. This can further contribute to female sense of isolation. In her studies of pregnancy and motherhood Zajicek (1979, 1981) found that 'choice' becomes a major factor in influencing positive self-image. She found that females who had unplanned pregnancies were more likely to have lower self-esteem and less positive feelings for their babies. This suggests that there would be different perceptions of self-image between females who have 'chosen' not have children and those who would like to have children.

Moreover, as friends and family transfer and/or add to their memberships from the 'career' group to the 'mother' group this can add to feelings of isolation for the female who has not conceived, as relationships start changing between the members of the two groups (Baker, 1989). This was found in this study. It seems that for those females wanting to conceive, the 'mother' group elevates in status and the 'career' group becomes associated with lower status and prestige. As a consequence of not gaining membership and hence entry into the higher status group a less positive self-identity ensues (Tajfel & Turner, 1979). In addition, given their professional position females spoke about not feeling as if they could share their experience freely with work colleagues, further contributing to feelings of isolation.

Read (1995) highlights how females can feel resentful about the treatment and the infertility experience in general. Consequently they can feel 'angry' and 'distressed' which their partners are unable to cope with. This can leave the female feeling abandoned, thereby increasing her sense of isolation. This was found in this study.

Infertile males also report feelings of isolation whilst going through the infertility experience (Mason, 1993).

5.4 Summary and conclusion

The key characteristic of the female infertility experience is a sense of isolation from friends, family and society. The experience can impact negatively on self-esteem and identity. A number of factors interact and contribute to this sense of isolation, aloneness and low self-esteem. Females seem to be acutely aware that their male partner is ambivalent towards having children and becoming a father. This is in contrast with her, at times overwhelming, desire for a child. This creates a distance between them. Furthermore, as a function of her childlessness the female is excluded from the ingroup 'mothers' and can be excluded from conversations and activities with this group as result (Miall, 1985). Females were also found to experience a sense of failure, which can impact negatively on their self-esteem and sense of identity. The female infertility experience is characterised by feelings of anger, grief and pain. These emotions are distressing in their own right, yet they also seem to compound the sense of isolation and aloneness as the female can feel misunderstood by her friends, family and partner and distant from them emotionally. Findings revealed that the infertility experience is emotionally, psychologically and physically devastating for the female. This finding is widely supported in the literature (e.g. Greil, 1997, Read, 1995, Gibson & Myers, 2000).

CHAPTER 6

FINDINGS & DISCUSSION 2: The Male Experience of Infertility

Overview

The chapter is arranged in the following sections:-

- Model of the male infertility experience (see Fig. 2).
- Category development – male infertility experience.
- Summary of the male experience of infertility.
- Critical reflection and discussion.

Figure 2. The Male Experience of Infertility

PRE-ACTIVE INFERTILITY

'Time to start a family'

- Decision to have a child
- Actively trying to conceive
- Partner not falling pregnant – partner visits GP

ACTIVE INFERTILITY STAGE

The psychological and emotional impact

Non Expression of feelings | **Compliance** | **Experience perceived as easier for male** | **Feelings of Inadequacy** | **Feeling marginalised**

PRAGMATIC AMBIVALENCE

- Ambivalence towards being a father
- Ambivalence towards having children

IMPACT ON COUPLE RELATIONSHIP = DISTANCE

POST-ACTIVE INFERTILITY

'Moving on'

Fatherhood
- Satisfaction

Facing future without children
- Acceptance

Perkins, J. (2006)

6.1 Category development: The Male infertility experience

No males interviewed were located in the Pre-Active Infertility Stage so none of the categories developed for males were assigned to this stage. Eight categories relating to the psychological and emotional impact of the male infertility experience were developed. Six were assigned to the Active Infertility Stage. Two were assigned to the Post-Active Infertility Stage. Full descriptions of all categories and their subcategories complete with comments taken from the interviews for the male infertility experience are listed in Appendix 12. These are outlined below. Comments are identified as to whether they were made by a male or female.

ACTIVE INFERTILITY STAGE

CORE CATEGORY: PRAGMATIC AMBIVALENCE

As males spoke about wanting a family or children their attitude toward fatherhood and children was balanced and matter of fact. This suggested their feelings could go one way or another e.g. happy if they become fathers and disappointed if not. This led to the development of the core category for males 'pragmatic ambivalence'. Males spoke about being a father and having children hence two sub-categories were created – 'pragmatic ambivalence towards being a father' and 'pragmatic ambivalence towards having children'. These sub-categories are closely related but with subtle differences.

Subcategory of 'Pragmatic ambivalence':- Pragmatic Ambivalence towards fatherhood

In response to the question regarding how they felt about the idea/reality that they may not be a father or have more children, males were pragmatic and did not express strong emotion. They reflected that they had not given a great deal of thought to the prospect of fatherhood and this seems to be directly related to their pragmatic emotional response.

Interviewee Comments:-

10-3.34 *Fathering children has never been a really big thing for me (Male)*

8-5.45 *My desire for being a dad was not as strong at the beginning, in fact when I think about it, I have never really thought too hard about, I'm not gutted that I won't be a dad (Male)*

5-6.30 *I don't think oh dear, if I don't have kids I don't what it'll do to me, I just don't feel like that. (Male)*

Subcategory of 'Pragmatic ambivalence':- Pragmatic Ambivalence towards children

Pragmatic ambivalence towards children is related to the physical presence of children.

Interviewee Comments:-

1.2-35.45 *I was probably quite blasé about it all (having a baby/IVF), if I'm honest I didn't really care if we had another child or not (Male)*

1.2-36 *This is probably going to sound awful, but I can remember distinctly thinking I really don't think I want to go through all this shit (IVF) to have kids. (Male)*

12-2.43 *There were times when I felt very frustrated, I remember asking myself if I really wanted another kid (Male)*

CATEGORY: COMPLIANCE

Males discussed how they had acquiesced to the treatment process even when they had grave doubts about doing so. This led to the development of the category 'compliance'.

CATEGORY: NON-EXPRESSION OF FEELINGS

Males said they made a conscious effort to not express their thoughts or feelings about the issue of infertility or the treatment process to their partner. This led to the development of the category 'non-expression of feelings'.

CATEGORY: INFERTILITY EXPERIENCE CONSIDERED 'EASIER' FOR THE MALE

This category was formed based on a number of references made by males about the infertility experience being physically and emotionally 'tougher' for the female and hence 'easier' for the male.

CATEGORY: FEELINGS OF INADEQUACY

Males talked about feeling helpless and not able to 'fix' the situation. There was a sense of the infertility experience rendering the male 'inadequate' which led to the formation of the category 'feelings of inadequacy'.

CATEGORY: MALE FEELS MARGINALISED

Males talked about feeling as if they had been overlooked during the infertility experience. This led to the development of the category 'Male feels marginalised'.

POST-ACTIVE INFERTILITY STAGE

Two categories signify the end of the Active Infertility Stage.

CATEGORY: FATHERHOOD

Males that became fathers regardless of method e.g. naturally, via IVF or adoption, talked about feeling a sense of satisfaction at becoming a father and having children.

CATEGORY: FACING A FUTURE WITHOUT CHILDREN

For males facing a future without children the experience is primarily characterised by acceptance and a need to move on. Males talked about being able to accept that they are not going to have children.

6.2 Summary of the male infertility experience

Males who participated have a 'pragmatic ambivalence' towards fatherhood and children. They adopted a compliant position in relation to treatment and did not express their feelings about the treatment process or how they felt about having/not having children, to their partner. The infertility experience tended to leave them feeling marginalised. Males perceived the infertility experience as more difficult for females and in turn felt a sense of inadequacy. Males that became fathers reported feeling satisfied whilst the

male that had not become a father reported that he had accepted this and was ready to move on. A male was still in the early stage of the infertility process and had not reached the Post-Active Infertility Stage.

6.3 Critical reflection and discussion

The male 'need' or 'desire' to become a father seems to be qualitatively different to that of the female's need or desire to become a mother. This could relate to the fact that fatherhood is not considered as central to male identity as motherhood is to female identity, as traditionally work plays a key role in male identity development (Crawshaw, 1995). As males talked about the possibility that they may not be a father or have another child there was a stark difference in their reaction compared to the reaction of the females to the same question. In particular, no male became tearful or verbally expressed strong emotion.

'Pragmatic ambivalence' may be explained to some extent by the fact that fatherhood is not central to male identity (Crawshaw, 1995) and in part to biological makeup (Mason, 1993). Pragmatic ambivalence influences the ways in which the male responds during the Active and Post-Active Infertility Stages in a number of different ways. It seems that pragmatic ambivalence toward fatherhood and children coupled with an awareness of how important having a child is to the female seems to influence the compliant position the male adopts in relation to treatment. Through non-expression of feelings the male complies with the female's decisions in relation to treatment options. Compliance is closely linked with non-expression of feelings. As males do not communicate their concerns regarding treatment they tend to 'go along' with the treatment process. This prompted a question about how they felt about participating in the study. Males admitted that they had 'gone along' with their partner's decision to participate. They also reported that they were pleased as they felt that they had benefited from the experience. Male compliance is likely to have had an impact on data collection, especially in the couple interviews, which took place before the individual interviews and before any benefit was experienced.

Males were asked what it was that made them consciously decide not to express their feelings to their partner during the infertility experience. Responses indicated that non-expression of feelings seems partly to be a function of the fact that the male feels that it is

not fair to add to the pressures on the female. It also seems to be due to males feeling as if they do not have the 'right' to complain when the female is going through 'so much'. Stanton (1991) found that males often cope with their pain by keeping it to themselves and focus on their partners feelings instead. At the same time it was found that females cope with their pain by sharing their feelings with their partners, who feeling powerless to change the situation can stop listening. In turn females can feel isolated and abandoned. This study found the same. Interestingly, it seems that males 'non-expression of feelings' is not restricted to the infertility experience. Studies of interaction patterns between couples reflect the dynamic described by Stanton (1991). These studies have shown that a male's grievances are centered on their partner's complaints and that they respond by withdrawing emotionally, withholding affection and can refrain from disclosing any of their feelings (Fitzpatrick, 1988; Noller & Fitzpatrick; Gottman & Levenson, 1988). Thus non-expression of feelings may not be a function of infertility per se, but given the range of emotions experienced by the males going through the experience this interaction pattern may be exacerbated. Another factor that may be at play here is that in contrast to females, boys and later males are more likely to have their emotional needs met by mothers and sisters, before they even become aware of them. As a result they do not necessarily develop a pattern of recognition, acknowledgement or nurturing of their own or others needs, so can be 'cut-off' from their and others emotional needs (Crawshaw, 1995). When interviews focused on feelings experienced by males during the infertility process males initially responded by saying that they were 'ok' or 'it hasn't been that bad'. With encouragement they started talking about the fact that they did not tend to feel comfortable talking about their feelings with their partner or with others. Interestingly, they appeared to feel uncomfortable admitting that they were not too 'bothered' about having children and actually apologised for and excused their feelings. This may have indicated that there was a perception that as a female, I would be judgemental of this. It would be interesting to see whether the males would talk differently to a male interviewer and if so, in what way. It would also be interesting to see what a sample of males who 'chose' to participate would have disclosed, compared with the present sample who had perhaps to some extent 'complied' with their partners decision to participate. It is not clear from this study whether the males were really 'ok' with the idea of not having children or whether they were 'cut off' from their emotions giving the sense that they were 'ok' (Crawshaw, 1995).

In contrast to many other situations in life males realise that they are not able to 'fix' the issue of infertility. Thus, they become redundant to some extent in their role as 'fixer' in this situation. This can result in feelings of helplessness and being powerless to change the situation. Consequently some males can feel inadequate at times during the infertility experience. This finding of 'feelings of inadequacy' is supported in the literature as a part of the infertility experience for males (Read, 1995).

Males felt somewhat marginalised. This feeling primarily related to the fact that the focus of treatment has to be on the female in the majority of cases, even in cases of male infertility. They talked about feeling left out, overlooked and cut out of the decision making process and the treatment process. Parallels can be drawn between the infertility experience and pregnancy and the arrival of a new baby. Males can often feel marginalised as the focus is mainly on the female and the female's focus is on her potential pregnancy and ultimately the birth of her newborn child. The male can feel excluded as a result of these changes in the relationship (Bee, 1994). In the case of infertility non-expression of feelings and pragmatic ambivalence are likely to contribute males being overlooked or not included in the decision making process, resulting in their feeling marginalised.

Male 'acceptance' of the fact that he may not have children or become a father is a process which appears to have occurred relatively quickly. However, this process of acceptance may have been happening over a period of time. Acceptance seems to be directly linked to the male pragmatic ambivalence towards fatherhood and having children.

6.4 Summary and conclusion

The infertility experience is psychologically and emotionally distressing for males but in quite different ways than it is for females. The key characteristic of the male infertility experience is a pragmatic ambivalence towards children and becoming a father. This ambivalence, when coupled with the distress being experienced by their female partner (see Chapter 5), seems to influence the way in which the male responds to the situation in a number of ways that interact. For example it was found that he can comply with fertility

treatment even though he experiences doubts about it. In addition, there is a tendency not to express his feelings to his partner about treatment or how he is feeling about the infertility issue. It seems this is partly due to wanting to protect their partner from their feelings and partly because they are aware of how important having a child is to their female partner. As a function of this non-expression of feelings, compliance and the medical focus on the female the male can feel marginalised throughout the infertility experience. Males can perceive the experience to be 'easier' for them than for females. They can experience feelings of helplessness in terms of being able to 'fix' the issue. This can in turn lead to feelings of inadequacy. Ultimately, although the infertility experience can be a negative one for males, it was not found to be as psychologically, emotionally or physically stressful as it is for females. This finding is widely supported in the literature (Greil, 1997; Read, 1995, Gibson & Myers, 2000).

CHAPTER 7

FINDINGS & DISCUSSION 3:

Male and Female experience of infertility: impact on the couple

Overview

The chapter is arranged in the following sections:-

- Model of the male and female experience of infertility: impact on the couple (see Figure 3).
- Category development – impact on the couple.
- Summary of the impact on the couple.
- Critical reflection and discussion.

Figure 3. Male & Female infertility experience – impact on the couple

PRE-ACTIVE INFERTILITY

'Planning a family'

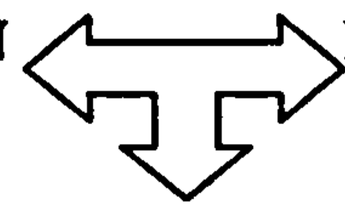
- Decision to have a child
- Actively trying to conceive
- Not falling pregnant – go to GP

ACTIVE INFERTILITY STAGE

LIFE PLANNING FOR THE FUTURE CEASES

The psychological and emotional impact of the infertility experience on the male and female in turn impacts on the couple relationship

FEMALE SENSE OF ISOLATION AMBIVALENCE ⟷ **MALE PRAGMATIC**



IMPACT ON COUPLE RELATIONSHIP

NON-COMMUNICATION ⟷ **DISTANCE**

COMMUNICATION ⟷ **CLOSENESS** ⟶ **GROW STRONGER**

POST-ACTIVE INFERTILITY

'Moving on'

Whether becoming a family or facing a future without children

LIFE PLANNING FOR THE FUTURE RECOMMENCES ⟷ **IF COUPLE STAY TOGETHER THEY EMERGE FROM EXPERIENCE A STRONGER COUPLE**

Perkins, J. (2006)

7.1 Category development: Male and Female infertility experiences: Impact on the couple

The psychological and emotional impact of the infertility experience on the male and female in turn impacts on the couple. No couples interviewed were located in the Pre-Active Infertility Stage so none of the categories developed for the couple were assigned to this stage. Two categories were developed for the impact on the couple and these were assigned to the Active Infertility Experience. Full descriptions of these categories and their subcategories complete with comments taken from the interviews for the impact on the couple of infertility experience are outlined in Appendix 13 Comments are identified as to whether they were made by a male or female.

CORE CATEGORY: IMPACT ON COUPLE RELATIONSHIP

The couple relationship is affected in different ways at different points of the infertility process. The core category for impact on the couple is 'Impact on couple relationship'. The impact of the infertility experience on the couple relationship has been broken down into 3 subcategories – 'distance', 'growing closer' and 'growing stronger'. Couples do not progress through these stages in a linear fashion. They tend to oscillate between closeness and distance throughout the infertility experience. At the same time they talk about growing stronger during the whole experience. Ultimately, providing the couple stays together throughout the Active Infertility Stage, it is likely that they will emerge from the experience 'stronger'.

Subcategory of 'Impact on the couple relationship':- Distance

Male pragmatic ambivalence and female sense of isolation interact resulting in distance between the couple. This distance can be triggered by a specific event such as a failed IVF attempt or more discreet factors e.g. knowing that they were not feeling the same about having a child, the female feeling unsupported, and the male feeling that he was being overlooked and/or not wanting to express his feelings.

Interviewee Comments:-

1.2-47.45 *We weren't reading off the same page of the hymn book, there was a divide. (Male)*

7.8-41.34 *Without doubt the intimacy between you changes, there's a big distance at times. (Female)*

Subcategory of 'Impact on the couple relationship':- Growing closer

Couples talked about times when they grew closer. Different factors can trigger a period of closeness for the couple e.g. realisation that they have only each other, periods of planning for a baby and hope that they will have a baby.

Interviewee Comments:-

3.4-6.20 *You realise that if it's only going to be the two of you, you need to be there for each other and support and love each other, so you become closer. (Female)*

5.6-35.48 *We've made a conscious effort to do things together, spend time with each other since this (fertility issues) all started. (Male)*

1.2-32.15 *Initially it brought us closer but it's all been so stressful, so it goes in cycles. (Female)*

Subcategory of 'Impact on the couple relationship':- Growing Stronger

Couples talked about their relationship growing stronger. They all reflected that they had become 'stronger' as a result of the process. Given the differing locations of the sample on the infertility continuum and the recurrent periods of distance followed by periods of closeness experienced this suggests that the couple becomes cumulatively stronger with the infertility process, even if they do not recognise this as the case at the time.

Interviewee Comments:-

4-16.22 *You don't come out of this experience unscathed, but we are lucky because it brought us together, and now we are stronger but it can make or break you (Female)*

12-11.39 *It's definitely made us stronger overall, but it's been so hard. (Female)*

7.8-37.50 *We've stayed together despite not being able to have children and we're stronger now. (Male)*

CATEGORY: COMMUNICATION BETWEEN COUPLE

Changes in the couple relationship were reflected in the pattern of communication between them. 'Communication' relates to communication about the infertility issue and in general. There are periodic breakdowns in communication. This led to the development of the category 'communication between the couple'. Periods of 'closeness' are characterised by communication. Appointments relating to the infertility issue (e.g. medical appointments) can act as a trigger for communication between the couple. Periods of 'distance' between them are characterised by non-communication. This finding led to the following two subcategories:-

- **Communication:** The couple tend to avoid discussion of the actual issue. Hence communication is affected and can actually break down at any given stage.
- **Non-communication:** Non-communication about the issue of infertility and related factors is disrupted when an appointment is pending. Thus appointments tend to trigger a period of communication as they provide a focus for the discussion around the issue. As a result they can serve as a joiner for the couple.

7.2 Summary of the impact on the couple

Female 'sense of isolation' combined with male 'pragmatic ambivalence' impacts on the couple by creating a distance between them. Distance between the couple affects communication and it can break down. Couples move between periods of distance and closeness. Periods of closeness are characterised by communication with each other. Appointments (e.g. medical) can also trigger a period of communication. Couples grow stronger with each period of closeness. Couples that stayed together emerged 'stronger' as a result of the experience.

7.3 Critical reflection and discussion

During 'couple' interviews, females and males talked about their experience seemingly freely. There were subtle differences in the way that females and males spoke about their experience in individual interviews compared to couple interviews. In individual interviews females used language that was stronger and expressed more emotion. Males

were more open about their 'ambiguity' towards children and fatherhood as well as other feelings e.g. feelings of inadequacy. One factor contributing to this could be that trust had been established in the couple interview in terms of speaking about the infertility issue. Alternatively, it could be because they either felt more comfortable talking without their partner being present (or more vulnerable without their partner in the case of females). The possible influence in male interviews of male 'compliance' and my being a female was discussed in chapter 6. The dynamic of restrained communication in the presence of each other reflects the category 'non-communication' to some extent. If individual interviews had not been conducted this dynamic would not have been observed. This could have implications for couple counselling in relation to the infertility issue. For example it indicates that individual sessions as well as joint sessions would be beneficial when working with the infertility issue. Counselling and infertility is addressed in Study 2.

Strain on the couple relationship was also apparent. The negative impact on the relationship of those going through the infertility experience is widely acknowledged (Salvatore *et al.*, 2001; Levin & Sher, 2000; Greil, 1997; Kumar & Leo, 2003; Leiblum *et al.*, 1998). Leiblum *et al.*, (1998) found that childless females reported that infertility had exerted a significantly greater negative impact on their marriage than those who became mothers. This finding is supported by a female who was facing a future without children. She felt that although they had emerged a stronger couple from the infertility experience, in order to stay together they needed to recover from the experience as a couple and replace the common goal of children with another life goal. The process of changing one's goal structures for the future is recognised as playing an important role in coming to terms with infertility and moving on (Clark, Henry & Taylor, 1991; Cole, 1988; Taylor & Schneider, 1989). Interestingly, this was the only interview that I felt I had to stop as it was moving into the realms of counselling. It was emotionally charged and the different positions between the male and female when 'facing a future without children' were evident e.g. male 'acceptance' and ready to move on and female needing to 'grieve' before being able to move on. These differing male and female experiences throughout the whole infertility experience if not reconciled by the arrival of a child can put intense strain on the couple relationship. This suggests the end of the Active Infertility Stage could be a crucial point for counselling to be offered. Even when treatment is successful

couples interviewed felt that counselling could be beneficial. This is not surprising given that marital problems have also been predicted for those who become parents following infertility treatment (McMahon, Ungerer, Beaurepaire, Tennant, & Saunders 1995).

7.4 Summary and conclusion

The different and at times competing needs of males and females throughout the infertility process can impact negatively on the couple relationship. The key characteristic of the couple experience of infertility is periods of 'distance' and 'non-communication'. This in turn seems to compound the characteristics of the male and female infertility experience e.g. female sense of isolation and male non-communication (see Chapters 5 and 6). Given that the infertility experience can span several years for many couples a consequence may be that the interaction pattern described previously can be amplified and enduring. This contributes to the distress that many couples experience in response to their infertility. The stressful nature of the infertility experience on the couple is widely reported in the literature (e.g. Leiblum & Greenfield, 1997; Burns & Covington, 1999; Greil, 1997; Salvatore *et al.*, 2001; Levin & Sher, 2000; Ow *et al.*, 2003).

CHAPTER 8

FINDINGS & DISCUSSION 4: The overall experience of infertility

Overview

The chapter is arranged in the following sections:-

- Model of the overall infertility experience (see Fig. 4).
- Category development – the overall model.
- Summary of the overall model.
- Critical reflection and discussion.

Figure 4. Overall Model of the Infertility Experience

PRE-ACTIVE INFERTILITY STAGE
Planning a family

- Decision to have a child
- Actively trying to conceive
- Not falling pregnant – female goes to GP

THE FEMALE EXPERIENCE | **IMPACT ON THE COUPLE** | **THE MALE EXPERIENCE**

ACTIVE INFERTILITY STAGE

The psychological and emotional impact of the active infertility stage

Overwhelming desire for child

Failure
- As female
- As person
- Body as failure
- Failing others

Emotions
- Grief
- Pain
- Anger

SENSE OF ISOLATION
- From partner
- From others
- When others have children
- Awareness of mans pragmatic ambivalence
- Loneliness

LIFE PLANNING FOR THE FUTURE CEASES

IMPACT ON RELATIONSHIP
- Distance
- Closeness
- Growing stronger

Non communicatio

Communication

PRAGMATIC AMBIVALENCE
- Toward Fatherhood
- Toward Children

Male feels marginalised

Compliance

Non-expression of feelings

Experience perceived as easier for the male

Feelings of inadequacy

POST- ACTIVE INFERTILITY
Active infertility stage ends with:-
- Pregnancy
- End of treatment
- The decision to face future without children
- Adoption

Becoming a mother
- Happy
- Complete
- Normal

Facing future without children
- Process of acceptance
- Grieving
- New direction for future

Whether becoming a family or facing a future without children
- If couple stay together they emerge stronger

LIFE PLANNING FOR THE FUTURE RECOMMENCES

Fatherhood
- Satisfaction

Facing future without children
- Acceptance

Perkins, J. (2006)

8.1 Category development: The overall infertility experience

Four categories were developed for the overall infertility experience. The core category relates to the infertility experience as a whole. The three remaining categories relate to the different stages of the infertility experience. These categories are briefly outlined. Full descriptions of all categories and their subcategories complete with comments taken from the interviews for the overall infertility experience are outlined in Appendix 14 Comments are identified as to whether they were made by a male or female.

CORE CATEGORY: INFERTILITY AS A LIFE STAGE

Couples talked about the way that the infertility process took over their lives and how the experience changed them as a person. A key theme that emerged is that individuals and as a consequence couples, qualitatively change as a result of their infertility experience, suggesting that the whole infertility experience constitutes a life 'stage'. The core category developed for the overall infertility experience was 'Infertility as Life Stage'.

Interviewee Comments-

12-6.51 *Even when you weren't having treatment it was there, our lives were ruled by it for years, and you come out of the experience a changed person. (Male)*

1-31.44 *Our lives have not been normal for so long, and it feels that we can now start getting things back to normal, but they will never be the same as they were before because we aren't the same. (Female)*

PRE-ACTIVE INFERTILITY STAGE

CATEGORY: DECISION TO HAVE A FAMILY

The Pre-Active Infertility Stage is primarily characterised by the decision to have a family. This led to the formation of the category – 'Decision to have a family'. There are subtle differences in the way couples and the individuals talk about the decision to have a family. From this three subcategories were developed:-

- **The female talks about 'wanting a baby':** The female talks about her decision to have a child as resulting from 'wanting a baby'. As such a female's decision is based on desire rather than a plan.
- **The male thinks in terms of it being 'time to start a family':** Male discourse is related to the 'timing' of having a family.
- **The couple 'plans a family' together:** The couple come together and talk about having a 'family' and then they 'plan' the way forward.

CATEGORY: FEMALE AS ACTIVE AGENT

Females 'took control' of the situation when couples first realised there may be an issue in conceiving. This led to the development of the category 'female as the active agent'. Females take control of the situation in two ways at this stage 1) She initially raises the possibility that there may be an issue conceiving 2) She takes responsibility and goes to the doctor. This led to the formation of two subcategories:-

- **Female as communicator:** The female raises the issue that there may be an issue in conceiving with her partner but waits a while before she does so.
- **Female as responsible agent:** When the female realises that there may be an issue she takes responsibility on herself to take control of the situation. She does not necessarily share this information with her partner.

Transition to the 'Active' Infertility Stage occurs when the GP confirms that there is an issue and the female and/or couple are referred for tests.

ACTIVE INFERTILITY STAGE

The Active Infertility Stage is characterised by activity concerned with finding a solution to the problem. The term 'Active Infertility' for this stage was chosen because the condition 'infertility' is not necessarily eradicated with the arrival of a child or the end of treatment. Moreover if an Active Stage ends with the arrival of a child the process of 'activity' may resume at a later date.

CATEGORY: INFLUENCE ON LIFE PLANNING

Couples made a number of references to how planning for the future had been affected by their infertility. This led to the development of the category 'Influence on Life Planning'. The experience seems to have a significant impact on the couple's ability to plan longer term. The Active Infertility Stage is characterised by 2 influences on life planning which led to two subcategories:-

- **Contingency planning:** When the prospect of not having a common goal of children is considered, life changing plans are discussed, in an abstract rather than concrete way.
- **Suspension of life planning:** The active infertility stage creates a state of 'limbo' characterised by the couple not being able to think or plan beyond the next appointment / monthly period. Thinking and planning for the longer term comes to a halt.

The end of the Active Infertility Stage is triggered by the arrival of a child and/or the end of treatment and the decision to face the future without children.

POST-ACTIVE INFERTILITY STAGE

Planning recommences at the end of the Active Infertility Stage. The third subcategory of 'influence on life planning' pertains to the Post-Active Infertility Stage:-

- **Recommencement of life planning:** It seems that planning recommences with the arrival of children or with the decision to face future without children. This characterises the beginning of the end of the active stage of infertility.

8. 2 Summary of the overall infertility experience

Once a couple decides to have a family they start actively trying to conceive. When they do not become pregnant the female raises the issue with the male prior to visiting her doctor. Transition to the 'Active' Infertility Stage occurs when the GP confirms that there is an issue and the couple are referred for tests. In the Active Infertility Stage a solution to the problem is sought and life planning for the future ceases and/or contingency plans are made. The Active Stage ends with the arrival of a child or at the end of treatment and

a decision to face life without children. Life planning for the future is suspended during the Active Infertility Stage and recommences during the Post Active Infertility Stage.

8.3 Critical reflection and discussion

Development of the concept 'stage' is relevant to the infertility experience because it suggests that there is a change in the quality, identity and characteristics of an individual or couple that transpires as a function of developmental experience (Butterworth & Harris, 1994). Thus it conveys the gravity of the infertility experience for those going through it.

It became apparent when conducting a review of the literature on stage development, that infertility had not been acknowledged. Instead it seems there is an implicit assumption that when an individual reaches adulthood, they will meet a partner and together they will make the transition to parenthood, should they decide to. As Monach (1993) found in his study of infertile couples, marriage perceptions are inextricably linked with expectations of childbearing.
Interestingly, the Active Infertility Stage, during which the individual and the couple identities are in 'crisis', has parallels with Erik Erikson's (1968) 'identity confusion/diffusion' experienced during the 'identity versus role confusion' stage of adolescence. During this stage of adolescence when 'identity confusion' is experienced the individual is struggling with questions concerned with 'who' they are, 'where' they belong and 'where' they are going in life. 'Identity confusion' during this stage, according to Erikson (1968), is characterised by four major aspects. The infertility experience parallels these four aspects as described below:-

- *Intimacy* – adolescents can fear commitment to or involvement in close relationships, which can result in isolation, amongst other things.

  Couples interviewed had already committed to a relationship. They withdrew from the relationship at points, resulting in the female feeling 'isolated' and the male feeling 'marginalised'.

- *Time perspective* – the adolescent experiences as inability to plan for the future or maintain a sense of time, associated with anxieties about change or becoming an adult.

  Couples interviewed ceased planning whilst they focused on their goal to have a baby. This could be due to anxieties relating to being 'childless' as for many infertility couples the goal of having children is highly prized and is intricately linked to higher order goals of fulfilment and happiness (Clark *et al.*, 1991).

- *Industry* – the adolescent experiences difficulty focusing on work or study, both of which require commitment. As a defence the adolescent can frenetically engage in a single activity to the exclusion of others or find it difficult to concentrate on tasks.

  Females interviewed talked about their desire for a baby becoming a major focus for them. The disruption to concentration at work is also recognised as a feature of the infertility experience for males and females (Read, 1995).

- *Negative identity* – the adolescent, in response to not knowing who or what they are or where they belong, may adopt a negative identity e.g. a punk, rather than have no identity at all.

  Females talked about how they felt the need to explain to people that they were experiencing difficulties conceiving and were having treatment, rather than have people think that they had 'chosen' not to have children. It seems that this may serve the function of giving themselves an identity of a female who is trying for children but having difficulties, which is preferable to a female who 'chooses' not to have children.

As couples enter into the Active Infertility Stage conception becomes their major life goal. However, during the Post-Active Infertility Stage, when identity 'confusion' for the couple and individuals is being resolved, planning recommences in line with new goals that are affiliated with the new identities e.g. parents or couple / individual without children.

8.4 Summary and conclusion

The different and at times competing needs and motivations of males and females around having a family are present from the very beginning of the infertility experience e.g. from the Pre-Active Infertility Stage through to the Post-Active Infertility Stage. The female adopts the role of responsibility and initially takes control. She retains this position throughout. The instance of the female taking control of the issue is supported in the literature (Dunkel-Schetter & Stanton, 1991). This is likely to be linked to the fact that her desire for a child tends to be stronger than the males. The infertility experience seems to create a role reversal with the female adopting role of 'fixer' which in turn seems to contribute to the male feelings of inadequacy and marginalisation. The interaction between these factors can impact negatively on the quality of couple relationship, a finding widely supported by the literature (Salvatore *et al.,* 2001; Levin & Sher, 2000; Greil, 1997; Kumar & Leo, 2003; Leiblum *et al.,* 1998). Infertility does not simply exert a negative impact on those individuals and couples for whom parenthood is an important goal. The experience would appear to result in a qualitative change in those individuals and couples who go through it, regardless of whether they have children or not. It is however important to note that if parenthood is not an important goal for an individual or couple then infertility may have fewer negative consequences and hence may not be perceived as a particularly stressful experience (Clark *et al.*, 1991).

CHAPTER 9

General Discussion – Study 1.

9.1 Study Aims:-

- To gain an understanding of the different emotional and psychological needs at any given time in of the infertility experience.
- To explore how infertility is experienced by the individuals within the couple and how this experience impacts on the couple as a unit.

9.2 Critical reflection and discussion

These aims have been met. Three distinct models of the infertility experience have been developed based on the findings. These models together resulted in a fourth model depicting the overall infertility experience for heterosexual couples. In providing an overall picture of the infertility experience for males, females and couples, these four models bridge a gap in the literature that was identified prior to commencing this research (see Chapter 1).

The infertility experience is both complex and dynamic and the potential value of these models is great. The models provide a platform from which research can be carried out in order to elaborate on and validate these findings with a view to broadening our understanding of the experiences of this client group. This will inform the practice of counselling psychologists. Moreover they could serve as a guide to practitioners new to the field of infertility. They could be used in work with clients as an interactive psycho-educational tool.

Whilst the aims of the study have been met it is important to highlight some caveats. One of the limitations was that the sample did not include a couple with male factor infertility. Five of the six couples that participated had female factor infertility and one couple had unexplained infertility. Findings need to be considered with this borne in mind. There is research suggesting that the relationship between gender and infertility distress is not affected by which member of the couple has the impairment with females tending to

experience more distress than males (Greil, 1997). This is not to say that infertile males do not experience distress, they do. They have been found to experience anxiety, self-blame and feeling 'less of a man' (Glover, Gannon & Abel, 1998). Mason (1993) in her study found that infertile males experience many of the same feelings that infertile females experience. This suggests that the relationship between gender and infertility distress is affected by which member of the couple is infertile. Read (1995) and Pengally (1995) would concur with this.

A second caveat it that couples in the present study were together. As a result this is likely to have a bearing on the findings. Research has found that given the stressful nature of the infertility experience many couples do separate (Salvatore *et al.*, 2001; Levin & Sher, 2000; Greil, 1997; Kumar & Leo, 2003; Leiblum *et al.*, 1998). For couples that do separate, the infertility experience may be characterised by unknown, additional factors compared to those couples who stay together.

A third caveat is that the sample is small and therefore caution should be exercised when interpreting findings. However, many of the findings are widely supported in the literature and compatible with the experience of two additional couples with whom I spoke following analysis who are currently experiencing difficulties conceiving and receiving treatment. This suggests that findings are relevant and applicable to others beyond the present sample. Further research needs to look at a larger sample to establish the extent to which the present findings are applicable to others going through the infertility experience.

The present study considered the infertility experience for those heterosexual individuals in a couple. It did not address the issue of involuntary childlessness for heterosexual or homosexual males and females with no partner and do not wish to have a child on their own. The experiences and needs of these potential client groups require investigation, as they are also relevant to counselling psychologists. Further research into the experience of this group of involuntary childless females and males is required in order to build a fuller picture of what constitutes childlessness and infertility in today's society.

The interviews were the most rewarding and challenging element of the research. I was anxious about the initial interviews for many reasons. Firstly, I was asking people to talk about an emotive and personal issue and I was concerned about how they would respond to me. It was my first experience of interviewing couples and as my pilot food interviews demonstrated, it is a very different experience to individual interviews. I had concerns about interviewing those I knew personally and what impact this would have on the study. Moreover, I had some concerns about interviewing people about their personal experience. These concerns were likely to have had some form of impact on data collection, especially in the first interviews. However as interviewing progressed these concerns rapidly abated as all the couples were open and responsive in interviews, both talking as a unit, and more so as individuals. The couples/individuals that had not had counselling reflected how useful it had been to talk about their experience in the interview. My counselling skills were beneficial in building relationships with interviewees. This helped interviewees feel safe and secure and permitted me to gain privileged emic (inside) knowledge of how the infertility process is experienced by the couples in the present study.

Data analysis was an anxiety provoking experience at times. It required total absorption and periods of great uncertainty and doubt. It was also very time consuming. The steps and guidance provided in Strauss & Corbin (1998) were an extremely beneficial aide, even though the reality is not as clearly defined as the book suggests. The process demanded creativity which Strauss & Corbin (1998) emphasise as a key quality in a researcher. In particular the process has compounded my philosophical position in so much that I believe findings are the result of relationships between concepts (Madill *et al.*, 2000) as opposed to being 'discovered' in the data. For example I observed myself picking up on 'dominant themes' following interviews and after the first listening of them. At the coding stage I recognised that my beliefs and experience were influencing the process and actually the 'dominant' themes were not necessarily so (based on fewer comments than other themes). This was a fascinating process and provided much scope for reflection in respect of what I brought to the research process and my clinical work. It also suggested to me that a rigorous approach to data collection reduces, if not removes, the presence of research bias in the findings.

9.3 Summary and Conclusions

The process of infertility and IVF treatment can be emotionally and psychologically distressing for males and females in quite different ways. These experiences can exert extreme stress on the couple relationship (Salvatore *et al.,* 2001; Levin & Sher, 2000; Greil, 1997; Ow *et al.*, 2003). In light of new guidelines from the National Institute for Clinical Excellence (NICE, 2004) stating that the NHS will provide 1 free cycle of IVF for all females aged between 23 and 39 who meet certain clinical criteria from April 2005 those individuals and couples undergoing treatment is set to soar. Thus counselling services need to be developed and made available to those who undergo treatment to meet this growing client groups needs.

The findings make apparent the importance of raising the awareness of those experiencing infertility of the potential implications for them. Moreover, they need to be made aware of the help that counselling can provide throughout the experience so that appropriate services can be utilised by clients as and when required.

Infertility and the resulting treatment for it, is a growing area in which there is an opportunity for counselling psychologists to develop and provide professional counselling services. There is also an excellent opportunity for counselling psychologists to utilise their considerable research skills to promote knowledge and understanding in this area.

CHAPTER 10

STUDY 2

Counselling and the Infertility Experience:

- **Identification of potential counselling and support needs of the male, female and couple going through the infertility experience.**

- **An exploration of perceptions and experiences of counselling.**

Study 2 - Research Method and Design

Aims

- To explore perceptions, beliefs and experiences of counselling in order to understand the factors involved in the decision making process regarding whether to have counselling for infertility.
- To identify potential counselling and support needs of the male, female and couple going through the infertility experience.
- To check the validity of the models of the infertility experience developed in Study 1.

10.1 Purposive sampling

Purposive sampling was used. This form of sampling requires choosing a selection of participants who illustrate the processes under research (Silverman, 2000). Hence a representative sample was needed so that a wide range of perceptions of counselling could be identified. In addition to this a representative sample was required in order to

identify potential counselling needs of the male, female and couple. Couples were selected according to the minimum criteria set out in Study 1 e.g. they all met the definition of 'infertility' – 12 months trying to conceive naturally and to have experienced sufficient difficulties conceiving to have led them to seek medical advice/treatment, either currently or in the past. An additional criterion was that couples included in the sample would have different experiences of counselling e.g. the inclusion of a couple in which neither member of the couple had had experience of counselling, a couple who had experience of couple counselling and a couple in which only one member of the couple had experience of counselling.

10.2 Characteristics of sample

Five volunteer couples were interviewed. The age range was 30 to 46 years. Four couples had explained infertility - two had female factor infertility and two had male factor infertility. One couple had unexplained infertility with a pending query relating to both male and female fertility. At time of interviewing four couples had children, one via adoption, two via IVF and one couple conceived naturally after 2 years of trying, one couple had no children and were preparing to start IVF treatment.

Counselling comments from interviews conducted in Study 1 were included in the analysis. This resulted in data from 10 couples in total. Given the sensitive nature of the topic under investigation demographic details are not provided for purposes of confidentiality (Lee, 1993).

10.3 Recruitment

The selection criterion set out for the present study required the sample from Study 1 to be expanded, primarily because none of the couples in Study 1 had experience of couple counselling and only two couples had one member who had experienced counselling. In addition, the sample in Study 1 did not include any couples with male infertility. A selection of new couples provided the opportunity to recruit one or more couples with male factor infertility.

Three couples were friends of the researcher. Two couples were not known by the researcher. Couples did not know each other. As in Study 1 the initial approach by the

researcher differed slightly on this basis. Two couples from Study 1 in which one member had experience of counselling were approached but one had moved away and was not contactable. The other couple were invited to participate via telephone. They were asked to think about it and contact me if they decided to take part. They did make contact and were recruited.

Couples known by the researcher were approached with a telephone call, the purpose and nature of the study was outlined and any questions answered. Known couples were made aware of the potential obligation they may have felt in agreeing to participate on the basis of the relationship with the researcher. To minimise this, they were given time to consider the decision to take part. A follow up information sheet also outlined the dual relationship in place and potential issues relating to this (see Appendix 15).

Couples were invited to contact the researcher if they decided to take part. They were assured no contact would be made if they decided not to take part and no explanation would be required.

Couples not known by the researcher were initially recruited via a mutual friend of the researcher and the couple. The friend was provided with a brief, verbal outline of the study in each case. Following this the participants were sent a letter of introduction by the researcher (see Appendix 16) and an information sheet (Appendix 17). Contact was made a few days later and questions were answered. Couples were invited to contact the researcher if they decided to take part and assured that no further contact would be made and no explanation required in the event they decided not to participate.

10.4 Theoretical Sampling

Theoretical sampling (Silverman, 2000) means that the choice of participants to interview next is informed by emerging concepts. The aim of initial data collection was to interview participants that would provide the richest data (Pidgeon & Henwood, 1998). Then data collection became more focused in line with emergent themes.

The aim was to gain a wide range of counselling perspectives and to identify potential counselling needs of the male, female and couple respectively. The couple with

experience of couple counselling were interviewed first. An interview with the couple in which neither member of the couple had any experience of counselling followed. It was anticipated that these 2 key sources of data would yield a range of emergent themes pertaining to the couple, male and female that could be compared for both similarities and differences. These themes would then guide the next stage of data collection (Strauss & Corbin, 1998).

A number of emergent themes relating to the identification of the potential counselling and support needs for couples, for males and for females (see Chapters 12, 13 and 14) suggested that it would be pertinent to then interview the couple who had not yet had treatment next.

10.5 Ethical Considerations

Infertility is a sensitive topic. With the exception of those that had experience of counselling the interviews may have been the first time that the individuals/couples taking part have spoken to anyone outside their relationship about their experience or to each other. This process could evoke new or underlying unexplored feelings for each individual and between them as a couple. With this in mind the same considerations and steps that are discussed in Study 1, Chapter 3 (3.6) applied to these interviews.

10.6 Confidentiality and consent

The same steps outlined in Study 1, Chapter 3 (3.6) were followed prior to consent forms being signed by all participants.

10.7 Equipment

Interviews were recorded on a Sony portable MiniDisc Recorder (model MZ-R50) with a Sony Electret Condenser Stereo Microphone (model ECM-MS907), using Sony Mini Discs (80 minutes duration).

10.8 Data collection

Fifteen interviews were conducted in total. Each couple was interviewed together first, and then individually. All five couples were interviewed in their homes.

Each interview lasted between 45 and 60 minutes. Prior to interviewing, participants were thanked for agreeing to participate. They were reminded of their right to withdraw from the study at any time without explanation. They were informed that they did not have to answer any questions they did not want to. They were shown how to turn off the recorder so that they had a sense of control and could exercise choice without having to ask the researcher.

Interviews were semi-structured. Initial interviews were the least structured with the aim of yielding a rich data set. In line with the grounded theory approach the focus of interviews became more specific as theory emerged. The first and final questions remained the same for each interview. These are provided in the following section.

10.9 Couple interview

The aim was to gain a brief overview of the couples' experience of infertility before moving on to ask them about their perceptions and experiences of counselling. To facilitate participation from both members of the couple, each couple interview opened with the following question –

"Who normally does the talking when you are at the doctor's or the hospital?"

Their answer was followed by the next statement –

"Well for my purposes, it may be that I ask 'X' specific questions, will that be alright?"

A list of questions/areas to be covered used in the first interview is listed in Appendix 18.

All couples were asked the following question –

"Can you tell me about your experience of infertility?"

This was followed by this question –

"Were you offered any support or counselling as a couple at any stage throughout the process?"

Everybody had unique experiences so some aspects may not have been captured during the interview. In order to account for this possibility each interview ended with the following question –

"I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or are there any questions that you are surprised I have not asked and would like to discuss?"

Finally, all couples were thanked for sharing their experience with me and asked whether they had any questions.

10.10 Individual interviews

To establish how the participants were finding the experience of talking about this potentially sensitive issue and how this may impact on the process and in which ways (Lee, 1993) the following question was asked at the beginning of the individual interviews –

"How did you find talking to me previously about your experience?"

It was explained to each participant that although they have gone through the infertility process as a couple, the purpose of the individual interview was to access their own unique, personal experience and to establish what their needs were/are going through the process. They were once again assured of confidentiality.

The next question was –
"How has your experience of infertility/difficulty conceiving affected you?"

This was followed by this question –
"Were you offered any support or counselling at any stage throughout the process?"

Questions/areas to be covered used in the first interview can be found in Appendix 19.

As with the couple interviews each individual interview ended with the following question –

"I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or are there any questions that you are surprised I have not asked and would like to discuss?"

Finally, participants were thanked and asked if they had any questions.

CHAPTER 11

Data Analysis

Overview

The same steps that were followed in Study 1 were followed in this study. A step-by-step guide of the analysis process is presented in this chapter, using an example from the 'female' data set. The analysis outlined was carried out on each data set – male, female and couple. The process is described in 'stages' for purposes of illustration however it was not a linear process as different stages of analysis were operating in tandem. There was a constant interplay between data analysis, collection and the developing themes.

11.1 Stage 1 – Open coding

As in Study 1 the actual recordings were used as a permanent record and I initially analysed directly from them (Pidgeon & Henwood, 1998). Analysis began immediately after the first interviews. Male, female and couple interviews were listened to once without making any notes. At this stage I was interested in getting an overall sense of the data, observing what tone was used and when, comparing interviews with notes taken during interviews regarding observed body language that accompanied comments and what impact my questions had on participant responses.

On second listening of the interviews I started open coding of the data (Strauss & Corbin, 1998). I stopped the disc every few seconds and considered what the participant was saying prior to 'coding' it. Each interview had a record, which included the location (time) on the disc of the comment being coded, the participant interview code and the label code. An example is provided in the following, codes are shown in bold:-

4-1.55 (Code = participant 4, location on disc- 1 minute 55 seconds)

To be honest honest, as a woman, I felt very, very angry **[anger – as a female]** as I told you before mm ...because I had counselling, I felt good after the counselling **[feeling good after counselling / counselling facilitating change?]** I mean I think literally, ok I think I can truly say **[emphasis on the truth of the statement being made]** that

counselling the third time, I mean before the third time [IVF treatment cycle] er made me sane again **[counselling helped to feel 'sane' again / counselling process instrumental in returning 'x' to a previous state of mind]** and it kind of helped me deal **[counselling as a process to facilitate 'dealing' with an issues / issues]** with the fact that I was jealous of females who were having kids when I didn't have any **[counselling facilitating self awareness]**

11.2 Memos and diagrams

Memos and diagrams were kept throughout the analysis and formed a key part of the process (Strauss & Corbin, 1998). All memos and diagrams were dated, noted participant and disc location codes, given a title and any other relevant information. The following is an example of a memo written for the data coded 4-1.55:-

MEMO – 4-1.55, 19/2/05. 'FEMALE'

ROLE OF COUNSELLING – related concepts = dealing with an issue, coming to terms with an event, having a 'main' issue, self-awareness, change, outcome = a return to previous state of mind.

There seems to be a 'main issue' that is brought to counselling. It seems that the experience of counselling serves a number of purposes. It can serve the function of raising self awareness around what the female is feeling about others/self/partner?, it can provide acknowledgement of an event not previously acknowledged – result of acknowledgement = legitimising event > giving permission and providing an opportunity to grieve for her loss/es?? Return to 'sanity', do some females feel 'insane' if they are not given the opportunity to talk about the event/how they are feeling? Need to explore/consider further. Counselling can help the female come to terms with the event and move on from it. This in turn can serve the role of helping the female continue with treatment. This links to Participant 9 who said that counselling helped her decide that she was ready to stop treatment. Seems that counselling plays a role in helping people decide whether to continue or whether to stop treatment? I need to explore the link with other female who had counselling and how others make this decision.

11.3 Stage 2– Development of categories and subcategories

Initial analysis of the 'female' data (first 2 interviews) yielded 36 concepts. Constant comparative analysis was used to examine similarities and differences of codes and concepts both within and between the 2 cases. Comparisons were also made with the couple and male data. 6 tentative categories were initially generated. At this stage all data feeding into developing categories were transcribed. File cards with tentative category labels were created, these were – 'identification of points throughout the infertility experience at which females may benefit from counselling', 'counselling needs', 'how counselling helped', 'the role of support groups', 'how counselling is perceived to help', 'counselling for issues experienced in response to key events'. Variation across line codes within each of these categories led to formation of subcategories. For example 'points at which counselling could be of benefit' appeared continually throughout individual and couple interviews. However, clusters of comments relating to key events across the infertility experience emerged.

For example:-

The comment below led to the subcategory **'The Pre-Active Infertility Stage'.**

17 – 29.12 *I think most women in general would go for counselling if it was offered right from the beginning, you know when you are not falling pregnant*

The comment below led to the subcategory **'The Active Infertility Stage '.**

13.14- 33.20 *You are just not yourself [during treatment] and if you can speak to someone while you're going through it who can understand what you are going through then I think it would really help*

The comment below led to the subcategory **'Key events and the issues experienced in response to them'**

9-40.00 *The dates that think you will conceive as a result of the treatment and don't become significant for ever, they are always going to be difficult for me.*

The comment below led to the subcategory **'The Post-Active Infertility Stage'.**

7-39.34 *I think at times that I can deal with this on my own [stopping treatment and accepting a future without children] but at other times I feel that something has to help me through the pain before I can move on.*

11.4 Stage 3 – Axial coding

Axial coding is the process of relating categories to subcategories along the lines of their properties and dimensions (Strauss & Corbin, 1998). At this point each tentative category title was laid out on a clear surface along with the relevant subcategory labels. All codes were manually allocated to subcategories. Discussion with a colleague led to the collapse of the 6 tentative categories into 3 categories and promoted the development of more subcategories.

Data was collected and coded until categories were 'saturated' (Glaser & Strauss, 1967). No new categories emerged after the initial 4 sets of interviews. As interviews had already been arranged with the final couple this went ahead. The data collection and analysis continued until the categories were saturated. Saturation was reached when the coding of data did not yield any new properties or dimensions that added variability to the categories.

11.5 Stage 4 – Selective coding

This stage is characterised by the process of integrating and refining the theory. The aim was to identify potential counselling and support needs of the male, female and couple and to explore perceptions and experience of counselling. Only categories that specifically related to the overall theory were included.

A core category emerged from the data which had more codes and more dense subcategories than any other category. The core category for females was **'IDENTIFICATION OF POINTS THROUGHOUT THE INFERTILITY EXPERIENCE AT WHICH FEMALES MAY BENEFIT FROM COUNSELLING'.** At this stage other categories were organised in terms of their relationship with this category. Two categories were directly related to the core category 1) How counselling helped or is perceived to help and 2) Infertility and the role of

support groups. The categories relating to female perceptions and experience of counselling and potential counselling and support needs throughout the infertility experience are presented and discussed in Chapter 12.

11.6 Credibility of current research

The issue of reliability and validity of qualitative research was discussed in Study 1 (Chapter 2, 4.6). Steps were taken both during and following the analysis process to demonstrate the credibility of the research. This was done in the following ways:-

- *Respondent validation*

During data collection as concepts and categories were being developed their validity was checked with participants. This involved going back to participants to clarify their previous account and/or to ask specific questions relating to concepts.

- *Independent judgement*

Once categories had been developed an independent judge (a counselling psychologist colleague who is not familiar with the field of infertility) was invited to allocate codes to the subcategories of each of the final categories. The aim of this was to rectify instances where there may have been bias and to ensure that codes were allocated appropriately. The overall fit of the data was good but following discussion and feedback with my colleague the categories and subcategories were refined.

- *Documentation*

A record of the analysis process including what was done, when it was done, how it was done and why it was done has been presented in this chapter. In addition a list of all categories and subcategories developed for female, male and couple experiences and perceptions of counselling and potential counselling needs, can be found in the Appendices (19-22). A definition of each category based on how it was arrived at is provided and all statements pertaining to each subcategory are included. This permits traceability of themes back to the data source.

- *Transferability*

Following analysis I spoke with 2 couples that participated in Study 1, neither couple had experience of counselling. They were given a copy of the couple categories and subcategories including definitions and comments. Males received a copy of the male categories and subcategories and females received a copy of the female categories and subcategories. There was a discussion about the categories and their subcategories, definitions and comments. They provided feedback on the findings. Each said that they identified with each of the categories (that applied to their personal experience) and the comments made by the males, females and couples respectively. This suggests that the potential counselling needs and perceptions identified in this research are relevant and applicable to others going through the experience of infertility beyond the present sample.

STUDY 2: FINDINGS & DISCUSSION

Overview

The findings and discussion section is comprised of four chapters:-

- Chapter 12 –Potential counselling needs of females going through the infertility experience and female perceptions and experiences of counselling.
- Chapter 13 – Potential counselling needs of males going through the infertility experience and male perceptions and experiences of counselling.
- Chapter 14- Potential counselling needs of couples going through the infertility experience and couple perceptions and experiences of counselling.
- Chapter 15 – General Discussion.

Chapters 12-14 include the following:-

- A section on category development.
- Comments taken from the actual interviews pertaining to the core category.
- A summary of the potential counselling needs, counselling experiences and perceptions under discussion e.g. female needs, perceptions and experiences.
- Critical reflection and discussion.

Chapter 15 includes:-

- A general discussion and conclusion for Study 2.

All categories developed in relation to each experience are briefly outlined in the relevant chapter. Data from interviews are used to illustrate core categories. Full descriptions of all categories and their subcategories complete with comments taken from the interviews can be found in Appendices 19-22.

CHAPTER 12

FINDINGS & DISCUSSION 1: Potential counselling needs of females going through the infertility experience and female perceptions and experiences of counselling.

Overview

The chapter is arranged in the following sections:-

- Category development – Potential counselling needs of females going through the infertility experience and female perceptions and experiences of counselling.
- Summary of the potential counselling needs of females going through the infertility experience and female perceptions and experiences of counselling.
- Critical reflection and discussion.

12.1 Category development: Potential counselling needs of females going through the infertility experience and female perceptions and experiences of counselling

One category relating to the potential counselling needs of females going through the infertility experience was developed. Two categories relating to females perceptions and experiences of counselling were developed. Full descriptions of all categories and their subcategories complete with comments taken from the interviews for the potential counselling needs of females and their perceptions and experience of counselling are listed in Appendix 20. These are presented below. Comments are identified as to whether they were made by males or females.

CORE CATEGORY: IDENTIFICATION OF POINTS THROUHGOUT THE INFERTILITY EXPERIENCE AT WHICH FEMALES MAY BENEFIT FROM COUNSELLING

Definition: -

Potential needs of females progressing through the infertility experience were identified. This led to the development of the core category 'identification of points throughout the infertility experience at which females may benefit from counselling'. Difficulties relating to infertility and/or related issues are present from the Pre-Active Infertility Stage through to the Post-Active Infertility Stage. Critical events can occur throughout the infertility process which can be distressing for females. Counselling may be beneficial for issues and events at any time throughout the infertility experience.

Subcategory of 'identification of points throughout the infertility experience at which females may benefit from counselling':- The Pre-Active Infertility Stage

Definition:-

Difficulties are encountered by females from the Pre-Active Infertility Stage yet counselling does not tend to get routinely offered to females by their GP. This indicates that counselling could be beneficial to support females from the point at which they experience difficulty conceiving. Findings indicate that if counselling is taken up at this early stage it could provide a sense of consistency for the female as she moves through the infertility experience.

Interviewee Comments:-

1-31.16 *I remember the doctors rushing me to make a decision about treatment [at point of diagnosis] but at that stage what I really needed was to talk to someone about my position [being infertile]. I wasn't ready to make decisions I wanted to talk about what it all meant to me, as a woman, first. (Female)*

17 – 29.12 *I think most women in general would go for counselling if it was offered right from the beginning, you know when you are not falling pregnant (Female)*

13.14-50.45 *I think that counselling before hand [before any investigations or treatment] is important and then if it doesn't work that relationship is already in place and you can go see the counsellor for support, that is really important (Female)*

Subcategory of 'identification of points throughout the infertility experience at which females may benefit from counselling':- The Active Infertility Stage

Definition:-

The infertility experience can evoke feelings of failure, anger, grief, guilt and isolation. This highlights the value of counselling for addressing these issues. Critical events were also identified as points at which counselling could be beneficial. Critical events can occur at any point of the infertility process and can be emotionally and/or psychologically distressing for the female. Counselling could be beneficial for working with the impact of these events either as they occur and/or in preparation of them occurring. Events include miscarriages, failed treatment cycles and other people falling pregnant.

Interviewee Comments:-

4-2.25 *It [counselling] helped come to terms with my miscarriage, which doctors don't acknowledge, they call it a loss of pregnancy, but to me it was my baby. (Female)*

9-24.44 *I found it very painful when someone else got pregnant at work, I*

couldn't really tell anyone how I felt, I felt so guilty and such a failure you know. I could of done with some help around that at the time (Female)

5-43.23 *I have struggled when others have announced pregnancies, I'm happy for them, but it just raises so much stuff in me I can't handle, you feel so alone with it all. (Female)*

Subcategory of 'Identification of points throughout the infertility experience at which females may benefit from counselling':- The Post-Active Infertility Stage

Definition:-

Transition to the Post-Active Infertility Stage is a point when difficulties can arise for females regardless of whether treatment has been successful or not. Issues can arise some time after treatment e.g. after the birth or adoption of a child. Females could benefit from counselling at this point.

Interviewee Comments:-

9-42.01 *At the end of all the treatment I think I probably would have benefited from talking to someone because I didn't know what came next for me, I mean it was obvious that I was never going to have my own baby (Female)*

7-39.34 *I think at times that I can deal with this on my own [stopping treatment and accepting a future without children] but at other times I feel that something has to help me through the pain before I can move on. (Female)*

15 – 16.32 *For me it was about a year after we adopted the boys that I really felt that I needed the support. Things were quite delayed in my case. So I had counselling and then I was able to work through how awful our situation had been and accept that crap things happen (Female)*

CATEGORY: HOW COUNSELLING HELPED OR IS PERCEIVED TO HELP FEMALES

Definition:-

Females with experience of counselling expressed only positive statements about it. Positive perceptions were held by females about how counselling could help. Ways in which counselling worked or was perceived to work included facilitating the process of moving on, decision making and providing neutral support outside the female's circle of close friends and family. This resulted in the development of three subcategories:-

- **Resolution and moving on:** Counselling was reported as having helped females to move on from where they were at the point at which counselling was received.
- **An opportunity to talk to someone outside your situation:** Females expressed reluctance to talk to friends and family about how they were/are feeling. This was primarily because the 'advice' offered is not always what they felt they needed. Counselling can provide an opportunity for the female going through the infertility experience to talk to someone outside her immediate circle about how she is feeling. The benefits of this are that females can talk freely and they can perhaps more importantly, be heard.
- **Decision making:** There are certain points at which decisions need to be made throughout the infertility experience. Counselling was found to play a role in facilitating the decision making process for one female.

CATEGORY: THE ROLE OF SUPPORT GROUPS

Definition:-

Females said talking to others who had also gone through the infertility experience reduced their feeling of isolation. This suggests group therapy and/or mutual support groups could be beneficial for some females. Concern was raised by a female who had accessed an Internet based support group. She feared that she could become too involved in the group/infertility issue and it could take over her life and so ceased to visit the site.

12.2 Summary of the potential counselling needs of females going through the infertility experience and female perceptions and experiences of counselling

Potential counselling needs were identified for females at each stage of the infertility process. Findings corroborate the characteristics of the female experience identified in Study 1. The value of introducing the concept of counselling from the point at which difficulties conceiving are encountered was raised. The Active Infertility Stage was found to be the stage during which females may benefit from counselling for emotional and psychological issues that arise in response to critical events and in relation towards the infertility issue itself. Potential counselling needs were found to arise at the Post-Active Infertility Stage for females regardless of whether they became mothers or not. Females held positive perceptions and had positive experiences of counselling both in general and for the infertility issue. They were all open to counselling.

12.3 Critical reflection and discussion

12.3.1 Reflections on the interview process

As in Study 1 females were all open and engaged in interviews. They appeared comfortable talking about their experiences and reflected that they had a 'need' to talk about their experience. This was particularly apparent in interviews with females in the Active Infertility Stage who had not experienced counselling. In contrast with Study 1, interviews were not as emotional, given the different research focus.

12.3.2 Potential counselling needs of females

Distinct counselling needs were identified at each stage of the experience. This highlights the complex and evolving nature of the infertility experience for females. Different ways that counselling may benefit females during the Active Stage were identified. These are compatible with the characteristics of this stage. The key characteristic of the female infertility experience is 'isolation'. Females can also feel unsupported and not understood. The process of talking to someone outside their situation and being listened to and supported could be of immense benefit to females experiencing isolation.

Females could benefit from counselling at the point at which they experience difficulties conceiving e.g. at the Pre-Active Stage. Intervention and support at this stage is likely to help females prepare for the experience. This is important as it seems that feelings become amplified throughout the experience.

At the Post-Active Stage females can experience a 'delayed' reaction in which they may be confronted with a host of unresolved issues, whether they become mothers or not. Counselling during the experience or post treatment may act as prevention against this reaction, which may affect bonding with a child/ren.

12.3.3 Female perceptions and experience of counselling

The most striking point throughout interviews was that all females were open to counselling both in general and for infertility. Females participating in both studies had positive experiences of counselling. Females with no experience of counselling were of the opinion that it could have helped or help them with difficulties they had experienced or were currently experiencing. Ways in which counselling was perceived by females to help were a good fit with the actual experiences of counselling described by females. Female openness to counselling and the support it can provide seems to be a function of the isolation that she can experience and the fact that the female infertility experience can be emotionally, psychologically and physically devastating (see Study 1; Greil, 1997; Read, 1995; Gibson & Myers, 2000).

Common triggers for females to access counselling are a crisis and/or in response to a critical event e.g. a miscarriage (Crawshaw, 1995). As discussed in Chapter 5, females can experience grief throughout the infertility experience and a critical event can 'legitimise' this grief. This could explain why some females access counselling when they do e.g. at a crisis point. This is certainly something that I have found in my clinical practice. In my experience females tend to access counselling when they feel they can no longer 'cope' without support. It is often considered to be a 'last resort'. Initially females can feel that they have 'failed' in some way for having sought counselling. This seems to be an extension of the pervasive sense of failure that is a characteristic of the female infertility experience (see Chapter 5). This sense of failure for having to access counselling was not reported in the present sample, but females that sought counselling did so in response to a crisis e.g. miscarriage or when they felt they 'could no longer cope'. Interestingly, despite the distress that they talked about experiencing females said that although they felt they could benefit from counselling they had not reached the point

they deemed it 'necessary'. What is deemed as 'necessary' is likely to differ from female to female. Research looking at this construct would be valuable.

12.3.4 Support for the female model of the infertility experience

Distinct counselling needs for females were identified which pertain to each stage of the infertility experience proposed in Study 1. This demonstrates how female needs change as a function of progressing through the experience. This lends support to a stage theory of infertility. Females talked of the experience as being distressing, painful, isolating and resulting in a sense of failure as well as feelings of grief and anger, especially at times of crisis. This provides support for the characteristics of the infertility experience. These findings are valuable and support the validity of the female model. The sample is small and further research utilising a broader female sample is still needed to further check validity and elaborate the female model of the infertility experience.

Study 1 revealed that when females become mothers they feel 'happy', 'complete' and 'normal' (Chapter 5). Findings revealed that the Post-Active Infertility Stage is more complex than initially proposed. Issues can arise for those females who become mothers as well as those who do not. This suggests that females tend to move through the infertility experience without necessarily fully exploring the impact on them as females. Not dealing with feelings and issues as they are experienced can, for some females, result in a 'delayed' reaction. This occurs during the Post-Active Infertility Stage. Further research into the experiences of females in the Post-Active Infertility Stage needs to be carried out. This would broaden our understanding of this important stage of the infertility experience with a view to informing clinical practice with this client group.

12.3.5 Application of findings

Despite difficulties experienced by females, counselling was not suggested or offered to any female by their GP. The focus for the GP is naturally biological rather than emotional. There seems to be an implicit assumption that should a female go to their GP to discuss difficulties conceiving they want to be referred for 'treatment' to facilitate this. This may be the case. Findings highlight the value of a GP referral being routinely accompanied by a counselling referral. Routine referral could serve the function of normalising the experience of infertility and of having counselling. Counselling could

help prepare females for the distressing nature of the infertility process. A referral could reduce the feelings of failure that can be experienced by females going through the infertility experience whilst at the same time give females 'permission' to seek appropriate support, should they need it, hence preventing or reducing the likelihood of them hitting a crisis point. Referral seems to be particularly important in cases of a diagnosis of female infertility e.g. premature ovarian failure (early menopause). In such cases a female may need to process what the diagnosis means to her before being 'rushed' to make a decision to have treatment, as happened to a female interviewed in this study. HFEA regulations state that counselling must be made available at licensed treatment centres (HFEA 1999). It is argued here that provision needs to be made for females at the Pre-Active Infertility Stage i.e. females awaiting diagnosis and treatment and those females who do not seek fertility treatment. Positive promotion of counselling and its benefits is likely to increase uptake of counselling by females.

Distinct counselling needs were identified for each stage of the experience. Thus a model of infertility counselling could be developed that accounts for needs that occur at each stage. A counselling model needs to be flexible so that it can be tailored to take account of an individual's unique experience. It is proposed that any model of counselling be developed in conjunction with further research building on findings from Studies 1 and 2.

It is important to acknowledge that not all females need or want counselling for their infertility. This is likely to be due to a number of factors e.g. their support network, the extent of their desire for a child and their self-esteem, to mention a few. Moreover, those females that do seek counselling may find that it is not what they need. For example 'Stephanie' (2005) wrote an account of her experience of infertility and counselling in the BACP journal. She found her long term, male therapist helpful during the Pre-Active Infertility Stage. However during the Active Infertility Stage, which in Stephanie's case was a few months into her treatment, she reflected that she was not getting her needs met in therapy. What she needed at this time was "an energy that would push her forward" (p.10). In reality the focus was on the question of how things would be if she did not become a mother. This is an important factor, particularly during the Active Infertility Stage. At time of treatment the female and couple are likely to feel a need to be optimistic and strong to cope with the rigorous demands of it. My clinical experience would concur

with this. They are also likely to be full of hope for the outcome of the treatment cycle and their future. As such they may not wish to discuss the more bleak and painful options at this stage. This highlights the importance of therapists having specialist knowledge of and training in infertility so that they can identify a clients support needs and work towards meeting them (Boden, 2005). Both the HFEA (2003) and the British Association of Counselling (BICA) (1999) support the need for infertility counsellors to have specialist knowledge and training. This research would argue the same.

12.4 Summary and conclusion

In addition to counselling throughout the Active Infertility Stage, females are likely to benefit from a suggestion or referral for counselling from their GPs from the point at which difficulties conceiving are encountered. Females may also benefit from counselling post treatment regardless of treatment outcome. It is important that those working therapeutically with this client group have specialist knowledge of infertility and related issues.

Further research into the female model of infertility is required so that an efficacious model of therapy can be developed for females to account for issues encountered at each stage of the infertility experience. Moreover it is proposed that counselling psychologists combine forces with other practitioners working in the field to positively promote counselling to females so that they can access it prior to a 'crisis' or events such as a miscarriage.

CHAPTER 13

FINDINGS & DISCUSSION 2: Potential counselling needs of males going through the infertility experience and male perceptions and experiences of counselling.

Overview

The chapter is arranged in the following sections:-

- Category development – Potential counselling needs of males going through the infertility experience and male perceptions and experiences of counselling.
- Summary of the potential counselling needs of males going through the infertility experience and male perceptions and experiences of counselling.
- Critical reflection and discussion.

13.1 Category development: Potential counselling needs of males going through the infertility experience and male perceptions and experiences of counselling

Two categories relating to the potential counselling needs of males were developed. One category relating to male perceptions and experiences of counselling was developed. Full descriptions of all categories and their subcategories complete with comments taken from the interviews for the potential counselling needs of males and their perceptions and experience of counselling are listed in Appendix 21. These are presented below. Comments are identified as to whether they were made by a male or female.

CORE CATEGORY: DESIRE FOR UNDERSTANDING

Definition:-

Males expressed a desire to have more understanding throughout the infertility experience in a few key areas. Primarily they wanted to know more about the female experience. This was with a view to knowing how to help their partner. Males would like their partner to have more of an understanding about the male experience. Males desired practical, psychological and emotional information regarding infertility treatment, particularly in cases of male infertility. Males believed that information about diagnosis and the treatment process would aid understanding. The most popular medium by which to convey this information is via a DVD.

Subcategory of 'Desire for understanding':- About the female experience

Definition:-

Males expressed a need to have more information about the emotional and physical female experience. This is so they would be in a better position to support their partner. Males expressed that they do not always know what to do 'for the best' to help their partner. This can leave them feeling helpless. Males believe that a greater understanding would place them in a better position to change this.

Interviewee Comments:-

14 – 22.45 *I think men need help to know what to do for the best and when, you just don't really know what it's like for them [females] (Male)*

18 – 18.21 *A man doesn't really understand the emotional side of things you see he tends to be more logical and they, we would benefit from understanding what a woman is feeling. You don't always know about the physical side of things either so you can feel really useless at times (Male)*

5 – 32.10 *It's sometimes hard to know what to do or say for the best, especially if she's not telling you how she's feeling. I would sometimes like to have an idea of what might help, because I hate feeling like I don't know what to do (Male)*

Subcategory of 'Desire for understanding':- Desire for the female to understand what the male might be feeling and experiencing

Definition:-

Males expressed a desire for the female to be given information about their experience and how they tend to deal with their feelings e.g. non-expression believing this protects their partner. Males are aware that they are perceived as not caring at times. They stressed this is not the case. They recognised that this was not helpful for their partner yet did not feel that it was easy or possible to express their feelings. This was mainly because the experience was perceived as easier for the male (by males) compared to the female.

Interviewee Comments:-

17.18 – 28.12 *I think it would be useful for 'x' to know what I am feeling because I don't think you do, do you? [male speaking to female] It looks like I don't care but I really do, it's in the back of my mind but I just don't talk about it all the time. (Male)*

2-65.01 *I think it would have helped 'x' [female partner] to know that I was feeling stuff about our situation but that I didn't express it because I was trying to protect her. I think I often came across as not caring, but that wasn't the case, it's just that it seems so difficult for women that you almost don't feel like you've got the right to put any extra pressure on her (Male)*

Subcategory of 'Desire for understanding':- About infertility and its treatment

Definition:-

It can be distressing for males when they are not made aware of what to expect in terms of diagnosis or treatment for infertility. Males expressed a need for information about the process of infertility and what their options were which would aid understanding of their position. Males wanted information about what they can expect and what would be required of them during the process. This was particularly important for males who had been diagnosed as the infertile member of the couple. Males want this information to be made available to them throughout the whole experience e.g. from the point they see their GP through to the end of treatment.

Interviewee Comments:-

18-14.32 *It's really difficult for a man, you go in and no-one explains anything. You are handed a pot and told to wank off in it and then you don't feel needed anymore. It might sound stupid but it would have been better if I was aware of all that before I went there. I want to know that other people have to do it too, you know some information about the process would have been good (Male)*

13.14 – 41.22 *I would tell the NHS or anyone that they need to provide information about the treatment and actual infertility and support to anyone going through infertility and not from someone in a white coat but from someone like you [pointing to me] who can talk to us like real people and use real language (Male)*

21.22 – 24.56 *Information about the practical, statistical and psychological aspects would have been invaluable. You know when you are pregnant you devour books and information, infertility is no different (Male)*

Subcategory of 'Desire for understanding':- The preferred format in which to receive information to aid understanding

Definition:-

In response to the questions of the preferred format to receive information the most popular answer males gave was via a DVD. The internet, books and leaflets were also acknowledged as sources of information. Males expressed they would not read a book. Feedback revealed that an informational DVD could serve the function of normalising the infertility experience, and in particular male infertility (for males). It was also suggested that a DVD could explain and promote the benefits of counselling.

Interviewee Comments:-

17.18 – 43.40 *A DVD telling men that it's quite normal [queried male infertility] and that they might benefit from talking to someone about it in confidence would be good. I suppose to explain what counselling is and how it can help (Male)*

17.18 – 28.19 *To put that [what each member of the couple is going through respectively] across in some way you know in a DVD would be great (Male)*

16-20.12 *I definitely think that I would have watched a DVD if there had been one but there wasn't, I found out everything I needed on the internet. I can tell you now that there was a lack of information in any format (Male)*

CATEGORY: IDENTIFICATION OF POINTS THROUHGOUT THE INFERTILITY EXPERIENCE AT WHICH MALES MAY BENEFIT FROM COUNSELLING

Definition: -

Potential counselling needs of males going through the infertility experience were identified. This led to the development of the category 'identification of points

throughout the infertility experience at which males may benefit from counselling'. Males experience issues in relation to infertility from the Pre-Active Infertility Stage through to the Post-Active Infertility Stage. Two points have been identified at which males may benefit from counselling. Both are located in the Active Infertility Stage. Counselling could benefit males to process the information that they have received regarding their future and identity whether it be about their fertility or whether they are going to be a father or not, amongst other things. Counselling may also be beneficial for any issues that males may experience in relation to infertility and/or related areas. These two points resulted in the following two subcategories:-

- **At point of diagnosis:** Males talked about how the diagnosis of male infertility is experienced as a shocking one. They talked about how it had the effect of them questioning their identity and how the news 'changed' their identity. Information regarding male infertility was in the case of one male, delivered in such a way that it did not take account of the potential shock which this news can evoke. This indicates that the offer of a counselling session following diagnosis could be beneficial to some males. The point of diagnosis in cases of female infertility or unexplained infertility did not emerge as a point at which counselling may be of benefit to males, in these interviews
- **At the end of a treatment cycle:** Males can feel marginalised throughout the infertility experience. The treatment process can be a difficult time for males as well as for females. It also ends hopes of becoming a father, at least for a period of time. This indicates that a counselling session at the end of a treatment cycle could be beneficial to provide males with an opportunity to talk through how they are feeling. Hence reducing the sense of feeling marginalised.

CATEGORY: MALE PERCEPTIONS AND EXPERIENCES OF COUNSELLING

Definition:-

Males expressed both openness and reluctance towards counselling and support groups. Openness was expressed towards counselling, especially if there was assurance that it would be confidential. Males said they would have definitely considered counselling if it had been factored into the treatment process. This highlights the fact that despite the

apparent openness males are more likely to go for counselling if it was 'obligatory' rather than actively requesting it. They expressed reluctance towards counselling for infertility. They said that whilst they would not have been 'offended' if counselling had been offered [which it had not in any case] it would not necessarily have been taken up. Males expressed a reluctance to talk in general about how they are feeling about the infertility experience. A male revealed that his reluctance was in part due to the fact that he did not want to discuss his feelings about treatment and his reluctance towards it. He felt that counselling could create a problem by highlighting this. The following two subcategories were developed:-

- **Openness towards counselling and support groups:** Males expressed openness to counselling, especially if they were sure it would be confidential. They said that counselling would have definitely been considered if it had been factored in to the treatment process. This highlights that despite the apparent openness it seems that males would be more likely to go for counselling if it was 'obligatory' rather than actively requesting it.
- **Reluctance towards counselling and support groups:** Males expressed reluctance in relation to going to counselling for infertility. Whilst males suggested that they would not be offended if counselling had been offered [which in each of the cases it had not] it would not necessarily have been taken up by most of them. Significantly males also expressed a reluctance to talk in general about how they are feeling about the infertility experience e.g. with others. A male revealed that this was in part a function of the fact that he did not want to discuss his feelings about treatment and his reluctance in relation to it as he had decided to 'go along' with what his partner wanted. In particular 'male pride' was highlighted as a factor contributing to not wanting to talk about male infertility. Interviews revealed that males, in general, seem to be able to accept and come to terms with their position [infertility], even when they are the infertile member of the couple. Hence they claim not to be too adversely affected emotionally and psychologically by the infertility experience [at least in relation to the females going through the infertility experience].

3.2 Summary of the potential counselling needs of males going through the infertility experience and male perceptions and experiences of counselling

The primary need identified for males was the desire for understanding throughout the experience. This included a desire to understand what the female experiences emotionally and physically. Males believe that this would help them know how to help their partner. As a result males believe they would feel less helpless. Males have a desire for females to understand what he may be experiencing emotionally and psychologically. This was deemed important by males as they do not always find it easy to express their feelings. There was also a desire to understand more about infertility and its treatment. The preferred format for delivering this information is via a DVD. This was in addition to the information that they would like to receive from medical professionals. Males expressed both openness and reluctance towards counselling. Two points at which males could benefit from counselling were identified - point of diagnosis in cases of male infertility and at the end of a treatment cycle.

13.3 Critical reflection and discussion

13.3.1 Reflections on the interview process

Males did not have as much to say as their female counterparts about the role of counselling. This was a contrast to Study 1 when males did talk about their experience and were actively engaged in the discussion. The interviews in this study flowed. Males appeared comfortable, demonstrated by their relaxed, open body language. I did not get the impression that they were holding back in response to my questions. In contrast to females, males did not have more to say beyond their initial response to my questions about counselling. When I attempted to explore statements or responses further, this resulted in expansion in some cases, but not always a great deal. The general sense was that male perceptions and experiences of counselling were straightforward, uncomplicated and were articulated accordingly. It seems that male pragmatic ambivalence towards fatherhood and having children extends to counselling.

The present sample included males with male factor infertility. Prior to interviewing I had anticipated that these males might have been less open. This was in part due to my clinical experience of working with this group. Moreover my experience is compatible with Mahlstedt (1985) who found that infertile males tend to be more reluctant than

infertile females to talk about their feelings. I also wondered what impact, if any, my gender would have on the interview process. I considered that it might be difficult for males to talk to a female about their infertility. These concerns were largely unfounded. Males did appear to speak openly and perhaps had more to say at times than those males who were not the infertile member of their couple. Becoming a father is likely to have been a factor influencing their experience and their willingness to talk about it.

When males initially started talking about their sperm counts/infertility I observed that they adopted a stereotypical 'macho' persona in terms of language and body stance. For example, males adopted a different accent e.g. a deep, cockney one. They used evocative language such as the word 'Jaffa' (a slang word for infertility, suggesting the male is 'seedless' in the way that a Jaffa orange supposedly is) and their 'bollocks not working'. This was noted as uncharacteristic when compared to the language and accent used throughout the interview. Humour was used at certain points during the interview and the overall sense was that this was an attempt to minimise the issue of their infertility and any related feelings. In contrast, there were points at which males talked more seriously about the shock of receiving the diagnosis of infertility.

13.3.2 Potential counselling needs of males

Findings revealed that males do not generally tend to experience the distress and intense sadness to the extent that their female partners do. This finding is supported in the literature (Greil, 1997; Read, 1995; Gibson & Myers, 2000). The overriding need identified for males was a desire for understanding. Males regularly raised the topic of wanting 'information', which at the stage of analysis was identified as a euphemism for wanting understanding. This desire for understanding possibly highlights the extent to which the male is marginalised and confused by the experience of infertility, even when he is the infertile member of the couple. The sense of inadequacy experienced by males (see Chapter 6) seems to be exacerbated by a lack of understanding about infertility and its treatment and about the female experience. For example, it was found that males can often be confused and at a loss as to what to say 'for the best' to help their partner. Furthermore, female anger (see Chapter 5) can lead to a sense that they have done 'something wrong' but they are not sure what this is. This can exacerbate feelings of inadequacy, compliance and marginalisation. Male desire to understand may to some

extent be a way of them feeling more in control of the situation and facilitate them in carving out a role throughout the process. It may help them make informed decisions in relation to treatment options, as opposed to the emotional decisions that they perceive their female partner may make. Males deserve to be given an opportunity to voice their concerns and feelings throughout the infertility experience. This is particularly important given male 'non expression of feelings' and sense of being 'marginalised' (see Chapter 6).

Males expressed a desire for females to understand more about their experience. This is important as they do not always find it easy to express their feelings. A desire to protect their partner seems to be a key factor for males not expressing their feelings about the infertility issue. Other factors may be that they find it too difficult, too painful, a sign of weakness or there may be a possibility that they fear that they may not be listened to by their partner, especially given that the tendency for them to be distressed. Males requested this understanding to take the format of a DVD, rather than a book, leaflet or website. This suggests that an easy access, non-confrontational and private approach to facilitating understanding, is desirable for males.

The shock of receiving a diagnosis of male infertility seems to be compounded by the way in which the news was delivered e.g. no preparation was given for the news and no counselling was offered in conjunction with their diagnosis. Males said this was a 'shocking' diagnosis to receive. They talked about the impact of diagnosis and how it called their 'male identity' into question. Glover *et al.,* (1998) point out that male infertility can lead to increased anxiety, self-blame and is perceived more as a threat than a loss. Thus their counselling needs are quite different to females. Diagnosis could be a crucial point for counselling to be introduced in a sensitive and encouraging manner. If males were to receive a routine referral to a counsellor at point of diagnosis then this could potentially increase male confidence. In turn it may empower them sufficiently to access this support at what can be a very difficult time.

13.3.3 Male perceptions and experience of counselling

Males were ambivalent towards counselling and expressed both openness and reluctance towards it. The infertility experience can have a negative emotional and psychological

impact on many males. Males expressed that they did not necessarily want to talk about how they were feeling, especially in cases where they are the infertile member of the couple. This finding is supported by Mahlstedt (1985) who found that her male infertile clients were reluctant to discuss their fears and feelings as openly as her female infertile clients. This is likely to be a major factor contributing to communication breakdown between couples. An informational DVD and/or counselling could play a role in helping males find ways of processing their feelings. Moreover they could be encouraged to communicate their feelings to their partner, so that they too may be supported through the experience.

In terms of the reluctance expressed towards counselling it may be that the features of the male infertility experience (see Chapter 6) could result in the sense that they do not have the 'right' to see a counsellor. Accessing counselling seems to be perceived by males to add to the pressure experienced by their partner, especially in cases of female factor infertility. Seeking counselling may also be perceived as a sign of weakness, which could compound the feelings of inadequacy that they may already be experiencing. Another factor that may contribute to this reluctance is that counselling and talking about feelings seems to be perceived by males as something that 'females do'. Counselling may be wrapped up in the femaleness of the infertility experience that males do not necessarily feel part of and hence do not tend to readily access. It is argued that if counselling were positively promoted directly to males this may serve the purpose of normalising it, thereby increasing the likelihood that males will access it should the need arise.

13.3.4 Support for the male model of the infertility experience

Findings yielded support for the characteristics of the male infertility experience. Males were found to experience sadness plus other identified features of the infertility experience e.g. feelings of helplessness (inadequacy), difficulty expressing their emotions (non-expression of feelings) and compliance (see Chapter 6). Whilst findings support the model of the male infertility experience more research is required utilising a broader sample of males. Research needs to focus on each of the characteristics and the stages of the male infertility experience to elaborate and further validate the male model.

Findings support a stage theory of infertility. Study 1 argued that infertility could bring about a qualitative change in those going it. The findings revealed that males experienced a perceived change to their identity as a function of the experience. This occurred both as a function of male infertility and the prospect of not becoming a father (regardless of who the infertile member of the couple was). This suggests the potential value of making counselling available to males to help them negotiate an identity transition.

13.3.5 Application of findings

Findings clearly highlight the value of having a resource that provides information about the female and the male experience. As a consequence of increasing male understanding females may feel less isolated, alone and angry going through the experience and hence the couple relationship would also benefit. Males are likely to benefit from the support of their partner if females have an understanding of their experience. In conjunction with further research appropriate informational and counselling resources appropriate to each stage of the infertility experience could be developed specifically for males.

Male uptake of counselling for infertility was less than female uptake. Males expressed openness to counselling but stressed the importance of knowing that counselling is confidential. Explicit assurance that counselling is confidential needs to be offered to males if they are to feel safe. Findings indicate that there may be a real need for males to be given an opportunity to voice their concerns and feelings throughout the infertility experience. This is particularly important given male 'non expression of feelings' and sense of being 'marginalised' (see Chapter 6). If males are offered counselling in a positive, non-judgemental way, this may serve the purpose of normalising it, thereby increasing the likelihood that males will access it if necessary.

Males reflected that they had not found it easy to talk about their infertility at the time of their diagnosis. Moreover they did not necessarily feel the need to talk. For them it was a private matter and not one for discussion. I have encountered this in my clinical practice, with a number of males articulating that they have been 'devastated' by the news but would prefer to 'deal with it on their own'. Furthermore many males do not share how they feel with their partners, leading to communication breakdown. This finding is supported by the literature (Abbey *et al.,* 1991; Mahlstedt 1985). Potential benefits of

counselling could be highlighted to infertile males along with information about how non-expression of feelings can lead to communication breakdown between the couple.

The area of diagnosis, both male and female, and the psychological impact of it on the individual and their partner requires further research. This is with a view to developing and tailoring appropriate psychological interventions for males at point of diagnosis.

13.4 Summary and conclusions

Findings revealed that males experience and deal with infertility differently to females. Consequently their needs are different. The key need identified for males was a desire for understanding. This highlighted the value of developing a resource providing information at each stage of the infertility experience for males. Males expressed a preference for a non-confrontational, easy access format that affords confidentiality e.g. a DVD. Further research to elaborate and check validity of the male model of infertility is required. It is proposed that the model in conjunction with further research can inform development of appropriate resources for males.

Males held mixed views towards counselling. It is argued that positive promotion of counselling emphasising confidentiality, specifically targeting males is likely to increase uptake. This is particularly important in cases of male infertility.

CHAPTER 14

FINDINGS & DISCUSSION 3: Potential counselling needs of couples going through the infertility experience and couples perceptions and experiences of counselling.

Overview

The chapter is arranged in the following sections:-

- Category development – Potential counselling needs of couples going through the infertility experience and couples perceptions and experiences of counselling.
- Summary of the potential counselling needs of couples going through the infertility experience and perceptions and experience of counselling.
- Critical reflection and discussion.

14.1 Category development: Potential counselling needs of couples experiencing infertility and couple perceptions and experiences of counselling

Two categories relating to the potential counselling needs of couples were developed. Four categories relating to couples perceptions and experiences of counselling were developed. Full descriptions of categories and subcategories, along with comments taken from the interviews are listed in Appendix 22. These are presented below.

CORE CATEGORY: IDENTIFICATION OF POINTS AT WHICH COUPLES MAY BENEFIT FROM COUNSELLING

Definition:-

Potential counselling needs of couples were identified leading to the development of this category. Couples going through the infertility experience do encounter issues as a function of it. Issues are present from the earliest stage of the infertility process through to post treatment. Issues can be experienced in response to critical events during the infertility process that can be distressing for the individuals/couple. Potential counselling points identified are in addition to feelings which may arise in relation to infertility and/or related issues, for which counselling may be beneficial, at any time throughout the infertility experience.

Subcategory of 'identification of points throughout the infertility experience at which couples may benefit from counselling':- Pre-Active Infertility Stage.

Definition:-

Couples are often referred for medical treatment without an opportunity to explore how they felt about infertility or whether they actually want children enough to have treatment. A potential need identified for couples experiencing difficulties was the opportunity for them to address and explore the issue of whether they actually want to proceed with treatment and what taking this route would mean to them. Another potential need identified was an opportunity for a couple to explore at the outset how they feel about their diagnosis and a potential future without children at the Pre-Active Infertility Stage. This is so they can begin to process the feelings.

Interviewee Comments:-

21.22 – 42.55 *I think a counselling session at the beginning or at the top of all this treatment should be offered to couples. I believe this is absolutely essential and it should be offered by a counsellor who perhaps has a line of communication with the IVF clinic or the GP (Female)*

9 – 53.34 *I mean we found ourselves on the treatment treadmill but we had not actually discussed whether we even wanted to be on it, why didn't someone ask us to stop and think about? I mean even though we had been trying for a baby we had never actually sat down and talked about what having a child would really mean to us and our lives and whether we really wanted that (Female)*

13.14 – 37.45 *We both think that people should be told about the difficulties or some of the issues they might encounter before you have any treatment don't we? (Female to Male), yeah definitely, preparation would have been very useful (Male)*

Subcategory of 'identification of points throughout the infertility experience at which couples may benefit from counselling':- At each stage of infertility as issues and feelings arise

Definition:-

Counselling could be beneficial for couples at any stage of the infertility experience as issues and feelings arise. The couple that had experienced couple counselling found it to be very helpful. Ways in which it helped were - with decision making, it enabled them to view their situation from different viewpoints and they gained insight into how infertility influenced the dynamics of their relationship. Couples without experience of counselling perceived it as a way to be able to learn how to provide support for each other during the whole process and also to be supported.

Interviewee Comments:-

16 – 17.21 *For me the biggest thing about the counselling was helping us to make our decision whether to tell our child about the donation that was a big thing for me to explore and work out. (Female)*

12-14.10 *I regret that we were never offered counselling more explicitly because we'd have definitely considered it; I know that I would have anyway.... I think it would have helped us to support each other better (Male)*

13.14 – 38.30 *It all becomes about the IVF and you can forget about being a normal couple and it would be good to be reminded why you were there in the first place, you know that you are a loving couple, you completely forget this and I think counselling would help this. (Female)*

Subcategory of 'identification of points throughout the infertility experience at which couples may benefit from counselling':- When treatment fails

Definition:-

The importance attached to the event of a failed cycle of IVF was identified as a point at which counselling could play an important role in helping the couple as a unit.

Interviewee Comments:-

13.14 – 51.25 *One thing I want to say is that I would like to doctors to always recommend counselling to couples if treatment fails, to me this is essential. (Male)*

17.18 – 55.23 *I know that if our treatment fails we will have to have some counselling to get through that (Male)*

Subcategory of 'identification of points throughout the infertility experience at which couples may benefit from counselling':- Post-Active Infertility Stage

Definition:-

The end of all treatment was identified as a potential point at which couples could benefit from counselling. This was raised by couples who had not had a successful outcome following treatment, by couples who had not reached that stage at time of interviewing, and by a couple who had had a child as a result of treatment. This demonstrates that regardless of outcome the process can be very stressful and issues can potentially arise following treatment, for which counselling may be beneficial.

Interviewee Comments:-

1.2-62.34 *I (Mal) would have jumped at the chance of counselling after the birth. Yeah I would have too (Female)*

9.10-33.15 *I feel that counselling would have been beneficial at the end of all the treatment, you feel so low and exhausted. In fact as a couple you are battered and bruised too (Female)*

14 – 22.47 *If we had not had children together God knows what would have happened, we'd have had to do something to help us deal with that (Male)*

CATEGORY: COUNSELLING TO FACILITATE COMMUNICATION AND UNDERSTANDING

Definition:-

Couple counselling facilitated both communication and understanding for the couple that had it. Couples reflected that following the joint research interview communication and understanding had been better between them. It seems that listening to each other talk about the infertility experience helped them to understand each other better. This understanding seems linked to the communication that occurs in the presence of a third party acting as a neutral facilitator. Discussion also encouraged further communication between couples following interviews. Couples reflected on the importance of communication whilst going through the infertility process. This recognition when linked with the finding that communication breakdown is a common feature of the infertility experience strongly suggests that couple therapy would be beneficial to many couples in order to avoid further breakdown in communication and understanding.

CATEGORY: PERCEPTIONS AND EXPERIENCES OF COUNSELLING

Definition:-

Both negative and positive perceptions and experiences of counselling were identified both in general and specifically in relation to the infertility experience. Positive perceptions of counselling tend to focus on the way that counselling is thought to work. The most common positive perception is that the process of counselling can help someone to see their situation from other view points. Another perception held is that

counselling can provide emotional and relationship support during the infertility experience. The experience of counselling for either infertility and/or other unrelated issues resulted in a change of perception from a negative view of counselling to a positive one, particularly for males in the sample.

A negative perception that emerged was that counselling is for 'mad people' and hence if one goes to counselling then they too are 'mad'. Linked to this perception is both suspicion and fear of counselling. This suspicion and fear seems to be borne out of the power that the counsellor is perceived to have. There was also a perception that counselling 'can't help' because it can't solve the issue e.g. provide a baby. There was also a belief that counselling could have a negative impact on the couple relationship because it would 'highlight' the division that existed between the couple. Two subcategories were developed: -

- **Positive perceptions and experiences:** Positive perceptions of counselling tend to focus on the way that counselling is thought to work. The most common positive perception is that the process of counselling can help someone to see their situation from other view points. Another perception held is that counselling can provide emotional and relationship support during the infertility experience. The experience of counselling for either infertility and/or other unrelated issues resulted in a change of perception from a negative view of counselling to a positive one, particularly for males.
- **Negative perceptions and experiences:** A common negative perception that emerged was that counselling is for 'mad people' and hence if one goes to counselling then they too are 'mad'. Linked to this perception is both suspicion and fear of counselling. This suspicion and fear is a function of the power that the counsellor is perceived to have. There was also a perception that counselling can't help because it can't solve the issue e.g. provide a baby. There was also a belief that counselling could have a negative impact on the couple relationship because it would 'highlight' the division that existed between the couple.

CATEGORY: INFERTILITY AS AN ISSUE FOR COUNSELLING?

Definition:-

The question of whether infertility is an issue that is relevant to counselling revealed that people held strong views in one or both directions e.g. yes it is or no it is not. In both directions, cancer in terms of severity of illness and the related experience was placed in a 'category' to which infertility was compared. For example infertility was placed in the same category as cancer because it was an illness that was accompanied by high levels of emotional distress. In contrast infertility was considered to be something that you had to 'get on with' because it was 'not like having cancer'. Two subcategories were developed:-

- **Infertility is an issue for counselling:** Infertility can be considered to be in the same category as bereavement, cancer and miscarriage in terms of the nature of the experience. Infertility was acknowledged as a medical issue that impacts on psychological well-being. For those that perceived infertility as a psychological and or emotional issue it was considered to be an issue that was relevant to counselling.
- **Infertility is not an issue for counselling:** Infertility is not always perceived as an illness. This gives rise to the perception that infertility is something that you are expected to 'get on with'. This perception seems to be in part generated internally but is further compounded by external factors. Counselling was not seen as a process that could help because it could not provide a solution to the problem e.g. a baby. The link between infertility and the issues e.g. relationship difficulties that might bring someone into counselling was not always made.

CATEGORY: LIMITED OR NO KNOWLEDGE OF BENEFITS OF COUNSELLING

Definition:-

Some couples had little or no knowledge of the potential benefits of counselling. There was a perceived sense that counselling could be beneficial although the ways in which it was thought to help were not clear.

CATEGORY: RELUCTANCE TO HAVE COUPLE COUNSELLING

Definition:-

Males explicitly expressed reluctance in relation to the prospect of couple counselling. They believed it would have brought their 'problems' to the surface and highlighted the division between them and their partner. A male perceived counselling to be a 'hand holding' exercise. Conversely, none of the females expressed reluctance towards couple counselling.

14.2 Summary of the potential counselling needs of males going through the infertility experience and male perceptions and experiences of counselling

Distinct counselling needs were identified for couples at each stage of the infertility experience. The key need is to facilitate communication and understanding. Counselling could benefit couples dealing with a number of specific issues as they arise. Both positive and negative perceptions of counselling are held in general and specifically for infertility. Males expressed reluctance towards counselling but no females did. Infertility was considered an issue for counselling when perceived as an illness and/or a form of bereavement, but not when perceived as something you have to 'get on with'. Some couples had a limited knowledge of what counselling is or how it could help. The value of GPs introducing counselling and its benefits was proposed.

14.3 Critical reflection and discussion

14.3.1 Reflections on the interview process

In both studies couples provided positive feedback about talking in the company of each other. It seems that communication around infertility and the related issues during interviews facilitates an understanding that had previously been absent between couples. I realised that the interviews were the first time that many of the issues raised had been discussed between couples or with a third party. As someone who has not personally experienced infertility, prior to embarking on this research I had assumed that couples would have discussed these issues with each other. This research and my clinical practice have shown this assumption to be unfounded.

Males were more open, frank and honest when discussing their feelings and concerns in the couple interviews than they had been with their partner prior to the interview. Thus an interview setting served to facilitate males in expressing their thoughts and feelings. This

contrasts with the male tendency to not express their feelings to their partner directly (see Chapters 6 and 13).

14.3.2 Potential counselling needs of couples

Non-communication was identified as the key characteristic of the infertility experience for couples (see Chapter 7). This finding was strongly supported in Study 2 and has been found to stem from the Pre-Active Infertility Stage. Hence the key counselling need for couples is to focus on communication. This could serve to reduce distance between the couple as they progress through the infertility experience. The key issue that emerged from the Pre-Active Infertility Stage was that couples in the sample did not spontaneously tend to speak about their difficulties in terms of what it meant to them as a couple or to the partner who was diagnosed as infertile. The issue of having children and the future with or without children does not tend to be discussed within couples. This is perhaps the starting point from which lack of discussion about other issues could begin e.g. diagnosis and treatment.

Non-communication may not be a conscious process. Monach (1993) in his study of infertile couples found that marriage perceptions are inextricably linked with expectations of childbearing. The prospect of having or not having a child may be too painful to address and discuss, once there is the possibility of infertility. Lack of communication may also be due to the shock of receiving a diagnosis of infertility and/or the hope that they will fall pregnant and become parents. Interestingly couples suggested that their GP played a role in this lack of discussion. They talked about how they were referred by their GP for investigations/treatment without it being 'suggested' that they talk things through first. This suggests that couples may not actively avoid the topic but that it may not occur to some couples to have the discussion about children and the future. This may be due to following social norms that propose that when one grows up they will get married and go on to have children (Monach, 1993). Consequently the issues are not even discussed. Certainly in my clinical work couples will often say that they had 'never thought about it' [having a child] and took it for granted that when they wanted to start a family they would be able to. Hence they never discussed it.

14.3.3 Couple perceptions and experience of counselling

The couple with experience of counselling found it to be a positive experience. It was only sought following 6 failed IVF cycles - the point at which they were told they would not achieve conception using this method. This indicates that couples like females (see Chapter 12) consider counselling in response to a 'crisis'. For this couple it was the female that instigated counselling. This is in line with the role that the female tends to play in initiating infertility treatment (Greil, Leitko, & Porter, 1988; McGrade & Tolor, 1981). This demonstrates that male compliance (see Chapter 6) can extend to embarking on counselling. Counselling helped this couple deal with their 'crisis' and to explore other options available to them. Prior to counselling this couple sought support from a male infertility support group (which partners could also attend). Initially the male did not want to attend but found it beneficial because talking to other infertile males served the function of 'normalising' his experience.

The differing and at times competing male and female perceptions and needs exerted their influence in relation to couple counselling. For example, females were all open to the idea of couple counselling. In contrast males expressed reluctance towards couple counselling.

Both positive and negative perceptions were held towards counselling in general and for infertility. Positive perceptions map onto the aims of counselling practice e.g. providing an opportunity to talk to someone outside the individual's/couple's situation, to be listened to, to talk freely without feeling judged, to help problem solve and to resolve conflict amongst other things. Negative perceptions seem to be rooted in the underlying belief that counselling is for 'mad' people. This seems to generate the implicit fear that counselling could lead to being 'locked up'. This perception places the counsellor in a position of power over the client. Significantly negative perceptions were reversed following an experience of counselling or through gaining knowledge of counselling. This highlights that knowledge and/or the experience of counselling may be the most important factor in terms of changing perceptions of counselling. Limited knowledge of counselling may explain why many individuals/couples only seek counselling at times of 'crisis' when it may seem that there is no other way forward.

The question of whether infertility was deemed to be an issue for counselling emerged. Results were mixed with some agreeing strongly that it is and with some arguing that it is not. When infertility is deemed to be a form of bereavement and/or an illness it seems that this is a form of legitimising the issue as one that is appropriate for counselling. This finding is supported in the literature (e.g. Crawshaw, 1995; Read, 1995). In contrast when infertility is perceived as 'something that you have to get on with' it is not seen as an issue for counselling. Interestingly, in the latter case it seems that the infertility issue is separated from issues that may lead an individual/couple to seek counselling. For example 'relationship issues' and 'not feeling yourself' were cited as reasons to seek counselling but not 'infertility' per se. This perception reveals that infertility itself is not considered a legitimate issue for counselling. Females were more inclined to consider infertility in terms of illness and/or as a form of bereavement and hence more likely to consider it as an issue for counselling. This reflects both the female experience of infertility (see Chapter 5) and their openness to counselling which maps onto their potential counselling needs, identified in Chapter 13. At the same time females were also of the impression that they were 'expected' to get on with it. This seemed to serve the purpose of minimising the experience, hence magnifying the negative response to it. This may explain in part the primarily female need to 'legitimise' the infertility experience and in particular why events such as miscarriages can legitimise the loss that they are feeling (see Chapter 5). In short it can give females 'permission' to have counselling (Crawshaw, 1995). Furthermore it seems that other people's perceptions can contribute to the female perspective that they are not 'coping' as well as they 'should' be which can add to the pervasive sense of failure felt by many females (see Chapters 5 and 13).

14.3.4 Support for the couple model of the infertility experience

Findings yielded support for the characteristics and stages of the couple model of infertility. Communication breakdown is the key characteristic for couples experiencing infertility (see Chapter 7). This was reported by all couples interviewed and was the main feature of their experience. Moreover the female tends to take control of their situation e.g. by instigating counselling and treatment options.

Distinct counselling needs were identified at each stage of the experience. The experience for couples is complex and evolves as they progress through the infertility experience. As

a consequence the needs of the couple change as they transition from one stage to the next. Although communication breakdown is a recurrent feature the nature of the breakdown differs between stages in line with the features of the stage.

14.3.5 Application of findings

One couple interviewed had sought counselling for infertility. A key issue that links to counselling uptake is the perception of infertility e.g. whether it is perceived as an illness or something that you have to 'get on with'. The benefits of counselling for infertility need to be explicitly outlined to all couples going through the experience if more couples are to consider it and benefit from it. The current estimate of uptake is 25% or less (Sundby *et al.*, 1994; Hernon *et al.*, 1995; Schmidt *et al.*, 2003). Counselling information needs to convey the message that infertility does not have to be something that couples 'have to get on with'. Highlighting benefits of counselling is particularly important given that couples interviewed had little or no knowledge of them. It is proposed that the optimal time to introduce counselling information would be the Pre-Active Infertility Stage. Findings indicate that a support group could be less threatening than couple counselling particularly for males. My clinical experience would concur with this. This suggests the value of promoting the benefits of support groups to couples.

Findings revealed that the topic of children and the future is not always discussed. Moreover, couples felt that they 'should have been encouraged' to have discourse on the issue prior to treatment. This suggests that discussion between the couple could be encouraged by GPs at point of referral for investigations/treatment. GPs could do this via distribution of a leaflet or other resource e.g. a DVD. This would not increase their workload.

Counselling could provide the opportunity to facilitate discussion for those couples that do not find it easy to communicate about the issue. If couples are encouraged to tackle this issue at the Pre-Active Stage there could be significant benefits. It could facilitate better understanding and communication during the Active and Post-Active Infertility Stages. This could in turn reduce some of the distress and anxiety that may be experienced by both members of the couple. Further research into communication patterns of infertile couples is required so that counselling psychologists can understand

more fully the point at which it breaks down. Then interventions can be developed and tailored for infertile couples with a view to preventing and resolving communication issues, with maximum effect.

Counselling is available at licensed treatment centres (HFEA, 1993, 1999, 2005; Jenkins *et al.* 2003). At many treatment centres the onus for seeking counselling is on the individuals/couples. Couples interviewed perceived counselling as a service that should be explicitly offered rather than one they seek out. This may happen in some cases in line with the HFEA code (1993) that states that 'support' and 'therapeutic' counselling should be provided in appropriate cases. However, a couple that experienced 9 years of infertility encompassing multiple IVF attempts, none of which were successful, said that they were not offered counselling once during this time. In addition a couple had experienced six failed attempts in quick succession without an offer of counselling being made. This raises the serious question of what constitutes an 'appropriate' case for referral to 'support' or 'therapeutic' counselling. It is argued that information about the counselling service should be available in the waiting room and via the consultant. Benefits of counselling need to be made clear.

The expectation held that counselling will be explicitly offered suggests passivity towards and a naivety of counselling in individuals and couples going through the infertility experience and hence a reliance on the medical professionals to inform them. This is something that practitioners in the field could work with if they were made aware of this need. Counselling psychologists can work on raising this awareness through distribution of information and building relationships with GPs.

Availability of information about the infertility experience, how counselling could benefit as well as information about how to find a counsellor at the Pre-Active Infertility Stage via GPs could encourage and help individuals/couples to seek counselling if the need arises.

14.4 Summary and conclusions

Positive and negative perceptions are held towards counselling. Perceptions held about infertility may explain why the current uptake of infertility counselling and support

services is less than 25% (Sundby *et al.*, 1994; Hernon *et al.*, 1995; Schmidt *et al.*, 2003). Couples perceive counselling as a service that should be explicitly offered by GPs and consultants. It is argued that couples would greatly benefit from being empowered at this difficult time in their lives. Clear information that positively promotes counselling for infertility and its benefits could encourage clients to access counselling from the point at which they experience difficulties conceiving. Hence feel more in control during the experience.

For couples the main benefit of counselling is likely to be through facilitating communication between the couple. This in turn could reduce strain on the relationship throughout the infertility experience.

Counselling psychologists can play a vital role in furnishing GPs with the information they need in order to promote communication and counselling to their patients.

CHAPTER 15

GENERAL DISCUSSION - STUDY 2

15.1 Study Aims:-

- To explore perceptions, beliefs and experiences of counselling in order to understand the factors involved in the decision making process around whether to have counselling for infertility.
- To identify potential counselling and support needs of the male, female and couple respectively going through the infertility experience.
- To check the validity of findings in Study 1.

15.2 Critical reflection and discussion

A range of counselling perceptions, both positive and negative, was identified. The potential influence perceptions may have on counselling uptake were discussed. Counselling experiences were positive and helped clients in a range of different ways, depending on the stage at which it was accessed and the presenting concerns.

Distinct counselling needs were identified for the female, the male and the couple at each stage of the infertility process. Moreover distinct counselling needs were identified within these stages, depending on the nature of the experience for the couple and individual.

Findings support the characteristics of the female, male and couple models of the infertility experience. Findings also support a stage theory of infertility. More research into each of the models of infertility needs to be carried out to elaborate and validate each of them.

Application of these findings is important. Findings can inform the ways in which counselling is promoted to those experiencing infertility. They can also inform the use and development of counselling interventions for these three client groups, at each stage of the experience.

It is important that those experiencing difficulties conceiving get the attention, support and information they need at the earliest possible opportunity. Counselling and its benefits need to be promoted positively to females, males and couples respectively. Information needs to be tailored specifically to each group if individuals and couples are to access support going through the infertility experience.

It is proposed that information regarding the emotional and psychological issues that may be encountered throughout the infertility experience could be routinely introduced at the Pre-Active Infertility Stage by GPs e.g. via a leaflet or DVD. The consequence being that if and when issues are encountered, the individual and/or couple can recognise their distressing experience and their response to it as 'normal'. This is likely to serve the purpose of normalising the process and could in turn reduce the distress experienced. GPs are very busy and it is perhaps unrealistic to expect them to have time to achieve this in reality. Counselling psychologists working in this field can facilitate this process by developing relevant literature and resources specifically for this client group. They can forge relationships with GPs, nurses and treatment centres and furnish them with information about the work that we do and the benefits for this client group in a clear, user friendly format.

It was established that a DVD format could be utilised in the development of a resource. A DVD would preferably include information about physical and medical processes in addition to the psychological and emotional impact of the infertility experience. It would also include information about how to find a counsellor. Study 3 is concerned with the development and production of a psycho-educational resource outlining the emotional and psychological impact of infertility on the couple and the individuals within the couple unit.

The aims of the study have been met although there are some caveats. Only one couple had experienced couple therapy and this was brief. The experience of counselling was positive. Further research looking at the advantages and disadvantages of counselling for infertility and its related issues is required. For example, via the exploration of differing experiences of couple counselling e.g. positive/negative and short/long term would be beneficial in terms of broadening our understanding of this area.

Given the research focus a second caveat is that all couples in the present study are heterosexual and still together. The experience of counselling and the role that it may play, positively and/or negatively, for couples who are no longer together has not been addressed. This is an important area that warrants further research given that many couples do separate as a result of the infertility experience (Salvatore *et al.* 2001; Levin & Sher, 2000; Greil, 1997; Kumar & Leo, 2003; Leiblum *et al.* 1998).

A third caveat is that this study did not address the potential counselling needs of those experiencing involuntary childlessness that are heterosexual or homosexual males or females who have no partner and do not wish to have a child alone or with a same sex partner.

In addition the potential counselling needs of those individuals/couples requiring egg, sperm or embryo donation have not been addressed in the present study. This is a very important and expanding area in the field of infertility. Whilst there is a body of research that is concerned with gamete donation and the role of counselling (e.g. Hewitt, 2002; Taylor & Bagshawe, 2003; Turner & Coyle, 2000) more research is still needed.

Knowledge and understanding of the needs of the three potential client groups outlined above is important. These groups are equally relevant to the work of counselling psychologists. Further research into the experience of this group of childless females and males is required if counselling psychologists are to develop a comprehensive, specialised counselling services tailored for these clients.

A fourth caveat is that a qualitative methodology has been employed hence the sample is relatively small. Caution should be exercised when interpreting the findings. However many findings are widely supported in the literature and are compatible with the experience of many of the individuals and couples that I see in practice. This suggests that the findings are relevant and applicable to others going through the experience of infertility. Further research needs to utilise a larger sample and a combination of quantitative and qualitative methodologies to establish the extent to which the present findings are applicable to others going through the infertility experience.

In terms of the research experience, in contrast with the interviews in Study 1 the content of the interviews in this study was less emotionally charged. As a result it felt easier to stick to the interview boundaries and not run the risk of straying into counselling territory. Despite the fact that this 'felt' easier I tried to remain aware of my role at all times so that I could adhere to my remit. Interviews felt less intrusive and I was more experienced than in Study 1, which meant that I felt more relaxed in my role as researcher. I believe that this impacted positively on data collection.

Data analysis was still an anxiety provoking experience. However knowledge gained from data analysis in Study 1 helped considerably. I was able to cope with the uncertainty the process evokes. I was also more confident about the process and trusted in it.

15.3 Summary and conclusions

Findings lend support to a stage theory of infertility and the characteristics of the female, male and couple models of the infertility experience proposed in Study1. It is important that those experiencing difficulties conceiving get the attention, support and information they need from the point at which difficulties are encountered.

A wide range of potential counselling needs was identified for females, males and couples respectively. Despite this the current uptake of counselling services by those experiencing infertility is 25% or less (Sundby *et al.*, 1994; Hernon *et al.*, 1995; Schmidt *et al.*, 2003). The important role that the GP can play in changing this was highlighted. GPs are in a position to manage individuals and couples expectations of the infertility experience. They are also in a position to promote the value of counselling to this patient group. Counselling psychologists need to work on developing appropriate resources for distribution to GPs to facilitate this process if those experiencing infertility are to access appropriate support.

Infertility is a specialist area and the HFEA (2003) and the British Association of Counselling (BICA) (1999) support the need for infertility counsellors to have specialist knowledge and training. Thus counselling psychologists working with a client experiencing infertility are responsible for familiarising themselves with the differing male and female experiences of infertility and how these impact on the couple unit so that

they can understand both the subjective experience and the counselling needs identified in this study.

CHAPTER 16

STUDY 3

Development of a pilot psycho-educational tool as an aide to provide information and support for couples experiencing infertility.

Study 3 - Research Method & Design

Video Production and Feedback session aims

- To develop a psycho – educational tool providing information and support to those going through the infertility experience, from the point at which difficulties conceiving are encountered e.g. Pre-Active Infertility Stage.
- To gain feedback regarding the relevance of the tool.
- To check the validity the findings of Studies 1 and 2.

16.1 Objectives

The objective was to make a pilot psycho-educational tool based on findings from Studies 1 and 2. The tool would provide insight and support for those experiencing infertility from the point at which difficulties conceiving are encountered e.g. The Pre-Active Infertility Stage. It is clear from findings in Studies 1 and 2 that experience and hence needs differ, depending on what stage of the infertility experience the individual or couple is at. Thus it was not intended to develop a tool relevant to all those going through the infertility experience.

Study 2 identified a DVD as the most popular medium for this aim. Moreover one of the benefits of a DVD is the user friendly layout. For example three different sections can be viewed individually e.g. one for the couple, one for the female and one for the male. Hence it was decided that an audiovisual medium would be used in the tool development.

Study 2 revealed that information about what the infertility process is like would be desirable for those going through it, particularly males (see Chapters 12- 14). The aim was to create a film that could provide insight into the key features of the female, male and couple infertility experiences, respectively. The intention was to provide the viewer with other perspectives of infertility by watching another couple, another female and another male talk about their feelings and experience e.g. males could gain insight into what other couples, other males and females may experience.

It was anticipated that watching the video could serve the role of normalising the viewers' response to their own infertility and in turn play a role in reducing distress. Another aim was to provide a sense of what a 'real' counselling session is like with a view to demystifying the process (see Chapter 15) as well as highlighting some of the potential benefits of counselling for infertility.

Following development of the video three couples viewed it. Couples were located at different stages of the infertility experience e.g. a couple had recently made the transition from the Pre-Active to the Active Stage, a couple had been in the Active Stage for one year and a couple was in the Post-Active Stage. Then feedback on the video was sought.

The feedback exercise served two purposes. First, to check validity of the infertility models developed in Study 1. Second to establish the point at which viewers deemed it appropriate or beneficial for the video to made available to those experiencing infertility. It was anticipated that this would support or refute both the characteristics of the infertility experience and the stage theory of the infertility experience established in Study 1. Suggestions for improvement of the video were also sought. This was with a view to developing an appropriate psycho-educational resource for those experiencing difficulties conceiving beyond this research.

16.2 Development of the audiovisual psycho-educational video

The researcher had no previous experience of filming or production and contacted a friend who is a scriptwriter and film director. The steps followed during the development of the video will now be outlined. Material presented to and discussed with the director was treated in confidence and all identifying information was removed from transcripts.

16.2.1 Preparation

A meeting was held with the director to discuss the aims of the video. She was given a copy of Studies 1 and 2 prior to meeting and was familiar with the research. Study 2 revealed that both individuals and couples would find information and preparation for the infertility experience beneficial at the point at which they visit their GP (see Chapters 12-16). Thus the video was intended for those in transition from the Pre-Active Infertility Stage to the Active Infertility Stage. The idea was to develop a pilot version of a video that could in theory be distributed to GPs and clinicians.

Following discussion with my research supervisor the original intention for the video had been to be explicit about characteristics of individual infertility experiences and discuss them each in turn e.g. the female sense of failure, followed by sense of isolation (see Chapter 5). It became clear that this would be a timely and costly procedure, given the volume of information that would need to be covered (see Chapters 5-8). Moreover the director advised that it might be too 'dry' and 'academic' for people to engage with. Instead she encouraged other ways of conveying the information. Following a discussion with my research supervisor it was suggested that we create an exemplar fictional couple, the director agreed with this plan.

The fictitious couple are called 'David and Sally', and their profile and experience is based on findings from research interviews and my clinical practice. The plan was to create a series of mini counselling sessions with me in the role of counselling psychologist, first with the couple and then with each individual. The aim of this study was to develop a psycho-educational video. Hence it was decided to set a task at the end of each section. This provided the viewer with a practical exercise that they could carry out in their own time, should they choose to.

Given time and cost constraints the director proposed that the film should be no longer than 30 minutes. The format agreed on was a brief introduction from me followed by 3 ten minute sessions e.g. one with the couple, the female and the male.

The director advised against fully scripting the scenes. Firstly, because the researcher did not have any experience of script writing. Secondly because she believed that using a

rigid script in this instance could result in an unnatural setting, which could look too staged. It was felt that this could potentially alienate the viewer and not meet the aim of the video. It was decided that actors would get a copy of all categories and related comments from Studies 1 and 2. This information was sent ten days prior to filming in preparation for improvisation. They each received an overview of each scene followed by a breakdown of the scene including aims for each section. All information was written and compiled by the researcher. Full outlines each of the scenes are provided in the Appendices - couple scene (Appendix 24), female scene (Appendix 25) male scene (Appendix 26). They also received a précis of the couple experience (Appendix 27), male experience (Appendix 28) and female experience (Appendix 29) of infertility including a copy of the relevant model taken from Study 1 (see Chapters 5, 6 and 7). Each précis included the general characteristics of the infertility experience. These characteristics were weaved into a context that built on Sally and David's profiles. This was to bring them to life with a view of helping the actor identify with the character they would be playing.

An excerpt from the couple scene is outlined below. It includes the aim and the introduction of the scene (Appendix 24):-

COUPLE SCENE

Aim of scene:-

To demonstrate how a breakdown in communication about 'the issue – infertility/not getting pregnant' creates a distance between the couple. This breakdown is due to the differing male and female experiences of infertility (these are outlined in the 'key issues' leaflet). The intention is to start out with distance between couple both physically and emotionally e.g. not touching each other, facing slightly away from each other, female hugging herself with arms in a protective pose, male looking defensive e.g. folded arms. I want to demonstrate how through talking to each other in the session the couple close this distance and come together by the end of the session e.g. holding hands/David's arm around Sally's shoulder.

The Scene:- Time = 10 minutes

PART 1– INTRODUCTION (2 minutes)

Aim: To introduce the couple, their history (briefly) and the problem

Jo: Hi David & Sally, nice to meet you both, thanks for coming today. How are you feeling?

Sally: A bit nervous actually

David: *shrugs* 'ok', *not really engaging.*

Jo: Ok, well perhaps you could tell me a bit about how long you have been together and how long you have been trying for a baby together?

Sally & David look nervously at each other

David (*to Sally*): "do you want to do it?"

Sally: 'ok' .... *Then Sally to tell me how long you've been together and how long trying and going to GP etc. using information from profile*

Sally refers to David now and again e.g. it's been about 2 years hasn't it David, who responds accordingly. Jo will respond to Sally at appropriate points and ask David or Sally questions if necessary to prompt conversation.

One professional actor and one amateur actor agreed to take part in the film. The professional actor was recruited by the director. The amateur actor was a friend of the researcher. Actors were each paid £100.00 for their contribution.

16.2.2 The end of scene tasks

A simple task was set at the end of each section e.g. a couple task, a female task and a male task (Appendix 30). Tasks were discussed with my clinical supervisor and my research supervisor. I had previously used these tasks in my clinical practice with positive feedback from clients. The aim of each task was to facilitate constructive communication between the couple.

16.2.3 Ethical Considerations

Not knowing the professional actors' background and knowing a little about the amateur actors' background it was important that each had a 'character' to act that was clearly detailed. Profiles of the couple (Appendix 31), the female (Appendix 32) and the male (Appendix 33) were developed. The rationale for providing profiles was due to the

sensitive nature of the topic. Also the experience of the fictional couple may have mapped on to either of their personal experiences. The aim was to make the character that they were acting separate from their own. Whilst the professional actor may have been trained to deal with this eventuality I could not be sure that the amateur actor had.

Both actors received a copy of the support organisations contact sheet (Appendix 4) to cater for the eventuality that the process had touched on any of their issues.

16.2.4 Equipment

A Sony DV handheld camera (model DCR – 8C19) and tripod were used in the filming in conjunction with a Sony microphone (model ECM – MS907) and Sony DV tape (model DVM60 Mini DV). The camera and the tripod were leased from City University Audiovisual department.

16.2.5 Filming

One day was allocated for filming. The team comprised of the researcher, two actors and the director. An initial meeting took place between the researcher and the director to clarify and finalise the aims and objectives of the video. A meeting with all the team followed, to run through the order of the day. The director made sure that the researchers' aims were conveyed to the actors. She also answered technical questions that the actors had.

Once filming commenced the director managed the day. There were regular consultations with the researcher throughout the day regarding the progress and the outcome of the scenes.

16.2.6 Editing

An editor from the BBC edited the video. The editor was a contact of the director. This process took 1 day in total with 4 hours in the studio for the final edit which myself and the director attended, to provide guidance and feedback regarding the finished product. The editor was paid £250.00 for her contribution.

16.2.7 From the master copy to multiple copies

The editor issued the researcher with a master copy on a tape. This was taken to a production company in Soho. Here it was advised that it was best to copy the film onto video tape (VHS) to guarantee that all the viewers could play it. The reason being that DVD formats differ greatly and there is no certainty that a copy would play on all DVD players. In order to achieve this, a 'glass copy' would need to be made and this requires a minimum of 5,000 copies. The pilot film was copied onto VHS tape.

16.3 Purposive Sampling

Couples at different points of the infertility experience were sent the video and subsequently interviewed. One couple had made the transition into the Active Stage but had not received a diagnosis or had any treatment at point of interviewing and were still hoping to conceive naturally. Another couple was in the Active Stage and had recently undergone IVF treatment, which had failed. The third couple were in the Post-Active Stage and had a three year old child via IVF. The rationale for selecting these couples was because couples and individuals at different stages of the infertility process were likely to provide feedback regarding both the experience conveyed and the stage theory of infertility. This would in part be based on when the video was deemed beneficial to view by the couples providing feedback. All couples had previously participated in either Study 1 or Study 2.

16.4 Distribution of the video

The three couples who agreed to participate were contacted by the researcher to make a date for the feedback sessions. Then the video was distributed to each of the couples. A cover note was sent with the film outlining the purpose of the feedback exercise (Appendix 34).

16.5 Recruitment

All couples who participated in Studies 1and 2 were asked at their original interview whether it was possible to contact them at a later date with a view to reviewing a psycho-educational tool that was going to be developed. All couples agreed. Prior to filming four couples located at different stages of the infertility experience were randomly selected and contacted by telephone to invite them to review the video. One couple was not in the

country at the time and were unable to participate. The other three couples agreed to participate.

16.6 Theoretical Sampling

The aim was to gain a wide range of feedback so it was decided that the couple who were at the early Active Infertility Stage would be interviewed first, followed by the couple who were located in the in the Post-Active Infertility Stage ending with an interview with the couple in the later Active Stage.

16.7 Confidentiality and consent

The same steps outlined in Study 1, Chapter 3 (3.6) were followed prior to consent forms (Appendix 5) being signed by all participants.

16.8 Equipment

Interviews were recorded on a Sony portable MiniDisc Recorder (model MZ-R50) with a Sony Electret Condenser Stereo Microphone (model ECM-MS907), using Sony Mini Discs (80 minutes duration).

16.9 Data collection

Nine feedback sessions were conducted in total. Couple interviews were conducted prior to individual interviews. This way the format remained the same as in Studies 1 and 2 at the same time as permitting relevant feedback regarding each of the sections. All three couples were interviewed in their homes.

Each feedback session lasted approximately 20 minutes. Prior to the session commencing, participants were thanked for agreeing to participate. They were reminded of their right to withdraw from the study at any time without explanation. They were informed that they did not have to answer any questions they did not want to. They were shown how to turn off the recorder so that they had a sense of control and could exercise choice without having to ask the researcher.

All interviews were semi-structured and focused on the content of the film, with the first couple and individual interview being the least structured. The aim of this was to yield a

rich data set. The focus of the interviews became more specific as key themes emerged. The initial and final questions remained the same for each interview and these are outlined in the following section.

16.10 The couple feedback session

To ensure participation from both members of the couple, each couple interview opened with the following open ended question -

"What did you both think of the film?"

Questions covered in the first interview can be found in Appendix 35.

Each interview ended with the following question –

"I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or discuss?"

Finally, all couples were thanked for sharing their experience with me and asked whether they had any questions.

16.11 The individual feedback session

Interviews commenced with the following question:-

"Thanks for feeding back on the couple section. Is there anything that you wanted to add about the couple section?"

This was followed by this statement and question:-

"Ok, I am now interested in hearing what you thought of the individual sections. Please feel free to be critical of any aspect of the film.

What did you think of the individual sections of the film?"

Questions/areas to be covered used in the first interview can be found in Appendix 36.

As with the couple interviews each individual interview ended with the following question –

"I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or discuss at this point?''

Finally, participants were thanked and asked if they had any questions.

CHAPTER 17

Data Analysis

Overview

Grounded theory principles were followed in the analysis process. A step-by-step guide of the analysis process is presented in this chapter, using an example from the 'female' data set. The analysis outlined was carried out on each data set - male, female and couple. The process is described in 'stages' for purposes of illustration however it was not a linear process as different stages of analysis were operating in tandem. There was a constant interplay between data analysis, collection and the developing themes.

17.1 Stage 1 – Open coding

As in Studies 1 and 2 the actual recordings were used as a permanent record and I initially analysed directly from the recordings (Pidgeon & Henwood, 1998). I listened to the male, female and couple interviews once without making any notes. At this stage I was interested in getting an overall sense of the data, observing what tone was used and when, comparing interviews with notes taken during interviews regarding observed body language that accompanied comments and what impact my questions had on participant responses.

On second listening I started open coding of the data (Strauss & Corbin, 1998). I stopped the disc every few seconds and considered what was being said and then coded it. Each interview had a record which included the location (time) on the disc of the comment being coded, the participant interview code and the label code. An example is below, data codes are shown in bold:-

5-3.15 (Code: participant = 5, location on disc = 3 minutes 15 seconds)

Yeah I mean I can see how useful it [the video] is **[video deemed useful]** because I really recognised myself **[viewer can identify with female]** in it and although I feel like I've moved through that stage **[video appropriate for a particular stage]** I think it would have really helped at the time **[video helpful at point when female starts experiencing**

the emotions highlighted in video] because you really do feel like you are not coping and that you are going a bit mad **[video helpful because female can feel as if not coping and going a bit mad]**. That really made see that how I was reacting was normal **[video playing a role in normalising coping mechanism/response to situation]**.

17.2 Memos and diagrams

Memos and diagrams were kept throughout the analysis and formed a key part of this process (Strauss & Corbin, 1998). All memos and diagrams were dated, noted participant and disc location codes, given a title and any other relevant information. An example of a memo written for the data coded 9-8.34 is set out below:-

MEMO – 5-3.15, 28 /7/05. 'FEMALE'

VIDEO PLAYS ROLE IN NORMALISING FEMALE RESPONSE TO INFERTILITY EXPERIENCE – How?

Identification with the female in video seems to engage the viewer. The process of demonstrating the key characteristics of the female infertility experience in this way seems to evoke recognition of the experience in the viewer. The process of seeing another female responding / coping in this way seems to serve the function of normalising the female viewers response e.g. 'not coping' and 'going a bit mad' to her own situation.

Does this identification and process of normalising have the potential to actually reduce distress though?? Need to explore/consider.

17.3 Stage 2– Development of key points and themes

Initial analysis of the 'female' data (first interview) yielded 23 concepts in total - 9 in relation to the validity of the models of the infertility experience and 14 in relation to the video. Constant comparative analysis was used to examine similarities and differences of codes and concepts within this case. Comparisons were also made with the couple and male data prior to the second set of interviews. Nine tentative themes were generated. Four themes pertained to the models of the infertility experience. These were – 'Couple characteristics of the infertility experience', 'Female characteristics of the infertility experience', 'Male characteristics of the infertility experience' and 'Stages of the

infertility experience'. Five themes pertained to the video. These were – 'Ways in which the video was perceived to be helpful', 'The role that the video was perceived to play in the promotion of counselling', 'Views of the video in general', 'Audiovisual video as a medium' and 'Ways in which the video could be improved'. At this stage all data feeding into developing themes were transcribed. File cards with tentative theme labels were created. The variation across line codes within each theme led to the formation of certain subcategories.

17.4 Stage 3 – Axial coding

For axial coding comments were allocated to the key themes along the lines of their properties and dimensions. At this point each tentative theme was laid out on a clear surface and all comments were manually allocated to a theme. This process led to the collapse of the nine tentative categories into six firm categories and promoted the development of further subcategories. Of the six categories, two pertained to the models of the infertility experience and four pertained to the video. Data was collected and coded until categories were saturated. Saturation was reached after analysis of the first two sets of interviews although the third set of data resulted in a denser set of categories.

17.5 Credibility of current research

Steps were taken both during and following the analysis process to demonstrate the credibility of the research. This was done in the following ways:-

- *Respondent validation*

During data collection as key themes developed their validity was checked with participants. This involved going back to the first participants to clarify their account and/or to ask specific questions relating to concepts. Future participants were also asked about their views and opinion of the video in relation to emerging key themes during the feedback session.

- *Independent judgement*

When the last themes had been developed an independent judge (a counselling psychologist colleague unfamiliar with the field of infertility) allocated comments to the

key themes. The aim of this was to rectify instances where there may have been bias and to ensure that codes were allocated appropriately.

- *Documentation*

A record of what was done, when it was done and why it was done has been presented in this chapter. In addition a list of all categories developed can be found in the Appendices (36 and 37). A definition of each theme based on how it was arrived at is provided and all statements pertaining to each of them are included. This permits traceability of themes back to the data source.

CHAPTER 18

FINDINGS & DISCUSSION: Feedback on the psycho-educational video.

Overview

NOTE: THE VIDEO IS BEST VIEWED PRIOR TO READING THIS CHAPTER

The chapter is arranged in the following sections:-

- Critical reflection and discussion 1: The researchers initial reflections and discussion on the pilot video.
- Category development – Validity of the models of the infertility experience.
- Summary of the key themes.
- Critical reflection and discussion 2 - Validity of the models of the infertility experience
- Category development – Value of the audiovisual psycho-education video.
- Summary of the key themes.
- Critical reflection and discussion 3 – Value of the audiovisual psycho-educational video.
- Summary and conclusion.

All categories developed in relation to the video are briefly outlined in this chapter. Data from interviews have been used to illustrate the core category. Full descriptions of all categories and their subcategories along with comments taken from the interviews can be found in Appendices 36 and 37.

18.1 Critical reflection and discussion 1: Researcher's initial reflections and discussion on the video

An initial viewing of the video took place prior to distribution to assess whether the aims of the video had been achieved. Initial observations made by the researcher are now discussed.

Although a pilot film is not going to be without flaws the video was deemed a valuable first draft. It can be used as a platform for the future development of such a video. On making and watching the video I was struck by the similarity achieved between the actors and the couples that I see in clinical practice plus those that were interviewed for Studies 1 and 2 albeit in a more stereotypical way. The comments that actors were provided with plus their skill enabled this. The end product looked more professional than anticipated and provided a firm platform from which to gain feedback with a view to updating and improving the video following the research.

Initial flaws observed are now highlighted. Seating arrangements were not appropriate as the counsellor is sitting on a higher level to the couple. In the male and female sections the counsellor's summaries do not all accurately reflect what the actor is actually saying in some places. Scenes were filmed more than once and the best parts were used in the final edit, based on sound and overall quality rather than the fit of the interactions. Given filming time (one day) and that the scenes were improvised not all of the features of the infertility experience have been communicated explicitly and comprehensively in the final edit. The nature of being in front of a camera led to some nervous waffling when in the role of 'counsellor' in parts. The attempt to convey a volume of information in a very short space of time resulted in sections where the counsellor talked for longer and more often than would perhaps happen in an actual counselling session. This could be slightly misleading for a viewer with no prior knowledge or experience of counselling. Furthermore summaries of the 'issue' are provided at times in the absence of information from the couple or individual. Thus the video may suggest to the viewer that counselling is much faster paced than it is in reality. It may give the impression that sweeping assumptions can be made by a counsellor about the couple and their experiences, which could possibly act as a deterrent. Finally, in line with the aim of the film to present an 'exemplar' couple, I feel that this aim was met but perhaps resulted in an extreme version

of an infertile couple. This may potentially alienate some viewers who do not identify with the characters. The above flaws would be addressed and rectified in any future production.

18.2 Category development – Validity of the models of the infertility experience.

Two categories were developed that provide support for the models of the infertility experience. These categories are briefly outlined. Full descriptions of all categories and their subcategories along with comments taken from the interviews relating to the video are listed in Appendix (36). Comments are identified as to whether they were made by a male or female.

CORE CATEGORY – THE CHARACTERISTICS OF THE INFERTILITY EXPERIENCE

The couple and their experience were deemed realistic. A couple suggested they were too 'stereotypical'. The female character was considered credible and to reflect the female experience, by females. Males perceived the male character and experience as realistic. All males and a female considered the male character in the video to be passive. Three subcategories were developed.

Subcategory of 'The characteristics of the infertility experience':- The couple experience

Definition:

The couple in the video and their experience was deemed realistic and to reflect the infertility experience in terms of the dynamics of their interaction and the feelings that they were expressing.

Interviewee Comments:-

17 – 1.01 *I think you've really captured the experience that the couple goes through. (Female)*

5.6 – 1.03 *The emotional differences and the interaction between the couple were spot on, we both said that (Female)*

18 – 2.32 *For me the couple on the film and what they are going through is an*

accurate portrayal of the couple dynamic, at least it really fits with our experience. (Male)

Subcategory of 'The characteristics of the infertility experience':– The female experience

Definition:-

Portrayal of the female character was deemed plausible and to reflect the female infertility experience. Females located said they identified with the female character and that her experience reflected their own. A female said that although her experience was not quite as bad as for the female on the video, she knew other females who had similar experiences.

Interviewee Comments:-

17 – 4.23 *It was quite weird watching it because the female was experiencing all of those things that I have experienced and am still experiencing, you know feeling of guilt, it being her fault and all of that (Female)*

5 – 4.35 *At the beginning and I suppose it continues throughout you do feel very alone and isolated and I think she was saying that (Female)*

17 – 5.19 *I could really identify with Sally [the female character in the film] because it was as if she was talking from the heart and I really knew what she was saying, because it's the same for me. (Female)*

Subcategory of 'The characteristics of the infertility experience': – The male experience

Definition:-

Males said that they could identify with the male's experience. The experience conveyed in the male scene was considered realistic in terms of the male feeling marginalised, avoidance of conversation for fear of upsetting their partner, feeling helpless and wanting children but not being 'desperate' to have them. A male expressed frustration that males tend to be perceived as the one 'who has the problem with communication'. The male character was perceived as 'passive' and 'stereotypical'.

Interviewee Comments:-

17.18 – 6.29 *I could relate to how he was experiencing it, that feeling shut out and a bit helpless really, but I don't think I'm that passive (Male)*

6 – 2.19 *I think he was a bit wimpy and I know that although males may not say much but they do feel a lot and I think that what he seemed to be feeling was pretty close to reality. It's clear he loved his wife and was trying to avoid talking about stuff for fear of hurting her and all that, I definitely do that or I should say did that 'cos I know better now (Male)*

CATEGORY: THE POINT AT WHICH THE VIDEO WAS CONSIDERED BENEFICIAL FOR INFERTILE COUPLES AND INDIVIDUALS TO VIEW

Definition:-

Different stages of the infertility experience were referred to both explicitly and implicitly in feedback interviews. Couples suggested the video would be most useful to view at the early stage of infertility e.g. when visiting their GP level or their fertility clinician. The value of the video at this stage was perceived to play a role in preparing couples and individuals for the emotional and psychological experience ahead of them e.g. Active Infertility.

18.3 Summary of the key themes - Validity of the models of the infertility

The couple and their experience were both deemed realistic and credible. The female character was considered plausible and to reflect the female infertility experience. The male experience was perceived as realistic. The male character was perceived as too passive. Different stages of the infertility experience were referred to in the feedback. Couples suggested that the video would be most beneficial for couples and individuals at the early stage of their infertility, when they are still trying to conceive naturally e.g. Pre-Active Infertility Stage.

18.4 Critical reflection and discussion 2: Validity of the models of the infertility experience

One aim of this study was to check the validity of the models of the infertility experience. This aim has been met. Feedback provides support for the models of the infertility experience both in terms of the stage theory and characteristics of the respective couple, female male infertility experiences. These are now discussed in turn whilst exploring potential issues with the findings.

The couple, female and male experiences were deemed realistic and credible by all providing feedback. This indicates that the characteristics of the experience captured and outlined in the models are valid in terms of the experience of participants who took part in this study. The closer the couple and individuals were to the experience being portrayed in the video e.g. the Active Infertility Stage, the more realistic and plausible it was perceived. It is important to point out that two couples interviewed also took part in Study 1 (the couple located in the latter phase of the Active Stage and the couple located in the Post-Active Infertility Stage). Thus there is a potential bias in terms of the validity of the experience based on these interviews and generalisations beyond the present sample cannot be drawn. However the couple that found it most realistic had not participated in Study 1. Moreover, those providing feedback made reference to the similarity of the experience conveyed on film to other couples/males/females that they knew. This suggests that the characteristics of the infertility experiences are likely to be applicable beyond the current research sample. Further research into the models with a different, broader sample is required to provide further support either for or against the models.

All reviewers said that they recognised and identified with the characters in the video and the experiences they were portraying. The male was perceived 'too passive' and it was proposed that he be portrayed as more 'aggressive'. The character was open to interpretation as the actor was provided with comments from all interviews. Hence the male character was to a large extent grounded in the data. Thus this feedback is interesting and is worthy of consideration. It may in part be a function of bias on behalf of the researcher in preparation for the video. In my clinical experience males can often

present as passive and at times disinterested, especially in couple counselling sessions. This happened in research interviews albeit to a lesser extent. Thus there is a possibility that my experience has impacted negatively on the representation of the male. This response may also be a function of the type of character of males interviewed. It is a possibility that the feelings evoked in response to the 'passive male' is in part a function of males feeling uncomfortable on being confronted by a 'compliant' male (see Chapter 6). This may have resulted in a desire to distance their self from this 'passive' version of the male in some way (Tajfel & Turner, 1986). No product is able to capture and convey an experience that all viewers relate to. Yet for a tool to be of value it needs to engage both members of the couple. Further research looking at the male experience of infertility at each stage of the experience in conjunction with an exploration of ways to accurately and sensitively portray this experience is required. The researcher also needs to further reflect on her role in this portrayal of the male as 'passive'.

The finding that the couple in the Post-Active Infertility Stage least identified with each experience featured may be a function of this couples personal experience. However it may be also be function of the fact that they now have their own child and they have moved so far from this stage that they do not identify with it strongly for reasons such as it is too painful to revisit or given that memory fades with time they do not recall it being as intense as it is suggested on the video.

Couples and individuals referred spontaneously to 'stages' of the infertility experience, implicitly and explicitly. This provides support for a stage theory of infertility. What has been revealed is a lack of clarity regarding the point at which the characteristics of the Active Stage (see Chapter 8) are first experienced. Couples identified with the characteristics of the models. The couple in the early Active Infertility stage had had been trying to conceive for two years but had not started treatment, did not have a diagnosis and were still hoping to conceive naturally at the time of interviewing. They had experienced all of the emotional characteristics of the Active Infertility Stage. Further, females in the Active Stage suggested that the video would have been useful when they had first visited their GP. This suggests that the distinction between the Pre-Active and Active Stages is more complex than initially proposed. For example there may be sub-stages within the Active Infertility Stage.

Infertility is a complex experience and further research is required to clarify the distinction both between and within these two stages. Further research could look into the experience of couples when they start experiencing difficulties conceiving. This could help to establish the point at which the characteristics of the Active Stage start to be encountered. The ways in which couples navigate their way through the stages requires further exploration so that appropriate support can be provided.

18.5 Summary and conclusion

Feedback regarding the video has yielded strong support for the models of infertility in respect of the characteristics of the experience and the stage theory. Given the small research sample and two couples providing feedback also participated in Study 1 caution should be exercised when regarding the validity of the models beyond the present sample. These models can provide a platform from which further research can build with the aim of broadening our understanding of the infertility experience for couples, males and females going through it.

The second stage of the feedback and analysis is presented in the next section. The focus is the value of the psycho-educational video.

18.6 Category development – Perceived value of the psycho-educational video.

Four categories were developed relating to the perceived value of the video. These categories are briefly outlined below. Full descriptions of all categories and their subcategories along with comments taken from the feedback sessions are listed in Appendix 37.

CORE CATEGORY – WAYS IN WHICH THE VIDEO WAS PERCEIVED TO BE OF VALUE

Definition:-

Reviewers perceived the video as useful. It was perceived to promote communication between couples as well as providing methods of achieving this. Females perceived the video as something that could help to normalise their emotional, behavioural and psychological response to infertility. Males perceived the video as promoting the value of both listening to their partner and expressing their feelings. It was seen as serving the function of normalising the male response to infertility. Males found the video valuable as it provided an insight into the female emotional experience. Three subcategories were developed.

Subcategory of 'Ways in which the video was perceived to be of value':– To the couple

Definition:-

A number of ways in which the video could be of value to couples experiencing infertility were perceived. Primarily it was seen to positively promote communication between the couple. This was achieved by highlighting the importance of communication and providing a way to do this in the form of the tasks set by the counsellor at the end of the couple scene. Couples said it served the function of normalising the difficulties being experienced by them. The video was seen as a way of preparing couples in advance for the psychological and emotional aspects of infertility. It was also considered to serve the function of stimulating thoughts and discussion between the couple about the infertility issue that they are faced with.

Subcategory of 'Ways in which the video was perceived to be of value':- To the female

Definition:-

Primarily the video was perceived as a means to normalise the female response to infertility. The video was deemed helpful in terms of highlighting the other forms of support available to females. It was seen to demonstrate that their male partner does have feelings and cares about the issue despite the tendency to avoid discussion. The video was perceived to serve as a reminder not to confront their partner with the issue when they walk in the door from work.

Subcategory of 'Ways in which the video was perceived to be of value':- To the male

Definition:-

Males perceived the video to help promote communication, particularly listening. It encouraged males to talk about their feelings. The video provided insight into the female emotional experience, which was deemed helpful. Finally the process of observing the male actor in the video was seen as serving the function of normalising the male response to the infertility experience. Comments are identified as to whether they are made by a male or female.

CATEGORY: THE ROLE THAT THE VIDEO WAS PERCEIVED TO PLAY IN THE PROMOTION OF COUNSELLING

Definition:-

The video was perceived to positively highlight the benefits of counselling. It demonstrated that counselling is not 'fluffy and patronising' and hence a 'good advert'. In particular it seems the video could play a role in promoting counselling for those with no experience or knowledge of it, particularly for males. A female pointed out that infertility is a very private issue and hence a video may not play a role in helping people to decide to have counselling. A male said that he was not open to the idea of counselling prior to viewing the video and that viewing it did not change this view.

CATEGORY: OVERALL VIEWS OF THE VIDEO

Definition:-

Feedback resulted in a range of suggested improvements to the video and a critique of it. This led to the formation of following two subcategories:-

- **Suggestions for improvement:** A number of valuable suggestions for improvements to the film were made. It was suggested that the male could be portrayed as being more assertive and active. The value of demonstrating and emphasising the confidential nature of counselling was suggested. The benefit of highlighting that counselling is a safe space for males to express themselves freely was pointed out. A male said that he would like to have received more information about treatment options and outcomes. Another suggestion related to using the film to explicitly help the female to see that it is not her 'fault' which it was thought would provide a contrast to the common misconception held by many people that infertility is a female 'problem' or 'fault'. The value of addressing the difficulty experienced by couples with unexplained infertility of not having a diagnosis was suggested.
- **Critique:** The primary criticism of the film was the fact that the female had experienced a pregnancy and subsequent termination, about which she expressed guilt feelings. Whilst the guilt feelings were deemed appropriate by viewers' two main issues regarding the termination were revealed. One is that the viewer may feel that as they have not had a termination then they do not 'need' counselling. The second is that the film evoked feelings of anger in the viewer towards the female for having had a termination. Linked to this is the fact that the female on the film had actually experienced a pregnancy which two of the viewers had not, hence she was deemed 'luckier' than they were. The result of this was that the viewer ceased to identify with her and disengaged with the film for a period of time. Another criticism revealed that the film was perceived as biased, both positively and negatively towards the male. Positively, in terms of it not 'being his fault' despite the fact that the couple supposedly had unexplained infertility. Negatively in that the female was perceived as demonstrating a fuller range of emotions than the male, which was not considered accurate. A male said that

although the message of the film – communication - was clear, it was perhaps too obvious. The couple in the Post Active Infertility Stage pointed out that there was too much emphasis on communication in the absence of information about treatment. A female suggested that the word 'painful' was used too often, which she did not think was helpful. A male suggested that too much information was crammed into a short amount of time.

CATEGORY: PERCEIVED VALUE OF AN AUDIOVISUAL MEDIUM

Definition:-

The audiovisual medium was viewed positively. It was perceived to be a user-friendly medium that would be chosen over other mediums e.g. books, leaflets or a talk. Factors contributing to this choice included privacy, convenience, being able to see a 'live couple' and limited effort on behalf of the viewer.

18.7 Summary of the key themes – Perceived value of the psycho-education video.

The video was perceived to be helpful to couples, females and males in a number of different ways. It was seen as positively promoting counselling, particularly for those who had no previous experience of it. A number of suggestions for improvement and critique of the video were provided. Use of an audiovisual medium was viewed positively, in particular because of the privacy it affords.

18.8 Critical reflection and discussion 3 Perceived value of the psycho-educational video.

The aim was to develop a pilot psycho-educational video then gain feedback regarding the relevance of it. These aims have been met. However there are some caveats. For example, findings are based on a small number of feedback sessions. Couples providing feedback did not include a couple from the Pre-Active Infertility Stage but two couples from the Active Stage and one from the Post-Active Stage. Hence caution needs to be exercised when interpreting the findings.

Communication breakdown was identified as the key issue encountered by couples in Study 1. The video addressed this issue in a way that was perceived positively. It was also perceived to help the viewer understand the sometimes competing needs of the members within the couple unit and how these needs can in turn impact negatively on the couple relationship. If a video like this can help couples to understand what is happening for each other and hence facilitate communication then the experience is likely to be less harrowing and stressful for them. For many couples a video like this could be sufficient to support them through the infertility experience and the need for counselling may not arise. Research has found that given the stressful nature of the infertility experience many couples do separate (Salvatore *et al.*, 2001; Levin & Sher, 2000; Greil, 1997; Kumar & Leo, 2003; Leiblum *et al.*, 1998). Thus if stress can be reduced the chances of couples separating may be reduced also.

Given that one in six couples experience difficulties conceiving (HFEA, 1999) there will be those who could benefit from counselling during the experience. The finding that the video was perceived to positively promote counselling is valuable. This means that a psycho-educational video is likely to be an effective method of providing important information about infertility and counselling. Information was identified as a key need for this client group in Study 2 (see Chapter 15). It is anticipated that an effective video could serve the function of increasing the uptake of infertility counselling and support services, which is currently less than 25% (Sundby *et al.*, 1994; Hernon *et al.*, 1995; Schmidt *et al.*, 2003).

Findings from all three studies have revealed that the infertility experience is not static. Needs of individuals and couples change as they progress through the experience. Thus there is potentially a demand for a series of psycho-educational films. Each film would ideally have a variety of options within it, which the medium of DVD could permit. For example, for a tool to be relevant and of value to this client group at each stage of infertility, DVDs would need to include different versions or scenarios so that viewers can select the one closest to their personal experience. Further research exploring the range of options that would be beneficial to this client group at each stage of the infertility experience is required.

The audiovisual medium was viewed positively primarily because of the privacy it afforded. Given the sensitive and hence private nature of the infertility experience this is an important factor. The infertility experience can be divisive in nature (see Study 1). Hence the act of viewing a video together that promotes understanding and communication can be joining. This is particularly important given that communication breakdown is the key characteristic of the couple infertility experience (see Study 1). Hence a tool such as this could potentially be of great value. In addition the audiovisual medium means that a high volume of couples can access a video such as this, meaning that more couples can potentially be reached than via another medium e.g. a book.

18. 9 Summary and conclusion

Feedback provided support for the characteristics of the couple, female and male experiences of infertility. A stage theory of infertility was also supported. Findings indicated that the stages of the infertility experience are more complex than initially proposed. The distinction between the Pre-Active and Active Stages needs to be more clearly defined as there may be a series of sub stages within the Active Stage. Further research into the transition from the Pre-Active to the Active Infertility stage is required. Research is also needed into each of the stages to capture the complexities of the infertility experience for couples, males and females.

The video was perceived to be of benefit to couples in the early period when they are still trying to conceive naturally. Feedback revealed that the optimal time to be given the film would be at the first appointment with the GP. Suggestions for improvement were made and it is hoped that these can be incorporated beyond the present study in order to develop a relevant psycho-educational tool. Findings from all three studies indicate the value of such a tool for those experiencing difficulties conceiving.

CHAPTER 19

SYNTHESIS

19.1 Research Aims and objectives

Study 1:

- To gain an understanding of the different emotional and psychological needs that might arise at any given point during the infertility experience.
- To explore male and female experiences of infertility and how these individual experiences impact on the couple unit.

Study 2:

- To explore perceptions, beliefs and experiences of counselling in order to understand the factors involved in the decision making process concerning the decision to embark on counselling for infertility.
- To identify potential counselling and support needs of the male, female and couple respectively.
- To check the validity of the findings from Study 1.

Study 3:

- To develop a pilot psycho–educational tool providing information and support to those going through the infertility experience.
- To gain feedback regarding the relevance of the tool.
- To check the validity of findings from Studies 1 and 2.

These research aims have each been met. A qualitative research paradigm was adopted throughout. A key feature of the research design was to interview couples together prior to interviewing individually. Moreover couples were located at different points of the infertility experience in each study. Use of a qualitative research design provided a unique perspective on the diverse and complex relationships, experiences and needs, both within and across couples. Individual experiences of infertility, at different points of the experience were also distinguished. A number of areas for further research to build on

the current findings and limitations of the research have been identified and proposed at appropriate points in each study.

19.2 Counselling psychology of infertility

19.2.1 The infertility experience

Prior to embarking on this research a gap in the literature was identified. There did not appear to be an overall coherent account of the infertility experience. This was addressed and three distinct models of the infertility experience have been developed – one for couples, one for males and one for females. A fourth model comprised of these three models was also developed. This depicts the overall infertility experience.

These models provide an overview of the key emotional and psychological characteristics of the infertility experience from the point at which difficulties conceiving are identified through to post fertility treatment. The infertility experience can be psychologically and emotionally devastating for females and males, albeit to a lesser extent for males. The experience affects females and males in different ways. These findings are supported in the literature (e.g. Greil, 1997; Read, 1995, Gibson & Myers, 2000; Crawshaw, 1995). Individual experiences impact negatively on the couple relationship primarily resulting in communication breakdown.

19.2.2 Infertility as a life stage

A key finding is the concept of infertility as a life stage. A stage theory was based on changes in the quality, identity and characteristics of individuals and couples that transpired as a function of their infertility experience, which occurs during pivotal childbearing stage of their lives. A stage theory conveys the gravity of the infertility experience for individuals and couples going through it.

The role of counselling psychologists is to work 'therapeutically with clients with a variety of problems, difficulties and life issues and crises' (BPS Division of Counselling Psychology, 2002). Thus a stage theory of infertility highlights the important role that counselling psychologists can play in this field.

19.2.3 Counselling for infertility

Distinct counselling needs of females, males and couples, at each stage of the infertility experience have been identified. Despite the difficulties encountered by many, research suggests that less than 25% of infertility patients take up psychological services (Sundby *et al.,* 1994; Hernon *et al.*,1995) or have the intention to use these services (Schmidt *et al.*, 2003).

Findings revealed that individuals and couples tend to access counselling at 'crisis points', despite experiencing issues prior to this. My clinical experience supports this. Factors likely to influence the low uptake of counselling services were identified. One is the perception of infertility that an individual holds. When infertility is perceived as an 'illness' or a 'bereavement' e.g. in cases of miscarriage, it is perceived as a legitimate issue for counselling. When perceived as 'something that you have to get on with' then it is not. Another factor is patient expectation that counselling is a service that is offered, as opposed to one that they seek out. As GPs do not routinely suggest or refer patients for counselling many do not consider it. Moreover, findings revealed that not everybody knew what counselling is, how it can benefit or how to find a counsellor.

19.3 Application of findings

19.3.1 Role of the GP

Findings revealed that information about the infertility experience and counselling at the point at which difficulties conceiving are encountered would be beneficial. It is proposed that if GPs have access to relevant information they could then distribute it to patients at this stage. Information is particularly important at point of diagnosis for males and females. Information would help prepare individuals and couples for the experience so they may feel more in control throughout. The element of preparation and control is important as it can reduce the stressful nature of the infertility experience (Dunkel-Schetter & Lobel, 1991).

19.3.2 Role of the counselling psychologist

Counselling psychologists are perfectly placed to use their considerable skills to benefit those experiencing infertility, inform professionals of all disciplines working with this patient/client group and inform the practice of counselling psychology. Findings

highlighted a number of ways in which counselling psychologists can contribute to the field of infertility: -

- They can work on developing appropriate information and resources for distribution to this client group via GPs.
- They can raise public awareness of the infertility experience so that individuals and couples can be more aware of what they may encounter both emotionally and psychologically and when they may encounter it. Hence prepare for it.
- They can target negative perceptions about infertility so it is not perceived as something to 'get on with' but rather an experience during which counselling may be of great value.
- They can promote the benefits of counselling both in general and specifically for the infertility issue so that understanding across the general population is increased.
- They can work on raising public awareness of how to find a qualified counsellor specialising in this area so that people can be proactive in accessing it.
- They can highlight and promote the benefit of positive behaviours e.g. communication between couples as they move through the stages of the infertility experience. This could in turn reduce some of the distress that many individual and couples experience.
- They can actively engage in research into this complex and fascinating area.
- They can work on developing and delivering appropriate and efficacious psychological interventions.
- They can work in partnership with other professionals working to ensure that those experiencing infertility get the range of support they need throughout the experience.

19.3.3 Models of the infertility experience

The models developed provide a firm platform from which further investigation can be conducted with a view to elaborating and validating each of them. Development of these models is important to the fields of counselling psychology and infertility for a number of reasons: -

- Models can be used as a tool for educating professionals working in the field of infertility about the emotional and psychological impact of it on males, females and couples respectively.
- They can be used in clinical work as a guide by practitioners to locate the position in the model of an individual/couple with a view to understanding the issues that they may be experiencing.
- Models can be employed as interactive psycho-educational tools in client sessions. The use of an interactive tool can be used to normalise the infertility experience for clients, facilitate their understanding about the experience and to facilitate communication between couples.
- Models can be used to inform professionals working in the field as to potential points at which to refer patients for counselling.
- They can inform the development of stage specific counselling interventions and programmes for males, females and couples respectively.

19.3.4 Development of a psycho-educational video

A key contribution of the research is the development of a pilot psycho-educational video. As far as the researcher is aware, there is currently no other video available that focuses solely on the emotional and psychological aspects of the infertility experience. Findings provide the basis to create an updated and improved version of this video. It is anticipated that a series of films could play a vital role in raising awareness of the infertility issue and of counselling. It is likely to be a very valuable resource for those going through the infertility experience.

Availability of such a tool is important given that 1 in 6 couples experience difficulties conceiving (HFEA, 1999). It is argued that for many people information and support at the beginning of the infertility experience may be sufficient to help them progress through the experience without having to endure overwhelming levels of emotional and psychological distress for long periods of time.

19.4 Infertility: A broader psychological perspective

From a broader psychological theoretical perspective it is clear from the research findings that the infertility experience is in large part influenced by gender and gender role

identification. Thus gender is an integral part of our understanding of the infertility experience and needs to be considered when developing and delivering psychological interventions for this client group.

Arguably the gender system is a social construct that is shaped by a given societys' cultural beliefs and values. Development is a gendered process (Kimmel, 2001); hence female and male gender roles are inextricably linked with both global and individual identity formation and will be culturally dependent. In the Western world there are clear distinctions between masculinity and femininity and clear beliefs about what constitutes each. For example, beliefs and behaviours associated with masculinity include emotional and physical control, denial of emotional vulnerability and the appearance of being strong (Gannon, Glover & Able 2004). Further, the ability to father a child is widely considered to be a key indicator of masculinity (Mason, 1993). In contrast beliefs and behaviours associated with femininity include emotional vulnerability, ability to express emotion, softness and sympathy plus childbearing and motherhood, which have traditionally been considered to be ultimate indicators of what it is to be feminine (Pfeffer, 1993; Crawshaw, 1995).

For many their 'gender role' goes unexamined until such a time when an event threatens it. Infertility is such an event. When faced with the possibility that a key criterion of ones gender role may be unfulfilled e.g. fathering a child or becoming a mother this is likely to be perceived as a considerable threat to ones identity. The impact of this can be devastating. Guidano (1983) quotes that ''the maintenance of one's perceived identity becomes as important as life itself'' (p.3) which indicates why the experience can be so devastating for many that are confronted with it. It may also explain in part why the number of people seeking IVF and related treatments is on the increase. It is important to note that the extent to which an individual identifies with their traditional gender role is likely to correlate with the distress they experience when faced with infertility and the way in which they will deal with this threat.

Infertility has traditionally been viewed as a female problem and as a consequence females have come to be 'expected' to experience more distress as a result (Berg, Wilson, Weingartner 1991). This view has been widely supported in the literature (e.g. Greil,

1997; Crawshaw, 1995; Gibson & Myers, 2000). This research also found that females tend to exhibit more distress in response to infertility. However the majority of infertility studies have focused on females and have not included male partners, which is likely to distort the perception generally held regarding the way in which infertility is experienced by males (Jordan & Revenson, 1999). In this research it was found that males also experience distress yet this may tend to get overlooked in society and in clinical practice due to the way that males have been conditioned to deal with this distress based on the traditional male gender role e.g. being strong and in denial of emotional vulnerability (Gannon *et al.* 2004). This theory is supported by Berg *et al.* (1991) who in their study of 104 couples following infertility treatment found no gender differences in the level of emotional strain experienced within couples. However findings revealed gender differences in factors associated with psychological distress, for example respondents linked 'low emotional strain' with 'masculinity'. Thus demonstrating that expectations may shape the experience of infertility in men and the ways in which it is, or rather how it is not, expressed. It is important that those working with client group do not take this to mean that males are not affected by their experience.

The received view of gender is constructed and this influences the construction of an individual's identity, which in turn shapes the nature of the infertility experience for males, females and hence couples. Implications of this for clinical practice are that just as theories about the self and the world are constructed they can be reconstructed in line with an individual and/or couples unique experience. Counselling provides a unique opportunity to do this, in particular if the therapist utilises therapeutic interventions informed by personal construct theory (Kelly, 1955). In fact from a personal construct perspective failure to reconstruct existing constructs in line with new experience results in psychological disorder (Winter, 1996). This may explain in part why some people tend to experience infertility distress more intensely and over long periods of time. This further highlights the potential benefits of counselling prior to, during and following infertility treatment to help negotiate a positive identity transition. This may play a particularly important role for males with a diagnosis of male factor infertility which can pose a significant threat to conventional views of masculinity (*Gannon et al.*, 2004)

Finally, Britain is a multi-cultural society so it is important that those working with this client group consider a clients cultural background in light of the differing cultural influences on gender roles and the associated beliefs as these are likely to be key factors that shape the infertility experience. An additional consideration is the extent to which IVF and similar treatments may be sought in order to keep up with culturally defined gender roles and the impact of this on those going through it both at the individual level and a societal level, particularly when IVF does not result in the desired outcome – a child.

19.5 Critical reflection on methodology

A grounded theory approach was employed. In particular the Strauss & Corbin (1998) version was adhered to. The decision to employ grounded theory was based on two key reasons 1) Its good fit with the research aims and 2) It is considered an appropriate approach for newcomers to qualitative research because it provides a better description of techniques that aid analysis than other forms of qualitative methodology (Pidgeon & Henwood, 1998). Post research I feel that these two reasons were both valid and appropriate.

The decision to follow Strauss & Corbin (1998) was because my philosophical position was most aligned with theirs. Prior to conducting the research I believed that findings are the result of constructing relationships between concepts (Strauss & Corbin, 1990, 1998) as opposed to believing they are to be 'discovered' in the data (Glaser, 1992). The research process has compounded this belief. At times I found myself 'discovering' what I believed to be 'dominant themes' following interviews and initial listening of them. At point of coding I recognised that my beliefs and experience were influencing the process and actually the 'dominant' themes were not necessarily so (based on fewer comments than other themes). This was a fascinating process and provided much scope for reflection in respect of what I bring to the research process and to my clinical work. It also suggested to me that a rigorous approach to data collection reduces, if not removes, the presence of research bias in the findings.

In each study the chosen approach permitted an in depth exploration of the infertility experience. This resulted in a set of categories that are firmly grounded in the data. In

terms of the 'steps' outlined in Strauss & Corbin (1998), whilst these are clearly articulated in the book the reality is far from straightforward. The analysis process was anxiety provoking, time consuming and complicated. 'Steps' operate in tandem and there were a number of analysis procedures occurring at any one time i.e. open coding of one data set, writing memos/diagrams relating to another data set, making links with other findings and seeking respondent validation of themes as they emerged and so on.

At times I found myself falling into the trap of 'forcing' data into categories (Glaser, 1990). Procedures such as stepping back from the data, axial coding and independent judgement played a vital role in minimising the impact of this on the final categories. The analysis process became less confusing with experience. My confidence in the process and my ability to do it grew with experience. I feel confident that the procedures followed in the analysis process resulted in a realistic account of the infertility experience and the needs of those going through it.

19.6 Summary and conclusions

Conducting this research has been an exhilarating, challenging and stimulating experience. It has compounded my belief in the importance of raising the awareness of the counselling psychology of infertility and ensuring that this client group get the emotional and psychological support they deserve. I fully intend to build on this research and share my findings with colleagues through publication and lectures. I also intend to promote the benefits of counselling to those experiencing it through my clinical practice and by updating and improving the video in preparation for distribution and via infertility support networks. It is hoped that fellow counselling psychologists will claim their place in this growing field and utilise their considerable skills to play a pivotal role in it.

It is argued that infertility is a specialist area and counselling psychologists working with client group are responsible for familiarising themselves with the differing male and female experiences of infertility and how these needs impact on couples so that they can meet them in their clinical work. Both the HFEA (2003) and the British Association of Counselling (BICA) (1999) support the need for infertility counsellors to have specialist knowledge and training. This research argues the same.

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SECTION C: PROFESSIONAL PRACTICE

THE CASE OF SARAH:

A reflexive exploration of the challenges encountered in the work with an infertile female client

1.0 PART A: INTRODUCTION AND THE START OF THERAPY

1.1 Introduction

I have chosen to present the case of 'Sarah'[2] for two key reasons. Firstly the case led me to reflect on my personal position in respect of a number of issues and consider ways in which this could impact on my clinical work with clients experiencing involuntary childlessness. Issues included use of donor gametes, the age at which pregnancy is achieved and the potential impact of this on the welfare of the unborn child/ren (HFEA, 1990). Secondly, it was my first opportunity to work with a client during a pregnancy following IVF treatment. This contrasts with the majority of my infertility counselling work which tends to be with clients following diagnosis, prior to and during treatment and/or when treatment fails. The case provided insight into what a female can experience when she has a 'successful' outcome to treatment. It highlighted how the reality of pregnancy can be a traumatic experience. For these reasons the work with Sarah was a key learning experience both personally and professionally.

I saw Sarah for 8 sessions over a period of 3 months. Sarah was 49 years old and 5 months pregnant with twins (following IVF treatment with donor sperm and donor egg) when she contacted me. She said she was finding the experience 'very traumatic'. She was feeling 'very anxious' and wanted to discuss these feelings. Sarah said she wanted to understand the 'shift' in her attitude now she was pregnant from one of 'idealising' pregnancy and motherhood to one of 'horror' at the reality of it.

I employed an integrative framework in the work with Sarah. I felt this approach was the most appropriate as it would permit me to focus on Sarah and her presenting concerns from different perspectives, hence work most effectively with Sarah in a limited time frame (Preston, 1998; Corey, 2001).

Consent to write about this case was obtained from Sarah.

[2] All names and identifying features have been changed to preserve client anonymity.

1.2 Summary of theoretical orientation

There is no one definition of integrative counselling (Clarkson, 1996). Theoretical integration is unlike technical eclecticism. Integration involves the creation of a conceptual framework within which compatible components of two or more theoretical approaches are synthesised to obtain a working practice that is more effective than working within a single theory framework (Norcross & Newman, 1992). Effective integration of models provides the therapist with a clear framework which guides the application of theory to practice. It is not about selecting tools and techniques with no clear rationale to support the choice (Corey, 2001).

The three models I draw on in my work as a counselling psychologist are the three primary traditions in counselling psychology - psychodynamic, cognitive-behavioural (CBT) and person-centred. Whilst these three models could be deemed incompatible by those working from a single model, Clarkson (1996) argues that when viewed from a broader integrative perspective they are mutually complementary. Moreover when combined a more complete and realistic version of the person can ensue. The extent to which each model is used and how it is used in practice is determined by the client and their presenting concerns (Corey, 2001; Colley & Bond, 2004; Rawson, 2003). A summary of each model with a focus on the main concepts utilised in the work with Sarah can be found in Appendix 40. A brief overview of the key ways in which the models were used with Sarah follows:-

- The core conditions of the person-centred model provided the foundations of the work. Particularly in the 'beginning stage' where the focus is on establishing strong therapeutic alliance (Culley & Bond, 2004).
- Psychodynamic theory played a central role in the assessment process with Sarah. In line with a brief psychodynamic approach the key techniques used in the work were transference and interpretation (Malan, 1963).
- The three main goals of CBT provided an overall framework for the work 1) to reduce Sarah's anxiety symptoms and facilitate resolution of her issues 2) to provide Sarah with coping skills and 3) to help Sarah challenge her underlying negative schemas (Moorey 1996).

1.3 The context of the work

I saw Sarah in private practice at my home in North London where I have been seeing clients for 3 years. I receive supervision from a chartered counselling psychologist once every three weeks for one and half hours. Referrals come via previous and existing clients, the Lister Hospital Assisted Conception Unit (where I used to work as an IVF counsellor) and the British Association for Counselling and Psychotherapy (BACP) website.

1.4 The referral

Sarah located my details on the BACP website where it states that I specialise in the area of infertility. When Sarah telephoned she spoke clearly and after a few moments she started crying. She provided a brief summary of her situation then asked whether I thought she was 'absolutely mad'. I reflected on this statement. I wondered whether this related to a core belief and/or whether other people had suggested this recently and how this might have made her feel. I also wondered whom I might represent for her and whether this person was judgemental and how this might present in the transference (Smith, 1996). I considered my response and potential impact on the therapeutic relationship. I thought it best at this stage to be congruent. I answered by saying that I did not think she was mad, on the contrary I thought she had been brave to make the call. Sarah said she was 'relieved' to finally be able to 'talk about' how she had been feeling. After the call I noticed that I felt slightly frustrated about the situation Sarah had presented. I explored these feelings at supervision later that week.

1.5 Convening the first session

Sarah arrived five minutes early for our session. She came straight from work and was smartly dressed. I greeted her warmly at the front door and introduced myself. Sarah laughed nervously and said she was feeling 'very nervous and stupid'. Her reference to feeling stupid reminded me when she asked if I thought she was 'mad' when she first telephoned. In line with the psychodynamic approach I decided not to respond directly to the comment as it seemed significant, if so she would likely return to it later in session (Jacobs, 1999). I distinctly recall feeling tight across my chest and anxious. I wondered whether this was in part resulting from my counter transference. I made a mental note to explore this in supervision.

1.6 The presenting problem

Sarah was 20 weeks into her pregnancy with twins when she sought therapy. She is single and conceived at age 49 following her third IVF treatment using donor sperm and donor egg. She said she was feeling 'totally shocked' that she was pregnant at all and being pregnant with twins compounded this. Consequently she was feeling 'very anxious' and 'terrified'. She was finding the pregnancy 'more difficult' than 'expected' and was 'worried' about what the future held. She believed she had made a 'terrible mistake' and she wanted it 'all to stop'. She said the 'reality' of the situation was a 'far cry' from how she 'imagined it would be' and she wanted to explore this as she had believed she 'really wanted this [pregnancy/motherhood] more than anything'. She expressed fears around being a single parent and was concerned that she would not 'cope'. Sarah said she wanted to talk about how she was feeling because she was concerned that she was not 'bonding' with her babies. She thought her stress would affect the babies. This led her to experience intense feelings of 'guilt'. She said that she was feeling 'very stupid' for getting herself 'into this situation' and believed she was a 'bad person'.

1.7 Initial assessment and formulation of the problem

Sarah had 'always wanted children' but she 'didn't meet the right man' until her late 30's. At 37 she and her then partner started trying to conceive. Four years later she was diagnosed as menopausal. She and her partner separated soon after. Sarah described this as a 'very difficult' experience for her because she had 'lost two of the most important things in her life'. A year later she met a new partner and after twelve months they had IVF treatment using a donor egg. During treatment her partner was diagnosed as infertile. Sarah said he found the diagnosis 'difficult to accept'. He ended the relationship soon after 'blaming' Sarah for 'pressurising him' to try for a child. Sarah was 'devastated' but more worried about how she was going to get pregnant as time was 'ticking on'. None of Sarah's subsequent relationships developed long-term. On her 49th birthday she decided that it was 'now or never' if she was going to be a mother. She proceeded with treatment as a single female.

In addition to biological and social factors, an unconscious part of Sarah's motivation to be a mother may have been wanting a child to love in a way that she had 'never been

loved' and/or to 'be loved' in a way that she had never been loved (Mander, 2000). Linked to this may have been her 'idealisation' of her close friends and siblings domestic situations – all of which included children (Cooper, 1996). Sarah perceived having children as being 'part of something' and 'never being lonely'. Sarah was the 'baby' of the family. Growing up she said she had always felt as if she was on the 'outside looking in' on the rest of her family. This theme was replicated in her adult relationships with friends/siblings and their families (Jacobs, 1998). It was now being replicated in her pregnancy. She described herself as 'merely their carrier' and was feeling 'lonelier than ever before'. Based on discussion with Sarah this seems to be a function of the fact that the twins were not genetically related to her. Thus the one thing she believed would meet her previously unmet needs had failed and she was feeling disappointed in the extreme about this (Smith, 2000).

Sarah was feeling 'trapped' and felt 'there was no way out'. There was a theme of being trapped throughout Sarah's life e.g. in her role as the 'baby of the family' (which she felt held her back), in various relationships with men and in her job as a teacher (prior to re-training as a social worker). On previous occasions when Sarah had felt trapped she said she had run away rather than deal with the situation. Being pregnant was creating anxiety because the defence of 'running away' was not an option. Consequently it seemed that she was being forced to face feelings associated with this experience in addition to unresolved feelings associated with earlier experiences that she had been suppressing for many years (Smith, 1996). Moreover it seems that the twins represented the 'object' responsible for this process which was impacting on her ability to bond with them (Mander, 2000).

Much of the anxiety that Sarah was experiencing was rooted in the reality of her situation and is common to many pregnant females regardless of how pregnancy was achieved (Klock & Greenfield, 2000). It seemed this anxiety was being exacerbated by Sarah's underlying negative schemata. The stressful event of becoming pregnant with twins had activated beliefs established in childhood that she 'was stupid' and 'not good enough', hence would 'not cope' (Clark, 1989). One of the manifestations of these beliefs was that she was going to be a 'bad mother' Winnicott (1969). This extended to the belief that she is a 'bad person' for having pursued fertility treatment. Sarah's belief that she is 'bad'

seems to have contravened the values of her superego resulting in strong feelings of 'guilt' (Smith, 1996). These beliefs are inextricably linked to the belief that she is 'stupid'. These maladaptive beliefs led her to perceive the impending birth of her twins as a 'danger event' (Clark, 1989). The event related on one level to her 'inability to cope' with the situation and on another to the loss of her 'freedom' as a result of becoming a mother.

1.8 Negotiating a contract and therapeutic aims

In session 1 Sarah expressed she wanted to feel 'safe in the knowledge that she had somewhere to talk' until the birth 'if necessary'. I felt it ethical to offer Sarah therapy until this point given her anxiety and presenting concerns. Setting an end date is a key feature of brief psychodynamic work and an integrative approach (Mander, 2000; Corey, 2001). Whilst we did not have a calendar date we did have a date linked to an inevitable event. Hence the point for ending was clear from the outset.

We agreed to meet every Tuesday at 5.00pm for 50 minutes. Procedures for holidays and cancellations were made clear. The psychodynamic model places great emphasis on breaks and endings (Jacobs, 1999). Prior to booking our first session I made Sarah aware that I had a two week holiday booked (over Christmas) which would allow us 5 sessions before I went away. I offered to refer her to a colleague but she declined. I made it clear to Sarah that I would be available to her each week before I went away and that the space was hers. The aim was to highlight my commitment to her and provide her with a sense of security, reliability and regularity during this difficult time. This is a key tenet of the psychodynamic approach (McLoughlin, 1995). Confidentiality was also explained to Sarah.

The aims that Sarah stated for therapy were: -

- To understand her fears around the future.
- To understand why being a mother had been 'so important' to her for so many years and why she now felt she 'didn't want to be one anymore'.
- To decide whether she wanted to give the babies up for adoption when they were born or whether to keep them.
- To reduce her anxiety.

1.9 Summary of biographical details of the client

Sarah is a single, heterosexual, 49 year old white English female. She is a social worker and lives alone in North London. Her father died suddenly 5 years ago with a heart attack. Her mother died two years ago, she had dementia and died following a series of strokes. She is the youngest of four siblings. She has two sisters and one brother. Her brother and one sister live outside London and she sees them 'now and again'. Her other sister Diane (not her real name) lives nearby, Sarah describes them as being 'very close'. She has three close friends who she sees regularly. All Sarah's siblings are married with children as are her closest friends. Sarah said that everyone had been 'very supportive' of her decision to have a child and are 'happy' she is now pregnant.

2.0 PART 2 – DEVELPOMENT OF THE THERAPY

2.1 The pattern of therapy

Sarah attended every session. Initially Sarah turned up a couple of minutes early for sessions. With each passing week she arrived a bit later than the previous. I acknowledged this pattern of lateness in session 4 and offered an interpretation relating to wanting to delay the impending arrival of the twins. Sarah responded ''Gosh yeah, it feels like I'm attempting to put off the inevitable, it's funny I'm late for everything at the moment. How interesting''. After this exchange, Sarah still arrived late but only by a minute or so. She also reported being more punctual outside sessions.

As Sarah sat down she did so with what looked like great effort and always let out a long sigh. It was as if she communicating in a non-verbal way how overwhelmed she was feeling (Smith, 1996). She would always arrange cushions around her and keep one on her lap, as if she was protecting herself. Sarah would start sessions talking about how her working week had been rather than focus on the pregnancy and related concerns. I noticed that she giggled as she talked and spoke in a babyish voice. It could be that this resistance was an expression of a defence against discussing the more threatening material, which tended to come out later in the session (Jacobs, 1999). As sessions developed Sarah giggled less and gradually started sessions speaking in her natural adult voice. Around this time she started focusing on more distressing issues earlier in the session.

2.2 Therapeutic plan and main techniques used

The overall plan was to help Sarah explore her fears and concerns regarding her pregnancy and motherhood which would ideally lead to the understanding she was seeking. In conjunction with this the plan was to challenge her maladaptive thought processes, educate her about the nature of anxiety and teach her coping skills with a view to reducing her anxiety symptoms (Clark, 1989).

The plan was to explore how the 'fantasy' of pregnancy and motherhood compared to the reality and the ways this was contributing to Sarah's anxiety (Cooper, 1996). This included an exploration of the 'trap' she felt she was in and what the twins 'represented' to Sarah and how this might be impacting on her attachment to them (Mander, 2000). My intention was to provide the 'container' (McLoughlin, 1995), the defined space and time in which meaning can be explored, via interpretations of Sarah's resistance, transference and my counter transference in the therapeutic relationship.

The plan was to reveal Sarah's underlying maladaptive schemas (Moorey 1996). A key tool employed was Socratic questioning. The plan was to identify Sarah's idiosyncratic meanings as they relate to her situation at the same time as looking for evidence for her negative beliefs. Verbal challenging was used to challenge Sarah's negative automatic thoughts and modify the underlying schemata. Sarah was educated about the nature of anxiety and she was taught coping skills with a view to reducing her anxiety and the potential impact of it on the twins (Corey, 2001). Homework tasks were set between sessions including diary keeping and daily thought monitoring records. Progressive relaxation techniques were taught to Sarah to reduce anxiety when she experienced it and to help her realise that she has control over her symptoms (Clark, 1989).

2.3 Key content issues

Feeling trapped and anxious about the pregnancy/arrival of the twins were key issues throughout the therapy. Sarah's desire to 'runaway' on holiday alone (without the twins) increased with each session. For obvious reasons this was not possible, which served to heighten her desire and the sense of being trapped. Related to these concerns was the issue of whether Sarah wanted to give the twins up for adoption when they were born. This was a conflicting issue for Sarah. She said she needed to know there was 'a way out'

but consequently this increased her feelings of guilt. Negative automatic thoughts stemming from underlying beliefs relating to being stupid, not being able to cope and being a bad person/mother were key themes in sessions. A central issue that emerged a few sessions into the therapy was Sarah's desire for a satisfying loving relationship with a man. She believed that being a mother of twins signified an end to achieving this desire 'forever'.

2.4 The therapeutic process and difficulties in the work

I instantly warmed to Sarah and really enjoyed working with her. I found her very honest and self-aware, yet looking for guidance. Sarah regularly invited me to provide this guidance. For example she would often ask me what I thought was best for her/the twins or what I thought she 'should do'. Not only was this not my responsibility as a therapist, it felt very onerous given that three lives were involved in the issues that Sarah was bringing. This resulted in me needing to be alert to this dynamic and resist her attempts to recruit me into the role which she said her mother had played when she was alive (Ryle, 1990). This was difficult at times as I did experience strong maternal feelings towards Sarah, particularly when she was distressed and needy (Mander, 2000). I was aware of being tempted on occasion to provide the guidance she was seeking. Temptation was particularly strong when her anxiety levels were high or when I thought she was making a mistake. On reflection I recognised that this was in part a function of the counter transference, in part due to a need in me to 'help' reduce her anxiety and support her through what was clearly a traumatic experience and also in part to my judgement about what I believed was 'right'. I needed to be constantly alert to the impact that Sarah had on me and how it could influence my responses to her so that I could minimise this. I also needed to be aware of what my opinions were so that I could keep them to myself.

At times Sarah expressed feelings of helplessness and I too felt this in terms of my ability to support her through her experience. Occasionally I found myself asking 'what is the point'. I felt that I was stuck with Sarah on what she called a 'runaway train'. I found myself wondering, like her, whether she would cope. I also had concerns about her age and what having two children would be like for her. Having explored this observation in supervision I became aware that this was primarily a function of the counter transference. This in turn helped me to bracket off my feelings of helplessness and work with Sarah in

a collaborative and proactive way through challenging Sarah's negative automatic thoughts (Mander, 1996).

Sarah adopted a 'chatty' style of communication with me in sessions which on the surface appeared very light hearted. This defence of 'chatting' suggested a 'resistance' to talk about her deeper issues (Smith, 1996). I observed that this made me feel uncomfortable. I also found it frustrating at times as I was aware that this created an avoidance of Sarah's more pressing issues. I was also aware of the limited time available. I tried to remain conscious of my process and limit the impact of it on the work but at times my discomfort/frustration resulted in me being more direct with Sarah than I would normally be. I reflected after a couple of sessions that Sarah's 'chatty' defence was partly facilitating Sarah to indirectly get her needs met e.g. by being chatty and avoiding the issue I observed that I fell into the trap of directing and guiding. Once I became aware of this I offered her this interpretation. The interpretation resonated with Sarah and she reflected that this is a 'habit' of hers, albeit she had been unaware that she was doing it until this point. This enabled us to explore the question of how this dynamic operates in relationships outside the therapy, thereby providing a triangle of insight (Jacobs, 1998, 1999).

Outside sessions I found myself experiencing concerns around some of Sarah's issues that had been present since we first started working together. I was concerned that these thoughts were judgemental. I was worried about the impact of these on the therapeutic relationship and on Sarah. I did not experience judgemental thoughts in sessions, at least not consciously. Rather the concerns seemed to flood in once Sarah left the session.

Some of my thoughts related to what Sarah referred to as her 'irresponsible' behaviour in pursuing treatment at 49 years of age. My thoughts directly mapped onto those of Sarah e.g. her age and how this would impact on her ability to be a healthy and active mother to the twins as they were growing up and into their adulthood i.e. she would be 70 years old when they turned 20. Another concern was her ability to bond with babies that were not genetically her own (this was based on the fact that Sarah said she had 'not thought this aspect through' prior to treatment). I had concerns about how she might juggle a full-

time job (which she could not afford to give up) and childcare for two children as a single mother.

Thoughts and concerns that did not directly map onto Sarah's related to the potential impact on the unborn children of being given up for adoption when they were born, having already been created from donated gametes. Moreover I wondered whether they would be separated if this was the choice Sarah made. On the other hand I had concerns about the impact on them if Sarah kept them but did not bond with them. At the same time Sarah was my client and I had concerns for her mental health if she made a decision to keep them out of a sense of obligation but did not want to. I also had grave concerns about Sarah making an irreversible decision to give the children up for adoption at birth whilst she was feeling so anxious and hormonal. I feared that she might live to regret this decision if she made it too soon.

I explored all of these concerns openly and honestly in supervision and personal therapy. This process enabled me to establish my personal position so that I could take ownership of my concerns. Following this I had more clarity which allowed me to be congruent and respond to Sarah's concerns in what I hoped was a less judgemental way (Mearns & Thorne, 1999). This facilitated a number of discussions that permitted us to explore the pros and cons of her various options at the same time as accessing Sarah's negative automatic thoughts. This enabled me to step back from a guiding role and empower Sarah to consider her various options. She responded well to this, demonstrated by her verbal engagement and her open body language.

2.5 Making use of supervision

For reasons outlined previously supervision played a pivotal role in the work with Sarah. I found the case challenging in a number of ways. Supervision provided a safe space for me to candidly explore my thoughts and feelings about Sarah's situation. This was essential as I did not want to bring my material or judgements into the work with her. I used supervision to express my frustration that she had not fully considered the implications of having treatment at 49 as a single parent using donated gametes. Using the supervision space I was able to recognise that much of my frustration stemmed from my work as an implications counsellor at the Lister Hospital with patients prior to

treatment with donated gametes. In my experience (and my colleague's) it can be difficult to engage clients at this stage in discussion about issues such as multiple pregnancy and attachment to the foetus/child. This was an issue I had previously brought to supervision on a number of occasions. Whilst I am able to appreciate the reasons why patients find it difficult to discuss these issues I feel strongly that this is a vital part of treatment in terms of the well being of patients, their partners and any children born. Working with Sarah gave me an insight into the negative impact of not exploring these issues at length prior to treatment. Exploration of this issue in supervision was beneficial to the work with Sarah as it has helped me to keep my personal feelings separate.

Sarah's multiple pregnancy meant that the therapy could end abruptly. I found this anxiety provoking and distracting. Reflecting in supervision about these feelings enabled me to establish that this stemmed in part from a sense that I felt I had to 'fix' the situation for Sarah and I could hear a clock ticking. This was compatible with Sarah's concerns and it seemed that through the transference I was picking up Sarah's frustration at my inability to meet her needs (Smith, 1996). I was also able to explore my need to help and the impotence I felt. I could then own this.

2.6 Changes in the formulation and therapeutic plan

A theme that emerged was Sarah's desire to have a long-term satisfying relationship with a man. She talked about 'losing' her two previous relationships in her quest to become a mother. Now Sarah had come to view her pregnancy and motherhood as a block to 'ever' achieving a fulfilling relationship. This was causing her high levels of anxiety and resentment towards the twins. Sarah was demonstrating all or nothing thinking around this issue. I reflected this back to Sarah and we worked in sessions towards her seeing things from a more realistic perspective using CBT techniques such as verbal challenging, constructing a dimension and finding exceptions to this belief amongst others (Clark, 1989).

On a deeper level it seemed that the pregnancy was serving the purpose of 'protecting' Sarah from exploring her beliefs around why she had not established a satisfying long-term relationship in her life so far. At the same time it was protecting her from facing her role in the break-up of previous relationships. As sessions progressed and repressed

material started to loosen (Smith, 1996), more details from Sarah's past emerged. Sarah expressed concern that she had never been able to 'maintain' a long-term relationship and believed this made her a 'failure'. I held back on interpreting the function that the pregnancy seemed to be serving as I believed that if she reached this conclusion on her own it would be more powerful (Winnicott, 1969). In session 6 Sarah made this link for herself explicitly in session saying ''well if I'm honest it's not the pregnancy or being a mother that is going to prevent me from having a relationship, that's about other stuff entirely''. Whilst we did not have time to explore these feelings or issues in this therapy contract we used it to help Sarah perceive her pregnancy and the future in less negative, absolute terms.

2.7 Changes in the therapeutic process over time

Sarah responded well to the collaborative nature of the work. The effect of this was that she became more proactive in sessions. Sarah became less chatty and more inclined to take control of sessions and focus on the issues she brought to therapy. I noticed that my belief in her strengthened as sessions progressed. This occurred in parallel with Sarah's process as she started believing that she would cope with her situation. This coincided with Sarah taking more control outside sessions. I noticed that by session 5 she was seeking guidance less than in previous sessions. At the same time I was feeling less inclined to provide guidance and the balance continually shifted with each session.

As I was gaining clarity in supervision about my concerns I was less distracted in sessions. Hence I could be more available to Sarah. Moreover I was able to be congruent in sessions and explore her concerns freely without the constant worry of appearing or being judgemental. I feel that this had a positive impact on the therapeutic relationship. This was demonstrated by Sarah saying that she felt 'completely safe' to say anything to me in the knowledge that I would not 'judge' her. At this stage Sarah stopped placing cushions on her lap, signalling that she did not feel the need to protect herself (Mander, 2000). Sarah's tendency to speak in a baby voice dramatically declined as sessions progressed and I felt less maternal towards her.

3.0 PART C – THE CONCLUSION OF THERAPY AND REVIEW

3.1 The therapeutic ending

In the 29th week of pregnancy the hospital started monitoring Sarah's twins on a weekly basis. She was warned that she could be taken in for a caesarean section 'at any point'. This coincided with our 6th session in the week that I returned from my break. Each session from this point was treated as a 'last session'. Endings can re-awaken previous experiences of separation and loss and the feelings relating to them (Jacobs, 1999). Therefore, I spent time acknowledging and exploring the feelings of anxiety around our 'ending' to help make the break a clean one and possibly the only positive separation experienced to date (Smith, 1996).

The final sessions focused on three key areas 1) How Sarah felt about the prospect of the twins arriving (and related issues) in preparation for the event 2) The therapeutic ending 3) A review of the work to date.

Session 8 was our final session as Sarah had been booked in for a caesarean two days later. We had a final review. In response to my question about how she felt about the therapy ending Sarah said she was 'feeing ok'. She said that she was feeling 'more able to cope' with her situation. She said that she believed she 'would be back'. I gave Sarah my assurance that she could contact me to book a session at any point. We said goodbye and I wished her luck.

3.2 Evaluation of the work

Sarah expressed that she had benefited 'enormously' from the work. She supported this by saying she was feeling less anxious and now knew ways of reducing her anxiety when she experienced it. She said she was feeling less trapped and had started planning for the arrival of the twins and had set-up a nursery for them. She had also made the decision to wait 6 months following the birth before deciding whether to give the children up for adoption. She was thinking in less absolute terms and no longer believed that becoming a mother meant she would never meet a life partner.

I feel that overall the work was effective as the goals for therapy were met. It was important that I had the space to explore my concerns and feelings otherwise I believe

they could have impacted negatively on the relationship and on Sarah. Consequently I feel that the therapeutic relationship was strong and this external support facilitated the work significantly. I do feel that the time pressure was not helpful. I would have welcomed more time to work with Sarah on issues that emerged in the course of the therapy i.e. her relationship with her parents, the sudden loss of her father five years previously and past relationships.

Finally, on reflection I am aware that I did not consider or explore Sarah's thoughts and feelings about me and what she imagined my personal situation to be in relation to her and her situation (Mander, 2000). Consequently I did not consider how this could impact on the work and the therapeutic relationship. I think this would have been valuable and in future I would consider these important factors.

3.3 Arrangements for follow-up

At present we have no further sessions arranged. Sarah called me when the twins were a week old. She left a message saying that she and the twins were doing well and that she would be in contact 'at some point in the future'. I have not heard from her since then (8 weeks ago).

3.4 What I learnt about psychotherapeutic practice and theory

I learnt that working within an integrative framework was extremely beneficial in a case such as Sarah's. The core conditions of the person-centred approach provided a firm platform for the work. In particular integrating a psychodynamic and CBT approach enabled me to work with Sarah on both a conscious and an unconscious level which I believe was effective in helping Sarah. Utilising a combination of compatible techniques from these three models permitted me to work effectively and creatively in a short time frame (Corey, 2001).

I found the complex issues that Sarah brought to therapy were challenging to work with compared to more specific, researched issues such as depression or anxiety, from both a practical and a theoretical perspective. Much of the time I was learning about the issues we were tackling from Sarah and I found that I needed to be especially careful about my assessment and formulation. This extended to the techniques used. I felt that the case

required me to be especially sensitive, careful and creative. This was a challenging and rewarding experience. There was potential to fall into the trap of being eclectic and choosing tools at random, particularly in instances where I felt anxious or de-skilled. Having a clearly defined theoretical framework reduced the possibility of this and informed the work throughout.

I have always subscribed to the value of supervision. This case has compounded this belief. I think it was essential in the work with Sarah and without it I think the work could have been a lot less effective or at worst a negative experience for Sarah.

Working with a clear ending date is a feature of an integrative framework and short-term therapies (Mander, 2000; Corey, 2001). I learnt that working without one can impact negatively on the therapeutic process if the therapist is distracted by this fact, as I was. This is an issue that I have been exploring in supervision as this is a feature of this type of work.

3.5 Learning from the case about yourself as a therapist

This was a challenging case and I have learnt a lot about myself as a therapist. I have learnt that I am more robust and can tolerate higher levels of anxiety than I realised. The case has highlighted a desire in me to try and 'fix' problems. I recognised that a symptom of not being able to fix the problem is that I can feel impotent and de-skilled as a therapist, resulting in feelings of helplessness. I have since worked on this in both my personal therapy and supervision and will continue to do so.

I have learnt that I can adapt to the restraints of working to a contract that could end abruptly due to the very issue that is the focus of the work. This is in contrast to therapy ending due to client choice, which is always a factor in therapeutic work. However I have learnt that I do not particularly enjoy working under these conditions as I find it distracting. Given the client group I work with this is a skill that I need to develop. I plan to do this through supervision, peer support and personal therapy.

I found some of the factors in this case contentious and it encouraged me to reflect on my position in a more focused way than I had previously. The work with Sarah compounded

my firm belief that I need to be aware of my moral, ethical and emotional position on topics that clients bring to therapy. Then I can ensure I take ownership of them and strive to minimise the impact they have on the client, the therapeutic relationship and my ability to remain within the therapeutic framework. I learnt that with the help of supervision I was able to bracket off my most conflicting beliefs and opinions and focus on Sarah and her frame of reference. At the same time I was able to be congruent about how I felt when appropriate. This felt anxiety provoking at times but I believe it positively impacted on the work. Hence I have learnt that I can take what feel like 'risks'. Moreover I have observed how this can benefit the therapeutic relationship.

Finally I have learnt that I really enjoy the challenge of working with clients with difficult and anxiety provoking issues such as those that Sarah was experiencing. I also believe that this is a growing area and I am keen to work on developing my skills so that I can work effectively with this client group.

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SECTION D: CRITICAL REVIEW OF THE LITERATURE

COUNSELLING PSYCHOLOGY OF INFERTILITY:

An Historical Perspective of Infertility and Counselling in the 20th and 21st Centuries.

Introduction

It is argued that to understand the complex psychological aspects of the infertility experience today infertility and the related experience should not be viewed in isolation but in context. Primarily because the psychological issues experienced and encountered by this population are largely due to the legacy of previously held attitudes, beliefs and practices.

The aim of this review is to explore the historical perspective of infertility so that the psychological impact of current issues and experiences can be understood within a frame of reference (Marsh & Ronner, 1996). Infertility will be placed in context by conducting a review of the literature from the early 1900s to the present day. The link between past and current issues in the literature will be continually explored throughout the Review. The rationale for choosing to examine the literature from the beginning of the 20th century onwards is provided in the next paragraph.

Statistics are available to support the existence of infertility spanning many centuries (Etmuller, 1699; Graham, 1784; Rosenberg, 1979; Marsh & Ronner, 1996; Pfeffer, 1993). However literature relating to the infertility experience is sparse. Hence literature from the period prior to the 20th century is not directly relevant to the aims of this Review. At the turn of the 20th century the declining birth rate in Britain was observed and raised concern (Pfeffer, 1993). This ignited interest in this area and led to some of the research relevant to this Review. For example, in 1905 the Fabian Society set up a committee to investigate the declining birth rate in Britain (Webb, 1907). Research carried out during this time (and through the first half of the 20th century) was concerned with the question as to why females were having fewer children. The aim was to provide incentives to procreate, as opposed to investigating infertility per se. The implicit assumption being that the declining birth rate was due to choice as opposed to involuntary childlessness.

This Review reveals a trend in the research that traditionally tended to focus on females who became mothers and overlook infertile females and their related experience, who did

not become mothers. Males were ignored almost totally in the research (e.g. Webb, 1907; Martin, 1989; Shorter, 1982; Gittens, 1982). Instead investigations have tended to be based on two key assumptions from the outset. One is that fertility is taken for granted. The second is that males are not affected emotionally by the experience of not being able to conceive as part of a couple. One key consequence of this is that the issues surrounding infertility may not have been fully understood. Hence those experiencing it have not been sufficiently catered for.

This in itself seems an alarming oversight. It demonstrates the extent to which infertility and those experiencing it have not been fully considered nor their experience and opinions valued and explored. It must be considered that if experienced researchers are susceptible to these assumptions it follows that professionals working in the field and members of the general population are also susceptible. This in turn is likely to have a significant impact on those going through the infertility experience. This is an essential consideration for counselling psychologists working with those experiencing fertility issues.

The psychological issues experienced by this population are both varied and complex. To address all of the areas is beyond the scope of this Review. However the Review will look at the treatment, attitudes and beliefs surrounding infertility in males and females respectively, where the biological cause is located within each. The real and potential psychological impact of these beliefs, attitudes and practices are also explored. The rationale for choosing to focus on these issues is because an understanding of the differing psychological impact on males and females and how these relate to the causal factors provides an essential framework for reference in the work of counselling psychologists with this client group. This is important because female infertility accounts for 40% and male infertility accounts for 30% of all cases, equating to 70% of all infertility cases. The remaining 30% of infertility is due to infertility in both partners and unexplained infertility (HFEA, 1999). Thus this framework of understanding will be relevant to at least 70% of clients.

1.1 Overview of theories of conception prior to the 1900s

Agricultural terms such as barren, seed and in/fertile provide important insight as to how infertility and the role of the female have come to be viewed over time. The application of these terms can be traced back to early theories of conception.

Prior to the turn of the eighteenth century the prevalent theory of conception was the 'semence' theory, which had been originally proposed by Hippocrates and Galen (Marsh & Ronner, 1996). Semence theory proposed that both the male and the female produce seed during intercourse and conception is the result of the seeds mixing. It was believed that if mixing were to occur then both the male and the female needed to experience an orgasm.

Just before the turn of the 18th century scientists started to question whether females actually produced seed. A popular and ongoing debate related to the question of whether a new being already existed in the seed, prior to intercourse. This gave rise to the question of where the new being existed e.g. in the ovary or in the semen. The Aristotelian view was that the new being existed in the seed provided by the male with the female providing the soil in which the seed would grow into a foetus. Semence theory had overridden the Aristotelian view for a number of years. Then Anton van Leeuwnehoek made the discovery of spermatozoa under the microscope in 1677 (Cole, 1930). This gave credence to the Aristotelian theory that microscopic beings did indeed exist and that they were present in the male seed. Thus the theory that emerged was that the male was responsible for 'planting' his seed in the female's soil. If a foetus developed the female had a 'fertile' environment. However if a foetus never developed, despite continued attempts, the female was considered to have a 'barren' environment. A male was only considered unable to father a child if he had impotence or a deformity, both of which were considered rare conditions. Even under these circumstances it was believed that providing the male could produce semen that could be inseminated then he could father a child (Marsh & Ronner, 1996). This highlighted the importance attributed to the male in the reproductive process and the relative ease with which he could father a child, provided that the 'soil' in which he planted his seed was fertile.

Consequently all manner of treatments for involuntary childlessness, the majority of which were unpleasant, were developed for and used by females in an attempt to increase and encourage a 'fertile environment' (Rosenberg, 1979). However, it should be pointed out that ultimately the overriding belief of the time was that children were a blessing from God, who in some cases chose to withhold that blessing (Pfeffer, 1993).

1.2 Infertility in Edwardian Britain

Theories of conception go some way to explaining why historically females and their bodies have been pathologised in the field of infertility whilst males have been overlooked and/or protected. In Edwardian times infertility or sterility, as it was referred to then, was viewed explicitly in medical texts as being a function of a disordered female being (Pfeffer, 1993). Whilst it was accepted that both a male and female are required to procreate, the focus was almost exclusively on the female and her body. The implicit assumption and message related to this practice is that a) females, or rather their bodies are faulty and hence to 'blame' for childlessness and, b) the process of procreation dominates female's lives and bodies whilst males are on the sidelines of the process, and hence remain unscathed. Whilst language has modified and understanding has grown considerably over the last century, these assumptions are still prevalent in contemporary literature. For example a common finding is that female's lives are devastated by infertility (e.g. Shorter, 1982; Read, 1995; Greil, 1997; Gibson & Myers, 2000). This implies that females are dominated by the desire to have a child and that males are on the sideline of this process and as a result not affected by it.

The finding that experiencing infertility is devastating for the female is widely supported. However the assumption that the male is not affected is misleading. For example, Mason (1993) found that infertile males experienced similar emotions to those of infertile females. The research component of this thesis also found this.

It is the job of counselling psychologists to be able to work with what is expressed and what is not expressed. In practice males may not express their feelings around the infertility experience as freely and as often as females (Mack & Tucker, 1996). However, it is a mistake to assume this is an indication that they are not experiencing negative emotions. We can draw on the research that highlights differences in male and female

coping and communication patterns to inform the work with those experiencing infertility. Stanton (1991) found that males cope with their 'pain' by keeping it to themselves and focusing on their partners feelings instead. There is a body of studies looking at interaction patterns between couples which reflect the dynamic described by Stanton (1991). These studies have shown that males' grievances are centred on their partner's complaints and that they respond by withdrawing emotionally, withholding affection and may refrain from disclosing any of their feelings (Fitzpatrick, 1988; Noller & Fitzpatrick; Gottman & Levenson, 1988). Given the range of emotions likely to be experienced by males going through the infertility experience, this interaction pattern may be amplified and enduring throughout the process.

Without doubt the two key assumptions 1) that a female is fertile and 2) that males are not affected by the experience of infertility, have exerted their influence on findings in the literature. However it is important to consider not only the root of the assumptions, but also the impact of them on the individual/couple experiencing infertility. For example it is important to be mindful of how these assumptions are likely to impact on the treatment of the individual/ couple from the social domain to the GP through to the treatment centre. Thus it is vital that counselling psychologists do not fall into the trap of treating the female and overlooking the male.

Looking at the root of these assumptions, it is of note that should a female have consulted a medical practitioner about difficulties in conceiving in the early 1900's she would have been classified according to the extent to which she matched a set of popular perceptions of what a 'normal' female is like in terms of physical appearance, behaviour, morals, habits and menstrual cycle (Mosucci, 1990). Doctors set these standards and the underlying assumption was that only a 'normal, feminine' female could have a baby (Mosucci, 1990). Psychologically the impact of this assumption is likely to have been profound and may have led to feelings of having 'failed' as a female. Indeed the sense of 'failure' both as a female and of her body failing her is a commonly held perception held by many infertile females today (Read 1995; Crawshaw, 1995; Mack & Tucker, 1996; Perkins, 2006).

Males were similarly compared to a set of external 'masculine' standards in order to measure their fertility e.g. bodily and facial hair, muscular development, voice and disposition of the penis, amongst other indicators (Mosucci, 1990). In the early 20th century these external characteristics were considered a more accurate measure of male fertility than the presence of spermatozoa (Corner, 1910). This highlights the limitations in knowledge at the time of the crucial role of spermatozoa in the fertilisation process.

Ignorance, such as that outlined above, is an important factor when one considers the rationale of the medical profession to focus predominantly on the woman in the early 1900's. Moreover, the focus on the female and her feminine form served the function of largely protecting the male from any fertility investigations. However, there are a number of other factors that also contributed to the tradition of the time that ostensibly bypassed the male and focused on the female. Firstly, it is important to bear in mind that the medical profession was predominantly male during the Edwardian period and it is reasonable to suspect that there may have been a reluctance to bring the essence of 'masculinity' into question. Secondly doctors were likely to have been reluctant to ask males for a sperm sample given the Edwardian attitude relating to masturbation, which was considered 'immoral' (Pfeffer, 1993). Thirdly, as previously discussed, medical knowledge until this point regarding the role of spermatozoa in the fertilisation process had been limited, thus rendering the request for a sperm sample unjustifiable. However, during the early part of the 20th century the important role that the male played in the conception process began to emerge, as the following excerpt from a physician's comment in The Lancet (Gibbons, 1910) demonstrates:

> "Although until apparently recently it was always assumed that the woman was at fault if the man seemed physically fit for the sexual act, we now know that *potentia coeundi* does not necessarily mean *potentia generandi*. It is only in recent years that we have come to learn how much men are to blame for sterile marriages".[3]

[3] *potentia coeundi* – sexual potency
potentia generandi – the ability to affect fertilisation

Despite this acknowledgement, females were still predominantly blamed for infertility, even when the male contribution to involuntary childlessness was the point of discussion (Sandelowski, 1990). It is important to consider what the psychological impact of this was on the male and the legacy that has been handed down. It could of course be argued that the male being protected was a positive factor for all males. However this does not account for the feelings that males might have experienced regarding infertility, especially in case of male infertility. Neither does it account for the effect of male infertility on females and the couple relationship. Mason (1993) has looked extensively at male infertility and has found that infertile males experience many of the same emotions that infertile females experience. In addition she found feelings of guilt and inadequacy that are experienced can be compounded by the fact that their infertility has caused their partner to suffer both emotionally and physically. Furthermore the male can be marginalised as a function of this protection (Mason, 1993; Perkins, 2006). Thus it is important that professionals working in the field of infertility are aware of the tendency in some males to keep pain to themselves. The fact that they do not disclose feelings should not be taken as evidence that they do not feel the experience (Stanton, 1991). There is a possibility that to do this may potentially contribute negatively to their experience of infertility, further marginalising them, and associated feelings are also likely to remain unexpressed as a result.

1.3 Infertility in Britain prior to and during the First World War and the 1920s

When considering infertility in Britain prior to and during the First World War and the 1920s it is important that political concerns regarding population decline and infertility are discussed. The birth rate had been steadily declining since 1866. As relations with Germany deteriorated, concern about this decline prompted research in the form of the 1911 Fertility Census which looked at the possible causes of the declining birth rate (National Birth Rate Commission, 1916). The aim of this research was to yield information that could then be used to encourage people to procreate. In theory this was so Britain could remain a dominant force in the world and there was particular interest in the middle classes procreating (Pfeffer, 1993). Whilst the research findings were inconclusive in terms of the extent to which childlessness was due to voluntary or involuntary limiting of children, they revealed that the middle classes were experiencing an epidemic of 'sterility' (Pfeffer, 1993). The research carried out both a fact finding

mission and a method of educating females about their bodies and conception. Hence it was an exercise in population control. It did not consider or attempt to address the emotional and psychological impact of involuntarily childlessness. It may even have contributed to distress of those who participated in the research. This demonstrates how the population of infertile males and females were overlooked at this time.

Concerns about the sterility epidemic were eclipsed in the 1920's. During this time there was growing concern regarding over population, due to decreasing death rates, which compensated for any decline in birth rates (Pfeffer, 1993). This saw the rise of 'antinatalism' and the focus shifted from finding out how to encourage procreation to how to control it. It was at this time that the first birth control clinics were set up (Leathard, 1980). In short, the infertile were once again sidelined as concerns about overpopulation overrode the biological, psychological and emotional needs of infertile people. This highlighted the way in which political concerns determined availability of treatment.

Political influence can be observed today, as in recent years the raised profile of infertility and the related experience has highlighted the lack of provision available on the NHS for this population. This in part has led to the National Institute for Clinical Excellence (NICE, 2004) to state that the NHS will provide one free cycle of IVF for all females aged between 23 and 39 who meet certain clinical criteria from April 2005. This was a particularly significant move as this is the first time that a UK government has accepted that infertile couples requiring IVF should be treated on the NHS (BioNews, 2005). This decision was intended to bring the UK in line with other European countries. The issue of whether one cycle could be more psychologically damaging than none, given that the success rate (live birth) for patients of all ages is still only 22% (HFEA, 1999) is a contentious one and will not be addressed here. Nonetheless it is an important issue and worthy of mention.

Notwithstanding the focus on issues of overpopulation in the 1920's, the interwar period in Britain did see a change in scientific and medical thinking regarding infertility and sterility. Whilst the norm prior to the First World War was to place blame for infertility on the female, despite evidence to the contrary (Gibbons, 1910), it was becoming

increasingly hard to ignore the role of the male in the conception process. This was largely due to the fact that during the war 400,000 troops were treated for sexually transmitted diseases, particularly gonorrhoea, directly impacting on their fertility (Hall, 1991).

Significantly, the male was still protected by the medical profession. Causal factors for sterility in males were considered to be a function of 'disease' whilst for females it was a result of 'nature' (Walker, 1925), the implicit assumption being that males were the 'victims' of their own sterility and hence blameless, which is in stark contrast to society's and the medical profession's view of females. Interestingly, contemporary research has found that, to a large extent, females 'collude' with the medical profession and protect males by assuming responsibility, at least socially, even when they are not biologically the cause (Cook, Golombok, Bish & Murray, 1995; Linblad, Gottlieb, & Lalos, 2000). The topic of infertility is often shrouded in secrecy (Bor & Scher, 1995; Jenkins, Corrigan & Chambers, 2003) and this can be compounded when the male is the infertile partner (Mason, 1993).

There is very little information to inform us what the experience of infertility was like for those experiencing it during the interwar period or why more females did not seek medical attention, as they have done since the 1960's. This lack of information may be explained in part because the majority of research carried out in the early part of the 20th century was concerned with females as mothers and the childless were excluded from such research (Gittens, 1982). In addition, costs to see a medical doctor for any complaint was high and many may not have had access to medical services on financial grounds hence females may not have had an opportunity to seek medical advice (Pfeffer, 1993). Consequently there was little opportunity to gather data for research on childless couples.

There is also another persuasive argument that may explain why so few females sought medical advice during the 1920's. In the earlier part of the 20th century there were a number of factors leading to childless females being able to care for a child. For example a high number of females died during or post labour, or at a young age, poor families often had more children than they could cope with and a high number of children became orphans as many fathers died in the First World War. Thus informal adoption between

family members was common practice, and may have met the emotional needs of many infertile females. However it is important to point out that prior to The Adoption of Children Act 1926, adoption of unrelated children was discouraged. Beyond this point there is a suggestion that formal adoption was actively used as a solution to sterility (Pfeffer, 1993). After 1926, there is also evidence that many females in and around the London area were actively seeking investigative infertility treatment from voluntary hospitals such as Guys and St. Bartholomew's (for a discussion of treatments being sought see Pfeffer, 1993). This other argument provides some potential insight into the increase of the modern day females' reliance on medical intervention to produce a 'solution' to the 'problem'

1.4 Infertility in Britain during the 1930's and World War II

During the 1930s the number of females seeking treatment started increasing. This coincided with increasing knowledge about the role of the male in the conception process, which exerted its impact on the range of treatments available. From the 1930's a number of doctors started to use Artificial Insemination with Donated semen (AID) to treat sterility. However AID was a contentious issue. Females accepting donated sperm were labelled 'immoral' and 'perverse' (Bendit, 1943) and accused of suffering from a 'neurotic child fixation', based on the assertion that any 'normal' female would have been 'satisfied' with an adopted child (Leitch, 1943). The doctors involved in this practice were also accused of having 'no ethics', demonstrated by their neglect of their patients' morality (Todhunter, 1944).

The link between male infertility and the treatment for it resulted in a great deal of shame being attached to it. The priority once again seemed to be concerned with minimising the social and psychological impact on the male. The protection of the male combined with the shame associated with male infertility and the related treatment resulted in shrouding the act of AID in a great deal of secrecy (Pfeffer, 1993). Significantly, as mentioned earlier, this secrecy is still common practice today. Females have been found to often take on the mantle of responsibility even if they are not the infertile member of the couple (Mason, 1993; Cook *et al.* 1995; Read, 1995; van Berkel, der Veen, Kimmel & to Velde, 1999; Linblad *et al.*, 2000).

In addition to secrecy serving as a protective function; it was also common in the early stages of using AID to mix some of the male's sperm with the donors. The belief being that the element of doubt would be of great psychological help to him in being a father to the child (PP Home Office and Scottish Home Department, 1960). This again highlights the tendency to overlook the psychological impact on the female going through the infertility experience. However, what it also demonstrates is a tendency to create a division within the couple by not attending to them as a unit but more as separate entities. Moreover it emphasised the tradition of constructing negative perceptions of the infertile female, which appear more striking in cases where the biological cause is located in the male. Even those enthusiasts in the 1940s who were advocating the use of AID presented a negative image of the childless female by arguing that a woman is neither physiologically nor psychologically complete until she has had a child (Pfeffer, 1993). There was a lot of contention surrounding AID socially, ethically, morally and politically. For example a survey carried out on behalf of Feversham Committee (1958), revealed that by 1948, AID had ceased to be available from the National Health Service (NHS) and was only available privately. Significantly, the social, political, ethical and moral issues relating to AID impacted negatively on the field of gynaecology. This led to reluctance on behalf of doctors to investigate the causes and treatment of infertility, as the NHS neither encouraged nor supported it. This meant that the field of gynaecology was not attractive to ambitious doctors and / or researchers. The resulting impact was that the field did not grow as fast as other medical fields at the time (Pfeffer, 1993).

1.5 Infertility in post World War II Britain

Despite the issues being encountered in the field of gynaecology, in 1945 the Family Planning Association (FPA) began opening what were known as Motherhood Clinics across Britain with the aim of facilitating involuntarily childless females to have children. The expansion of these clinics was rapid. By 1960 there were 311 clinics of which 246 gave advice on infertility (FPA Working Party, 1962). Whilst this was an important advance, infertility was still marginalised. The FPA was more concerned with contraception. Despite the focus on contraception the FPA did campaign for the NHS to improve services for the investigation and treatment of infertility for another 3 decades, but without much success.

The 1950's saw the rise of research into the psychological aspects of infertility. This coincided with the new idea that a high proportion of female infertility - some estimates suggested as high as 75% of cases - was a function of psychological rather than physiological disorders (Marsh & Ronner, 1996). This was in part due to the realisation that success of infertility treatments was limited (e.g. Noyes, Hertig & Rock, 1950; Simmons, 1956). Instead of considering that medical science was not advanced enough to effectively treat infertility, the logic that prevailed was that in cases where infertility was not 'cured' by physical intervention then it was not a function of a physical problem but a psychological one. It was also due in part to the growth of the psychoanalytic movement of the time, particularly in America. Not surprisingly the resulting articles predominantly drew on psychoanalytic theory. Females do not emerge favourably as once again they are considered to be at 'fault', only this time psychologically as opposed to physiologically.

During the 1950's *Fertility and Sterility* published a series of articles exploring the link between infertility and psychological factors. Examples of article topics included were: sexual and marital adjustment to infertility; a psychodynamic approach to the study of infertility and ambivalence and conception, amongst other aspects relating to infertility (Pfeffer, 1993). Common theories of the time suggested that infertility in females was due to a deep seated conflict between husband and wife, a desire to thwart the husbands' needs and an unconscious rejection of motherhood (e.g. Lorenz, 1951; Rubin, 1947). Kroger (1952) suggested that in addition to the hostility felt towards their husband, females were reluctant to give up their newly found careers and this was also a contributing factor to female infertility.

Freudian theory that neurotic females are unable to conceive for unconscious reasons has exerted great influence on the thinking of professionals in this field over the years. Freud's theories have stood the test of time, for example Pines (1990) writes about her experience of clinical work with infertile females and discusses the role of the unconscious and how it can be 'responsible' for infertility. Edelmann & Connolly (1986) challenged this view of the unconscious being responsible for infertility. They reviewed a number of studies exploring the impact of psychological dysfunction on fertility and the impact of infertility on psychological functioning. They concluded that the impact of

psychological functioning on infertility is uncertain but that infertility most certainly has psychological consequences for some couples going through the infertility experience.

It is important to consider that the belief that psychological factors contribute to, and in some cases are responsible for, infertility has penetrated the collective unconscious. This includes the medical and therapeutic professions but also the wider population, including those experiencing infertility (Mack & Tucker, 1996). The potential for adverse psychological impact on infertile females and males is great and needs to be considered in work with this group.

It is noteworthy that during the 1950s whilst research was investigating the psychological aspects of infertility, the psychological and emotional needs of this population were still not being adequately addressed or catered for therapeutically. Consequently females and males were not likely to be offered emotional support whilst going through the infertility experience. In the 1950s infertility patients in America were beginning to be referred for psychological counselling (Marsh & Ronner, 1996). This was primarily in cases of extreme stress and anxiety or in cases where it was adversely affecting the marriage of the infertile couple. Thus it seems that in the domain of infertility in the 1950's, the role of the counsellor was to provide crisis intervention as opposed to support or therapeutic counselling.

In contrast, today in Britain the Human Fertilisation and Embryology Authority (HFEA) state in their Code of Practice (1990) that three distinct types of counselling must be available at licensed treatment centres. These include "implications counselling", "support counselling" and "therapeutic counselling". However, the HFEA Code of Practice also states that "no-one is obliged to accept counselling" (p. 28, HFEA, 1999). Furthermore it states that implications counselling "must" (p.29) be made available to everyone, but that support or therapeutic counselling should be made available in "appropriate cases" (p.29). A point to consider is that this only caters for those who have chosen the treatment route, which for many may be some years into their infertility. At present there is no specific provision available on the NHS at the GP level for those at the earlier stages of their infertility or for those who do not proceed with fertility treatment.

1.6 Infertility in Britain - the 1960s and beyond

In the 1960s fears of overpopulation were once again taking hold. Scientific advances led to the availability of two revolutionary contraceptives - the Pill and the intrauterine device (IUD). The 1960s were characterised by the rise of research and campaigns into promoting birth control in direct response to increasing fears of overpopulation. The FPA were still more concerned with preventing pregnancy and by the 1960's only 1.6% of its patients were infertile (FPA Working Party, 1962). Concerns about the causes of the decline in fertility of the previous years were forgotten. Instead the declining birth rate, which was now considered desirable, was attributed to an improved knowledge base and birth control methods (Sloan, 1983), not infertility. Ironically by the latter part of this decade investigations into the reasons why males and females did not have children were inextricably linked to the evaluation of services provided by birth control providers. In short not having a baby was the key measure by which the effectiveness of family planning was monitored (Pfeffer, 1993). This highlights how the infertile were used to contribute to and inflate family planning statistics.

Until now pharmaceutical companies had experienced more success with the development and distribution of birth control preparations than preparations to aid fertility. However, in 1963 the first gonadotrophic preparation called Perganol, used to stimulate ovulation, was developed (Brown, 1986). This marked the turning point for the field of infertility. Medical practitioners who prescribed gonadotrophins grew wealthy and their professional reputations thrived (Pfeffer, 1993). At the same time infertile females and couples were given hope.

The physiological, emotional and psychological dangers posed to females undergoing this treatment were not small (Papworth, 1990). It is worth pointing out that at the time there were few restrictions or regulations imposed on medical research (Pfeffer, 1993). Therefore females did not have to be briefed about the risks involved. Doses of gonadotrophins were difficult to judge; as a result the multiple birth rates soared. The impact of multiple pregnancies and births are known to put significant strain on females and their partners physically, psychologically, emotionally and financially (Collopy, 2002; Balen & Jacobs, 2003; Jenkins, Corrigan & Chambers, 2003). However politically this was a contentious issue because multiple births significantly increased health care

costs in neo-natal units (Koivurova, Hartikainen, Gissler, Hemminki, Klemetti, Jarvelin 2004) and in the first five years of the child's lives (Henderson, Hockley, Petrou, Goldacre & Davidson 2004). This new infertility treatment put additional strain on already under-funded health services and still does today. Fears of overpopulation were also being fuelled by the increase of multiple births (Martin, 1965). Combined, these factors served the purpose of infertility and its treatment becoming a more controversial issue than ever before.

Despite the risks posed to females, Robert Edwards and Patrick Steptoe in 1968, who were at the time developing their in vitro fertilisation technique, found that females were keen, in fact too keen, to volunteer to act as 'guinea pigs' (Edwards & Steptoe, 1981). Thus females' actions seem to have supported the view that they were 'desperate' to have children and this desperation in turn was seized on by the professionals working in the field to justify their methods.

Predictably, based on previous decades, the general lack of interest in infertility continued throughout the 1970's. In a series of articles published in the British Medical Journal, the topic of infertility was left out (Pfeffer, 1993). A survey carried out in the late 1970's reflects the lack of interest, knowledge and treatment of the time. The survey investigated patients' experiences of doctors' responses to infertility and revealed that in the majority of cases the advice given was to 'relax and keep trying'. If this failed then there was an encouragement to adopt (Owens & Read, 1979).

In 1974, the government eventually responded to pressure from campaigners and reluctantly agreed to take over the FPA clinics and incorporate them into the NHS run services (Pfeffer, 1993). Whilst there was little difference in the success of tests offered by private and NHS doctors, those patients who could afford to, chose to see a private doctor for their infertility. The reasons given by patients for this were that it was 'quicker' and that private doctors were more 'understanding and sympathetic' to patients needs (Owens & Read, 1979). Thus the discovery that to be treated quickly and with understanding, made by those who were involuntarily childless, contributed to the growing trend to pay for private infertility treatment. The ensuing result being that instead of improving provision for this population on the NHS, over time the infertile

have come to be expected to pay for their treatment. As mentioned previously this changed in April 2005 when the NHS committed to provide 1 free cycle of IVF for all females aged between 23 and 39 who meet certain clinical criteria (NICE, 2004).

1978 saw the birth of the first baby conceived in vitro. This was a significant event for both the medical profession and the involuntarily childless. The event ignited interest in gynaecologists who then started getting involved in this work. The growth of treatment centres was swift and by 1986, 23 clinics were offering IVF in the UK, with 4 more clinics planning to open (Pfeffer, 1993). The field of infertility was all of a sudden a very attractive option for the first time to the medical profession. This was primarily due to the considerable financial gains on offer. These financial gains highlight how the infertile population finally came to the attention on the medical profession.

Despite the NHS takeover of the FPA clinics in 1974, by 1982 provision for infertile females within family planning clinics was on a dramatic decline. A survey carried out by the FPA in 1982 revealed that of the 192 health authorities in the UK only 67 provided advice for those experiencing infertility. By 1984 this had decreased to 40 out of 145 health authorities (Leathard, 1985). A look at politics can provide at least part of the explanation for this decline. In 1976 the Labour government had given both private and NHS patients the same priority on the waiting list, thus removing the benefit of seeing a doctor privately. However, in 1980 this policy was reversed by the Conservative government, who had come into power the previous year. This was a function of the Heath Services Act 1980, which minimised the restrictions on private medicine within the NHS (Pfeffer, 1993). Once again the infertile were victims of the political mood.

Significantly, counselling in the field of infertility is a relatively new development (Emmy-Jennings, 1995). Until the 1990s even though some people would have sought counselling, it was not formally offered at treatment centres and still is not offered at the GP level. Traditionally doctors or nurses provided the role of counsellor for this population. The significant change came when the HFEA stated in their Code of Practice (1990) that three distinct types of counselling must be available at licensed treatment centres. As discussed in section 1.5 these include "implications counselling", "support counselling" and "therapeutic counselling".

1.7 The legacy – Infertility: a biological, social and/or political issue but not necessarily a psychological one

In summary, whilst there is a large body of research about the political, medical and social influences on infertility during the 1900s there is comparatively very little research about the psychological and emotional impact of the infertility experience on the woman, man and or couple. There is no doubt that the political, medical and social arenas have influenced the psychological and emotional experience of infertility. From a broader psychological theoretical perspective it is clear that the infertility experience is also in large part influenced by gender and gender role identification.

It is argued that in addition to understanding the role of political and biological influences, social influences such as gender and traditional gender roles need to form an integral part of our understanding of the infertility experience for males and females and hence couples. Arguably the gender system is a social construct that is shaped by a given societys' cultural beliefs and values. Development is a gendered process (Kimmel, 2001); hence female and male gender roles are inextricably linked with both global and individual identity formation and will be culturally dependent. In the Western world there are clear distinctions between masculinity and femininity and clear beliefs about what constitutes each. For example, beliefs and behaviours associated with masculinity include emotional and physical control, denial of emotional vulnerability and the appearance of being strong (Gannon, Glover & Able 2004). Further, the ability to father a child is widely considered to be a key indicator of masculinity (Mason, 1993). In contrast beliefs and behaviours associated with femininity include emotional vulnerability, ability to express emotion, softness and sympathy plus childbearing and motherhood, which have traditionally been considered to be ultimate indicators of what it is to be feminine (Pfeffer, 1993; Crawshaw, 1995).

For many their 'gender role' goes unexamined until such a time when an event threatens it. Infertility is such an event. When faced with the possibility that a key criterion of ones gender role may be unfulfilled e.g. fathering a child or becoming a mother this is likely to be perceived as a considerable threat to ones identity, which on a broader level extends to roles assigned and assumed in society. The impact of this can be devastating. Guidano (1983) quotes that ''the maintenance of one's perceived identity becomes as important as

life itself" (p.3) which indicates why the experience can be so devastating for many that are confronted with it. It may also explain in part why the number of people seeking IVF and related treatments is on the increase. It is important to note that the extent to which an individual identifies with their traditional gender role is likely to correlate with the distress they experience when faced with infertility and the way in which they will deal with this threat.

The received view of gender is constructed and this influences the construction of an individual's identity, which in turn shapes the nature of the infertility experience for males, females and hence couples. Implications of this for clinical practice are that just as theories about the self and the world are constructed they can be reconstructed in line with an individual and/or couples unique experience. Counselling provides a unique opportunity to do this, in particular if the therapist utilises therapeutic interventions informed by personal construct theory (Kelly, 1955).

Moving forward in this field the diversity of cultures and the gender roles particular to each, need to be understood and accounted for given that Britain is an ever evolving multi-cultural society. An additional consideration is the extent to which IVF and similar treatments may be sought in order to keep up with culturally defined gender roles and the impact of this on those going through it both at the individual level and a societal level, particularly when IVF does not result in the desired outcome – a child.

As this Review has explored, the necessity to treat infertility via medical means has unfortunately led to the psychological impact of the experience being largely ignored, minimised, dismissed or overlooked. For example whilst, understandably, there is a wealth of research in medical journals about infertility, psychologists have largely ignored it. A systematic review back to 1997 of the Counselling Psychologist and the British Psychological Society's (BPS) journal Counselling Psychology Review, revealed that no infertility related studies were published in this period. The main body of infertility literature is comprised of contributions from nurses, medical practitioners and counsellors working in the field.

The classification, cause and medical treatment of infertility explain the pivotal role that the medical model plays in this field. The role of the medical model is not disputed here. What is argued here is that infertility should not be considered a purely medical issue. The psychological research that has been conducted in this field provides evidence that while infertility is a biological condition, it is a condition that can negatively impact on the psychological well being of the individual/couple (Edelmann & Connolly, 1986; Read, 1995; Mason, 1995; Salvatore, Gariboldi, Offidani, Coppola, Amore & Maggini, 2001; Levin & Sher, 2000; Greil, 1997). If psychologists do not conduct research into this area and if professionals working with this population overlook the existing psychological research, this in turn increases the potential of the medical model to influence the way in which the infertility experience is perceived and made sense of. The impact of this will be explored in the next paragraph.

The generation and maintenance of the construct 'infertility' as a purely medical condition which is to be treated accordingly is pervasive. Inextricably linked with this construct is the belief assumption that infertility is a female problem and hence they will experience more distress than their male partner (Berg, Wilson, Weingartner 1991). The consequence of this construct is those who hold it, both professionals in the field and the infertile may minimise, dismiss or overlook the emotional and psychological impact of the infertility experience, particularly for males. The consequence of this may mean that the experience is more difficult for those going through infertility than it needs to be. However there is a key issue inherent in the literature that has undoubtedly distorted the perception and understanding of the infertility experience for males as the majority of infertility studies have focused on females and have not included male partners (Jordan & Revenson, 1999). Yet males do experience distress but this may tend to get overlooked in society, in clinical practice and hence research due to the way that males have been conditioned to deal with this distress based on the traditional male gender role e.g. being strong and in denial of emotional vulnerability (Gannon *et al.* 2004). This theory is supported by Berg *et al.* (1991) who in their study of 104 couples following infertility treatment found no gender differences in the level of emotional strain experienced within couples. However findings revealed gender differences in factors associated with psychological distress, for example respondents linked 'low emotional strain' with 'masculinity'. Thus demonstrating that expectations may shape the experience of

infertility in men and the ways in which it is, or rather how it is not, expressed. It is important that those working with client group do not take this to mean that males are not affected by their experience.

A key part of the work of counselling psychologists is psycho-education. If there is an absence of psycho-education about the psychological impact of the infertility experience then there is a chance that people's expectations of themselves and the infertility experience are not being managed. This can have negative consequences for those going through the infertility experience as it can result in feelings of inadequacy resulting in a lack of coping skills (Kroger, 2000). This in turn can impact on the ability of an infertile individual/couple, who are experiencing a life crisis, to adjust to their situation (Moos & Shaffer, 1984, 1986). It is essential that practitioners in the field understand the influence and impact of gender roles on the infertility experience so that they can work this framework in mind.

Unfortunately, the dominance of the medical model has had and continues to have a direct negative impact on the ability of counselling psychologists to provide a service to this client group. If infertility is seen as a purely medical condition with either minimal or no psychological impact then, GP and treatment centre referrals to psychological counselling will remain limited, as will the instances of self-referral. Research suggests that less than 25% of infertility patients take up psychological services (Sundby, Olsen & Schei 1994; Hernon, Harris, Elstein, Russell & Seif, 1995) or have the intention to use them (Schmidt, Holstein, Boivin, Sangren, Tjornhoj-Thomsen, Blaabjerg, Hald, Nyboe Anderson & Rasmussen 2003). Thus of the remaining 75% of people, those that may need psychological support may not be getting referred or feel it is appropriate to self-refer.

1.8 Summary and conclusions

This Review has focused on how political, social and economic factors over the last century have in combination led to the medicalisation and privatisation of infertility. It explored how collective assumptions and practices across the decades resulted in limited research into the psychological and emotional experience of those experiencing infertility. How this led the infertile and the influence of traditional gender roles on the

experience to be overlooked, minimised or ignored was discussed. It has demonstrated that the consequence of the combination of these factors resulted in limited psychological intervention or support being developed for and offered to the infertile, particularly males. It has been argued that it is very likely that there is a large population of individuals/couples are not getting the support they may need. Given the limited research it is clear that there is a need for more research into the psychological and emotional factors relating to infertility. At the same time the importance of attending to the psychological impact of infertility needs to be emphasised and promoted to those professionals working in the field.

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Appendices

APPENDIX 1

Information sheet to known participants – Study 1

Joanne Perkins – MSc Counselling Psychology Research Dissertation.
Department of Psychology, City University, London

"Infertility" - your experience

What is the research project about?

I am conducting research into the experience of infertility. The aim of this research is to gain an understanding of the psychological and emotional impact of the process of infertility. It is hoped that this understanding will contribute to the development of counselling practice in the field of infertility.

What do I need to do?

I am planning to conduct a series of interviews, firstly with you as a couple together and then with each of you separately. The research will take the form of a semi-structured interview during which you will be asked a few open questions that relate to your personal experience of infertility.

Although I am looking for your unique perspective of infertility it is the topic that is the focus of my study. So I would like to assure you that I will not be making judgements about you, your relationship, your choices or your views, instead I see you as the expert in this domain. I am aware that how you feel and what you think about the questions may change over time but it is how you view things now that is important to the study.

Your honesty would be appreciated throughout the interview. If you do not wish to answer any of the questions you are not required to do so. Each interview should last no longer than 1 hour in total. It may be necessary to contact you at a later stage of my research for further data collection, if you do not wish to be contacted you can indicate this by placing an asterisk beside your printed name on the consent form.

Do I have to take part?

I am aware that because of our existing relationship there is a possibility that you may feel compelled to agree to take part in the study. However, I want to emphasise that there is absolutely no obligation on you to do so.

It is important that you feel comfortable with your decision and that if you agree to participate you do so of your own free will. In light of this, I would encourage you to discuss and make the decision together as a couple as well as thinking about how you feel as an individual about taking part. I will be happy to answer any questions that either of you have.

Should you decide that you would like to take part could you please contact me within the next 4 weeks and we can discuss arrangements.

If you do not contact me I will take that to mean that you have decided that you do not wish to participate. Please be assured that your decision will be respected and I will not ask you about it and you do not need to offer any explanation.

Is it confidential?

All data will be treated as strictly confidential. Any matter arising in either the joint or the individual interviews will be not be disclosed to any other party under any circumstances.

Who else will know that I have taken part?

Please be assured that every step will be taken to protect your anonymity. Your participation will not be discussed with any other participants or other parties. Once all of the data has been collected all your details will be destroyed leaving no link between you and your data. Furthermore, any references to comments from interviews used in the final report will be quoted anonymously.

Is what I discuss during my individual interview confidential?

I can assure you that anything discussed during individual or joint interviews is strictly confidential and will not be repeated or alluded to at any stage to any third party, including your partner. It is your choice whether you wish to share what you discussed with your partner or anybody else in your personal interview.

I have not spoken to anyone about this before and I am not sure how I will react?

I am aware that this is a sensitive issue and that this may be the first time that you are discussing your personal experience either as an individual and/or as a couple.

It is hoped that you will find the process of talking about your experience cathartic, enlightening and liberating. However, you may also find it difficult or upsetting at times and this is natural.

Due to the nature of our discussion, issues may be raised that cannot be explored during the interview, for ethical reasons. It is my responsibility to make sure that our discussion remains within the boundaries that you have agreed to

discuss. If the discussion does stray from the area that you have agreed to discuss, please be aware that I will sensitively but firmly change the focus back to the interview.

I will provide you with details of organisations that you can contact should you decide that you want to discuss any issues further, in confidence.

What if I want to withdraw from the study?

You are free to withdraw from the study at any time, without having to provide any explanation as to your reason for doing so. You are not obliged to answer any question that you do not wish to. You may also stop either of the interviews at any stage should you feel you want to for any reason.

What will happen when I see you socially?

You can be assured that your neither your participation or anything discussed during the interviews will be referred to or discussed at any time in the future, either socially or in casual conversation, with either yourselves or any third party.

What if I want to talk some more after the interviews?

After the interviews you may decide that you would like to discuss your experience further. With this in mind, I have attached a list of numbers and organisations that can put you in touch with professional counsellors and support groups that you may find useful.

APPENDIX 2

Letter of introduction to unknown participants – Study 1

Ms J Perkins
164b Albion Road
Stoke Newington
N16 9JS

<Date>

Contact telephone number: 07986 390 185
Email address: jo.perkins@virgin.net

Dear < >,

Following your conversation with [name of mutual friend], I am writing to introduce myself and my research project.

My name is Jo Perkins and I am in the 2nd year of the 3 year Counselling Psychology Programme at City University, London.

I am currently working on my MSc research dissertation and the topic that I am researching is 'infertility'. I have enclosed an information sheet which outlines the aim of the study and answers some questions that you might have.

I am aware that it is not an exhaustive list and that you may have your own questions that you want answering before you decide whether or not you would like to take part. In light of this please feel free to contact me in confidence on the above number or email address and I will be more than happy to go through any questions you have. Please be assured that by making contact you are not obliged to take part if you do then decide that you would rather not participate for any reason.

Should you like to discuss the study further or your decision to take part please would you contact me within the next 4 weeks? I would like to confirm that I will not contact you or [name of mutual friend] if I do not hear from you.

Yours sincerely

Jo Perkins
Counselling Psychologist in training.

APPENDIX 3

Information sheet to unknown participants – Study 1

Joanne Perkins – MSc Counselling Psychology Research Dissertation.
Department of Psychology, City University, London

"Infertility" - your experience

What is the research project about?

I am conducting research into the experience of infertility. The aim of this research is to gain an understanding of the psychological and emotional impact of the process of infertility. It is hoped that this understanding will contribute to the development of counselling practice in the field of infertility.

What do I need to do?

I am planning to conduct a series of interviews, firstly with you as a couple together and then with each of you separately. The research will take the form of a semi-structured interview during which you will be asked a few open questions that relate to your personal experience of infertility.

Although I am looking for your unique perspective of infertility it is the topic that is the focus of my study. So I would like to assure you that I will not be making judgements about you, your relationship, your choices or your views, instead I see you as the expert in this domain. I am aware that how you feel and what you think about the questions may change over time but it is how you view things now that is important to the study.

Your honesty would be appreciated throughout the interview. If you do not wish to answer any of the questions you are not required to do so. Each interview should last no longer than 1 hour in total. It may be necessary to contact you at a later stage of my research for further data collection, if you do not wish to be contacted you can indicate this by placing an asterisk beside your printed name on the consent form.

Do I have to take part?

It is important that you feel comfortable with your decision and that if you agree to participate you do so of your own free will. In light of this, I would encourage you to discuss and make the decision together as a couple as well as thinking about how you feel as an individual about taking part. I will be happy to answer any questions that either of you have.

Should you decide that you would like to take part could you please contact me within the next 4 weeks and we can discuss arrangements.

If you do not contact me I will take that to mean that you have decided that you do not wish to participate. Please be assured that your decision will be respected and I will not ask [name of mutual friend] about it and you do not need to offer any explanation.

Is it confidential?

All data will be treated as strictly confidential. Any matter arising in either the joint or the individual interviews will be not be disclosed to any other party under any circumstances.

Who else will know that I have taken part?

Please be assured that every step will be taken to protect your anonymity. Your participation will not be discussed with any other participants or other parties, including [name of mutual friend]. Once all of the data has been collected all your details will be destroyed leaving no link between you and your data. Furthermore, any references to comments from interviews used in the final report will be quoted anonymously.

Is what I discuss during my individual interview confidential?

I can assure you that anything discussed during individual or joint interviews is strictly confidential and will not be repeated or alluded to at any stage to any third party, including your partner. It is your choice whether you wish to share what you discussed with your partner or anybody else in your personal interview.

I have not spoken to anyone about this before and I am not sure how I will react?

I am aware that this is a sensitive issue and that this may be the first time that you are discussing your personal experience either as an individual and/or as a couple.

It is hoped that you will find the process of talking about your experience cathartic, enlightening and liberating. However, you may also find it difficult or upsetting at times and this is natural.

Due to the nature of our discussion, issues may be raised that cannot be explored during the interview, for ethical reasons. It is my responsibility to make sure that our discussion remains within the boundaries that you have agreed to

discuss. If the discussion does stray from the area that you have agreed to discuss, please be aware that I will sensitively but firmly change the focus back to the interview.

I will provide you with details of organisations that you can contact should you decide that you want to discuss any issues further, in confidence.

What if I want to withdraw from the study?

You are free to withdraw from the study at any time, without having to provide any explanation as to your reason for doing so. You are not obliged to answer any question that you do not wish to. You may also stop either of the interviews at any stage should you feel you want to for any reason.

What will happen when I see you socially?

You can be assured that your neither your participation or anything discussed during the interviews will be referred to or discussed at any time in the future, either socially or in casual conversation, with either yourselves or any third party.

What if I want to talk some more after the interviews?

After the interviews you may decide that you would like to discuss your experience further. With this in mind, I have attached a list of numbers and organisations that can put you in touch with professional counsellors and support groups that you may find useful.

APPENDIX 4

Organisation Contact Sheet

Useful Contacts

ACEBABES
ACeBabes offers support on pregnancy following fertility treatment, multiple births, donor conception for donors and recipients, decisions surrounding frozen embryos, trying for siblings or deciding to end treatment and telling children how they were conceived. Provides a quarterly newsletter, sub-group newssheets, meetings, personal contacts for specific conditions and interactive website.
Tel: 01332 832558
Website: www.acebabes.co.uk

BRITISH INFERTILITY COUNSELLING ASSOCIATION (BICA)
BICA aims to promote high quality, accessible counselling services for those with fertility problems. It offers information to patients seeking details of counsellors specialising in infertility.
Tel: 0114 263 1448
Website: www.bica.net

CANCERBACUP
This charity offers independent, accessible information, practical advice and support for people affected by cancer. Its range of information booklets includes how cancer treatments can affect fertility (and the future fertility of teenage patients).
Tel: 0808 800 1234
Website: www.cancerbacup.org.uk

CHILD BEREAVEMENT TRUST
This charity's philosophy is based on learning from families who have experienced the death of a baby or child or from children who have experienced the death of their mother, father, brother or sister.
Tel: 0845 357 1000
Website: www.childbereavement.org.uk

CHILDLESSNESS OVERCOME THROUGH SURROGACY (COTS)
The main objective of COTS is to pass on collective experience to surrogates and would-be parents, helping them to understand the implications of surrogacy before they enter into an arrangement and to deal with any problems that may arise during it.
Tel: 0844 414 0181
Website: www.surrogacy.org.uk

DAISY NETWORK PREMATURE MENOPAUSE SUPPORT GROUP
Daisy Network provides support and information for women who have gone through an early menopause. Members can speak to others who have been through egg donation cycles, both successfully and unsuccessfully. Also publishes fact-sheets and a quarterly

newsletter and has an annual open day.
Website: www.daisynetwork.org.uk

DONOR CONCEPTION NETWORK (DC NETWORK)
DC Network provides contact and support for people who have children conceived, or who plan family creation, using donated gametes through donor insemination (DI) and IVF with donor sperm or donated eggs. Also provides support for adult offspring of donor conception.
Tel: 020 8245 4369
Website: www.dcnetwork.org

GENETIC INTEREST GROUP (GIG)
A national alliance of patient organisations with a membership of over 130 charities which support children, families and individuals affected by genetic disorders.
Tel: 020 7704 3141
Website: www.gig.org.uk

INFERTILITY NETWORK UK (I N UK)
I N UK provides emotional support via an evening telephone counselling service, putting patients in touch with others. There is a regional network and local support groups. Practical support is provided in factsheets, a quarterly magazine, through medical advisers and in publications available to purchase.
Tel: 08701 188088
Website: www.infertilitynetworkuk.com

MISCARRIAGE ASSOCIATION
The Association provides support and information on pregnancy loss.
Tel: 01924 200799
Website:
www.miscarriageassociation.org.uk

MORE TO LIFE
A national support network providing a support service for people exploring what life without children has to offer – both involuntary childlessness, and those for whom fertility treatment is no longer a consideration.
Tel: 08701 188 088

MULTIPLE BIRTHS FOUNDATION
The Multiple Births Foundation provides professional support and information about all aspects of multiple births.
Tel: 020 8383 3519
Website: www.multiplebirths.org.uk

NATIONAL CHILDBIRTH TRUST (NCT)
The NCT helps parents to have an enriching experience of pregnancy, birth and early parenthood, providing local support and contacts for social networking. It runs antenatal classes and provides information on maternity issues, breastfeeding and postnatal support including specialist groups for Caesareans and miscarriage.
Tel: 0870 444 8707
Website:
www.nctpregnancyandbabycare.com

NATIONAL ENDOMETRIOSIS SOCIETY
The Society provides a helpline, local groups and clubs, a newsletter and other publications, workshops and conferences.
Tel: 0808 808 2227
Website: www.endo.org.uk

NATIONAL GAMETE DONATION TRUST (NGDT)
The NGDT was founded as a registered charity in April 1998 in order to raise awareness of, and seek ways to alleviate, the shortage of sperm, egg and embryo donors in the UK. The NGDT is a central reference point for donors, recipients and health professionals.
Tel: 0845 226 9193
Website: www.ngdt.co.uk

NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE (NICE)
NICE is part of the NHS. It is the independent organisation responsible for helping patients, health professionals and the public to make decisions about treatment and health care.
Tel: 020 7067 5800
Website: www.nice.org.uk

PROJECT GROUP ON ASSISTED REPRODUCTION (PROGAR)
PROGAR campaigns in two main areas: for the right of people with fertility difficulties to informed choice and quality of care, including counselling; and for the right of people to have access to identifying information about their genetic origin.
Tel: 0121 622 3911
Website: www.basw.co.uk/progar

PROGRESS EDUCATIONAL TRUST (PET)
This UK charity provides information and debate on assisted reproduction and human genetics, promoting discussion among patients, the wider public and professionals on their social, legal and ethical implications. PET holds regular public debates and conferences and produces a free web and email news and comment service, BioNews, with support from the Department of Health.
Tel: 020 7278 7870
Website: www.progress.org.uk

STILLBIRTH AND NEONATAL DEATH SOCIETY (SANDS)
SANDS provides support for parents and families whose baby is stillborn or dies soon after birth.
Tel: 020 7436 5881
Website: www.uk-sands.org

SURROGACY UK
A website and message board produced to support and promote surrogacy in the UK. It was conceived by Elizabeth Stringer and Carol O'Reilly, who have been involved in surrogacy since 1994 (between them they have carried six surrogate children).
Tel: 01531 821889 (10am–2pm)
Website: www.surrogacyuk.org

TERRENCE HIGGINS TRUST (THT)
THT is the leading HIV and Aids charity in the UK and the largest in Europe. It provides a helpline staffed by a team who can respond to all HIV-related enquiries, and provides clear, accurate, current and comprehensive signposting, referral, information, support and advice.
Tel: 0845 1221 200
Website: www.tht.org.uk

TWINS AND MULTIPLE BIRTHS ASSOCIATION (TAMBA)
TAMBA provides support for families with twins, triplets or more, and for professionals involved with their care. It has a network of local Twins Clubs and specialist support groups, and provides publications and information packs.
Tel: 0870 770 3305
Website: www.tamba.org.uk

UK DONORLINK
A pilot voluntary contact register set up to enable people conceived through donated sperm and/or eggs, their donors and half-siblings to exchange information and – where desired – to contact each other. The register is for anyone over 18 who was conceived with donated sperm or eggs, or who donated in the UK before the Human Fertilisation and Embryology Act came into force in August 1991.
Tel: 0113 278 3217
Website: www.ukdonorlink.org.uk

VERITY
Verity is a self-help organisation for women affected by Polycystic Ovary Syndrome (PCOS) and is dedicated to improving the lives of sufferers.
Website: www.verity-pcos.org.uk

USEFUL WEBSITES
There are many websites that provide information about infertility and opportunities to ask questions and exchange personal experiences with others. A few that patients have mentioned to us are:
www.fertilityfriends.co.uk,
www.may-b-baby.co.uk and
www.gettingpregnant.co.uk.
Let us know of others you find helpful.

APPENDIX 5

Consent form

CITY UNIVERSITY

DEPARTMENT OF PSYCHOLOGY

Informed consent signature sheet

I acknowledge that I have read and understood the description of the study given on the previous page. I hereby give my consent to take part in the study.

I understand that all individual information collected about me will be kept strictly confidential and will not be transmitted to third parties with any identifying information without my further consent in writing. I understand that I may withdraw from the study at any time without giving a reason and without incurring any penalty.

The asterisk next to my name indicates that I do not wish to be contacted again.

Signature	Name	Date
1)		
2)		
3)	Jo Perkins	

APPENDIX 6

Interview schedule: couples with children – Study 1

Couple interviews: Opening script

Firstly, I would like to thank you for agreeing to take part in the research.

The whole interview should take no longer than an hour. It will be in two sections.

During the first section, which should last 15 to 20 minutes, I will ask you some open ended questions about when and how you realised that you were experiencing difficulties conceiving.

In the second part, the discussion will focus on how the possibility that you may not have a/another child affected you as a couple.

Do you have any questions at this stage? If you do have any questions any at any point, please feel free to ask them.

Who normally does the talking when you are at the doctors/hospital about this?

OK well for my purposes it may be that I ask X specific questions, will that be all right?

It would be a good time to sign the consent forms now.

Sign consent forms.

You do not need to answer any questions if you don't want to.

Alternatively if at any stage during the discussion you want to stop, just press this button (the stop button on the mini disk recorder). You don't need to explain your reason why if you don't want to.

Are you ready? Shall we begin?

Commence interview.

<u>1st Half of interview</u>

1) When did you first realise that you were experiencing difficulties conceiving naturally? (Who was it).

Note: The following questions served as a guide and were not explicitly asked if answers were provided in the discussion resulting from the initial questions.

2) **If not together** - Did they share their concerns with the partner and how e.g. ongoing or just as a one off?
3) What were both of your initial feelings and concerns when you realised that you were not getting pregnant? **Ask each person**

4) Did you discuss your feelings with him/her/each other about the concerns you were having about not getting pregnant/getting pregnant?
5) **If not,** what prevented him/her/them?
6) Are you a couple that would normally discuss feelings with each other e.g. was this different or similar to other issues that you have experienced as a couple?

If there was no natural progression to the 2nd half of the interview the following was said - OK, if it is ok with you we will move on to the next phase of the interview.

2nd Half

1) How has this experience affected you both as a couple?

Note: The following questions were my personal guide and were not explicitly asked if answers were provided in the discussion resulting from the initial questions.

2) How did it affect the hopes and dreams you had for the future?
3) Were friends / family aware of what you were going through?
4) What was their reaction – do you feel that they treated you or talked to you differently to before? If not shared with others - what factors contributed to the decision to keep it secret?
5) How do you think others perceived you as a couple going trough this experience?
6) How did you come to the decision to have IVF – **to both?**
7) How did the experience impact on your identity as a couple e.g. a couple going through IVF?
8) How has having a baby changed the way you feel about yourselves– to both?
9) How has it changed your dreams & hopes for the future?
10) Did you consider having or were you ever offered counselling – if so what kind – did they take up offer if not why not?
11) What do you feel would have been most beneficial to you in terms of support throughout the process and at what stage would you have most welcomed it?

Closing:

I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or are there any questions that you are surprised I have not asked and would like to discuss?

Do you have any questions before we finish?

Thank you.

APPENDIX 7

Interview schedule: Couples without children – Study 1

Couple interviews: Opening script

Firstly, I would like to thank you for agreeing to take part in the research.

The whole interview should take no longer than an hour. It will be in two sections.

During the first section, which should last 15 to 20 minutes, I will ask you some open ended questions about when and how you realised that you were experiencing difficulties conceiving.

In the second part, the discussion will focus on how the possibility that you may not have a/another child affected you as a couple.

Do you have any questions at this stage? If you do have any questions any at any point, please feel free to ask them.

Who normally does the talking when you are at the doctors/hospital about this?

OK well for my purposes it may be that I ask X specific questions, will that be all right?

It would be a good time to sign the consent forms now.

Sign consent forms.

You do not need to answer any questions if you don't want to.

Alternatively if at any stage during the discussion you want to stop, just press this button (the stop button on the mini disk recorder). You don't need to explain your reason why if you don't want to.

Are you ready? Shall we begin?

Commence interview.

<u>1st Half of interview</u>

7) When did you first realise that you were experiencing difficulties conceiving naturally? (Who was it).

Note: The following questions served as a guide and were not explicitly asked if answers were provided in the discussion resulting from the initial questions.

8) **If not together** - Did they share their concerns with the partner and how e.g. ongoing or just as a one off?
9) What were both of your initial feelings and concerns when you realised that you were not getting pregnant? **Ask each person**
10) Did you discuss your feelings with him/her/each other about the concerns you were having about not getting pregnant/getting pregnant?

11) **If not,** what prevented him/her/them?
12) Are you a couple that would normally discuss feelings with each other e.g. was this different or similar to other issues that you have experienced as a couple?

If there was no natural progression to the 2nd half of the interview the following was said - OK, if it is ok with you we will move on to the next phase of the interview.

2nd Half

12) How has this experience affected you both as a couple?

Note: The following questions were my personal guide and were not explicitly asked if answers were provided in the discussion resulting from the initial questions.

13) How did it affect the hopes and dreams you had for the future?
14) Were friends / family aware of what you were going through?
15) What was their reaction – do you feel that they treated you or talked to you differently to before? If not shared with others - what factors contributed to the decision to keep it secret?
16) How do you think others perceived you as a couple going trough this experience?
17) How is/has the experience impacting/impacted on your identity as a couple e.g. a couple going through investigations / IVF?
18) Have you considered having or were you ever offered counselling – if so what kind – did they take up offer if not why not?
19) What do you feel would have been most beneficial to you in terms of support throughout the process and at what stage would you have most welcomed it?

Closing:

I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or are there any questions that you are surprised I have not asked and would like to discuss?

Do you have any questions before we finish?

Thank you.

APPENDIX 8

Interview schedule: individual with children – Study 1

Individual Interview:

I am interested to know whether you had a discussion with 'X' (partner) following our last interview.

Did you find it helpful?

What happened afterwards?

How are things now?

How did you find talking to me about your issues?

Moving the focus on to you as an individual. I am aware that you have gone through the whole process as an individual as well as together as a couple. The purpose of this interview is to explore how the experience has been for you personally, as an individual but also as a male/female.

Are you ready to start?

How has your experience of infertility/difficulty conceiving affected you personally?

Note: The following questions were my personal guide and were not explicitly asked if answers were provided in the discussion resulting from the initial questions.

How did your perception of yourself/future change when you realised that you may not become a mother/father? In which ways?

How did this make you feel?

How did you feel as a result of your experience before having 'x' (child's name)

How do you feel now?

How has your perception of yourself/future changed since becoming a mother/father?

Closing statement:

I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or are there any questions that you are surprised I have not asked and would like to discuss?

Do you have any questions?

APPENDIX 9

Interview schedule: individual without children – Study 1

Individual Interview:

I am interested to know whether you had a discussion with 'X' (partner) following our last interview.

Did you find it helpful?

What happened afterwards?

How are things now?

How did you find talking to me about your issues?

Moving the focus on to you as an individual. I am aware that you have gone through the whole process as an individual as well as together as a couple. The purpose of this interview is to explore how the experience has been for you personally, as an individual but also as a male/female.

Are you ready to start?

How has your experience of infertility/difficulty conceiving affected you personally?

Note: The following questions were my personal guide and were not explicitly asked if answers were provided in the discussion resulting from the initial questions.

How did your perception of yourself/future change when you realised that you may not become a mother/father? In which ways?

How did this make you feel?

Closing statement:

I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or are there any questions that you are surprised I have not asked and would like to discuss?

Do you have any questions?

APPENDIX 10

Example of the analysis process taken from the female data set

Demonstration of the Analysis Process

Overview

An example of the stages of analysis is provided here to demonstrate how themes were developed from the raw data. The example uses data collected from female participant number 9. This participant was chosen at random.

Stage 1 – Open Coding

At the open coding stage of data analysis the disc was stopped every few seconds whilst I considered what the participant was saying before 'coding' it. Each interview had a record which included the location (time) on the disc of the comment being coded, the participant interview code and the label code. Data codes are shown in bold and preliminary notes are written to the right of the transcript:-

Participant Code & location on recording	Commentary	Initial notes
9 – 1.00 9 – 1.37 9 – 1.48 9 – 2.01 9-2.10 9 – 2.20 9 – 2. 32	People kept saying "ooh, you're over 30 you really do need to get on with it" **[pressure from others]**. After I went to the doctor we got put in touch with an IVF unit and the investigations began. Oh I felt like a piece of meat really **[felt like piece of meat]**, you queued up for your injections, I never got anybody's name, they never knew who the heck I was **[sense of being invisible]**. I always had the sense of being in the wrong place, a feeling that I should have queued somewhere else first **[feeling as if getting it wrong/being in the wrong]** and they always insisted that you were present in the hospital em to erm do various injections and various things. You know the process or rather they (the clinic) were very interesting, they weren't particularly communicative **[clinic/medical staff not communicative]** so em they would say things	Pressure comes from external sources re: age - what is the impact of this on female and treatment decisions? Consider Link between feeling 'invisible/ overlooked' and feeling like a 'piece of meat' Getting it wrong - due to lack of confidence? Linked to sense of failure? Medical staff deemed not be

like ''Oh dear, oh, you've only produced 3 eggs'' and you'd think...it's a bit like going to the dentist when you need a filling ''Tut, tut, tut' **[feeling judged by medical staff for 'performance']** (wagging finger to demonstrate being admonished) you know, and you'd think '' I haven't done this on purpose!''.**[Feeling blamed/It's not my fault]** You think, so what does this mean? **[confusion/looking for meaning]** (big sigh and long pause)

communicative other than to 'judge'.

Feeling as if her fault - feeds in to sense of failure? Compounded by sense of medical professionals 'judging' her?

In search of a reason - turns to self?

9- 2.51 It ultimately was very difficult to enter into a discussion
9-3.04 with anybody about anything **[difficult to communicate with others]** and I just found that frustrating **[frustration with communication difficulties]** but more than that it
9- 3.17 felt judgemental **[feeling judged]**, but to be fair, you are so dosed up with hormones **[hormones influence**
9 – 3.28 **perceptions?]** and you are not really responding very well to anything and all you can think ''Oh I've failed,
9 – 3.39 I've failed and this was my only chance'' **[I've failed]** erm so that wasn't a particularly comfortable experience
9-3.47 (pause) **[uncomfortable experience]**
I suppose it really was quite an overwhelming experience **[overwhelming experience]** to be honest and with the
9-3.59 benefit of hindsight, I think that if I hadn't been so
9-4.12 panicked about timing, you know, come on you're 31 come on, come on, I would have taken more time about it
9-4.23 **[time pressure impedes thinking time]** I did feel that the
9 - 4.33 nurses were great and that was a question of information **[importance of information giving]** and so much more
9 – 4.45 personal **[personal approach important]** and oh I don't know I guess it felt as if they were much more committed
9 – 4.57 to your success and they were absolutely sweet. Yeah I really liked the nurses **[good relationship with nurses]**.
9 – 5.13 Particularly when I went for my second IVF treatment. My first attempt had failed and that had been just terrible
9 – 5. 24

Difficulty communicating with others - linked to feeling judged and seems to result in sense of failure or at least compound it? Result = frusturation

uncomfortable - both physically and psychologically?

Pressure of time seems to result in the uptake of treatment and hinders the thinking/decision process/planning? What are the implications of this? How can this be minimised?

Highlighting the important role of nurses in treatment process - this relationship seems to reduce feelings of

9- 5.33	quite frankly **[terrible = impact of failed attempt]** I knew the stats but you still feel very hopeful, you have to otherwise what's the point? You see I couldn't have gone into it thinking it wouldn't work because that is what kept me going when it got tough **[Hope and it's role in treatment process]**. Besides I was so determined to have baby I thought that this alone would be enough to help the process along **[determination to have a baby] [wishful thinking]**. Ha, as if! I soon learnt that that really wasn't the case, that would have been too easy and the one thing IVF isn't is easy or straightforward **[IVF difficult and complicated]**. Anyway then I went for a second attempt and that attempt resulted in 6 weeks of pregnancy but not more than that and they were fantastically good and fantastically supportive and we had family crises which meant that I was all over the place **[support provided when pregnancy failed]**. But in the first attempt that failed what the doctors didn't have for me, and I'm not talking for other people here, was any rapport with the patients **[Doctors had no rapport when treatment fails]**, from my point of view and it's very difficult to be sensible about it because of course it didn't work, **[difficult to be 'sensible' when treatment doesn't work]** of course had it worked it would have been very different. But I wanted to see them and talk about why the process hadn't worked **[need to talk about why treatment failed]** and they said "fine yeah come in to the hospital and we'll get someone to talk to you I suppose"**[staff perceived as reluctant to talk to her]** and they made me sit in the waiting room where I sat with all the women I'd been with for egg collection the Friday before and they were coming back for implantation techniques and I was waiting to discuss why it hadn't worked **[difficulty of sitting in area with people at earlier stages of treatment after IVF failure]** and nobody had thought about it. When I eventually talked to	invisibility? Hope plays a key role in spurring the female (and couple?) along throughout treatment. Role of wishful thinking. Impact of this hope when treatment fails?? Explore Contrast between support when pregnancy fails and lack of rapport from doctors when IVF is not successful. The need to know why it didn't work not met by doctors? Is this a trend or just the experience of this woman? Why is there this difference and how does this shape the experience of achieving pregnancy/failure of attempt? Explore Difficult to be logical when faced with disappointment of failed cycle - result of sense of failure and/or failed hope? There is a real need for information about why treatment fails but nt always provided? Bu is it possible to provide this information in each
9 - 5.43		
9 – 5.59		
9 - 6.15		
9-6.25		
9 – 6.36		
9 – 6.45		
9-6.49		
9 – 6.58		
9-7.13		

them they said that they couldn't really think of anything they could tell me, blah de blah **[no explanation available re: why treatment failed]**. That was pattern throughout all my treatment until my 6th attempt when the Director of medicine said ''I'm just not treating you

9 – 7.26 anymore, it's been a difficult decision, but blah de blah ..this IVF route is just not going to work for you, and I recommend that you start thinking about egg donation, **[termination of treatment programme by doctor]** dah

9-7.41 de dah de dah....then gradually I became aware that I was hoping for was a miracle **[realisation that she was waiting for a 'miracle']** and I mean a proper miracle not

9-7.58 one of those miracles that people tell you about when their infertility is unexplained and the IVF triggers it or seems to start things off **[awareness that she had no possibility of conceiving naturally and hence no hope was left]**. I realised that I needed to look at this because I couldn't go on like that not just because they wouldn't treat me but for my own sanity **[decision to process this realisation/position]**

I went to see the counsellor and she was very good **[counsellor/counselling good]**, but less of a counsellor and more of a ''this is what you should do -bang, bang bang bang (hitting hand on table) and perhaps that's what I needed **[sense that counselling was not like counselling because it was directive]**. You see at the time that we were doing it (IVF) there were lots of success stories, there was a television programme about people who had done very well [media influence on hope/pursuing of treatment] and it did cover people who didn't have successes but you sort of thought that you weren't going to be like that so I just kept going for treatment **[ignoring stories where failed IVF]** .

case? No. So where does this leave woman? Feeling as if she failed?

Female/couple not making decision to stop treatment but doctor - what is impact of this? Control taken from couple - good or bad?

Does hope and the treatment process result in denial of reality of situation if so how does this operate and what is the impact on the female/couple e.g. physical, financial and psychological. Whose ethical responsibility is it to stop treatment?

Is male in denial? Explore

How best to deal with 'denial' sensitively and appropriately?

What are people's perceptions of counselling? This suggests that a directive approach as was taken here was considered to be 'not like counselling' - important to manage expectations re: counselling and provide information about the different

		ways in which it can work
9-8.07	Having had counseling I think that now I can understand the benefits of talking to other people **[counselling beneficial] [talking about issue beneficial]** but at the time it was *my* infertility which meant that I went through it all alone **[infertility is a personal issue and not one for sharing]** and for longer than I should have done **[non discussion resulted in pursuing treatment for longer than 'should']**.	The process of counselling highlights benefits of talking about the issue BUT infertility is very personal and not an issue that females necessarily want to share with others - need to explore reasons contributing to this

Memos and diagrams

Memos and diagrams were kept throughout the analysis process and formed a key part of it (Strauss & Corbin, 1998). They served a number of functions. In brief they provided a record for ideas and hunches, represented relationships between concepts, guided theoretical sampling and helped to organise the vast amount of data. Storyline memos formed the basis for writing the storyline when it came to integrating the final categories (Strauss & Corbin, 1998). All memos and diagrams were dated, noted participant and disc location codes, given a title and any other relevant information. The following is an example of a memo written for the female data set coded 9-8.34:-

MEMO – 9-8.36, 12/2/04. 'FEMALE'

GRIEF – related concepts = failure, pregnancy, communication.

It seems that miscarriage provides a focus which allows grief to be expressed. There is a suggestion that a miscarriage legitimises the feelings of grief that were present in response to the infertility prior to falling pregnant. What do females who do not become pregnant do with these feelings of grief? Based on the other female interviews it seems that the feelings are not shared readily with others. How does this relate to the concept 'failure' – do females that have a pregnancy 'to point to' feel they have more of a right to grieve or that are they more comfortable because they have 'been pregnant'?

Stage 2 – Development of Categories and Subcategories

Following open coding the analysis of the overall female data set yielded 41 concepts. This was achieved through the process of constant comparative analysis where the similarities and differences of codes and concepts both within and between cases were examined in detail. Comparisons were also made with couple and male data. This process resulted in the generation of 11 tentative categories from the original 41 concepts.

Tentative Category labels:-

- Failure
- Grief
- Hope
- Communication with partner
- Communication with others
- Isolation
- Pain
- Anger
- Not feeling understood
- Need for a child

At this stage in preparation for the next stage of the analysis process all data feeding into developing categories were organised in a separate MSWord document with the appropriate participant code and location on the recording. Remaining data which was not considered directly relevant to the focus of the present research was stored safely in another document. The document with relevant data was then printed so that individual comments could be isolated from each other and be used as individual pieces of data. Scissors were used to separate comments which resulted in a number of individual comments being available for the next stage of analysis. File cards with tentative category labels were also created and the variation across line codes within each category led to the formation of different subcategories where appropriate.

Stage 3 – Axial coding

This involved the process of relating categories to subcategories along the lines of their properties and dimensions (Strauss & Corbin, 1998). At this point each tentative category title was laid out on a clear surface along with the relevant subcategory labels. All data (comments) were then manually allocated to the relevant subcategories. Time was then spent organising, discussing and reflecting on the fit of the data with the category and subcategory labels it had been assigned to. Data was reorganised and discarded until the best fit between data and categories was achieved. This process led to the act of collapsing the 11 tentative categories into 8 categories and promoted the development of more subcategories.

The 8 categories developed were:-

- Sense of Isolation
- Sense of Failure
- Overwhelming Desire for a Child
- Emotions
- Becoming a Mother
- Facing a Future without Children
- Difficulties in Communication with Others
- Not feeling understood by Medical Staff

Stage 4 – Selective coding

This stage involved the process of integrating and refining the model (Strauss & Corbin, 1998). The aim was to build a model that accounted for the female infertility experience and only categories that specifically related to the overall model and which were a good fit with the core category were included. A core concept had emerged which had more codes and subcategories than any other category which was selected as the core category for females - 'SENSE OF ISOLATION'. At this stage five of the seven remaining categories were selected and organised in terms of their relationship with the core category:-

- Sense of Failure
- Overwhelming Desire for a Child

- Emotions
- Becoming a Mother
- Facing a Future without Children

At this stage it was decided that the following categories would be left out of the final model. Whilst they were relevant to the overall understanding of the topic under investigation their fit was not as good with the core category as the other categories:-

- Difficulties in Communication with Others
- Not feeling understood by Medical Staff

APPENDIX 11

Female Categories – Study 1

RESEARCH CATEGORIES – FEMALES

Overview

Each category is first described before presenting definitions of each of the subcategories within the category. Subcategory definitions are followed by a record of comments taken directly from the interviews.

ACTIVE INFERTILITY STAGE

CORE CATEGORY: A SENSE OF ISOLATION

The infertility experience is characterised by an intense state of isolation from her partner, friends and family. Participants conveyed a real sense of feeling that as the female, they go through this experience alone. Overall, females feel unsupported and misunderstood. This state is contributed to by different people and situations in their lives.

Subcategory of 'Sense of Isolation': Not feeling understood or supported by Partner

Throughout the experience there is strong sense that the female feels that her partner does not understand the pain she is feeling or her need to have a child. The result is that she feels unsupported within the relationship.

Comments:-

7.8-50.29	He doesn't seem to understand the pain I am in. *(Female)*
7.8-49.01	I am not feeling understood by x, I need support to deal with this (accepting that they are not going be have children). *(Female)*
6-39.40	I don't think he really understands how difficult it is for me *(Female)*
9-38.17	I felt that he (husband) thought I was being self indulgent *(Female)*
11-19.34	I think he struggled to get where I was coming from at times and see how I was experiencing it. *(Female)*
1-20.07	I want him to ask me what is going on, he needs to understand. *(Female)*
1-29.05	I wanted sympathy from him, I needed hugs and for him to just listen to

how I felt, I didn't get that. *(Female)*

1-37.05 I cried all the time. There were days where I just felt that I can't cope with today. He was unaware of all that, I don't think he'd ever understand that*(Female)*

1-30.59 He didn't understand, he used to get frustrated with me when I needed to just let it out, it was like he couldn't handle it *(Female)*

1.2-45.53 I hated him at times, he'd say things like ''now isn't a good time for treatment'', I knew I didn't have long, he just didn't understand. *(Female)*

1.2-11.50 I didn't feel like he understood at all. *(Female)*

1.2-41.50 I felt so let down by x, I would have left him to have the baby alone, he just couldn't understand my need. *(Female)*

Subcategory of 'Sense of Isolation': Not feeling understood or supported by others

The female goes through the infertility experience with the sense that no-one else understands what she is going through. The focus extends from partner to general 'others'. As a result the female can feel unsupported on every level and as though she is going through the whole experience on her own.

Comments:-

1.2-46.36 No-one understood my need or my position *(Female)*

1.2-47.04 No-one really understood, so I really felt like I went through it without support. *(Female)*

6-10.35 I don't think people can really understand what it's like unless they've had problems *(Female)*

7-8.42 People do try, but how they possibly understand what it feels like *(Female)*

4-47.23 I don't people understood just how difficult it was for me at times. *(Female)*

6-11.02 People don't really understand what you're going through *(Female)*

9.10-15.40 Others can't possibly understand what you are going through. *(Female)*

9-23.31 Family all of a sudden stop asking you what is happening and you feel

all at sea *(Female)*

6-45.13 People don't ask you what's happening but you want them to, you want to talk to them about what is happening they need to understand *(Female)*

6-7.25 People have sort of stopped asking me, I think that people will think I'll fall apart, which sometimes you do. *(Female)*

1-21.30 It's a very personal subject, it's not always easy to talk about, people don't always understand that *(Female)*

Subcategory of 'Sense of Isolation': Isolation when others have children

The feelings of isolation can be compounded when friends and family have children. Once friends have children the dynamic between them changes. Discussions about the experience of labour and having children coupled with changing social situations can feel excluding. In the absence of the motherhood experience a divide is created which further isolates the childless female.

Comments:-

9-12.21 There is an element of isolation when your friends have kids*(Female)*

9-13.29 It's weird going to children's parties without children, you feel like a spare part, you speak a different language*(Female)*

9-17.42 It's very isolating, there are things you can't join in on, for example pregnancy and labour stories. You can't contribute, that feels awful. *(Female)*

9-16.34 You feel left out when your friends are talking about their babies and all that stuff. *(Female)*

7-34.35 I appreciate that it's selfish, but when friends have babies you do feel a bit left out. *(Female)*

7-35.13 You can't join in when your girlfriends are talking about labour and being mum's. *(Female)*

7-12.11 It's lonely, you feel different to friends and family who have children*(Female)*

Subcategory of 'Sense of Isolation': Awareness of male pragmatic ambivalence

The female has a strong sense that her desire for children is not matched by her partner. Although it may not have been discussed between the couple the female is acutely aware of the males' pragmatic ambivalence towards children and as a result IVF treatment. This further contributes to the sense of going through the experience seemingly alone and often feeling misunderstood.

Comments:-

9-52.34 I felt that he could live without children *(Female)*

6-52.21 There are times when I think he could happily live without children *(Female)*

1-35.11 I don't feel that he was ever bothered about having children *(Female)*

1-44.29 The man's need is never going to be as much as the woman's*(Female)*

1.2-39.33 I felt he couldn't give a toss about the IVF or having a baby. *(Female)*

1.2-36.33 I felt that he didn't care if we had another child or not *(Female)*

7-37.23 His need has never been as strong as mine, at times it was like he didn't even want children. *(Female)*

Subcategory of 'Sense of Isolation': Loneliness

The whole experience is a lonely one for the female. Not feeling understood, feeling unsupported and being infertile when combined contribute to a sense of aloneness.

Comments:-

6-25.43 I've felt so alone at times it's unbearable *(Female)*

5.6-10.19 I feel like I'm doing it all alone. *(Female)*

1-42.32 It's very lonely *(Female)*

1.2-46.30 I didn't feel like I had any support at all, it was very lonely. *(Female)*

4-41.21 It' s a weird place to be (infertile), you feel really quite isolated *(Female)*

9-16.24 It's a very lonely place to be – infertile. *(Female)*

9.10-16.24 It's something (Infertility/treatment) that you feel like you go through alone. *(Female)*

CATEGORY: SENSE OF FAILURE

A sense of failure is seemingly present throughout the whole infertility experience. The sense of failure is many layered. It is both global and specific. The female talks of being a failure as a female, being a failure as a person, failing others and in turn talks of her body failing her.

Subcategory of 'Sense of Failure': Failure as a female

A widely held assumption is that a female should be able to have a child biologically. This assumption seems to gives rise to a belief held by females experiencing infertility that if a female can not have a child then she is a 'failure'.

Comments:-

9-12.13	I didn't feel like I was a woman, I was failing *(Female)*
9-25.47	You feel guilty because you can't (have a baby), I'm a woman I should be able to that *(Female)*
6-1.11	I feel like a failure as a woman, I'm not able to do what I'm meant to (have a baby). Overall, I've felt less of a woman, my self-esteem has plummeted. *(Female)*
1.24.05	There's an expectation that as a woman that is what you do (have babies) and for some reason I couldn't. *(Female)*
9.10-30.40	Being told you've failed again, it's just crushing for a woman to hear that. *(Female)*

Subcategory of 'Sense of Failure': Failure as a person

The infertility experience impacts on the sense of self. This sense of failure as a person is acknowledged by the female as being largely generated by herself rather than imposed by others.

Comments:-

9-6.15	But I wanted to see them and talk about why the process hadn't worked, why I'd failed. *(Female)*
9-3.04	all you can think ''Oh I've failed, I've failed and this was my only chance'' erm so that wasn't a particularly comfortable experience. *(Female)*

9.47.10 I felt worthless and hopeless before (having children) in every area. *(Female)*

9-51.36 Before I had my children I felt like a huge failure, no one made me feel that I made myself feel that. *(Female)*

6-1.25 That is the main thing I've felt is a failure. *(Female)*

6-14.45 I'm really conscious of people thinking we are to blame for our situation, you know that we're, or rather I, am responsible in some way. I suppose that this feeling judged links in to my feelings of failure. *(Female)*

6-16.43 No one has ever said it's me, but I take it all on. As far as I am concerned I am the failure. *(Female)*

6-17.04 I feel that it's my fault because he's deposited it (his sperm) and then what I do with it is my problem and I'm not doing it right *(Female)*

3.4-7.25 I was not used to failing, I took it as a personal failure (not falling pregnant). *(Female)*

7-21.31 It's so hard to fail in this fundamental area especially when you are successful in work and other areas of your life. *(Female)*

Subcategory of 'Sense of Failure': Body as failure

The female feels let down by her own body. Just as she feels that she is a failure as a female, a person and that she has failed others, she feels that her body is failing her in her quest to bear a child.

Comments:-

7-4.31 Your body fails you and you fail everyone else. *(Female)*

1-11.23 I needed to know why my body was failing me *(Female)*

4-3.57 I felt like a failure, any idiot can shag and have a baby, but I couldn't, my body couldn't. *(Female)*

Subcategory of 'Sense of Failure': Failing others

The female feels that she has failed others by not providing a child. Those that she feels she has failed extends to partner, family and other people close to the female.

Comments-

9-30.47 I felt that if I can't give him a baby he will want leave me *(Female)*

9-42.39 At big family gatherings it was so painful, feeling like I hadn't contributed to the next generation. *(Female)*

7-5.31 I feel like I've let x down, I can't provide him with children *(Female)*

6-5.00 I feel like I've let others and myself down when my period arrives each month. *(Female)*

6-21.01 I really hate to let people down, and this (not falling pregnant) is part of that. *(Female)*

CATEGORY: - EMOTIONAL RESPONSES

The infertility experience influences the emotional state of the female. There were three specific emotional responses that were repeatedly expressed in relation to the infertility experience - anger, pain and grief. They were not the only emotions experienced but they were the most frequently expressed emotions.

Subcategory of 'Emotional responses':- Anger

Anger experienced in relation to the issue of infertility tends to be expressed in a general sense e.g. irritability with others, general bad mood.

Comments:-

4-2.01 as a woman I felt very angry, I became very snappy and stroppy. *(Female)*

1.27.18 before I started the treatment I was all over the place, I would really feel angry and would lose my temper so easily. *(Female)*

7-10.37 I have felt very angry about our situation *(Female)*

6-2.42 I'm in a permanent bad mood, people are getting on my nerves all the time, I'm just not as tolerant as I used to be. *(Female)*

11-13.01 There have been times when I have felt very angry and short tempered *(Female)*

9-32.10 There have been times when I've felt so irritated and angry at everyone, just me against the world. *(Female)*

1-37.02 If I hadn't got pregnant, I would have just got worse I think, more unhappy and more irritable *(Female)*

Subcategory of 'Emotional responses': Pain

The infertility experience is talked about as a painful one for the female. This emotional pain can be so intense it can manifest physically at times.

Comments:-

7-12.01 It's been so utterly painful, the whole experience and if I'm honest I'm still in pain, I think I always will be to some extent. *(Female)*

9-13.24 It's sometimes hard to remember just how painful it was. *(Female)*

11-16.02 It's a very painful experience to go through *(Female)*

9-24.44 The pain was physical at times. *(Female)*

7.8-50.29 He doesn't seem to understand the pain I am in. *(Female)*

Subcategory of 'Emotional responses': Grief

The experience of not having a child can induce a grief reaction. The feelings experienced in response to not falling pregnant / having a baby are characteristic of feelings related to bereavement. The expression of this grief is facilitated when there is an actual pregnancy resulting in miscarriage to focus on.

Comments:-

9-8.34 I understand the processes of grieving, I mean I was very fortunate that I did have a pregnancy that I could point to and that I could grieve about, it provided a focus for the overall grief I was feeling about not falling pregnant. *(Female)*

9-8.39 Having a focus for my grief made it easier but I was grieving before my miscarriage for the child we might not have. *(Female)*

7-34.21 To me it's a grief process, it's not easy to accept that you won't have a child. *(Female)*

7-37.23 To me you don't have to lost 'someone' to be bereft, I have lost the opportunity to have 'someone'. *(Female)*

CATEGORY: AN OVERWHELMING DESIRE TO HAVE A CHILD

The way that the females talked about their desire to have a child suggests that their desire can be overwhelming and ever present. Over time the goal of having a child becomes the focus for the female. The need/desire seems to increase as the chances of having a child reduce.

Comments:-

1-7.37	That (a baby) was all I wanted, it was everything to me *(Female)*
1-6.57	I didn't care where he was coming from, I was obsessed with it (having a baby). *(Female)*
1.2-31.20	That's (a baby) all I wanted regardless of x, I'd have done it without him if I'm honest
2-22.45	It never seems to leave the woman, it might go into the back ground for a bit, but you know they are thinking about it all the time *(Female)*
1-9.34	I just had a desperate need (to have a child), probably because I knew I couldn't *(Female)*
4-13.12	For a while you do become almost obsessed with having a baby, you almost forget whether you really wanted one or not before. *(Female)*
7-42.35	It becomes a serious goal, you think about that and nothing else, the more you can't have one the more attractive it becomes. *(Female)*
7-34.12	It (having a baby) became very important to me, vital. *(Female)*
5.6-13.00	The fact that I'm not being successful seems to increase my sense of urgency, I want a child and I want that now. *(Female)*
5.6-14.30	It's an absolute need for me, I need to have a child and the need seesm to be increasing. *(Female)*
6-3.21	I'd like to think I don't think about it all the time, but if I'm honest I do. *(Female)*
9-12.54	I felt that I couldn't see where I could go without a family. I suddenly realised that it was all I'd wanted. *(Female)*
9-13.24	Everything seemed to focus on it, every decision. *(Female)*
9-34.06	I was obsessed by it (having a baby) I suppose *(Female)*

POST-ACTIVE INFERTILITY STAGE

CATEGORY: BECOMING A MOTHER

Becoming a mother of a child, whether naturally, via IVF or adoption, brings about a change in the emotional state of the female. The female talks about feeling happier, complete, more content and 'normal' once she becomes a mother.

Subcategory of 'Becoming a mother': Feeling happy

The female that has a child/children talks about feeling happier since becoming a mother.

Comments:-

1-26.45 I am so much happier and much more settled now *(Female)*

4-28.01 It's been life changing, having a child, I think any mother would say that, I can say that I am much happier *(Female)*

9-43.34 I'm much more fundamentally happy and I am more open to helping others in the same situation. *(Female)*

Subcategory of 'Becoming a mother': Feeling complete

The female that has a child/children talks about feeling complete since becoming a mother.

Comments:-

1.2-31.43 I feel a completely different person, (since having baby), I suppose I am now complete *(Female)*

11-17.23 It's made me feel complete *(Female)*

4-26.23 I don't feel the need to achieve anything anymore; I've done what I need to do. *(Female)*

Subcategory of 'Becoming a mother': Feeling normal

Females expressed feeling normal since becoming mothers.

Comments:-

1-36.01 I feel normal now [since becoming a mother] *(Female)*

4 – 27.02 I suppose becoming a mother made me feel like a normal woman

11-17.46 I used to feel like an outsider and now I feel like I fit in, with all the other women so I feel more normal *(Female)*

CATEGORY: A FUTURE WITHOUT CHILDREN

There comes a time when treatment stops and the female has to face a future without children and not being a mother. This signifies the start of the process of acceptance, a continuation of the grieving process and looking for a new direction in life.

Subcategory of 'A future without children': Process of acceptance

At this stage the female facing the future without children talks about starting the process of accepting that she is not going to have a child or be a mother. This suggests that until the point at which it becomes clear she is not going to have children she does not give up hope of having a child.

Comments:-

8-52.12 For me I now need to work on accepting that I'm never going to be a mother, I haven't accepted that yet. *(Female)*

8-53.18 You know for a woman to accept that she's not going to ever be pregnant, give birth or be a mother is such a big thing. I need to try and do that now. *(Female)*

Subcategory of 'A future without children': Grieving process

For the female facing the future without children, the process of accepting that they are not going to be a mother, feeds into the grieving process that starts during the active infertility stage.

Comment:-

8-53.45 It's a grieving process I suppose, I have lost out on something major and I need to work through that, I can't just 'move on', before I move on I need to deal with all this. *(Female)*

Subcategory of 'A future without children': A new direction

In the face of a future without children the female talks about wanting to find a new direction in life now she is not going to be a mother that will fulfil her emotionally.

Comment:-

7.8-41.02 You see he (partner) would be happy to just get on with life, I can't. I need to find something that can replace the void that I feel emotionally, so I suppose that I'm talking about a whole new direction in life. *(Female)*

APPENDIX 12

Male Categories – Study 1

RESEARCH CATEGORIES –MALES

Overview

Each category is first described before presenting definitions each of the subcategories within the category. Subcategory definitions are followed by a record of comments taken directly from the interviews.

ACTIVE INFERTILITY STAGE

CORE CATEGORY: PRAGMATIC AMBIVALENCE

There is a pragmatic ambivalence towards fatherhood and children for the males. Whilst they would like a family or children males seem to have a balanced, matter of fact attitude toward fatherhood and children that could go one way or another e.g. happy if they become fathers and disappointed if not. This pragmatic ambivalence has been broken down into two sub-categories – pragmatic ambivalence towards being a father and pragmatic ambivalence towards having children. These sub-categories are closely related but with subtle differences.

Subcategory of 'Pragmatic ambivalence': Pragmatic Ambivalence towards fatherhood

The male 'need' or 'desire' to be a father seems qualitatively different to that of the female's need or desire to be a mother. The males talk about 'disappointment' at the idea/reality of not being a father. This seems directly linked to the male assertion that they have not given a great deal of thought to the prospect of fatherhood.

Comments:-

3-2.33 I was very disappointed that I was not going to be a father but not devastated. *(Male)*

5-10.37 I don't look at people with children and think I can't wait to be a dad, I know I'll like it but I'm not desperate. *(Male)*

10-3.34 fathering children has never been a really big thing for me *(Male)*

8-5.45 My desire for being a dad was not as strong at the beginning , in fact when I think about it, I have never really thought too hard about, I'm

not gutted that I won't be a dad *(Male)*

8-6.37 It's never really been a big deal for me personally (being a biological father). *(Male)*

8-11.39 I've never really felt any strong emotions about all this (not fathering a child) *(Male)*

8-21.17 The whole parenthood thing doesn't really bother me too much, if you brought me in a 2 week old baby now, I just wouldn't really be too interested, it's not important to me. *(Male)*

8-22.30 It's weird, I don't feel that there is any expectation on me to have kids from colleagues and stuff, I don't think men think about babies like women do. *(Male)*

8-23.53 I don't think that a man needs to be a father, I know I'd be a great dad and I love children, but I accept that I won't be a dad. *(Male)*

7.8-22.18 I didn't have a picture of the future, I didn't have a vision of dogs, cats and kids, being a father probably wasn't that important to me *(Male)*

5.6-14.20 I mean I would like children but I don't 'need' them, it's not like that*(Male)*.

5.6-15.37 I think that men feel more relaxed about kids because they don't need to have children genetically*(Male)*

5-6.30 I don't think oh dear, if I don't have kids I don't what it'll do to me, I just don't feel like that. *(Male)*

2-23.44 I wanted children, but for a man it's just different compared to the woman's need. *(Male)*

8-1.32 To be honest I didn't really have any feelings towards the position we in (infertile) until we were advised to go for IVF. *(Male)*

Subcategory of 'Pragmatic ambivalence': Pragmatic Ambivalence towards children

The ambivalence towards children is related to the physical presence of children.

Comments:-

12-1.50 At one stage I thought that's it we're not going to have more children, but I never felt too upset by that, I'm not sure if that's cos I had a daughter already. *(Male)*

12-2.43 There were times when I felt very frustrated, I remember asking myself if I really wanted another kid *(Male)*

1.2-36.45 I was probably quite blasé about it all (having a baby/IVF), if I'm honest I didn't really care if we had another child or not *(Male)*

2-11.46 I don't ever remember thinking, I would like x number of kids, I didn't really think about it to be honest *(Male)*

8-3.51 Kids were not a big deal to me at the time, they just weren't then *(Male)*

8-5.28 I remember the first stages of IVF and thinking to myself 'what on earth am I doing this for?', Why am I spending £4,000 for something when I don't even know if I want kids, I know it sounds awful, but it's how I felt. *(Male)*

8-3.10 This is probably going to sound awful, but I can remember distinctly thinking I really don't think I want to go through all this shit (IVF) to have kids. *(Male)*

8-26.12 There's been hope along the way but it's funny I've almost felt relief when the first couple of treatments didn't work, isn't that awful. I just wasn't ready at that time for children. *(Male)*

8-27.41 I have a great lifestyle and I see a child as perhaps affecting that really *(Male)*.

8-28.0 In recent attempts I've felt a bit disappointed when it hasn't worked but my attitude has been to see it like a flip of a coin, if it comes down and we're pregnant are going to have a child great, but if we're not, no big deal. *(Male)*

CATEGORY: COMPLIANCE

The male talks in terms of going along with the process of treatment. Pragmatic ambivalence toward fatherhood and children coupled with an awareness of how important having a child is to the female seems to influence the compliant position he takes in relation to treatment. This compliance is demonstrated through non-expression of feelings (the next category to be discussed).

Comments:-

2-58.38 I went with it (the treatment) because I knew how much it meant to her, it wouldn't have been fair to stop the process. *(Male)*

1.2-53.25 I went along with it because you (to wife) were the one who had to go through everything, I didn't feel I had the right to say anything. *(Male)*

8-28.28 To be honest I did initially voice concerns about going for IVF but it meant so much to her I could see that she really wanted it, so I went with it. *(Male)*

8-4.53 We probably went through with it (IVF) because her desire was so strong, it was clearly something she wanted to do *(Male)*

10- 1.17 I was never the active partner in deciding to have a family *(Male)*

10-3.31 To a large extent I went along with IVF because x wanted to, I would rather have not gone that route *(Male)*

10-4.48 I definitely felt swept along to some extent, x (partner) was the driving force *(Male)*

CATEGORY: NON-EXPRESSION OF FEELINGS

There is a conscious effort on the male behalf to not express their emotions. This seems to be partly due to the fact that the male feels that is not fair to add to the pressures on the female. It also seems to be due to not feeling that they have the 'right' to complain when the female is going through 'so much'. Through this non-expression of feelings the male complies with the female's decisions in relation to treatment.

Comments:-

12-5.40 She went through so much, I felt that I didn't have the right to complain, or have any feelings. *(Male)*

12-6.40 I think that what I was going through was insignificant compared to what she had to go through, I didn't feel it was right to say how I was feeling. It didn't seem fair. *(Male)*

10-18.08 I wouldn't have dreamed of saying how left out I felt or what I was feeling during the process, you assume that your suffering is so much less than the woman, you feel you don't have the right to complain. *(Male)*

10-16.39 She's got so much on her plate you tend not to feel able to express your feelings *(Male)*

7.8-19.30 I remember thinking 'do we really want to go through all this (IVF)?', but I didn't say anything *(Male)*

1.2-25.05 I could see how much x wanted to do it (IVF), it was everything to her, so I took the decision myself to not say anything. *(Male)*

1.2-26.0 Seeing how much it meant to x I didn't really give them (my feelings) that much thought. *(Male)*

1.2-24.30 I didn't say anything but I really doubted whether we should go for the IVF. I just didn't see the point we had so much already, so we didn't discuss it. *(Male)*

1.2-53.27 I didn't feel I had the right to say anything. *(Male)*

5-1.06 I do try and protect her from what I'm feeling *(Male)*

3-9.09 You do put your own feelings aside to some extent *(Male)*

3-10.48 There were times when you think, well this is what I want, but you don't necessarily say anything because it is not fair. *(Male)*

2-60.30 I suppose you keep a lot in to protect her in some way, she's going through so much, she doesn't need to hear that you are feeling left out or not sure about having a baby. *(Male)*

5-21.17 I have feelings but it's not really fair to say anything 'cos she's going through so much *(Male)*

CATEGORY: INFERTILITY EXPERIENCE CONSIDERED 'EASIER' FOR THE MALE

The infertility experience is considered by males to be physically and emotionally tougher for the female and hence 'easier' for the male.

Comments:-

2-10.04 guys don't really talk about it, we're not like women who need to talk about it because it's so much more difficult for them *(Male)*

5-5.32 I'm in an easier position, I don't have to go through all the physical stuff *(Male)*

5-22.22 I feel a bit selfish, cos I don't have to go through the physical and emotional stuff, I don't feel like I do. *(Male)*

5-22.31 I feel like it's so much easier for me *(Male)*

3-7.35 The woman has to go through all the shit and you want to try and

support her *(Male)*

10-16.46 The physical and the emotional side is so much more demanding of the woman. *(Male)*

CATEGORY: FEELINGS OF INADEQUACY

In contrast to other situations in life males find that they are not able to 'fix' the issue of infertility. Thus, they become redundant to some extent in their role as 'fixer' in this situation. This can result in the male feeling helpless and powerless to change the situation. Thus the infertility experience can induce feelings of inadequacy in the male.

Comments:-

10-19.39 It's hard to watch the woman you love suffering and feel so helpless *(Male)*

5-20.43 I realised that I couldn't fix it (the infertility). That is really hard, I want to protect her but can't do anything. *(Male)*

5-22.06 I feel a bit helpless because I can't fix it and that is what I do normally, I sort things out when I can. *(Male)*

5-22.41 I wish I could take more of the burden *(Male)*

5-23.44 I almost wanted to be the one who was responsible at least I could deal with it then, I can't sort this one out. *(Male)*

5-25.12 I feel now that my way of fixing things is to talk to x and let her be emotional and just be there for her. In a way that is fixing stuff and I feel more useful. *(Male)*

5-26.37 I think I've stopped trying to protect her from stuff that she is going to be upset about anyway, I can't protect her. *(Male)*

2-24.20 Men are generally control freaks and when you can't control things it is horrible, you can't control this stuff, it makes you feel small. *(Male)*

1.2-57.12 I didn't understand so I feel like I can't really help. *(Male)*

2-51.23 You feel so useless and hopeless throughout the whole situation *(Male)*

2-57.21 I felt even more useless when I wasn't really consulted about the decision to go for it. *(Male)*

7.8-19.02 I don't think I was very helpful, I was an awkward arse, I felt pretty useless. *(Male)*

CATEGORY: MALE FEELS MARGINALISED

The focus of treatment tends to be on the female. As a result the male can feel marginalised during the active infertility stage. This is characterised by feeling left out, overlooked and cut out of the decision making process and the actual treatment process. Non-expression of feelings and pragmatic ambivalence are likely to contribute to the male being overlooked or not included in the decision making process.

Comments:-

2-53.34 I can honestly say that I don't remember being asked at any point how I felt about this (IVF). I was kind of cut out of the decision. *(Male)*

2-60.33 She doesn't need to hear that you are feeling left out *(Male)*

1.2-27.0 Seeing how much it meant to x (partner) I didn't really give them (my feelings) that much thought. *(Male)*

1.2-11.56 My attitude was well, it you don't include me how can I understand what you are going through *(Male)*

2-3.58 Men take a lot for granted in these situations, they're on the sidelines if you like. *(Male)*

6-39.53 It's horrible how they take her away to do stuff, I'm not invited along, and when she gets back I can't understand what's made her so upset because I wasn't there. *(Male)*

12-4.09 It's hard as a man, you're trying to stay involved all the time, the focus is always on the female, it's hard. *(Male)*

10-16.34 It feels very impersonal, you don't get treated as an equal (as the male). *(Male)*

10-15.26 With IVF the man is left on the sidelines, it's all about the woman. In fact it's all about the woman from the beginning actually. *(Male)*

10-16.53 You feel shut out as a man, you are excluded, you a complete spare part. *(Male)*

POST-ACTIVE INFERTILITY STAGE

CATEGORY: FATHERHOOD

Males that become fathers regardless of whether this happens naturally, via IVF or adoption talk about feeling a sense of satisfaction.

Comments:-

2-59.23 I am satisfied now that we are a family, I wouldn't change it for the world. *(Male)*

3-13.57 I don't think having a child changes you as a person but I suppose I feel more content and satisfied with my life now. *(Male)*

10-23.45 I feel that I can relax now and get on with the rest of my life. I feel like I've got a role now, being a father and that's good. *(Male)*

12-21.23 Coming in the door at the end of the day knowing your family are waiting for you is great, it's a very satisfying feeling to be honest. *(Male)*

CATEGORY: A FUTURE WITHOUT CHILDREN

For males facing a future without children the experience is primarily characterised by acceptance and a need to move on. Males talk about the being able to accept that they are not going to have children. This acceptance is characterised by a matter of fact attitude to the situation and a sense that acceptance is something that happens relatively quickly and

not a process that happens over time. This seems to be directly linked to the male pragmatic ambivalence towards fatherhood and having children.

Comments:-

7.8-42.34 I don't 'need' (hand gesture emphasising the word need) them (children), it's not like that, I've accepted that we won't be having them. *(Male)*

8-30.56 You know, the way I see it, nobody has died here, lets move on and get on with our lives. Although I know that it's not easy for her to do that. *(Male)*

8-6.33 To me it's black & white, when I realised that we might not be able to have kids, I just accepted that. It's never really been a big deal for me personally. *(Male)*

8-18.40 I don't think I've really given much thought to the fact that I'm never going to be a dad; I've just accepted it. *(Male)*

2-17.36 I kind of looked at it and thought well if this isn't going to happen I need to accept that it's not and get on with other things. That wasn't a problem for me. *(Male)*

2-42.45 I don't see the point in dwelling on the negative stuff, you can't change it, so you get on with it. *(Male)*

APPENDIX 13

Couple Categories – Study 1

RESEARCH CATEGORIES – THE COUPLE

Overview

Each category is first described before presenting definitions of each of the subcategories within the category. Subcategory definitions are followed by a record of comments taken directly from the interviews.

CORE CATEGORY: IMPACT ON COUPLE RELATIONSHIP

The impact of the infertility experience on the couple relationship has been broken down into 3 phases - **distance, growing closer and growing stronger.** Couples do not progress through the stages in a linear fashion. Couples tend to oscillate between closeness and distance throughout the infertility life stage. At the same time they talk about growing stronger during the whole experience. Ultimately, providing the couple stay together throughout the active infertility stage they emerge from the experience 'stronger'.

Subcategory of 'Impact on the couple relationship': Distance

The couples talked about a 'distance' between them during the process. This distance can be triggered by a specific event e.g. a failed IVF attempt or more discreet factors e.g. knowing that they were not feeling the same about having a child.

Comments:-

1.2-32.45 It drove us apart in the middle *(Male)*

1.2-46.30 That drew us apart I knew he wasn't thinking the same as me (about having a baby). *(Female)*

1.2-47.46 We weren't reading off the same page of the hymn book, there was a divide *(Male)*.

7.8-41.35 Without doubt the intimacy between you changes, there's a big distance at times. *(Female)*

7.8-51.03 We have been dealing with it in our own ways and that creates a distance. *(Male)*

11.12-5.40 When the treatment is not working a real distance starts growing between you. *(Female)*

11.12-14.20 When there's been a failed attempt you just can't really talk about it, you go into your own world and try to deal with it on your own. *(Female)*

11.12-15.30 You build yourself up with so much hope that when it doesn't work you can't deal with it, you go into your own little world. *(Male)*

5.6-17.34 There have been periods when we're not very close to each other, we just kind of get on with it on our own. *(Male)*

Subcategory of 'Impact on the couple relationship': Growing closer

This phase is characterised by the couple growing closer to each other. Different factors can trigger a period of closeness for the couple e.g. hope, planning, realisation that they have only each other.

Comments:-

3.4-6.21 You realise that if it's only going to be the two of you, you need to be there for each other and support and love each other, so you become closer. *(Female)*

5.6-35.49 We've made a conscious effort to do things together, spend time with each other since this (fertility issues) all started. *(Male)*

5.6-19.45 We are trying to come to terms about all this together as a couple, so we can stay close rather than drifting apart. *(Female)*

1.2-32.16 Initially it brought us closer but it's all been so stressful, so it goes in cycles. *(Female)*

11.12-5.28 All the planning and the hope keeps you going and you feel close then. *(Male)*

Subcategory of 'Impact on the couple relationship': Growing Stronger

This phase is characterised by the increased strength of the couple's relationship. Couples reflected that they had become 'stronger' as a result of the process. This suggests that the couple becomes cumulatively stronger throughout the infertility process, even if they do not recognise this as the case at the time.

Comments:-

4-16.22 You don't come out of this experience unscathed, but we are lucky because it brought us together, and now we are stronger but it can

make or break you *(Female)*

12-11.39 It's definitely made us stronger overall, but it's been so hard. *(Female)*

1.2-32.49 Now we're through it we are definitely stronger *(Male)*

7.8-37.51 We've stayed together despite not being able to have children and we're stronger now. *(Male)*

7.8-37.12 The whole thing has definitely made us stronger. *(Female)*

5-2.00 This process had made me realise how much I love x, I suppose it's made me appreciate our relationship more and made us stronger. *(Male)*

9.10-28.00 It's been so hard, but we are definitely stronger as a couple now. *(Female)*

9.10-31.42 The process is so tough, you just don't have time to process how strong we've become *(Male)*

CATEGORY: COMMUNICATION BETWEEN COUPLE

Communication between the couple changes during the infertility process. A pattern of non-communication about the actual issue and the feelings related to it develops. This seems to give rise to tensions in the couple that result in conflict about a seemingly innocuous and unrelated event. On the other hand, appointments seem to act as a catalyst and create a change in the pattern of communication. So the active infertility stage is characterised by periods of communication followed by periods of non-communication. The pattern of communication is directly linked to the quality of the relationship at any given stage.

Subcategory of 'Communication between couple':- Non-communication

The couple tend to avoid discussion of the actual issue. Hence communication is affected and can actually break down at any given stage.

Comments:-

7.8-18.50	In the early stages we probably didn't discuss things directly with each other. *(Male)*
7-41.12	I found it very difficult to talk to him at times and he didn't ask so basically we didn't communicate and still don't to some extent, at least not about the situation. I would say it tends to come out in other subtle ways when we argue. *(Female)*
5.6-7.30	It's hard talking to each other about what we're feeling, we tend to argue about other stuff that we wouldn't really argue about instead of dealing with the real issue. *(Male)*
5.6-10.0	You realise that when you don't talk to each other it's bad but you get caught in this pattern. *(Male)*
5.6-39.0	Although we don't always do it, we've learned how important it is to communicate, because we weren't for a good while. *(Female)*
5.6-31.50	So far we've not discussed treatment and stuff, but of course we need to. We seem to be avoiding that one. *(Female)*
1-16.37	We've fallen into the trap of not telling each other what we are feeling and not asking each other, even though we know that it's not all ok. We just argue about the mess in the kitchen and stupid things like that. *(Female)*
1-16.51	There is a lot of secrecy between us*(Female)*
1.2-59.34	There were so many suspicions, fears and anger, I couldn't talk to him, so we weren't communicating*(Female)*
11.12-15.45	Some things are so painful you kind of say nothing to each other, at least not about the issue, instead you argue about other stuff. *(Male)*

Subcategory of 'Communication between couple': Communication

Non-communication about the issue of infertility and related factors is disrupted when an appointment is pending. Thus appointments tend to trigger a period of communication as they provide a focus for the discussion around the issue. As a result they can serve as a joiner for the couple.

Comments:-

1.2-13.45	Appointments were great because it made us talk about it, we never talked enough about it together. *(Female)*
11.12-17.21	Clinic appointments were always a source of communication, because we'd be going together and that would bring about a conversation. *(Female)*
5.6-10.56	It's good when we need to talk about appointments and stuff cos it forces us to communicate with each other, which we may have been avoiding. *(Male)*
5.6-10.56	Going to appointments means that we come together and talk about stuff, that's really good. *(Female)*

APPENDIX 14

Overall Experience Categories – Study 1

RESEARCH CATEGORIES – OVERALL EXPERIENCE OF INFERTILITY

Overview

Each category is first described before presenting definitions of each of the subcategories within the category. Subcategory definitions are followed by a record of comments taken directly from the interviews.

CORE CATEGORY: INFERTILITY AS A LIFE STAGE

Couples talked about the way that the infertility process took over their lives and how the experience changes you as a person. A key theme that emerged from this study is that individuals and as a consequence couples, qualitatively change as a result of their infertility experience, suggesting that the whole infertility experience constitutes a life 'stage'.

Comments:-

6-9.46	It's happening everyday, there's always a call to make or someone I've got to see. It's become a really big part of our lives, whether we like it or not, it's like you become part of the whole process. *(Male)*
9-29.16	The treatment treadmill just takes over your life *(Female)*
9-34.12	I realised that so much time had passed, I mean years, where all of my decisions had been based around the possibility of having a baby *(Female)*
9-36.15	I regret that, I don't think you shouldn't put your life on hold like that for so many years *(Female)*
9-53.51	I made a lot of sacrifices for this, I moved office to be near the clinic, I didn't leave my job just in case I got pregnant, our lives were effectively put on hold. The result is that I have become a different person over the years. *(Female)*
1-31.44	Our lives have not been normal for so long, and it feels that we can now start getting things back to normal but they will never be the same as they were before because we aren't the same *(Female)*

12-6.51 Even when you weren't having treatment it was there, our lives were ruled by it for years, and you come out of the experience a changed person. *(Male)*

4-16.22 You don't come out of this experience unscathed, but we are lucky because it brought us together, and now we are stronger but it can make or break you *(Female)*

CATEGORY: DECISION TO HAVE A FAMILY

Couples talked about the decision to start a family. There are subtle differences detectable in the discourse suggesting that the 'decision' to have a family is different for the male, the female and the couple. This is demonstrated in the following three subcategories.

Subcategory of 'decision to have a family': The female's decision

The female talks about her decision to have a child as resulting from 'wanting a baby'. As such a female's decision is based on desire rather than a plan.

Comments:-

7.8-24.40 I'd started noticing babies and realised that I really wanted one, my maternal urges were kicking in. *(Female)*

1.2-1.56 I just really wanted another baby to me it wasn't about timing or it not being part of the plan. *(Female)*

Subcategory of 'decision to have a family': The male's decision

Male discourse is related to the 'timing' of having a family.

Comments:-

9.10- 10.12 I wanted the time to be right to have a family, I needed to feel that we were settled and secure. *(Male)*

7.8-25.50 I suppose the time we started trying was a good a time as any. *(Male)*

1.2-1.45 I didn't feel it was the right time to have a child; we weren't very secure financially or otherwise at the time. *(Male)*

12-1.32 It was just the right time to have another child *(Male)*

Subcategory of 'decision to have a family': The couple's decision

The couple come together and talk about having a 'family' and then they 'plan' the way forward.

Comments:-

5.6- 1.12 We sat down and talked about having a family and planning it together, you know when it would be a good time, how many kids and stuff. *(Female)*

3.4-2.43 We had busy careers and we realised that we needed to make plans if we were going to have a family, so we talked about it. *(Male)*

11.12- 2.33 We talked about having another child and decided it was what we wanted, we had always planned to have more than one child we wanted to be a family. *(Female)*

CATEGORY: FEMALE AS ACTIVE AGENT

The female is the first to realise that there may be an issue in conceiving which is related to the arrival of her period each month. The female is the active member of the couple in terms of dealing with the potential issue. This happens in two ways demonstrated by two subcategories.

Subcategory of 'Female as active agent': Female as communicator

The female raises the issue that there may be an issue in conceiving with her partner but waits a while before she does so.

Comments:-

9.10-0.45 There was a gradual awareness that I wasn't falling pregnant, after a while I raised the issue with x (husband). *(Female)*

7.8-2.00 There was a gradual suspicion that there was a problem when I wasn't falling pregnant and after a few months I talked to x (husband) about my concerns. *(Female)*

1.2-0.24 I knew something was wrong but I didn't tell him for quite a while, I did eventually though *(Female)*

5.6-0.45 I felt suspicious when I wasn't falling pregnant and after a couple more

periods I talked to x. *(Female)*

Subcategory of 'Female as active agent': Female as responsible agent

When the female realises that there may be an issue she takes responsibility on herself to take control of the situation. She does not necessarily share this information with her partner.

Comments:-

5.6-3.34 Once I realised something was perhaps wrong I was straight down the GP to find out what was going on. *(Female)*

7.8-6.50 I took control of the situation. I booked an appointment with the doctor and just got on with it, I wanted to get it sorted. *(Female)*

1.2 -1.18 I'd been going to the doctor to try and find out what was going on, but he didn't know *(Female)*

9.10-0.35 My instant reaction was to get it sorted, so I made an appointment with the doctor, I naively thought it would be that easy. *(Female)*

CATEGORY: INFLUENCE ON LIFE PLANNING

The infertility experience seems to have a significant impact on the couple's ability to plan longer term. It seems that the over all state is one of 'limbo' throughout the infertility experience. The prospect of not having children generates abstract contingency plan discussions about the future. The end of the active infertility life stage signifies a trigger point at which life planning can recommence.

Subcategory of 'Influence on Life Planning': Suspension of life planning

The active infertility stage creates a state of 'limbo' characterised by the couple not being able to think or plan beyond the next appointment / monthly period. Thinking and planning for the longer term comes to a halt.

Comments:-

6-4.33 I don't really think about the future, it has affected the future because I don't plan anymore. I think in terms of the next appointment, that is my plan. *(Female)*

6-6.25 I think in month cycles, I can't think of the bigger picture. *(Female)*

6-5.33 I tend to live in the here and now, probably because the future is too horrible to think about *(Female)*

5-4.14 I'm not really looking into the future, it's difficult to plan *(Female)*

7.8-21.0 The process just means that you kind of stop planning anything. *(Male)*

4-6.01 I never really looked into the future I used to live day to day, it's hard to think about the future when you don't' know what's going to happen. *(Female)*

Subcategory of 'Influence on Life Planning': Contingency planning

When the prospect of not having a common goal of children is considered, life changing plans are discussed, in an abstract rather than concrete way.

Comments:-

5-17.09 We'd have to fill our time with different things and have different plans (without children). *(Female)*

9-34.41 We did consider dramatic plans for the future in the event of not having a child, you know selling up and stuff. That helped. *(Female)*

8-32.00 We have started to look towards the future without children and we may do something fairly radical like sell up and move abroad. *(Female)*

7.8-39.40 We need to replace the common goal of children with something else for the future otherwise we are in danger *(Male)*

5.6-16.15 We've spoken about what will happen if we can't have kids, we'd probably live abroad or something. *(Male)*

9.10-3.38 We did discuss having a radical change of lifestyle if we couldn't have children, you know sell up and buy a ranch in America or something. *(Female)*

Subcategory of 'Influence on Life Planning': Recommencement of life planning at the end of active stage of infertility.

It seems that planning recommences with the arrival of children or with the decision to face future without children. This characterises the beginning of the end of the active stage of infertility.

Comments:-

7.8-21.25 Now it's all over we can start planning our lives, we need to think about the future and how we are going to live our lives. *(Female)*

9-34.12 I realised that so much time had passed, I mean years, where all of my decisions had been based around the possibility of having a baby, that has all changed now (we have children). *(Female)*

1-31.44 Our lives have not been normal for so long, and it feels that we can now start getting things back to normal but they will never be the same as they were before because we aren't the same but we can plan our future. *(Female)*

9-40.55 I can plan now I've got children, we can talk about the future. I can plan more for myself, because part of my job is done. I've also become part of the community now that I have children. *(Female)*

APPENDIX 15

Information sheet to known participants – Study 2

Joanne Perkins – DPsych Counselling Psychology Research

Department of Psychology, City University, London

"Infertility" - your experience

What is the research project about?

I am conducting research into the experience of infertility and the role of counselling. I am also aiming to identify potential counselling and support needs of the male, female and couple going through the infertility experience.

The aim of this research is to broaden our understanding of the infertility experience so that the needs of those going through it can be met by counselling psychologists working in the field. Another aim is to develop an appropriate tool that can be given to those experiencing infertility with the intention of providing support and reducing distress.

It is hoped that the understanding gained and the tool that is developed will contribute to the development of counselling practice in the field of infertility.

What do I need to do?

I am planning to conduct a series of interviews, firstly with you as a couple together and then with each of you separately. The research will take the form of a semi-structured interview during which you will be asked a few open questions that relate broadly to your personal experience of infertility and more specifically to your perception of counselling and whether you have been offered counselling at any stage for the infertility issue or whether you have accessed counselling or considered accessing it at any stage.

Although I am looking for your unique perspective of infertility and counselling it is the topic that is the focus of my study. So I would like to assure you that I will not be making judgements about you, your relationship, your choices or your views, instead I see you as the expert in this domain. I am aware that how you feel and what you think about the questions may change over time but it is how you view things now that is important to the study.

Your honesty would be appreciated throughout the interview. If you do not wish to answer any of the questions you are not required to do so. Each interview should last no longer than 1 hour in total. It may be necessary to contact you at a later stage of my research for further data collection, if you do not wish to be contacted you can indicate this by placing an asterisk beside your printed name on the consent form.

Do I have to take part?

I am aware that because of our existing relationship there is a possibility that you may feel compelled to agree to take part in the study. However, I want to emphasise that there is absolutely no obligation on you to do so.

It is important that you feel comfortable with your decision and that if you agree to participate you do so of your own free will. In light of this, I would encourage you to discuss and make the decision together as a couple as well as thinking about how you feel as an individual about taking part. I will be happy to answer any questions that either of you have.

Should you decide that you would like to take part could you please contact me within the next 4 weeks and we can discuss arrangements.

If you do not contact me I will take that to mean that you have decided that you do not wish to participate. Please be assured that your decision will be respected and I will not ask you about it and you do not need to offer any explanation.

Is it confidential?

All data will be treated as strictly confidential. Any matter arising in either the joint or the individual interviews will be not be disclosed to any other party under any circumstances.

Who else will know that I have taken part?

Please be assured that every step will be taken to protect your anonymity. Your participation will not be discussed with any other participants or other parties. Once all of the data has been collected all your details will be destroyed leaving no link between you and your data. Furthermore, any references to comments from interviews used in the final report will be quoted anonymously.

Is what I discuss during my individual interview confidential?

I can assure you that anything discussed during individual or joint interviews is strictly confidential and will not be repeated or alluded to at any stage to any third party, including your partner. It is your choice whether you wish to share what you discussed with your partner or anybody else in your personal interview.

I have not spoken to anyone about this before and I am not sure how I will react?

I am aware that this is a sensitive issue and that this may be the first time that you are discussing your personal experience either as an individual and/or as a couple.

It is hoped that you will find the process of talking about your experience cathartic, enlightening and liberating. However, you may also find it difficult or upsetting at times and this is natural.

Due to the nature of our discussion, issues may be raised that cannot be explored during the interview, for ethical reasons. It is my responsibility to make sure that our discussion remains within the boundaries that you have agreed to discuss. If the discussion does stray from the area that you have agreed to discuss, please be aware that I will sensitively but firmly change the focus back to the interview.

I will provide you with details of organisations that you can contact should you decide that you want to discuss any issues further, in confidence.

What if I want to withdraw from the study?

You are free to withdraw from the study at any time, without having to provide any explanation as to your reason for doing so. You are not obliged to answer any question that you do not wish to. You may also stop either of the interviews at any stage should you feel you want to for any reason.

What will happen when I see you socially?

You can be assured that your neither your participation or anything discussed during the interviews will be referred to or discussed at any time in the future, either socially or in casual conversation, with either yourselves or any third party.

What if I want to talk some more after the interviews?

After the interviews you may decide that you would like to discuss your experience further. With this in mind, I have attached a list of numbers and organisations that can put you in touch with professional counsellors and support groups that you may find useful.

APPENDIX 16

Letter of introduction to unknown participants – Study 2

Ms J Perkins
164b Albion Road
Stoke Newington
N16 9JS

<Date>

Contact telephone number: 07986 390 185
Email address: jo.perkins@virgin.net

Dear < >,

Following your conversation with [name of mutual friend], I am writing to introduce myself and my research project.

My name is Jo Perkins and I am in the final year of the 3 year Counselling Psychology Programme at City University, London.

I am currently working on my Doctoral research and the topic that I am researching is 'infertility'. I have enclosed an information sheet which outlines the aims of the study and answers some questions that you might have.

I am aware that it is not an exhaustive list and that you may have your own questions that you want answering before you decide whether or not you would like to take part. In light of this please feel free to contact me in confidence on the above number or email address and I will be more than happy to go through any questions you have. Please be assured that by making contact you are not obliged to take part if you do then decide that you would rather not participate for any reason.

Should you like to discuss the study further or your decision to take part please would you contact me within the next 4 weeks? I would like to confirm that I will not contact you or [name of mutual friend] if I do not hear from you.

Yours sincerely

Jo Perkins
Counselling Psychologist in training.

APPENDIX 17

Information sheet to unknown participants– Study 2

Joanne Perkins – DPsych Counselling Psychology Research

Department of Psychology, City University, London

"Infertility" - your experience

What is the research project about?

I am conducting research into the experience of infertility and the role of counselling. I am also aiming to identify potential counselling and support needs of the male, female and couple going through the infertility experience.

The aim of this research is to broaden our understanding of the infertility experience so that the needs of those going through it can be met by counselling psychologists working in the field. Another aim is to develop an appropriate tool that can be given to those experiencing infertility with the intention of providing support and reducing distress.

It is hoped that the understanding gained and the tool that is developed will contribute to the development of counselling practice in the field of infertility.

What do I need to do?

I am planning to conduct a series of interviews, firstly with you as a couple together and then with each of you separately. The research will take the form of a semi-structured interview during which you will be asked a few open questions that relate broadly to your personal experience of infertility and more specifically to your perception of counselling and whether you have been offered counselling at any stage for the infertility issue or whether you have accessed counselling or considered accessing it at any stage.

Although I am looking for your unique perspective of infertility and counselling it is the topic that is the focus of my study. So I would like to assure you that I will not be making judgements about you, your relationship, your choices or your views, instead I see you as the expert in this domain. I am aware that how you feel and what you think about the questions may change over time but it is how you view things now that is important to the study.

Your honesty would be appreciated throughout the interview. If you do not wish to answer any of the questions you are not required to do so. Each interview should last no longer than 1 hour in total. It may be necessary to contact you at a later stage of my research for further data collection, if you do not wish to be contacted you can indicate this by placing an asterisk beside your printed name on the consent form.

Do I have to take part?

It is important that you feel comfortable with your decision and that if you agree to participate you do so of your own free will. In light of this, I would encourage you to discuss and make the decision together as a couple as well as thinking about how you feel as an individual about taking part. I will be happy to answer any questions that either of you have.

Should you decide that you would like to take part could you please contact me within the next 4 weeks and we can discuss arrangements.

If you do not contact me I will take that to mean that you have decided that you do not wish to participate. Please be assured that your decision will be respected and I will not ask [name of mutual friend] about it and you do not need to offer any explanation.

Is it confidential?

All data will be treated as strictly confidential. Any matter arising in either the joint or the individual interviews will be not be disclosed to any other party under any circumstances.

Who else will know that I have taken part?

Please be assured that every step will be taken to protect your anonymity. Your participation will not be discussed with any other participants or other parties, including [name of mutual friend]. Once all of the data has been collected all your details will be destroyed leaving no link between you and your data. Furthermore, any references to comments from interviews used in the final report will be quoted anonymously.

Is what I discuss during my individual interview confidential?

I can assure you that anything discussed during individual or joint interviews is strictly confidential and will not be repeated or alluded to at any stage to any third party, including your partner. It is your choice whether you wish to share what you discussed with your partner or anybody else in your personal interview.

I have not spoken to anyone about this before and I am not sure how I will react?

I am aware that this is a sensitive issue and that this may be the first time that you are discussing your personal experience either as an individual and/or as a couple.

It is hoped that you will find the process of talking about your experience cathartic, enlightening and liberating. However, you may also find it difficult or upsetting at times and this is natural.

Due to the nature of our discussion, issues may be raised that cannot be explored during the interview, for ethical reasons. It is my responsibility to make sure that our discussion remains within the boundaries that you have agreed to discuss. If the discussion does stray from the area that you have agreed to discuss, please be aware that I will sensitively but firmly change the focus back to the interview.

I will provide you with details of organisations that you can contact should you decide that you want to discuss any issues further, in confidence.

What if I want to withdraw from the study?

You are free to withdraw from the study at any time, without having to provide any explanation as to your reason for doing so. You are not obliged to answer any question that you do not wish to. You may also stop either of the interviews at any stage should you feel you want to for any reason.

What will happen when I see you socially?

You can be assured that your neither your participation or anything discussed during the interviews will be referred to or discussed at any time in the future, either socially or in casual conversation, with either yourselves or any third party.

What if I want to talk some more after the interviews?

After the interviews you may decide that you would like to discuss your experience further. With this in mind, I have attached a list of numbers and organisations that can put you in touch with professional counsellors and support groups that you may find useful.

APPENDIX 18

Interview schedule: Couples – Study 2

Couple interviews: Opening script

Firstly, I would like to thank you for agreeing to take part in the research.

The whole interview should take no longer than an hour.

I am going to start by asking you some open ended questions about your experience of infertility.

I will then ask you some open ended questions about whether psychological support was offered to you or whether you accessed any, and if so what kind.

Do you have any questions at this stage? If you do have any questions any at any point, please feel free to ask them.

Who normally does the talking in general/ when you are at the doctors/hospital about this?

OK well for my purposes it may be that I ask X specific questions, will that be all right?

It would be a good time to sign the consent forms now.

Sign consent forms.

You do not need to answer any questions if you don't want to.

Alternatively if at any stage during the discussion you want to stop, just press this button (the stop button on the mini disk recorder). You don't need to explain your reason why if you don't want to.

Are you ready? Shall we begin?

Commence interview.

<u>Interview:</u>

1) Could you briefly tell me about your experience of trying for a child?

2) Were you ever offered any support or counselling – if so what kind and at what stage– did they take up offer if not why not etc?

Note: The following questions served as a guide and were not explicitly asked if answers were provided in the discussion resulting from the initial questions.

3) If not offered ask - Did you ever consider having counselling? If so why? If not why?

4) How did counselling help? OR How do you think counselling can help those going through this experience?
5) What do you think counselling is?
6) Have you ever had counselling for anything else (confirm that they do not need to disclose what for).
7) What do you feel would have been most beneficial to you in terms of support throughout the process and at what stage would you have most welcomed it? E.g. Book, video, informational talk etc.
8) If you had your time again would you have counselling?
9) What would you say to or advise anyone going through the infertility experience??

Closing statement:

I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or are there any questions that you are surprised I have not asked and would like to discuss?

Do you have any questions?

Thank participants for sharing their experience and their time in taking part.

APPENDIX 19

Interview schedule: Individuals – Study 2

Opening question for individual

I am interested to know whether you had a discussion with 'X' following our last interview.

Did you find it helpful?

What happened afterwards?

How are things now?

How did it feel talking to me / an outsider?

Moving the focus on to you as an individual.

Interview:

1) Did you ever consider having counselling for yourself/as an individual?
2) How did your experience of counselling affect you / your relationship? OR
3) What do you think would have happened if you had had couple counselling and/or individual counselling?

Note: The following questions served as a guide and were not explicitly asked if answers were provided in the discussion resulting from the initial questions.

4) If you did have counselling, how many sessions did you have
5) If your partner had counselling but you didn't how did this impact on your relationship/the experience of infertility, if at all?
6) If you never considered having counselling for your infertility experience what factors do you think contributed to this e.g. beliefs/ attitudes/ concerns?
7) If counselling had been mandatory at the treatment centre how would you have felt?
8) What would you have found useful when you were going through your experience e.g. support group, information. and how do you think this would have helped you?
9) At what point would you like to receive information about counselling support, if at all?

Closing statement:

I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or are there any questions that you are surprised I have not asked and would like to discuss?

Do you have any questions?

Thank participant for sharing their experience and their time in taking part.

APPENDIX 20

Female Categories – Study 2

RESEARCH CATEGORIES - FEMALES

Overview

Each category is first described before presenting definitions of each of the subcategories within the category. Subcategory definitions are followed by a record of comments taken directly from the interviews.

CORE CATEGORY: IDENTIFICATION OF POINTS THROUHGOUT THE INFERTILITY EXPERIENCE AT WHICH FEMALES MAY BENEFIT FROM COUNSELLING

Potential needs of females going through the infertility experience were identified during the interviews. This led to the development of the core category 'identification of points throughout the infertility experience at which females may benefit from counselling'. Interviews confirmed that females do indeed experience issues in relation to the infertility experience. Moreover these issues are present from the pre active stage of the infertility process through to the post active infertility stage. There are also issues experienced in response to critical event during the infertility process that are distressing for the female member of the couple. Identification of these issues suggests the points at which counselling could be beneficial for females going through the infertility experience. These points are in addition to the needs for counselling about the infertility issue itself or related issues which may be beneficial at any point of the infertility experience.

Subcategory of 'identification of points throughout the infertility experience at which females may benefit from counselling': The Pre-Active Infertility Stage

Issues are encountered by females from the pre-active infertility stage yet counselling does not get offered at the GP level. The fact that issues are encountered indicates that therapy would be beneficial to work with these issues from the point at which a female is experiencing difficulty falling pregnant. There is also an indication that counselling could provide a sense of consistency for the female going throughout the infertility experience if it is taken up in the early stages. Even when counselling was not considered at the pre

active infertility stage the value of receiving information about counselling at the GP level was raised.

Comments:-

1-31.16	I remember the doctors rushing me to make a decision about treatment [at point of diagnosis] but at that stage what I really needed was to talk to someone about my position [being infertile]. I wasn't ready to make decisions I wanted to talk about what it all meant to me, as a woman, first. *(Female)*
10-41.27	..... I think there should be more attention paid to that side [emotional] in the early stages. Instead you are propelled into the physical side of everything. *(Male)*
17 – 29.12	I think most women in general would go for counselling if it was offered right from the beginning, you know when you are not falling pregnant *(Female)*
17 – 34.12	I think that if counselling had been offered when I was at the NHS that would have been really helpful, I needed it I think from the beginning *(Female)*
17 – 34.29	If you get introduced to someone at the very beginning of the whole process, that you could see each time you go for a test it would have been so much easier. You see in the early days you wait ages for an appointment and then you have a blood test and are told to wait another 6 months that is so frustrating and upsetting, especially if the test results are normal and I would have liked to talk to someone then *(Female)*
13.14-50.45	I think that counselling before hand [before any investigations or treatment] is important and then if it doesn't work that relationship is already in place and you can go see the counsellor for support, that is really important *(Female)*
21 – 5.23	... it would have been nice to have a leaflet or a number or just something at that stage [at the GP stage, prior to referral] because I had no idea of what lay in the road ahead. Then I could have had it in a drawer for when I needed it further in to the process. I suppose you could call it an introduction *(Female)*

21-21.11 I think, to use a counselling term, that you need 'holding' between the point of being told you are going to need assistance and then starting assistance, because I think that so much can happen in that time. As long as people are made aware that they are not receiving treatment by having counselling. *(Female)*

13 – 19.32 I actually went for counselling before I had my first treatment. I was struggling because I wasn't falling pregnant. *(Female)*

21.22 -46.04 You see it's all so medical that talking to a real person at the beginning would be good and that's why I think a counselling session would have been useful at that point *(Female)*

Subcategory of 'identification of points throughout the infertility experience at which females may benefit from counselling': The Active Infertility Stage

Females talked about the distressing nature of the infertility experience and how it results in feelings of failure, anger, grief, guilt and isolation. As such the value of counselling for these issues as they arise was identified. Critical events were also identified as points at which counselling could be beneficial. These critical events can occur at any point of the infertility process and can be emotionally and/or psychologically distressing for the female. There is an indication that counselling could be beneficial for working with any issues that are experienced in response to these events as they occur and/or in preparation of them occurring. Events include miscarriages, failed treatment cycles and other people falling pregnant.

Comments:-

21 – 17.23 A service that could support people through the emotional side of infertility would be good, you know throughout the experience. It's important not to give false hope but there's definitely a need *(Female)*

17.18 – 12.16 You feel like a number, you see someone different each time and I think it would be helpful to see someone like a counsellor who knew your case and knew you, it feels so impersonal when it's a really big deal to you going through it *(Female)*

17.18-12.23	If you can be helped to see that you are not a failure that would be priceless, you just feel so bad about yourself, it's unbelievable *(Female)*
21-22.00	I didn't think I thought that counselling would be so important in the infertility process but having reflected today on our experience I really do think it's something that is necessary throughout the whole process, especially the treatment stage *(Female)*
4-2.29	It [counselling] also helped me to accept that I was jealous of women who had kids when I didn't, that was important, I felt so isolated and angry *(Female)*
21.22 – 44.50	You know on the NHS at least you see so many different people and you are always kept waiting and then you feel like they've got no time for you so to have ½ an hour with someone who you know has got that ½ an hour for you would be so important. *(Female)*
4-2.25	It [counselling] helped come to terms with my miscarriage, which doctors don't acknowledge, they call it a loss of pregnancy, but to me it was my baby and I was grieving *(Female)*
9-24.44	I found it very painful when someone else got pregnant at work, I couldn't really tell anyone how I felt, I felt so guilty and such a failure you know. I could of done with some help around that at the time *(Female)*
9-40.00	The dates that think you will conceive as a result of the treatment and don't become significant for ever, they are always going to be difficult for me. *(Female)*
3.4-31.09	I needed counselling to deal with my miscarriage before I could even consider another attempt. *(Female)*
5-43.23	I have struggled when others have announced pregnancies, I'm happy for them, but it just raises so much stuff in me I can't handle, you feel so alone with it all. *(Female)*
13 – 1.38	When I started bleeding [10 days after embryo transfer] I phoned the hospital and they just said 'Oh well it didn't work', they didn't ask me if I was ok or whether I wanted to talk to anyone, nothing. I really needed to talk about what had happened. *(Female)*

13.14 - 32.50	My advice to anyone going through this [infertility] is to get as much help as there is out there for them, you know counselling or whatever because it's a really hard time and the 4 weeks of treatment in particular is tough. *(Female)*
13 – 3.28	The two week wait between putting the embryo back and finding out if you are pregnant is quite simply the worst part of the whole process; you are just all over the place. *(Female)*
13.14- 33.20	You are just not yourself [during treatment] and if you can speak to someone while you're going through it who can understand what you are going through then I think it would really help, perhaps someone who has gone through it themselves even *(Female)*
21.22 – 40.41	For 'x' the worst bit as he said was the news breaking [about the sperm test] and then he dealt with that, but for me it got worse as we got deeper into the process, that's when I started to feel a bit lost. *(Female)*

Subcategory of 'Identification of points throughout the infertility experience at which females may benefit from counselling': The Post Active Infertility stage

The end of treatment, signaling the transition to the Post-Active Infertility Stage is a point when issues can arise for both those females whose treatment has been successful and for those for whom it has not been successful. Issues can also arise some time after treatment e.g. after the birth or adoption of a child. Counselling could be beneficial at this point to work with a host issues that may arise in response to the end of treatment.

Comments:-

9-42.01	At the end of all the treatment I think I probably would have benefited from talking to someone because I didn't know what came next for me, I mean it was obvious that I was never going to have my own baby *(Female)*
7-39.34	I think at times that I can deal with this on my own [stopping treatment and accepting a future without children] but at other times I feel that something has to help me through the pain before I can move

on. *(Female)*

15 – 16.32 For me it was about a year after we adopted the boys that I really felt that I needed the support. Things were quite delayed in my case. So I had counselling and then I was able to work through how awful our situation had been and accept that crap things happen *(Female)*

CATEGORY: HOW COUNSELLING HELPED OR IS PERCEIVED TO HELP

Females that had experienced counselling made only positive statements expressed about it. There were also positive perceptions held by females about how they believed counselling could help. The ways in which counselling worked or was perceived to work included facilitating the process of moving on, decision making and providing neutral support outside the female's circle of close friends and family.

Subcategory of 'How Counselling Helped or is perceived to help':- Resolution and moving on

Counselling was reported as having helped females to move on from where they were at the point at which counselling was received.

Comments:-

9-7.41 I went to see the counsellor and she was very good, but less of a counsellor and more of a ''this is what you should do..bang, bang bang bang (hitting hand on table)'' and perhaps that's what I needed *(Female)*

9-9.49 I took up the offer of counselling, but it was less counselling, more you know ''what are we gonna do!'' which was what I needed but I... it possibly helped me to move from where I was which was *(Female)*

4-2.22 Counselling made me sane again so then I could move on *(Female)*

4-7.52 I had counselling and this resolved a lot for me, it's hard to recall just how bad it was actually. You feel so stuck when you are in it *(Female)*

Subcategory of 'How counselling helped or is perceived to help':- An opportunity to talk to someone outside your situation

Females expressed reluctance to talk to friends and family about how they were/are feeling. This was primarily because the 'advice' offered is not always what they felt they needed. Counselling can provide an opportunity for the female going through the infertility experience to talk to someone outside her immediate circle about how she is feeling. The benefits of this are that females can talk freely and they can perhaps more importantly, be heard.

Comments:-

13 - 20.30	I found counselling really helpful, I only had about 4 or 5 sessions but it meant that I wasn't talking to my mum and my sisters about it all the time and they weren't telling me the same stuff all the time, I suppose it was an outlet for me *(Female)*
5.6-25.35	I have definitely considered therapy to talk about how I am feeling. *(Female)*
17 – 11.21	You stop wanting to talk to friends about it because they say some really hurtful patronising things even though they don't intend it that way *(Female)*
17.18–40.36	You kind of do your own counselling you know if you've got a husband you can really sit down and talk to and your friends and family, but to have an outside opinion would be really useful *(Female)*
15.16 – 77.12	I think counselling is important because people are less likely to talk to friends and family about their infertility because in the media there are so many horror stories out there, everyone has an opinion *(Female)*
21.22 – 31.01	I'm very open with my friends but I found was that my friends didn't understand male infertility and they just kept telling me 'oh you'll be fine' and in effect didn't engage with me and the situation. I found that really hurtful. I just wanted to be heard not be jollied along, I suppose that counselling could provide that opportunity *(Female)*
4-23.45	You can't go through something so harrowing without being heard, it is just too much, you need to keep your head and to do that you need to be heard. For me, that's where counselling comes in. *(Female)*

Subcategory of 'How counselling helped or is perceived to help':-

Decision making

There are certain points at which decisions need to be made throughout the infertility experience. Counselling was found to play a role in facilitating the decision making process for one female.

Comments:-

4 – 11.06 Counselling helped me to make the decision about whether to continue with treatment which before I had it I wasn't sure how I felt about going on. Whilst this was a decision for both of us, it was vital for me to first find out whether I wanted to go through with it *(Female)*

CATEGORY: THE ROLE OF SUPPORT GROUPS

Females talked about how helpful they had found talking to others who had gone also gone through the infertility experience in terms of reducing feelings of isolation. This suggests that group therapy and/or mutual support groups could be beneficial for some females going through the infertility experience. Concern was raised by a female who had accessed an Internet based support group. She feared that she could become too involved in the group/infertility issue and it could take over her life.

Comments:-

3.4-14.40 It's always quite useful to hear other people's stories, you feel less alone *[female speaking in couple interview].*

7-42.10 It's good to speak to others who have gone through the same experience. *(Female)*

5-46.12 It is quite nice when you realise that others have gone through it too. I suppose that's been useful *(Female)*

9-22.22 It can be very useful talking to others who have gone through it, it can be a good support because you feel so isolated a lot of the time *(Female)*

16 – 17.45 It's really weird infertility because women seem to really benefit from the whole support group thing, you know going out for drinks or chatting *(Male)*

15.16 – 7.11 We met a lot of people going through what we were going through and I

thought they were a bit mad and extreme I just didn't think I would become like that a few moths down the line, but when I did they were very helpful to me *(Female)*

17 – 35.02 I did start using the support groups on the web and I but my concern with all that was that I could see myself becoming quite addicted to it all you know and I really don't want it [infertility] to take over my life to that extent. It does already without reading and reliving what everyone else is going through on a daily basis you know I could imagine getting obsessed with it *(Female)*

APPENDIX 21

Male Categories – Study 2

RESEARCH CATEGORIES - MALES

Overview

Each category is first described before presenting definitions of each of the subcategories within the category. Subcategory definitions are followed by a record of comments taken directly from the interviews.

CORE CATEGORY: DESIRE TO UNDERSTAND

Males expressed a desire to understand more throughout the infertility experience in one way or another during the interviews. The type of understanding that they desired related to wanting to know more about what the female goes through during the infertility process. Males said that they would like females to have more of an understanding about how they [males] might be feeling throughout the infertility experience. They also expressed a desire for information in order to understand what might be involved in the treatment of infertility practically, psychologically and emotionally. This was of particular importance in cases of male infertility. This understanding would be gained from having access to information about diagnosis and the treatment process. Males reported that the most popular medium by which to convey this information would be via a DVD.

Subcategory of 'Desire for understanding':- About what the female experience

Males expressed a need to have more information about what the female experiences during the infertility process both emotionally and physically. The primary reasons that males gave for wanting more information is so that they would be in a better position to support their partner. There was a sense that males feel as if they do not know what to do 'for the best' to help their partner which can leave them feeling helpless. Having a greater understanding was thought to help place them in a better position to change this.

Comments:-

14 – 21.00 As a man I say you've got to be supportive which is not always easy cos you don't always know how *(Male)*

18-12.02 It's really important to be able to understand what she's going through

because you feel like you get it wrong a lot of the time and I'd like to know a bit more about it *(Male)*

17.18 – 32.13 It might seem minor but it would be really helpful to know a bit about what the woman might feel ....and how you can cooperate with each other you know *(Male)*

14 – 22.45 I think men need help to know what to do for the best and when, you just don't really know what it's like for them [females] *(Male)*

18 – 18.21 A man doesn't really understand the emotional side of things you see he tends to be more logical and they, we would benefit from understanding what a woman is feeling. You don't always know about the physical side of things either *(Male)*

2-32.31 ...it is difficult to know as a man what is going on or what to do for the best at times. *(Male)*

5 – 32.10 It's sometimes hard to know what to do or say for the best, especially if she's not telling you how she's feeling. I would sometimes like to have an idea of what might help*(Male)*

Subcategory of 'Desire to understand':- Desire for the female to understand what the male might be feeling and experiencing

Males expressed a desire for the female to be given information about what they might be feeling and how they tend to traditionally deal with their feelings. Males seem to be aware that they are perceived as not caring at times, which they stressed is not the case. They recognised that this was not helpful for their female partner yet did not feel that it was easy/possible to express as the experience was perceived as easier for the male (by males) compared to their female partner.

Comments:-

18 – 18.30 I think women would benefit from understanding what a man might be feeling, it would help her to know that I do care, I just don't find it that easy to tell her myself, I feel like I just back off *(Male)*

17.18 – 28.12 I think it would be useful for 'x' to know what I am feeling because I don't think you do, do you? It looks like I don't care but I really do, it's

in the back of my mind but I just don't talk about it all the time. *(Male)*

2-65.01 I think it would have helped 'x' to know that I was feeling stuff about our situation but that I didn't express it because I was trying to protect her. I think I often came across as not caring, but that wasn't the case it's just that it seems so difficult for women that you almost don't feel like you've got the right to put any extra pressure on her *(Male)*

Subcategory of 'Desire to understand':- About infertility and its treatment

It seems that males are not made aware of what to expect in terms of diagnosis or treatment for infertility. Males expressed a need for information about the process of infertility and their options in order to understand their position. They wanted information about what they can expect and what would be required of them during the process. This was particularly important for males who had been diagnosed as the infertile member of the couple. It was found that this information would be beneficial throughout the experience e.g. from the point they see their GP through to the end of treatment.

Comments:-

21.22 – 14.45 I don't want my GP to be a quasi counsellor but information would have been useful, you know I wasn't aware of what my options were or whether I could do anything to improve my result *(Male)*

21.22 – 44.34 I wonder if it was called an advice centre where you would see an expert who could tell you about the process and what to expect, then that would definitely have been something that you would do I think *(Male)*

18-14.32 It's really difficult for a man, you go in and no-one explains anything you are handed a pot and told to wank off in it and then you don't feel needed anymore. It might sound stupid but it would have been better if I was aware of all that before I went there. I want to know that other people have to do it too you know some information about the process would have been good *(Male)*

13.14 – 41.22 I would tell the NHS or anyone that they need to provide information about the treatment and actual infertility and support to anyone going

through infertility and not from someone in a white coat but from someone like you [pointing to me] who can talk to us like real people and use real language *(Male)*

21.22–44.39 I would have definitely liked an information session *(Male)*

21.22 – 23.11 We would have welcomed any information that we could have got, I remember looking for a book and finding nothing for me *(Male)*

21.22 – 24.56 Information about the practical, statistical and psychological aspects would have been invaluable. You know when you are pregnant you devour books and information, infertility is no different *(Male)*

22 – 14.21 The major thing that was missing for me was no leaflet, no guidance about what to expect which defined the experience *(Male)*

21.22 -48.28 To me it's not a semantic difference whether you call it counselling or advice, to me it's actually qualitatively different, I would want advice *(Male)*

21.22 – 37.23 Having talked about this today my overriding memory is the lack of information which contributed to my experience, negatively *(Male)*

21.22 – 8.27 For me I would have liked more practical information, you feel as if you are on a conveyer belt, you really don't know what the next step is. For example if your first sperm test fails then to know what happens then would have been good and so on. You often feel suspended. Having that information would help you prepare emotionally *(Male)*

Subcategory of 'Desire to understand':- The preferred format in which to receive information to aid understanding

Males expressed the need for information to aid understanding. On being asked how they would like to receive this information the most popular answer was via a DVD. The internet, books and leaflets were acknowledged as a source of information. Males said that they would not have read a book. There is an indication that a DVD could also serve the role of normalising the infertility experience. In addition to information giving and normalising, A DVD could explain and promote the benefits of counselling.

Comments:-

17.18 – 43.40 A DVD telling men that it's quite normal and that they might benefit from talking to someone about it in confidence would be good. I

	suppose to explain what counselling is and how it can help *(Male)*
17.18 – 28.19	To put that [what each member of the couple is going through respectively] across in some way you know in a DVD would be great *(Male)*
13.14 – 42.03	I think information about the process is essential, a DVD would really be something that I would have welcomed, I don't think I would have bothered to read a book *(Male)*
18-11.43	I believe that the most useful thing would have been a DVD that explains both the medical and the emotional and psychologically. Because a man doesn't really know what to do for the best. I don't think I'd be bothered to read a book if I'm honest *(Male)*
18 – 19.17	I can tell you now a bloke won't read a book, I've been on the internet but I would definitely watch a DVD, it would be helpful to have some information *(Male)*
18 – 12.24	In a way I would like a DVD to provide a type of counselling over the TV, I know it's not the same but you know it's less in your face and you do it in your own time *(Male)*
3 -14.21	I did want information but I wasn't really up for talking to anyone about it all and I didn't have the time or inclination to read a book, so I suppose a DVD would have been the best. I might have read a leaflet but you get so many of those I'm not sure *(Male)*
16-20.12	I definitely think that I would have watched a DVD if there had been one but there wasn't, I found out everything I needed on the internet. I can tell you now that there was a lack of information in any format *(Male)*
21.22 – 25.06	You know when you are pregnant you devour books and information, infertility is no different *(Female)*

CATEGORY: PERCEPTIONS AND EXPERIENCES OF COUNSELLING

Males expressed both openness and a reluctance to counselling and support groups. Openness and reluctance were expressed both within and across males in the sample.

Openness was expressed towards counselling, especially if the male was sure that it would be confidential. Males said that they would have definitely considered counselling, if it had been factored in to the treatment process. This highlights that despite the apparent openness it seems that males would be more likely to go for counselling if it was 'obligatory' rather than actively requesting it. Males expressed reluctance towards counselling for infertility. They said that whilst they would not have been 'offended' if counselling had been offered [which in each of the cases it had not] it would not necessarily have been taken up by the majority of the males in this sample. Males also expressed a reluctance to talk in general about how they are feeling about the infertility experience e.g. with others. The following two subcategories were developed:-

Subcategory of 'Perceptions and experiences of counselling': Openness towards counselling and support groups

Males expressed openness to counselling, especially if they were sure it would be confidential. They said that counselling would have definitely been considered if it had been factored in to the treatment process. This highlights that despite the apparent openness it seems that males would be more likely to go for counselling if it was 'obligatory' rather than actively requesting it.

Comments:-

1.2 – 62.09	I would have gone for individual therapy if I knew it was confidential *(Male)*
17.18 – 47.12	If think that if counselling was obligatory I would definitely go *(Male)*
3.4-22.14	I would have probably used counselling if it had been sold to me as 'part of the package', you know as part of the treatment, but it wasn't*(Male)*
15.16– 8.23	For me it was more that you feel more of a bond with people that you are going down the same road at the same time as, you are all in a very difficult situation and there's a camaraderie you know ''what's wrong with you or whatever'' *(Male)*
16 – 11.02	I think that the fact that there were only 6 people at the group made it easier for me to talk about our issue or rather my issue *(Male)*
16 - 12.27	When you get there you know why you are all there, it's a bit like being

an alcoholic once you have said those words in the open then you relax about it, you feel a lot less like you've been singled out because you can hear from others in the same boat *(Male)*

12-13.47 I don't remember being offered counselling, so I don't know whether I'd have benefited but I would have probably gone for a session to see *(Male)*

16 – 17.02 I think counselling plays an important role in today's society where you don't have a close knit family living close by, you know you can't just talk to anyone about this stuff, or at least you don't want to anyway *(Male)*

17.18 – 38.08 I suppose I see counselling as keeping you up there and to help keep you going, so I would consider it, yeah *(Male)*

Subcategory of 'Perceptions and experiences of counselling': Reluctance towards counselling and support groups

Males expressed reluctance in relation to going to counselling for infertility. Whilst males suggested that they would not be offended if counselling had been offered [which in each of the cases it had not] it would not necessarily have been taken up by most of them. Significantly males also expressed a reluctance to talk in general about how they are feeling about the infertility experience e.g. with others. A male revealed that this was in part a function of the fact that he did not want to discuss his feelings about treatment and his reluctance in relation to it as he had decided to 'go along' with what his partner wanted. In particular 'male pride' was highlighted as a factor contributing to not wanting to talk about male infertility. Interviews revealed that males, in general, seem to be able to accept and come to terms with their position [infertility], even when they are the infertile member of the couple. Hence they claim not to be too adversely affected emotionally and psychologically by the infertility experience [at least in relation to the females going through the infertility experience].

Comments:-

22 – 3.19 I wouldn't have been offended if they had offered me a leaflet or a number but I'm not affected by the fact that they didn't. I might have thought it was a nice touch but I wouldn't have used it *(Male)*

21.22– 4.37	I wasn't asked about how I was feeling by the GP or even given a number just in case I wanted to speak to someone [about male infertility], but to be honest with you I wouldn't have used it anyway *(Male)*
21.22 – 44.31	I personally would not particularly have wanted to sit down with a counsellor at that stage [before treatment] *(Male)*
21.22 – 44.45	I would have shied away from someone asking me about how we were being affected by it all or how we were coping, I'd have said "no thanks mate" *(Male)*
16 – 17.12	For me the support group and a counselling session was enough for me, as a person I don't feel the need to keep going over something that isn't going to change. It was really helpful but I didn't feel the need to continue with it *(Male)*
14 – 18.39	For me I never thought about counselling, it just didn't occur to me and if it had I probably wouldn't have gone *(Male)*
3-17. 51	For me I'd already decided to go along with treatment even though I didn't particularly want to so I don't think it would have been helpful to discuss this issue with someone as it could have caused problems *(Male)*
3-6.35	I don't think you can really be helped [by counselling] because you either have a baby or not, it's black & white. *(Male)*
3- 18.12	For me counselling was not something I would have considered, I didn't want to talk about how I was feeling because it wasn't that bad for me *(Male)*
15.16-8.41	The problem with all of that [support from others going through the same experience within a support group setting] is that when they get pregnant they drop you from their lives as if you don't matter any more and that really put me off *(Male)*
16 – 17.45	It's really weird infertility because women seem to really benefit from the whole support group thing, you know going out for drinks or chatting for me men are completely different, we don't want to go out with each other and talk about we are feeling. We are very different to women and so are our needs I suppose *(Male)*

15.16-9.29	I find meeting people quite difficult so going to someone's house to open your heart up to people about what you are going through is difficult to say the least [in reference to support group] *(Male)*
17.18 – 49.02	If [infertile] men could get over their male pride and you could get to see some of those people I am convinced that they would accept what had happened much easier, but I suppose the problem is getting to see them in the first place *(Male)*
17.18 – 43.33	Thinking about it something that I think men need is if a man find's out he can't produce the goods and it's all down to him then that must really affect blokes and I'd say that they'd bottle it up inside them .....I mean it's a very male pride thing you don't think 'oh my bollocks aren't working so I'll go down the pub and talk to me mates about it' that just ain't gonna happen. *(Male)*
2 – 10.04	....guys don't really talk about it [infertility], we're not like women who need to talk about it because it's so much more difficult for them *(Male)*

CATEGORY: IDENTIFICATION OF POINTS THROUHGOUT THE INFERTILITY EXPERIENCE AT WHICH MALES MAY BENEFIT FROM COUNSELLING

Potential needs of males going through the infertility experience were identified during the interviews. This led to the development of the above category. Interviews confirmed that males do indeed experience issues in relation to the infertility experience. Moreover these issues are present from the early stages of the infertility process through to post treatment. Two points have been identified as potential counselling needs of males, both of which are during the active infertility stage. These points are in addition to the needs for counselling about the infertility issue itself or related issues relating which may be beneficial at any point of the infertility experience.

Subcategory of 'identification of points throughout the infertility experience at which males may benefit from counselling': At point of diagnosis

Males talked about how the diagnosis of male infertility is experienced as a shocking one. They talked about how it had the effect of them questioning their identity and how the news 'changed' their identity. Information regarding male infertility was in the case of one male, delivered in such a way that it did not take account of the potential shock which this news can evoke. This indicates that the offer of a counselling session following diagnosis could be beneficial to some males. The point of diagnosis in cases of female infertility or unexplained infertility did not emerge as a point at which counselling may be of benefit to males, in these interviews.

Comments:-

21.22 – 9.33 When I got my second [sperm] test results, that was a total shock to me and that was the worst part of the whole process for me. She [the GP] basically told me "well that means that you probably won't be able to have children now" and we were then referred instantly for treatment. I had not prepared at all for that mentally which perhaps was my fault by that was tough. It made me reevaluate what it was to be a man *(Male)*

16-14.02 For me I needed to work out what it all meant, you know a man with no sperm, that was a shock to me and I needed to work out how it changed me as a man, which news like that does. *(Male)*

21.22 – 16.50 I did feel low about the situation and myself at that time, the hardest thing for me emotionally was thinking I was a jaffa and that I wouldn't have my own children, that was really tough *(Male)*

16 – 14.21 I felt awful when I received my diagnosis that I was infertile I just felt so guilty for 'x' [partner] that was on top of my own feelings of being a real man and not having my own children and all that, everything changed for me at that point, I changed in terms of my identity. *(Male)*

21.22 – 40.41 For 'x' the worst bit as he said was the news breaking [about the sperm test] *(Male)*

21.22 – 14.45 I don't want my GP to be a quasi counsellor but information would have been useful, the GP couldn't even explain the results on the sperm test and I was left feeling really awful *(Male)*

21.22 – 15.01 ...the GP couldn't even explain the results on the sperm test and I was left feeling really awful *(Male)*

Subcategory of 'identification of points throughout the infertility experience at which males may benefit from counselling': At the end of a treatment cycle

Males can feel marginalised throughout the infertility experience. The treatment process can be a difficult time for males as well as for females. It also ends hopes of becoming a father, at least for a period of time. This indicates that a counselling session at the end of a treatment cycle could be beneficial to provide males with an opportunity to talk through how they are feeling. Hence reducing the sense of feeling marginalised.

Comments:-

12-19.34 When you end treatment, all they do is say when do you want to make your next appointment for treatment. I wanted to talk to someone about how I felt, you know what it meant to me that I wasn't going to be a Dad, at least not at that stage *(Male)*

8-39.12 You see for me I feel that I've accepted that we won't ever have

children but I did feel disappointed at the end of all our treatment but you are just left to your own devices and I didn't really have anyone to talk to about how I felt, you know what it means to me that I won't be a father. *(Male)*

10 – 43.12 I remember feeling a bit processed, you see your wife is being rushed to make a decision about the next treatment cycle, but no one addressed me and actually I would have liked to talk to someone about how I was feeling about the last cycle failing, before we moved on to another one. *(Male)*

APPENDIX 22

Couple Categories – Study 2

RESEARCH CATEGORIES – COUPLES

Overview

Each category is first described before presenting definitions of each of the subcategories within the category. Subcategory definitions are followed by a record of comments taken directly from the interviews.

CORE CATEGORY: IDENTIFICATION OF POINTS AT WHICH COUPLES MAY BENEFIT FROM COUNSELLING

Potential counselling needs of couples were identified during the interviews, leading to the development of the above category. Interviews in Study 1 established that those going through the infertility experience do encounter issues as a function of it. Moreover these issues are present from the early stages of the infertility process through to post treatment. There are also issues experienced in response to critical events during the infertility process that are distressing for the individuals/couple. The points identified are in addition to feelings which may arise in relation to infertility and/or related issues, for which counselling may be beneficial, at any time throughout the infertility experience.

Subcategory of 'identification of points throughout the infertility experience at which couples may benefit from counselling': Pre-Active Infertility Stage.

Interviews revealed that couples were referred for medical treatment without being provided with the opportunity to explore how they feel about infertility or whether they actually wanted children enough to have treatment. Thus a potential need identified for couples experiencing difficulties was the opportunity for them to address and explore the issue of whether they actually wanted to proceed with treatment and what taking this route means to them. Another potential need identified was an opportunity for a couple to explore how they feel about their diagnosis and a potential future without children at the Pre-Active Infertility Stage, so that they can begin to process the feelings.

Comments:-

21.22 – 40.57 I think the NHS could save a lot of money if they gave you a counselling session at point of referral to establish whether couples'

	actually want assistance or even children actually. No-one even asked us *(Male)*
21.22 – 20.37	I have to say that we were both very shocked and dislocated about the whole situation actually when we got the diagnosis, we didn't really know what to do with it *(Male)*
9.10 – 28.00	..even though we kind of knew we still both felt very hurt and confused and I suppose angry when we realised that we were faced with the possibility that we might not have children together *(Female)*
21.22 – 42.55	I think a counselling session at the beginning or at the top of all this treatment should be offered to couples. I believe this is absolutely essential and it should be offered by a counsellor who perhaps has a line of communication with the IVF clinic or the GP *(Female)*
21.22 -45.47	I hate to talk about money but in the real world it is about money and I agree with 'x' in that the NHS could save a lot of money if they gave you a session early on with information because you might not be so keen to pursue the treatment route *(Male)*
21 – 21.17	As long as people are made aware that they are not receiving actual treatment by having counselling, I think that the NHS would save a lot of money if they could just get couple's to stop and think before they go headlong into the treatment system*(Male)*
9 – 53.34	I mean we found ourselves on the treatment treadmill but we had not actually discussed whether we even wanted to be on it, why didn't someone ask us to stop and think about? I mean even though we had been trying for a baby we had never actually sat down and talked about what having a child would really mean to us and our lives and whether we really wanted that *(Female)*
13.14 – 37.45	We both think that people should be told about the difficulties or some of the issues they might encounter before you have any treatment don't we? *(Female),* yeah definitely, preparation would have been very useful *(Male)*
21.22-41.02	It seems that there is an assumption that if you go to the GP then you want treatment *(Female)*
21.22 – 40.53	A big question was whether we even wanted treatment , we went along

to the unit because we were referred, we didn't actually discuss it *(Male)*

13.14 – 38.20 I think counselling could help to prepare people for treatment and the impact. So many people break up and that's not surprising *(Male)*

17.18– 18.10 We actually got referred without being asked about what we wanted to do next, I suppose we wanted to be referred but we never discussed it *(Female)*

Subcategory of 'identification of points throughout the infertility experience at which couples may benefit from counselling': At each stage of infertility as issues and feelings arise

It was revealed that counselling could be beneficial at any stage of the infertility experience as issues and feelings arise. A couple that had experienced couple counselling found it be very helpful. For example, with decision making, they found they were able to view their situation from a different viewpoint and they also gained an insight into how infertility influenced the dynamics of their relationship. Couples who did not have counselling perceived it as a way to be able to learn how to provide support for each other during the whole process and also to be supported.

Comments:-

16 – 17.21 For me the biggest thing about the counselling was helping us to make our decision whether to tell our child about the donation that was a big thing for me to explore and work out. *(Female)*

15.16-24.57 By having counselling we were able to work out how we felt about our situation and it also helped us decide to tell our child if we had one about the donation, which we hadn't intended to, that was quite major *(Male)*

12-14.10 I regret that we were never offered counselling more explicitly because we'd have definitely considered it; I know that I would have anyway.... I think it would have helped us to support each other better *(Male)*

15.16-31.13 We got enlightenment [from counselling], me in particular [female], I realised that I was protecting 'x' and that this was actually pressure on me. Once I was aware of this I could change it, it revealed how we were

dealing with the infertility as a couple *(Female)*

15.16 – 58.36 I personally think of infertility as something that you need to have straight in your head before you go talking about it. However in our case I thought we had it sorted but everything changed when we went to counselling because they are professional and they come up with ways of thinking about your issue that you would never have thought about in a million years *(Female)*

17.18-39.13 I think we would consider going for counselling if our stuff continues because you are going to need some kind of support to get through it *(Male)*

5.6-24.01 .... we have needed to talk to someone about what we are going through, haven't we? (F*emale to male)* Yeah I think so *(male)*

13.14 – 38.30 It all becomes about the IVF and you can forget about being a normal couple and it would be good to be reminded why you were there in the first place, you know that you are a loving couple, you completely forget this and I think counselling would help this. *(Female)*

Subcategory of 'identification of points throughout the infertility experience at which couples may benefit from counselling': When treatment fails

The importance attached to the event of a failed cycle of IVF was acknowledged as a point at which counselling could play an important role in helping the couple as a unit.

Comments:-

13.14 – 51.25 One thing I want to say is that I would like to doctors to always recommend counselling to couples if treatment fails, to me this is essential. *(Male)*

17.18 – 55.23 I know that if our treatment fails we will have to have some counselling to get through that *(Male)*

17.18 37.12 I think a counsellor would be really good if it didn't work and that's where I really see it playing a role *(Male)*

17.18 – 37.19 You see on the build up to treatment you are all excited but if it [treatment] doesn't work you must be devastated so to have a counsellor there to say " it hasn't worked this time but you can try again" you know to try and keep you positive or to help you decide when you will

be ready to try again or whatever it is you need. I see it a bit like a sports psychologist who keeps you up there (pointing upwards) *(Male)*

18 – 20.01 I'm very aware of the needs we'll have if it doesn't work and how counselling could help *(Male)*

Subcategory of 'identification of points throughout the infertility experience at which couples may benefit from counselling': Post -Active Infertility stage

The end of all treatment was identified as a potential point at which couples could benefit from counselling. This was raised by couples who had not had a successful outcome following treatment, by couples who had not reached that stage at time of interviewing, and by a couple who had had a child as a result of treatment. This demonstrates that regardless of outcome the process is very stressful and issues can potentially arise following treatment, for which counselling may be beneficial, in cases when treatment has been successful as well as when it has been unsuccessful.

Comments:-

1.2-62.34 I *(Male)* would have jumped at the chance of counselling after the birth. Yeah I would have too *(Female)*

9.10-33.15 I feel that counselling would have been beneficial at the end of all the treatment, you feel so low and exhausted. In fact as a couple you are battered and bruised too *(Female)*

17.18 – 37.53 You know there must come a point for loads of couples when it's not going to happen and they have to stop and to have that counselling to get you into the mind where you can accept this is important I think and I would say that that is not a woman's thing but a couple's thing *(Male)*

14 – 22.47 If we had not had children together God knows what would have happened, we'd have had to do something to help us deal with that *(Male)*

22 – 12.11 Surely there's counselling for those people that go through years of treatment and are then still not successful, I assume there is. For me that is essential I am just so glad that we didn't have to go through all that *(Male)*

CATEGORY: RELCUCTANCE TO HAVE COUPLE COUNSELLING

Males explicitly expressed reluctance in relation to the prospect of couple counselling. They believed that it would have brought their 'problems' to the surface and highlighted the division between them and their partner. Counselling was perceived to be a 'hand holding' exercise. Conversely, none of the females expressed reluctance towards couple counselling.

Comments:-

21.22–48.37	I would not particularly want someone to sit there for ½ an hour and squeeze our hand *(Male)*
1.2 – 62.01	It [couple therapy] would have highlighted the division between us, so I would have been quite reluctant to go for it *(Male)*
7 – 43.12	I don't really see the point in having therapy as a couple as it could just have made our problems come to the surface, so I wouldn't have been keen to have it*(Male)*
1.2 – 61.42	I would have been against counselling because my feelings would have come out and she'd have known I didn't want to go through it [IVF]. *(Male)*

CATEGORY: COUNSELLING TO FACILITATE COMMUNICATION AND UNDERSTANDING

The couple with experience of couple counselling reported that they found it facilitated both communication and understanding. In addition other couples reflected that following the joint research interview communication and understanding had been better between them. It seems that listening to each other talk about the infertility experience helped them to understand each other better. This understanding seems linked to the communication that occurs in the presence of a third party acting as a neutral facilitator e.g. the format of the joint interview. The discussion also encouraged further communication between the couple following the interview. Couples also reflected on the importance of communication whilst going through the infertility process. This recognition when linked with the finding that communication breakdown is a common

feature of the infertility experience strongly suggests that couple therapy would be beneficial to many couples in order to avoid further breakdown in communication and understanding.

Comments:-

15.16– 60.12	For me the best thing you need to do going through this is talk to each other, because that is the first thing that goes *(Male)*
15.16 – 60.23	Although we are very good at communicating we did find ourselves avoiding certain topics or issues, you know the tricky ones. Counselling really helped us to talk about these issues and this meant that we could understand each other better, couldn't we? *(Female)* Yeah definitely, *(Male)*
5.6-25.20	We're ok at the moment but if things get rocky again I think we'll consider counselling *(Female)*
1-1.03	Following the joint interview we both said that was a relief to talk to about everything, and we carried on talking afterwards so it felt really useful. *(Female)*
2-1.52	It was helpful for us to both talk to you because I could understand a bit more about what was going in for her. I quite enjoyed it, it was nice. *(Male)*
1-3.36	Even after that 1 session where we talked openly to you, I feel that he's much more understanding *(Female)*
5-0.23	It was useful to talk to you together, we never get the opportunity to talk in that forum, it helped me and I definitely think it helped her. It also paved the way for us to continue the discussion after we saw you *(Female)*
2-3.56	It was helpful for me to understand the process that she went through. Men take a lot for granted in these situations, they're on the sidelines if you like, so by talking in this way I got an insight. *(Male)*
6-0.30	I quite liked the forum where I could hear 'x' talk, it really helped me to understand what she's really going through. *(Male)*

CATEGORY: – PERCEPTIONS AND EXPERIENCES OF COUNSELLING

Both negative and positive perceptions and experiences of counselling were identified both in general and specifically in relation to the infertility experience. Both positive and negative perceptions were held among the individuals interviewed.

Subcategory of 'Perceptions and experiences of Counselling': Positive perceptions and experiences

Positive perceptions of counselling tend to focus on the way that counselling is thought to work. The most common positive perception is that the process of counselling can help someone to see their situation from other view points. Another perception held is that counselling can provide emotional and relationship support during the infertility experience. The experience of counselling for either infertility and/or other unrelated issues resulted in a change of perception from a negative view of counselling to a positive one, particularly for males.

Comments:-

13 – 25.20	I think of counselling as talking to someone outside your situation listening to you tell them about your situation and having an erm an open mind on what's going on for you and trying to help you understand maybe or help you see what's going on in your life a little different to how you are looking at it. You're looking at it this way and they might see it from another way but you are so in it you are not looking at other opportunities, that's how I see counselling. *(Female)*
13-27.30	Counselling can help you see another way around things and help you see that it [infertility] is not the worst thing in the world. *(Female)*
14.13-31.20	You automatically assume that they [counsellors] are part of the Health Authority but they're not they are independent people who just want to help you talk about your problems and perhaps give you some tips about how to cope better. At least that's my experience *(Maale)*
14- 21.29	The way I see it is that the doctor's see it like clinical but counselling gives that bit more of emotional support, that you might not think you need but you do *(Male)*

21.22 – 49.06	For me counselling has had a lot of bad press and I know that counselling is not about someone sitting there with their head to one side saying 'mm' it's so much more than that *(Female)* well I suppose then that would be helpful to many people *(Male)*
14 – 18.21	Now that I've had counselling I see that it helps you to come to terms with things and help you get on your life, you know move on *(Male)*
14 – 20.12	I was very skeptical before I had counselling but now I see it as a good thing *(Male)*
16 – 11.09	I hated going along to the [male infertility support] group, it ended up being fine but I hated it, in fact I quite enjoyed them in the end, it was the same with the counselling *(Male)*

Sub category of 'Perceptions of counselling': Negative perceptions and experiences

A common negative perception that emerged was that counselling is for 'mad people' and hence if one goes to counselling then they too are 'mad'. Linked to this perception is both suspicion and fear of counselling. This suspicion and fear is a function of the power that the counsellor is perceived to have. There was also a perception that counselling can't help because it can't solve the issue e.g. provide a baby. There was also a belief that counselling could have a negative impact on the couple relationship because it would 'highlight' the division that existed between the couple.

Comments:-

13 - 24.10	You really don't want to go for help because you don't want them to think 'Oh yeah, she really isn't right in here' [gesturing to head] and they refer her here and the next thing you know you are in a psychiatric unit *(Female)*
13.14 – 30.36	There is a sense that to go and see a counsellor it's something to do with madness *(Male)*
13- 23.13	If you've never been to counselling you are going to think counselling is for mad people*(Female)*
13 – 21.20	I must say that when I used to phone my sister after my counselling sessions I sued to say "I've just left the lady who is trying to work out if I'm mad or not" *(Female)*

13.14 – 30.47	Yeah, you've got to be careful what you do and what you say, what words you use just in case they think *(Male)* yeah in case you trigger something and they think 'yeah, she needs this kind of help, this kind of straight jacket' I know it's not like that but that is the perception. *(Female)*
14 – 16.45	Before I had counselling [for another, unrelated issue] for me counselling was from a psychiatric point of view, well I was thinking that someone was evaluating you and seeing if you're mad or something, I used to think it was them prying into your life and intruding. *(Male)*
1.2 – 61.53	I would have been against counselling because my feelings would have come out and she'd have known I didn't want to go through it [IVF]. I would have been against counselling because my feelings would have come out and she'd have known I didn't want to go through it [IVF]. *(Male)*
15.16-50.02	If we were numb nuts and not clued up I think we'd have probably thought a counsellor is someone who could make you do things that you didn't want to do or give you advice and that you'd..erm come up with ..erm the wrong thing to do because of it. *(Male)*
15.16-57.32	You kind of can't help thinking of counsellors in the same way as other medical professionals or social workers and you don't necessarily expect them to have good interpersonal skills, which of course they do *(Female)*

CATEGORY: INFERTILITY AS AN ISSUE FOR COUNSELLING?

The issue of whether infertility is an issue that is relevant to counselling revealed that people held strong views in either one or both directions e.g. yes it is or no it is not. In both directions infertility was compared to cancer as either being in the same category or not in the same 'category' as infertility.

Subcategory of 'Infertility as an issue for counselling?': Infertility seen as an issue for counselling

Infertility can be considered to be in the same category as bereavement, cancer and miscarriage in terms of the nature of the experience. Infertility was acknowledged as a medical issue that impacts on psychological well-being. For those that perceived infertility as a psychological and or emotional issue it was considered to be an issue that was relevant to counselling.

Comments:-

17.18 – 17.21 I see infertility causing a lot of problems down the road for many couples, not so much us because we have been able to really chat but I would imagine that many couples split up over it *(Male)*

21.22 – 25.03 I think infertility should be leafleted in the same way the miscarriage, bereavement and other issues are. It effects you both emotionally and psychologically so why not? *(Female)*

21.22 – 25.23 I do consider infertility to be similar to bereavement in that you are experiencing a loss of something that might have been central to your view of your life and for people that aren't lucky enough to have support from friends or family then counselling should definitely be available *(Female)*

15.16 -58.12 I definitely see infertility as an issue that is relevant for counselling *(Female)*

15.16 – 78.43 If people could go to the GP and be referred to see someone then I think they would. That happens if you've got cancer why should infertility be treated differently? It is an illness and it is still very distressing *(Female)*

17.18 – 15.47 I think it's [infertility] is a medical issue but in our case of unexplained infertility it becomes psychological because you feel so frustrated and stressed by it all *(Male)*

3.4 – 12.12 Without doubt infertility is definitely an issue for counselling, how could it not be? I know that not everyone would agree but I do *(Male)*

Subcategory of 'Infertility as an issue for counselling?': Infertility not seen as an issue for counselling

Infertility is not always perceived as an illness. This gives rise to the perception that infertility is something that you are expected to 'get on with'. This perception seems to be in part generated internally but is further compounded by external factors. Counselling was not seen as a process that could help because it could not provide a solution to the problem e.g. a baby. The link between infertility and the issues e.g. relationship difficulties that might bring someone into counselling was not always made.

Comments:-

13.14 – 31.26	You tend to think you have to get on with it and no-one suggest otherwise, I mean it isn't like cancer or anything *(Male)*, mm yeah *(Female)*
15.16- 78.54	I think the problem is that essentially infertility is not considered an illness therefore you are expected to 'get on with it' and you buy into that too which is why I think that more people don't consider having counselling *(Male)*
13 -25.49	I don't think of infertility as being something that you have counselling for. I had it because I didn't feel like myself but I didn't really associate not feeling myself with infertility but of course it was all about that *(Female)*
3 – 6.35	I don't think you can really be helped [by having counselling] because you either have a baby or you don't *(Male)*
21.22 – 28.02	For me I might go for relationship counselling if it had started affecting our relationship, is that infertility counselling? I wouldn't think of it as that actually, even if infertility was the trigger *(Male)*

CATEGORY: LIMITED OR NO KNOWLEDGE OF BENEFITS OF COUNSELLING

Couples in the present study had little or no knowledge of the potential benefits of counselling. There was a perceived sense that counselling could be beneficial although the ways in which it was thought to help were not clear.

Comments:-

13.14-32.23	If 'x' wanted counselling for this [infertility] then I would support her but I wouldn't really know what they could do, but I think she could have benefited from it *(Male)*
12 – 13.51	....I don't know whether I'd have benefited from it [counselling] *(Male)*
17.18 – 37.00	I would be intrigued to see what the counsellor at the unit is like and I will go if they offer it, I'm not really sure what to expect though *(Female)*
12-14.21	...we never thought about it [counselling] because we weren't told what the benefits could be *(Male)*

CATEGORY: AVAILABILITY OF COUNSELLING

Counselling was not made available by GPs. However the value of making of counselling available at the time of first visiting the GP was repeatedly expressed. It was pointed out that whilst people may not be ready or need counselling at that point there would be value in the concept being 'introduced' to them. It also emerged that not everyone knew how to find a counsellor. If was articulated that if counselling had been introduced by their GP then it may have been accessed had the need arisen at any time throughout the infertility experience.

Comments:-

15.16-79.23	People need some sign posting so that they know where to go if they want to [for counselling/support groups], it's about giving people options *(Male)*
15 – 17.21	If people knew how to access counselling then I think it would be so much better for people, in my experience people don't' know how to go about it and they should be made aware it's out there. *(Female)*
21 – 5.23	I suppose that I didn't expect to get support from my GP and given my profession I know how to access the support I need. However it would have been nice to have a leaflet or a number or just something at that stage because I had no idea of what lay in the road ahead then I could have had it in a drawer for when I needed it. I suppose you could call it an introduction *(Female)*
21.22– 7.30	In the early days you think 'oh great I've come to the doctor so I'm going to get pregnant' and feel really hopeful. But it would have been nice to have pointed in the right direction at that point but I wouldn't have used it necessarily *(Female)*
18 – 20.14	I think counselling should be more widely available in general as well as for counselling, but people just don't offer it to you and you don't really know how to find one so I've never actually had it, but I would have benefited from it at various points in my life. *(Male)*

CATEGORY: NO COUNSELLING OFFERED

None of the couples that took part in the study were offered counselling by their GP. Individuals/couples were not offered counselling at any point during their infertility experience at the time of interviewing. Couples that accessed counselling once they reached the treatment centre were not explicitly offered counselling.

Comments:-

7.8-34.52 You know we were never offered counselling, in all those years [10 years]. *(Female)*

5.6-23.50 we've not been offered counselling yet and the GP hasn't suggested it, but we have needed to talk to someone I think *(Female)*

3.4-20.10 During the whole time, no-body said you should perhaps talk to someone about this, never.*(Male)*

15.16 – 22.31 I find it bordering on neglect when the GP doesn't support you for your infertility and we weren't supported. *(Male)*

15.16 – 23.09 The only support we found out about was via the hospital and that was because we asked questions, lots of them, but if we hadn't gone for treatment we'd have been alone *(Female)*

13.14-15.11 You know we were never offered any support at any stage, even when I was in hospital with hyper-ovarian stimulation syndrome [as a result of treatment] *(Female)*

15.16 – 41.23 We were lucky to have asked the questions we did and seek out information because we weren't offered help or support explicitly at the hospital and not at all at the GP*(Female)*

17.18-15.31 Counselling has never been mentioned to us by the GP, no it's certainly not been suggested *(Male)*

CATEGORY: COUNSELLING OFFERED BUT DECLINED

Some couples interviewed recalled that counselling was offered to them when they were receiving treatment at the IVF clinic but they declined it. Reasons for declining were twofold. First couples were not aware of the benefits of counselling and second they felt there was 'no point' as only one session was offered.

Comments:-

1.2-61.30	Counselling was offered but it was only 1 session so we thought what's the point? So we didn't even discuss it. *(Female)*
12-14.10	I regret that we were never offered counselling more explicitly because we'd have definitely considered it, but *(Male)*
12-14.11	we never thought about it [counselling] because we weren't told what the benefits could be. *(Male)*

APPENDIX 23

Female film scene

FEMALE SCENE

Aim of Scene:- To convey your overwhelming desire for a child and how you are shocked by how much it hurts. I want you to talk about how misunderstood, unsupported and isolated you feel. I also want you to try and convey what you need from David e.g. holding, listening, talking, support etc. I also want you to talk about your anger, frustration and feelings of failure as a female, a person, a wife, a daughter and your body as a failure.

PART 1– INTRODUCTION (1 – 2 mins)

Aim: To introduce Sally alone and get her to reflect on how it was to speak to me before in the couple interview

Jo: Hi Sally, how did you find talking to me together before?

David: It was a relief, it was good to hear David talking like that, he never opens up and it really helped me to see his point of view.

You know at the end when he held me/my hand it felt so good, it might seem like a small thing but to me it's not, it lets me know he is there for me and that I can rely on him.

PART II – ACKNOWLEDGEMENT OF FEMALE FEELINGS/EXPEREINCE (7 minutes).

Aim: To get Sally talking about how she feels using comments etc. from interviews/model. Ask Sally to express what she needs from David

Jo: Sally I appreciate that you are going through this experience together as a couple, but what I am interested in now is talking to you about how you are finding this experience, as a female, you know as an individual.

Jo will interact, prompt and respond to Sally at appropriate points throughout the following

Sally: Well at times I can't seem to think about anything else other than getting pregnant, it's like I'm obsessed and I feel out of control. I see pregnant people all around me and it makes me feel so sad, and I also feel resentful, you know, especially when people I know announce pregnancies, it's so hard, I just can't help thinking "why can't I get pregnant?" It's just so unfair. Then I feel guilty for being selfish.

Sometimes I feel like I'm not coping with this at all, you know why can't I just get on with things? Everyone tells me to 'relax, it'll all be fine" and I just want to scream, because it's not fine is it? I know

they are trying to help but I don't want their advice, so I find myself withdrawing from them and isolating myself even more.

I can't believe other females feel this bad, which makes me feel even more of a failure, you know I can't have a baby and then I can't cope with not having a baby! That's it you see, I feel like such a failure. This is a new thing for me, you know I've always worked hard at school, at work and I have always got what I wanted, I can't believe I can't do the one thing a female 'should' be able to do, how pathetic is that?

I sometimes think I'm being punished for having (termination/promiscuous past), I know it's stupid but I do think that sometimes otherwise it just doesn't make sense. I wouldn't blame David if he went off to find someone who can give him a baby, I wouldn't stay with me, especially when I am feeling irritable, I just feel like I drive people away.

I don't think he even wants a child; he just doesn't seem bothered about it all. I think he's happy to just carry on with his life, I don't understand it. But of course he won't talk about it.

PART III – ENDING (1 or 2 mins).

Aim: To encourage Sally to communicate with David and to raise HER awareness of the support available to her e.g. INUK, friends, counselling etc.

Jo: How are you feeling now?

Sally: Much better for talking about it etc.

Jo: *To summarise what Sally has said/the female experience and then ask:*
How do you think things will change from now on?

Sally: I am going to start planning to talk to David rather than letting things build up and then springing things on him when I feel I can no longer cope. I am going to contact INUK etc. I am going to try not to beat myself up for the feelings that I am having

Jo: *To end the session and set a task (to be decided).*

END: *Jo to provide a summary to camera of the female experience and how they tend to they deal with it. Emphasise the importance of communication about the issue and dispel the myth that they are not coping and that they are a failure. Outline the ways in which they can help their selves an their male partner.*

Suggest that females carry out the task that was given to Sally if they have not already

APPENDIX 24

Male film scene

MALE SCENE

Aim of Scene:-

To highlight pragmatic ambivalence towards both fatherhood and children. To also highlight the key issues for the male from model e.g. compliance, non-expression of feelings, feeling marginalised, feeling inadequate, thinking that experience is easier for the male emotionally and physically. I want the female to see that you do have feelings about the situation that you are in. I want her to see that you are trying to protect her by not talking about your feelings. I want you to say that you feel that at times you feel you have no right to say how you feel because she is finding it so difficult and you feel that you don't have a 'right' to put extra pressure on her.

PART 1- INTRODUCTION (1 – 2 mins)

Aim: To introduce David alone and get him to reflect on how it was to speak to me before in the couple interview

Jo: Hi David, how did you find talking to me together before?

David: e.g. Well it was better than I expected actually, I was dreading it. I only came along because she wanted me to.

I do find it very difficult to see Sally sad, but I suppose there's no avoiding that, I just need to let her do that and accept that I can't fix it.

PART II – ACKNOWLEDGEMENT OF MALE FEELINGS/EXPEREINCE (7 minutes).

Aim: To get David talking about how he feels using comments etc. from interviews/model. Ask David to express what he needs from Sally

Jo: David I appreciate that you are going through this experience together as a couple, but what I am interested in now is talking to you about how you are finding this experience, as a male, you know as an individual.

David: *I will interact with David throughout but I want David to talk about the following:-*

- Not feeling as if you have been consulted about having treatment, feeling as if your opinion doesn't count. Talk about not knowing if you even want children this way (IVF),

the cost etc. You feel a bit guilty for not wanting children as much as Sally seems to.

- Talk about how Sally seems to hit you with 'it' when you walk in the door from work, and you just don't know how to cope with that etc.

- Feeling that you can see how badly Sally wants a baby and how you 'go along' with everything because you do not want to be responsible for 'hurting her further'.

- I want you to convey that you are lost and do not know what to do for the best. Talk about how you don't feel the need to talk about how you are feeling, but this doesn't mean that you don't have feelings, you just deal with them differently. Say that you don't think about it all the time, but that you know Sally does. In terms of what you feel, you feel sad, you worry about the future and what will happen if you don't have children e.g. what will you both do 'instead', who will look after you in your old age, talk about not passing your genes on etc.

- Say how much you love Sally and how she has suggested that you'll leave her because she can't give you children but how this is ridiculous because you love her for her and that it breaks your heart that she thinks you will leave her because of this. Emphasise that you have no intention of this. At the same time acknowledge that the friction between you is a problem and that you do feel concerned for the future if this continues and express your desire to improve the current state of the relationship

PART 3 – ENDING (1 or 2 mins).

Aim: To encourage David to communicate with Sally and to not feel so inadequate.

Jo: How are you feeling now?

David: Better for talking about it etc.

Jo: *To summarise what David has said and then ask:*
How do you think things will change from now on?

David: I am going to start telling Sally how I feel and I am going to let her tell me how she is feeling without feeling guilty or as if I want to 'fix' it.

Jo: *To end the session and set a task.*

END: *Jo to provide a summary to camera of the male experience and how they tend to they deal with it. Emphasise the importance of communication about the issue and dispel the myth that they need to protect their partner. Outline the ways in which they can help their female partner.*

Suggest that males carry out the task that was given to David they have not already.

APPENDIX 25

Couple film scene

COUPLE SCENE

Aim of scene:-

To demonstrate how a breakdown in communication about 'the issue – infertility/not getting pregnant' creates a distance between the couple. This breakdown is due to the differing male and female experiences of infertility (these are outlined in the 'key issues'). The intention is to start out with distance between couple both physically and emotionally e.g. not touching each other, facing slightly away from each other, female hugging herself with arms in a protective pose, male looking defensive e.g. folded arms. I want to demonstrate how through talking to each other in the session the couple close this distance and come together by the end of the session e.g. holding hands/David's arm around Sally's shoulder.

Scene:- Time =10 minutes

PART 1– INTRODCUTION (2 – 3 mins)

Aim: To introduce the couple, their history (briefly) and the problem

Jo: Hi David & Sally, nice to meet you both, thanks for coming today. How are you feeling?

Sally: A bit nervous actually

David: *shrugs* 'ok', *not really engaging.*

Jo: Ok, well perhaps you could tell me a bit about how long you have been together and how long you have been trying for a baby together?

Sally & David look nervously at each other

David (*to Sally*): "do you want to do it?"

Sally: 'ok' .... *Then Sally to tell me how long you've been together and how long trying and going to GP etc. using information from profile*

Sally refers to David now and again e.g. it's been about 2 years hasn't it David, who responds accordingly. Jo will respond to Sally at appropriate points and ask David or Sally questions if necessary to prompt conversation.

Part 2 – COMMUNICATION (5 – 6 minutes)

Aim: To demonstrate distance between couple and facilitate communication about the 'issue' then show couple growing closer throughout scene towards the end of part 2.

Jo: It sounds like it's been a tough time for you both, how have things been between you?

Once again Sally is to start talking at this point. She is looking a bit more relaxed now than at the beginning but looks nervously towards David now. David is looking uncomfortable and defensive, he has still not said much. Jo will interact at appropriate points to prompt, clarify and respond with both members of the couple.

Sally in this section you are going to aim to convey and talk about the following:-

- That you are feeling alone and unsupported.
- I want you to talk about how you feel as if David avoids the topic, give an example e.g. you might say that you don't always find it easy to say how you are feeling but that you might say I've had a bad day today and what you want him to do is say 'oh no, tell me how you are feeling' but he just says 'oh, what's for dinner or shall we pop out for a drink to cheer you up then'.
- Explain that you don't need cheering up, but that what you need/want is to talk about how you are feeling.
- Also talk about how you want to understand how he is feeling too, but that he clams up.

Jo (to David): How are you feeling David, how do you see things?

David (quietly): well I just never know what to say, I mean there are times when everything I do or say seems to be wrong. I know that some days when I walk in the door from work she has been crying and I just can't handle that,

Jo to interject and ask David to tell Sally

David (to Sally) I feel so bad for you, I just want to make it better but I feel so inadequate. So I suppose I try to avoid any conversation because I think it will make you feel worse, I just don't know what to do to help you.

Sally is slowly softening towards David.

Sally: You see it's the *not* talking about it that makes me feel worse and David just doesn't seem to understand that,

Jo to interject and ask Sally to tell David

Sally (to David) Well that just makes me feel so unsupported and the weird thing is that you think you are helping me!

David: Sally I am really sorry, I wasn't aware of that and I suppose that if I'm honest, I don't always want to talk about it either, if I've had a hard day that is the last thing I want but youalways seem to catch me when I am feeling stressed.

Sally: Yeah I can see him roll his eyes when I burst into tears etc.

Jo to interject and remind Sally to tell David

Sally: ...The only time I can get you to talk about things is when we have an appointment, as that gives us something to focus on doesn't it?

David: yeah, it does, but also you seem to be less tearful then too, so I probably find it easier.

Continue with dialogue including sections from interviews and profiles. Feel free to bring in any situations about family having kids etc e.g. David trying to protect Sally and Sally thinking David doesn't care etc. Feeling like the 'odd ones out compared to friends/family' etc.Talk to each other about how you are both feeling. Jo to facilitate conversation when necessary.

Jo: I can see how difficult this is for both of you and I am wondering if you've ever actually sat down and talked about what having a baby or a family actually means to you both and what the prospect of not having one means to you?

David and Sally both look at each other and look a bit surprised at this question and then they consider whether they have had this conversation.

Either one of you or both of you say that you haven't actually done this, and talk about how it's just something that 'you do isn't it?' e.g. get married, have kids etc. DO NOT DISCUSS IN SESSION but both agree that it is a conversation that you feel you should have, especially before you embark on any treatment.

Part 3 – ENDING AND TASK (2 mins).

Aim: To acknowledge how the couple have come together during the session and highlight the value of communicating & set homework task

David and Sally are now touching e.g. holding hands.

Jo: How has it felt today talking to each other about how you are feeling?

Both David and Sally respond positively, for example

Sally: it's felt really good, I feel much closer to David already, I can see how difficult this has all has been for him" "That's what I needed, him just to listen, not try and fix it" etc

David: it's been much better than I thought, I never really wanted to come along today, I only came because Sally wanted to, but I feel that we've cleared the air"..."I still feel that there is a lot to talk about and I hope that we can continue to do this"

Jo: *To set the Homework Task –Provide a rationale for it too e.g. important to have a planned time for two main reasons. Firstly so that Sally knows that there is a designated time at which they have agreed to talk about the issue and their future and secondly so that David knows when the conversation is to take place and can prepare for it, rather than try to avoid it.*

TASK: To sit down at a pre-arranged time that is convenient and relaxing for both of you. It's important that you both feel safe and in control when you have the conversation. Discuss what having a family means to you both and why, what it means to you if can't etc. Use pens and paper if you want. Make sure that both of you join in the conversation etc, not just one. Both listen to each other.

END: *Jo to provide a summary to camera of how the way different ways in which the male and female experience infertility and the ways that they deal with it can lead to misunderstanding between the couple. This misunderstanding can lead to a communication breakdown which can leave both members of the couple feeling resentful, lonely and upset. Emphasise the importance of communication and affection at all times. Remind couples that they love each other and that they must try to hold on to this and not lose sight of their relationship. Suggest that the couples carry out the task that was given to David and Sally if they have not already had that conversation.*

APPENDIX 26

Précis of the couple experience

COUPLE EXPERIENCE OF INFERTILITY

Key issues for the couple: - Periods of Non-Communication leads to distance between you both. ***There are periods of communication and this is when you get closer to each other but these are interspersed with periods of non-communication.***

After about 12 months (I year ago) of having unprotected sex without falling pregnant Sally went to the doctor. At this stage David was sent for a sperm analysis which came back 'ok' and then Sally underwent a series of tests under the GP e.g. blood tests, smear test etc. After 4 months she was referred to the local hospital for further investigations.

At present, as a couple you have had 1 appointment and Sally's menstrual cycle is being monitored. You are currently waiting to find out what happens next and you have an appointment in a few weeks. It is a very frustrating time; Sally just wants to get on with things and David wants to find out what the problem is. Since you started trying for a baby, 2 years ago, David's sister Fiona has had twins, his brother Mark has recently had a son and Sally's best friend and sister, Vicky, have also had children, and Vicky has just announced that she is pregnant again. Friends and colleagues have had children in this period too.

If you find that IVF is a viable option for you both, Sally has made it very clear that she is keen to go for it and she is talking about 'when we have treatment' not 'if'. As a couple you have never actually sat down and really discussed the future – with or without children. You have both been avoiding the topic, particularly David. It is too painful; besides you are still at the stage where you are hoping that you will have a child/family, as you still have many options to try (e.g. treatment, adoption). You have not had a discussion about whether you both want to have treatment and what it involves for you both as a couple. This is unlike you as a couple because normally you talk about everything, especially the 'big' decisions that affect both of you e.g. job changes, house moves, car purchases, holidays, family issues etc.

David, although you haven't said anything to Sally, you are feeling reluctant to have treatment - you have heard that it is a difficult process for the female to go through, you are aware of the low success rates (22% of treatment cycles result in a live birth) and you are also aware of the costs (it's about £3, 000 and can be as much as £5, 000, depending on the IVF unit you go to and the type of treatment/screenings you will need to have). You are not even sure that you want children. You can't help seeing it all from a logical perspective and would want more information before proceeding with anything. Sally, you on the other hand are seeing it from an emotional perspective – you want a baby and you will do whatever you have to do to get one, you don't care how much it costs or how 'difficult' it is. You also really believe that you could be one of the 22%.

In terms of the money, you have got access to £12,000 so could afford about 3 attempts without borrowing money. This is money that you have been saving for

years and it is your savings for the future. It is all that you have got. This is a concern for you David as you are thinking in the long term and this money is your 'security'. Sally does not see it this way, as far as she is concerned having a child is her/your future and her/your security, she does not care about the money. ***Remember that you have not talked about your thoughts/feelings around this issue though!!***

Between the two of you things have been rocky recently. Sally you feel that David is not bothered about having children and you don't feel as if he wants to talk about 'it' (not falling pregnant/treatment/the future etc). This hurts you and you are feeling unsupported and alone. You are also feeling as if you have failed him in your marriage as you can't provide him with a child, this feeling has got worse since his brother has had a baby recently. This leaves you felling 'guilty'. Sally you have also had concerns that he might go off and find someone else who can 'give him a child'. David you are concerned about Sally, you hate to see her so upset, insecure and low. You are feeling lost and do not know what to do to help Sally through this. You are also feeling sad that you both have to go through this experience. These issues/feelings are creating a distance between the two of you.

APPENDIX 27

Précis of the male experience

MALE EXPERIENCE OF INFERTILITY

Key issues for the male (when not the infertile member) – David you are ultimately feeling a pragmatic ambivalence to children/fatherhood e.g. if it happens 'great' if it doesn't well that's 'ok' too. You are feeling marginalised e.g. taken for granted, not consulted re: treatment/future, you do not tend to express how you are feeling for fear of hurting Sally. You are feeling inadequate because you can't make things 'better' or fix the situation. You feel that it is so much easier for you as a male both emotionally and physically (in terms of investigations etc) and this is difficult for you. The result is that you are 'going along' with what Sally wants because of all the above e.g. you are complying with the treatment route even though you are not sure you want to.

David you are feeling sad that you might not be able to have children but you are not overwhelmed with sadness in the way that Sally seems to be. You are aware of how upset Sally is and you feel that by saying that you are sad too, this will only put extra pressure on her. You feel as if you don't have the 'right' to complain. By not expressing your feelings you are actually trying to protect Sally. You find the recent change in Sally disconcerting, she used to be so easy going and fun but over the last year or two she has become unpredictable, tearful, and angry. At times you feel like you can do or say nothing right. You are feeling pretty helpless and you want to try and 'fix' things and normally you would be able to. But this is different, you can't change it. You wish that it was you who were the infertile one, at least then you could take some responsibility.

When you try to cheer Sally up by saying things like "don't worry everything will be ok" she seems to get angry with you or just withdraws into herself and cries even more. You are feeling really sorry for Sally and for you both as a couple but don't know how to help, this makes you pretty inadequate. Sally has said to you that she feels guilty and as if she has failed you in some way because she can't give you a child. What she doesn't seem to understand is that it is her you love and want. Although you would like a family you are not so devastated about not having a child if you can't have one. The important thing is that you are both together. But when you say this to her she just gets more upset and says you don't care or understand. You really are at a loss.

APPENDIX 28

Précis of the female experience

FEMALE EXPERIENCE OF INFERTILITY

Key issues for female (in cases where infertility is unexplained or suspected female cause) – You have an overwhelming desire for a child and you are primarily feeling isolated, you are also feeling like a failure and you are angry. You find not falling pregnant each month a very painful experience.

Sally you are finding it difficult when others announce pregnancies, you want to be happy for them and you are, but at the same time you feel resentment. For example you can sometimes think 'why not me', it's not that you wish them any ill; you just wish you could fall pregnant too. Your thoughts leave you feeling guilty and thinking that you are a bad person.

You are also feeling as if you are 'not coping' and that you are making a 'big deal' of not being able to have a child. There is a sense from others that you should be able to 'carry on' but you are not finding this easy to do. People try to help but they just don't seem to understand what you are going through and they say end up saying all the wrong things like " oh it'll be ok, you're still young, it'll happen" and "just relax" etc.

As time goes on you are feeling less inclined to talk to your friends and your mum about what you are going through as you don't want to be a burden to them. You also don't want them to pity you. In addition to this you also don't want to hear their opinions and advice because it can feel patronising and it just hurts you too much. You feel like people just don't understand you and what you are going through. This leaves you feeling, misunderstood, unsupported and alone.

You are also feeling like a failure. For example you feel that you are a failure as a female because getting pregnant is the one thing you are meant to be 'able' to do. You feel like a failure in life as you are not used to not getting something that you want, and that you have worked towards. You are a hard worker and have been successful in your career as a PA so not falling pregnant is a whole new experience for you. You feel that you are letting everyone else down and failing them too e.g. David and your mum.

You feel that David doesn't care whether you have children or not. He seems fine about it and you can't understand this. You feel that he is avoiding talking about it and you feel that he is avoiding you too at times, this just adds to your sense of isolation and leaves you feeling unsupported. All you want is for him to talk to you, listen to you and to hold you. You don't want him to 'fix it' but he always tries to make you 'feel better', which can at times make you feel worse. If he just listened and let you have a good cry you would feel better but you feel guilty for crying. You can also feel angry if he seems annoyed with you or walks away from you. You are also scared of driving him away. You just want to get pregnant and for all of this to end, why does it have to be so difficult?

APPENDIX 29

Tasks for each scene

Tasks for each scene

COUPLE

- To make a date with each other, weekly to discuss how they are each feeling. This is to be a 2 – way conversation and timed.
- To discuss what having children or not having children means to each of them as a couple.

MALE

Encourage the male to think about what having children or not having children means to him. Ask male to take time to consider how he is feeling about his current situation and to talk to express these feelings. Emphasise that he try to avoid protecting her from his feelings and trying to 'fix' the situation.

FEMALE

Encourage female to spend some time thinking about how she feels and to give herself permission to feel this way. Remind her that she does not have to suffer in silence or alone. Point out the value of keeping a diary of thoughts and feelings, as it will always be there for her. Remind her that there are organisations out there that can support her through this time. Encourage her to speak to her partner, but remind her not to expect him to be at his most receptive when he comes in from work, instead propose that she makes a time to talk to him and let him know that she really needs him to listen to her. Then she can tell him how he can help her.

APPENDIX 30

Couple Profile

COUPLE PROFILE

David & Sally met 8 years ago and they have been married for 4 years. They started trying for a baby 2 years ago. It had got to the stage where they felt ready to be parents. There were a number of factors contributing to this stage in their life. For example, their student loans had been paid, they both had good jobs and they were financially secure. They had recently moved from a 1 bedroom flat into a 3 bedroom house. Some of their friends were starting to try for babies around that time too. Friends, colleagues and Vicky's family had also started asking David and Sally when they were going to 'have a family'.

David and Sally have got a strong, loving relationship. In the past they have had difficult issues to deal with e.g. family illness, job losses and periods of time apart due to David's work. They have always managed to work through difficult issues and would consider themselves to be a couple that talk things through and support each other.

Cause of infertility: currently it is unexplained but there is a suspected female cause which is currently under investigation.

APPENDIX 31

Female Profile

FEMALE PROFILE

FEMALE BACKGROUND

Age: 34
Name: Sally
Job: PA in the City

Brief family background
Sally is 1 of 2 children. She has 1 sister, called Vicky (32 years old). Vicky has a 1and half year child and has recently announced that she is pregnant again.

Sally's Mum and Dad are both still alive and still together. Sally is very close to both parents but particularly to her mum. Recently Sally has become aware that her mum is feeling torn between feeling happy that she is a Grandmother to Vicky's twins and that there is another baby on the way and being there to support Sally through this experience. Sally hates that what she is going through causes her mother so much pain. She really wants to be able to tell her Mum that she is pregnant so that she can stop worrying about her. This is an added pressure for Sally.

Sally has always been quite close to Vicky but since she had her babies she has found it more difficult to talk to her. Sally feels that their different experiences have separated them somewhat. For example Sally feels that Vicky doesn't seem to understand how difficult this is for her. Vicky never really asks Sally how things are going, instead she says things like "oh stop worrying, everything will be fine, just relax". Sally feels that Vicky doesn't really accept that there is a problem and that it is a terribly upsetting experience. Sally thinks that Vicky feels uncomfortable around her and that she tries to protect her from her children/pregnancy. For example, by not telling her about the current pregnancy until she had her 3 month scan, this was different to the previous pregnancy with the twins, when Sally was the first person after Vicky's husband that she told (at 7 weeks). This actually makes Sally feel worse, more isolated and distant from her loved ones.

** Sally feels guilty about the past (David may or may not know it's up to the actress playing Sally). She either has concerns re: 1 of the following:-

- Not being ready for a child before now and feeling as if this is payback time for leaving it 'too late'
- A termination at 18 years old
- A promiscuous youth resulting in an STD (sexually transmitted disease)

APPENDIX 32

Male Profile

MALE PROFILE

MALE BACKGROUND

Age: 35
Name: David
Job: IT Consultant

Brief family background
David is 1 of 3 children. He has 1 sister, called Fiona (31 years old) and 1 bother, called Mark (33 years old). Fiona had twins 20 months ago and Mark had a son 3 months ago.

David parents are both still alive. They separated 15 years ago when David was at university.

David is quite close to his mum and dad but they don't live very close and so he doesn't see them very often. They are not aware of the difficulties that David and Sally are experiencing in trying to get pregnant. David tends not to talk to them about personal matters and they haven't asked about David and Sally's plans. David is quite close to Fiona and is very close to his brother Mark. David is really happy that they have both got their families and he enjoys spending time with their children and being a good uncle. David does not tend to relate his siblings situation e.g. having children, to his own e.g. not having children, but he is aware that it upsets Sally to be around them for too long.

APPENDIX 33

Film covering letter

Jo Perkins
164b Albion Road
Stoke Newington
London
N16 9JS

<<Date>>

Dear

Please find enclosed the video as promised. Once again, I would like to thank you both in advance for agreeing to take the time to watch the video and then provide feedback.

As discussed the feedback I am looking for relates to the content of the film with a view to updating and improving it so that it can be a useful resource for those going through the infertility experience. I am interested to know what you thought of the film in general and what you thought of the different sections e.g. the couple, female and male sections. I have a few simple questions relating to the film that I will ask you both when we speak. Your honest opinions would be much appreciated.

I look forward to hearing from you so that we can arrange a convenient time to meet.

Best wishes

Jo

APPENDIX 34

Interview schedule: Couples – Study 3

Couple Interviews: Opening script

Firstly I would like to thank you for agreeing to take part in this stage of the research.

The interview will take no longer than 20 minutes. At this stage I am interested in getting your feedback on content of the film. Please be as honest as possible and feel free to criticise it.

Sign consent forms.

Commence interview.

Interview schedule

1) What did you both think of the film in general?

Note: The following questions were my personal guide and were not explicitly asked if answers were provided in the discussion resulting from the initial questions.

2) What did you think about the couple section?
3) Was it helpful to watch and if so in what way/s? If not why not and in what way/s?
4) Do you think you would have found it helpful to view when you were experiencing your own difficulties conceiving? If so how and at what point?
5) How do you feel it could be improved?
6) Is there anything that you feel should not have been included?
7) Is there anything that you feel should have been included that was not?
7) Is there anything that you would change?

Closing statement:

I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or discuss at this point?

Do you have any questions?

Thank both participants for their time and feedback.

APPENDIX 35

Interview schedule: Individuals – Study 3

Individual Interviews: Opening script

Thanks for feeding back on the couple section. Is there anything that you wanted to add about the couple section at this point?

Ok, I am now interested in hearing what you thought of the individual sections. Please feel free to be critical of any aspect of the film.

Interview schedule

1) What did you think of the individual sections of the film?

Note: The following questions were my personal guide and were not explicitly asked if answers were provided in the discussion resulting from the initial questions.

2) Did you watch both the male and the female sections?
3) What did you think about the male section?
4) What did you think about the female section?
5) If you watched both sections please explain which was useful – why and how?
6) Do you think you would have found either section helpful to watch when you were experiencing your own difficulties conceiving and if so how?
7) At what point do you think it would be most beneficial to view (if at all)?
8) How do you feel it could be improved?
9) Is there anything that you feel should not have been included?
10) Is there anything that you feel should have been included that was not?
11) Is there anything that you would change?

Closing statement:

I believe that I have covered all that I need to know, however, is there anything that you feel you would like to add or discuss at this point?

Do you have any questions?

Thank participant for their time and feedback.

APPENDIX 36

Categories: Validity of the models of the infertility experience

RESEARCH CATEGORIES – VALIDITY OF THE MODELS OF THE INFERTILITY EXPERIENCE

Overview

Each category is first described before presenting definitions of each of the subcategories within the category where applicable. Subcategory definitions and categories in cases where there is no subcategory are followed by a record of comments taken directly from the interviews.

CORE CATEGORY – THE CHARACTERISTICS OF THE INFERTILITY EXPERIENCE

Feedback was provided by couples who took part in the research, regarding the characteristics of the infertility experience conveyed in the tool. The couple and their experience were deemed as realistic. A couple suggested that they were too 'stereotypical'. The female character was considered credible and reflected the female experience by females. The male character and experience was perceived as realistic by males. A couple suggested that the male was also stereotypical. The male character in the film was considered too passive by all males and a female

Subcategory of 'The characteristics of the infertility experience':- The couple

Couples providing feedback on the couple section stated that the couple in the tool and their experience seemed realistic and reflected the infertility experience. Couples in the Active stage considered them the most realistic, in terms of the dynamics of their interaction and the feelings that they were expressing. Whilst the couple in the Post Active Stage considered the couple experience as 'quite accurate' they did not consider that their experience as 'bad' the couple on the film. They also thought the couple was too stereotypical.

Comments:-

5.6 – 0.15 I found the couple very realistic, we both did, we really believed that they were going through it, you know the stuff they were saying and

the way they obviously felt and were together *(Female)*

3.4 - 0 .27 ...the couple is too stereotyped i.e. he doesn't want to talk about it, he looks like he only wants to go to the pub with his mates, whereas every month she's in tears. *(Male)*

3.4 – 0.15 What the couple seem to be experiencing is actually probably quite accurate, I don't think we were quite as bad as that but there were issues for us like that at points, you know in terms of communication *(Female)*

17 – 1.01 I think you've really captured the experience that the couple goes through. *(Female)*

5.6 – 1.03 The emotional differences and the interaction between the couple were spot on, we both said that *(Female)*

17.18 – 1.23 We both thought how similar the couple in the film was to us a few years ago and to so many other couples that we know who are in the same situation as us. It's very believable. *(Male)*

18 – 2.32 For me the couple on the film and what they are going through is an accurate portrayal of the couple dynamic, at least it really fits with our experience. *(Male)*

Subcategory of 'The characteristics of the infertility experience':– The female

Feedback from females revealed that the portrayal of the female character was plausible and reflected the female infertility experience. Females located in the Active Infertility Stage said they could identify with the female character and that her experience reflected their own experience. The female located in the Post Active Infertility Stage did feel that although her experience was not quite as bad as for the female on the tool, she knew other females who had similar experiences.

Comments:-

3 – 2.56 She is what I imagine is typical of a woman going through infertility, I was not like that or at least not that bad, but women I know have been like that and they have had a really tough time of it. *(Female)*

5-4.23 She [Sally] fell into the same trap as I did, assuming that it was all her

fault and her body's fault, then feeling guilty even though it was unexplained infertility *(Female)*

5 – 2.12 I found Sally very believable and her experience really reflected mine, except the termination. *(Female)*

17 – 4.23 It was quite weird watching it because the female was experiencing all of those things that I have experienced and am still experiencing, you know feeling of guilt, it being her fault and all of that *(Female)*

5 – 4.35 At the beginning and I suppose it continues throughout you do feel very alone and isolated and I think she was saying that *(Female)*

17 – 5.19 I could really identify with Sally [the female character in the film] because it was as if she was talking from the heart and I really knew what she was saying, because it's the same for me. *(Female)*

Subcategory of 'The characteristics of the infertility experience':– The male

Feedback from the males revealed that the male actor as a character was perceived to be too 'passive' and 'stereotypical'. Despite this males located in the Active Infertility Stage said that they could identify with the male's experience even though they considered themselves to be less passive. The experience conveyed in the male scene was considered realistic in terms of the male feeling shut out, trying to avoid conversation about the issue for fear of upsetting their partner, feeling helpless and wanting children but not being 'desperate' to have them. The male in the Post-Active Infertility Stage expressed frustration that males tend to be perceived as the one 'who has the problem with communication'.

Comments:-

6 – 0.22 I didn't really identify with the male as a person because he was quite passive, but I can identify with his experience, you know what he's saying and what he's feeling even though he isn't like me *(Male)*

17.18 – 5.06 I found the male's feelings accurate but he was perhaps a bit too quiet. I think that what he talked about was true though, you know that getting in the door from work and feeling like he can do nothing right and not wanting to upset her further, it's so like that *(Male)*

18 – 7.09	I can see where he's coming from, you know he's saying that he does want children but it's not essential, you know, in the way it is for his wife, but your wife thinks you don't care about kids and it's not true you are just not desperate for them, you know if it happens great but if not you know you'll cope, you are more worried about what it will do to your wife if it doesn't happen to be honest *(Male)*
17.18 – 6.29	I could relate to how he was experiencing it, that feeling shut out and a bit helpless really, but I don't think I'm that passive *(Male)*
5 – 9.45	I didn't find the male section as useful to watch as the female one because 'x' is not like the man, although he does similar things, he's not as closed off, but I am aware from talking to others that a lot of men are like the one in the video *(Female)*
6 – 2.19	I think he was a bit wimpy and I know that although males may not say much but they do feel a lot and I think that what he seemed to be feeling was pretty close to reality. It's clear he loved his wife and was trying to avoid talking about stuff for fear of hurting her and all that, I definitely do that or I should say did that 'cos I know better now *(Male)*
5.6 – 4.52	We thought the female was more relevant to me than perhaps the male was to 'x' *(Female)* yeah you see I don't think I was as passive as that, because it's just not in my character, but having said that some other blokes we know have been like that, I suppose it's hard for you to strike the right balance for everyone *(Male)*
4 – 2.43	Why is it always that the bloke has the problem of communication? Are we really that bad? I know I'm not *(Male)*
4 – 3.45	I found the male very stereotypical, I am not disputing that some men are actually like that but I am not so I found it difficult to really tune into him. *(Male)*

CATEGORY: THE POINT AT WHICH THE TOOL WAS CONSIDERED BENEFICIAL FOR INFERTILE COUPLES AND INDIVIDUALS TO VIEW

Different stages of the infertility experience were referred to both explicitly and implicitly to in the feedback interviews. Couples providing feedback suggested that the film would be most useful to couples and individuals at the early stage of their infertility e.g. when they visit their GP level or their fertility clinician. The value of the tool at this stage was perceived to play a role in preparing couples and individuals for the emotional and psychological experience ahead of them e.g. Active Infertility. The couple in the latter phase of the Active Infertility Stage said that once people start having treatment their needs change. Hence the needs at this point are different compared to needs in the earlier phase when they are still trying to conceive naturally. Feedback revealed that the film was not necessarily appropriate or relevant for those going through the Active Infertility Stage once they have embarked on treatment. However the female who was in the Post-Active Infertility Stage and the couple in the Active Infertility Stage suggested that support and information is necessary when treatment fails. The female in the Post-Active Infertility Stage said that she could see the need for a series of DVD's of this nature for each stage of the infertility experience.

Comments:-

5.6 – 13.12 I think that the situation [infertility] changes as you go along and for me I think this video would be useful at the point you are told you are going to have to have treatment for your problem, to help you prepare for the road ahead, even if you don't know what the problem is exactly *(Female)*

4 – 7.02 I personally did not find the film useful but of course I don't think I was meant to as we now have a child and this is clearly not for people in our position, perhaps a few years ago it would have been more useful, you know pre-treatment, I'm not sure *(Female)*

18 – 6.01 For me this film is something that you should get at your first appointment when you go to the doctor 'cos you can't fall pregnant. *(Male)*

3 – 4.12 Being a woman who has been through the whole experience I see that there is potentially a need for a series of films, because this film is not necessarily applicable to someone further down the line, as the focus then tends to be more on the treatment and treatment failure, I see it more as a film that someone would watch earlier in the whole process

	(Female)
5.6 – 1.24	I particularly see the film being for couples in crisis or perhaps heading for it, which this [infertility] can do to you. *(Male)*
4 – 6.12	For me this film is not relevant for those that have gone through the treatment route because you have different needs once you do this *(Female)*
5-2.38	It would have been especially helpful to see this about a year ago, when we going for tests and stuff and I was all over the place. *(Female)*
5.6 – 0.21	I could imagine that I, well I suppose we, would have found it very useful to have been given something like that when we first went to the GP, you know something to prepare us for it. *(Male)*
17.18 – 6.52	We think that you need something like this right at the beginning because as you move through the experience and start having treatments a) everything changes for you so your needs are different and b) you've kind of worked out the hard way what the experience is like *(Female)*
17.18 - 7.27	This film is for people who still hoping to fall pregnant naturally but are upset by it 'cos it's not happening, they are the ones that need to know what happens later on *(Male)*
3.4 – 10.37	For me the most crucial part of the infertility experience is the treatment and when it fails. That is when you need support both as a couple and as individuals, not so much at the early stages *(Female)*
17.18 – 7.11	When you are going through treatment you want to talk about options and outcomes and your needs are different by this stage but earlier on you need this kind of information, you know about what it's like for the couple and the man and woman *(Male)*

APPENDIX 37

Categories: Value of the film as a psycho-educational tool

RESEARCH CATEGORIES – VALUE OF THE FILM AS A PSYCHO-EDUCATIONAL TOOL.

Overview

Each category is first described before presenting definitions of each of the subcategories within the category where applicable. Subcategory definitions and categories in cases where there is no subcategory are followed by a record of comments taken directly from the interviews.

CORE CATEGORY – WAYS IN WHICH THE TOOL WAS PERCEIVED TO BE OF VALUE

The tool was perceived as useful by those providing feedback. For couples it was perceived to promote communication as well as providing methods of achieving this. For females it was primarily seen as a tool that could help to normalise their emotional, behavioural and psychological response to infertility. For males the tool was perceived as promoting the value of both listening to their partner and expressing their feelings. It was seen as a tool that serves the function of normalising the male response to infertility. Males also found the tool valuable as it provided an insight into the female emotional experience.

Subcategory of 'Ways in which the tool was perceived to be of value':– To the couple

Couples providing feedback perceived a number of ways in which the tool could be of value to couples experiencing infertility. It was primarily seen to positively promote communication between the couple by highlighting the importance of communication and by providing a way to do this in the form of the tasks set by the counsellor at the end of the couple scene in the tool. Couples located in the Active Infertility Stages said that it served the function of normalising the difficulties being experienced by them. The tool was perceived by couples proving feedback as a way of preparing couples in advance for the psychological and emotional aspects of infertility. In addition, the tool was seen to

serve the function of stimulating thoughts and discussion between the couple about the infertility issue that they are faced with.

Comments:-

5.6 – 14.12	Even when you think you are a couple that are good at communicating this video reminds you that it is very difficult to talk about the actual issue and that is good *(Male)*
5.6 – 0.37	I think the film could be used to stimulate thoughts about you can deal with the whole situation as well as showing you a bit about how counselling works *(Male)*
5.6 – 1.10	You see even though it doesn't feel as if we reacted like that, I mean I think we communicated better than that, but anyway the fact that we still recognise all of it suggests that we did go through it like that I suppose, so people should have access to something like this rather than finding it out for themselves, don't you think *(Female)* yeah definitely *(Male)*
6 – 9.11	I think it's essential for couples and men I suppose to talk about the situation and this video really brings that home, it makes it very clear just how important that it and that is a good message. *(Male)*
17.18 -12.01	It's a good way to get the couple talking to each other and that can only be a good thing *(Male)*
5.6 – 6.23	We really liked the tasks, didn't we? It was explained very well and you could see why you'd do it *(Female)*
5.6 – 6.35	Even though we feel that we talk a lot I think we'll do the task because it makes a lot of sense to do that, you know meet each week to have a chat about where we're at. *(Female)*
5.6 – 15.23	Although I think that the 2nd task was good, I think it is more helpful for the male to talk about the future and the possibility of not having them, cos as a woman I don't think I can ever really believe that it's not going to happen, but that maybe means that having the conversation is even more important, I don't know. I think we'll still have the conversation though *(Female)*
17.18 – 12.23	It was really nice to see the couple having the same sort of problems we've had and sometimes still do have....it makes you feel more

normal and less alone I suppose *(Female)*

5.6 – 13.52 It was very clear, you could see the problem, see how it was summed up and there was a rationale for the task so you could see it would be useful to do, which makes it more likely that you will do it. *(Male)*

17.18 – 11.24 I think for couples to be able to watch something like that is helpful 'cos you are so lost and feel like you as a couple aren't coping very well so seeing another couple just like you is very helpful *(Male)*

5.6 -9.12 I think that if you were given this video at the first consultation at the clinic if you've not had any help or support before that point the video would be an excellent way of preparing you for the emotional rollercoaster, you know provide you with that insight that you are lacking at that stage *(Male)*

3 – 9.12 I can see the value of the tasks; women are so much more into things like that than men, and you have catered for that I think. *(Male)*

Subcategory of 'Ways in which the film was perceived to be of value':– To the female

Females primarily saw the tool as something that normalised the female response to infertility. The tool was deemed helpful in terms of highlighting the other forms of support available to females. It was also seen to demonstrate that their partner does have feelings and cares about the issue despite the tendency to avoid discussion. A female said that the film served as a reminder not to confront their partner with the issue when they walk in the door from work.

Comments:-

5 – 5.34 I really liked the task and totally see how it would help and in fact I have found that the support network via the clinic is really helping me and I have been keeping a diary which has also been really good I think *(Female)*

3 – 7.02 I see that this could be of help to a woman who is not coping at all with her situation, to see that other women go through it too, you know that it can be normal to react like that *(Female)*

17 – 10.02 I think it's good for the woman to be reminded that she can get support elsewhere and not to rely on her partner *(Female)*

17 – 9.42 I think that this film might help women to see that their partner is actually on side when they watch this which is important because you often feel that they aren't because of their avoidance, their behaviour confuses you and this explains it a bit *(Female)*

5 – 9.12 I really recognised the female tendency to start talking to their partner the second they walk in the door (laughs) and it is quite poignant to see that on the film, even though you know you are doing it. It serves as a reminder not to catch him when he least needs it *(Female)*

5-3.15 Yeah I mean I found it [the film] useful because I really recognised myself in it and although I feel like I've moved through that stage I think it would have really helped at the time because you really do feel like you are not coping and that you are going a bit mad. That really made see that how I was reacting was normal. *(Female)*

5 – 2.29 It was quite weird to see someone talking about all the things you've been feeling, but helpful too, you know to see someone else goes through it too. *(Female)*

17 – 9.01 I think this film could be of real help to women because they can see that they are not alone and that they are normal or rather the way they are being is normal. It shown them how their partner is feeling which is important, as you can think they don't care, which just adds to your stress *(Female)*

3-9.23 It also shows that men are actually more in tune with you than you think and that a lot of their behaviour is because they care about you and what you're going through which is important because you often feel they don't care 'cos of the way they are being *(Male)*

Subcategory of 'Ways in which the film was perceived to be of value':–

To the male

Males providing feedback perceived the tool to help in the following ways. It was seen to promote communication, particularly listening, but also by encouraging males to talk about their feelings. Feedback revealed that the tool provided insight into the female

emotional experience, which was deemed helpful. Finally the process of observing the male actor was seen as serving the function of normalising the male response to the infertility experience.

Comments:-

5 – 11.01 It was interesting because I felt that the male task was quite wishy washy but 'x' didn't agree he liked it, he said it was unrealistic to suggest to a man to write his feelings down or get support, 'cos he won't. *(Female)*

5.6 – 13.01 When I was watching the bloke in the couple section I recognised that this is what most men are like and I think if men can watch this they would feel like they were more normal, it's powerful to see what others go through and to see you are not the only one, it helps to make you feel less inhibited *(Male)*

5 – 9.56 It was really good to see you telling the male to communicate it's so important, because they just don't and it's good for them as well as you for them to talk. *(Female)*

18 – 12.56 It's helpful to see what the woman is going through, I mean you do know it but it tends to be more anger directed at you so you don't always get the chance to hear her talking like that *(Male)*

18 – 13.04 It was good that you told the man to listen 'cos I must admit I think I do but I probably don't do it enough or as well as I could. I should also tell her how I am feeling more, I definitely don't do that enough *(Male)*

5 – 10.13 I also think you made a very important point when you told the man to listen they are so busy trying to resolve everything they forget to do this crucial thing. *(Female)*

6 – 5.16 I think the film will really help men understand what their partner is going through emotionally, I have had to learn over time for myself but it's all there in the film and I think men should watch this 'cos half the time you don't know what to do for the best *(Male)*

18 – 12.01 The man is a bit weak but it's helpful to see that someone else is going through what you're going through and dealing with it in a similar way, but also to be given other ways of dealing with it you know having that set time to talk I think that's a good idea *(Male)*

CATEGORY: THE ROLE THAT THE FILM WAS PERCEIVED TO PLAY IN THE PROMOTION OF COUNSELLING

Feedback revealed that the tool positively highlighted the benefits of counselling. For example, comments suggested that the tool demonstrated that counselling is not 'fluffy and patronising' and hence a 'good advert'. In particular, based on the feedback, it seems that the tool could play a role in promoting counselling for those that have no prior experience or knowledge of it, particularly for males. A female pointed out that infertility is a very private issue and a tool may not play a role in helping people to decide to have counselling. A male said that he was not open to the idea of counselling prior to viewing the tool and viewing it did not change this view.

Comments:-

3 – 10.02 I personally chose to get my support from counselling for my miscarriage as it got to a stage where no-one I knew could help me because it was so private and this is where other resources like counselling come in handy, the video highlights that. *(Female)*

17 – 8.02 I think that the film was a positive voice for counselling in general but more for infertility, 'cos you don't always think that what you are going through is relevant enough *(Female)*

18 – 9.12 I think if blokes see this then they would definitely see counselling in a positive light, especially if they had a negative view of beforehand *(Male)*

6 – 4.12 I think the film did show that counselling is not all fluffy and patronising, I think it's a good advert for it especially for men 'cos women are more open to it anyway *(Male)*

4 – 7.25 I dam not really open to the idea of counselling for myself, so the film didn't make me think it's something I want to do, although I can't imagine that anything would really make me think otherwise, *(Male)*

3 – 7.12 I firmly believe in counselling for this issue, although for me I only sought it when I had a miscarriage and although I personally wouldn't have responded to this because I already knew about counselling and had had it for other issues, but I do think it has value for those who are

not aware because I imagine that it can be daunting for some people *(Female)*

5.6 – 8.03 The video definitely highlighted the benefits of counselling, I know what it involves but so many don't and this was a good advert for it *(Female)*

5.6 – 8.18 we think that it would definitely encourage people to try counselling *(Male)*

5.6 – 8.35 I think that if you didn't know what counselling was and then you watched that it would make you think that it could be useful *(Male)*

3 – 8.05 I think that this film could demonstrate to those who know nothing about counselling that it would be worthwhile to do if they are feeling as if they are not coping *(Female)*

3.4 – 5.40 I can see that the film would be helpful to watch, but in all honesty, the journey into infertility is such a private one that I am not sure that seeing a tape will help people to decide they want to get into counselling, it just depends on the person I suppose*(Female)*

CATEGORY: OVERALL VIEWS OF THE TOOL

Feedback in general resulted in both suggestions for improvements to the tool and a critique of it. Suggestions for improvement to the tool included:-

- Changing the portrayal of the male, making him more assertive.
- Ways in which to highlight the benefits of counselling for male viewers were suggested e.g. making it explicit that it is a service which confidential.
- Using the tool to explicitly help females come to terms with their/their partner's infertility in order that it is something they do not blame themselves for.
- It was suggested that the tool could be used to address the difficult issue of not having a diagnosis for couples with unexplained infertility.

The critique provided feedback that revealed both a positive and negative bias towards the male on the tool. It was suggested that in the tool the female is shown as experiencing a broader range of emotions compared to the male. In addition, the tool evoked a negative response in three viewers (one male and two females) in relation to the fact that the

female had experienced a termination. Finally it was suggested by one male that perhaps there was an attempt to convey too much information in a short space of time.

Subcategory of 'Overall views of the tool':- Suggested improvements

A number of valuable suggestions for improvements to the film were made. It was suggested that the male could be portrayed as being more assertive and active. The value of demonstrating and emphasising the confidential nature of counselling was suggested. The benefit of highlighting that counselling is a safe space for males to express themselves freely was pointed out. A male said that he would like to have received more information about treatment options and outcomes. Another suggestion related to using the film to explicitly help the female to see that it is not her 'fault' which it was thought would provide a contrast to the common misconception held by many people that infertility is a female 'problem' or 'fault'. The value of addressing the difficulty experienced by couples with unexplained infertility of not having a diagnosis was suggested.

Comments:-

6 – 2.12 I think it would have been good to show the male as being a bit more active or aggressive about the situation *(Male)*

6 – 3.45 In my opinion, those that get the best out of counselling are those that let it all go 'cos they know it's confidential and if you could show that anything goes and really make it clear that it's all confidential then I think males would be more likely to go for it, you know that they can say anything to you about how they are feeling *(Male)*

3.4 – 9.51 You see as I recall as difficult as the early stages are you are full of hope as you have the treatment option open to you, so perhaps the film would be better off looking at all the options and outlining ways of supporting the couple through that. *(Female)*

4 – 6.31 ...as a man, I think you really want to know more about the treatment and outcomes and all of that, not the emotional stuff *(Male)*

5.6 – 5.58 We have found that everyone seems to assume that it's a woman's problem or fault and I don't think the film dealt with that enough, but you did when you interviewed us and it was the first time anyone had

pointed that out to us and it really helped so I think it would be good to put that in there somewhere, it would be very useful for people *(Female)*

5.6 – 10.02 I think if you are going to appeal to people going through unexplained infertility it would be really helpful to show how important it is for the couple to get a diagnosis, you know in our experience we have both wanted to be the ''cause'' (making inverted comma sign with both hands) so that we could get on with dealing with it *(Male)*

6 – 3.04 If males could see counselling as a place to let go of their anger and frustration, I think it would appeal to them. You see I don't think that we feel safe to do that for fear of being judged or upsetting someone, but counselling allows you to do this so this is a good opportunity to show men that *(Male)*

5 – 4.46 I think it would have helped if you could have helped her see that it wasn't her fault even more than you did, you know perhaps more explicitly. *(Female)*

Subcategory of 'Subcategory of 'Views of the overall film': Critique

The primary criticism of the film was the fact that the female had experienced a pregnancy and subsequent termination, about which she expressed guilt feelings. Whilst the guilt feelings were deemed appropriate by viewers' two main issues regarding the termination were revealed. One is that the viewer may feel that as they have not had a termination then they do not 'need' counselling. The second is that the film evoked feelings of anger in the viewer towards the female for having had a termination. Linked to this is the fact that the female on the film had actually experienced a pregnancy which two of the viewers had not, hence she was deemed 'luckier' than they were. The result of this was that the viewer ceased to identify with her and disengaged with the film for a period of time. Another criticism revealed that the film was perceived as biased, both positively and negatively towards the male. Positively, in terms of it not 'being his fault' despite the fact that the couple supposedly had unexplained infertility. Negatively in that the female was perceived as demonstrating a fuller range of emotions than the male, which was not considered accurate. A male said that although the message of the film – communication - was clear, it was perhaps too obvious. The couple in the Post Active Infertility Stage pointed out that there was too much emphasis on communication in the

absence of information about treatment. A female suggested that the word 'painful' was used too often, which she did not think was helpful. A male suggested that too much information was crammed into a short amount of time.

Comments:-

3.4 -2.42 I wonder if the termination guilt is such a good idea. It sends the message, oh right she has a good reason to feel bad about not having kids, but I don't so I don't need counselling, I'm normal, whereas she's not *(Female)*

5 – 1.12 I actually felt angry towards the female for having a termination and because she'd actually been pregnant, she was lucky to have had that luxury, I haven't. So I suppose I totally lost sympathy with her, I know that's awful but I couldn't help it. *(Female)*

5.6 – 12.48 We both felt quite angry when she said she felt guilty for having a termination, that is just so unfair. You see we have unexplained infertility so we have never even had the luxury of being pregnant so we immediately put her into another category. She cannot know what it's like to never be pregnant even if she didn't feel able to go through with it at that age. I think that whilst all her feelings were the same she doesn't need to say that, although you should keep in the bit about her blaming herself, 'cos that is definitely true. *(Female)*

3 - 11.37 I can see where she was coming from with the guilt she was feeling but perhaps you could have kept this guilt more general rather than explicitly talking about the miscarriage *(Female)*

5 – 4.45 I felt it was perhaps a bit biased towards the man, you know that it was accepted that it wasn't his fault *(Female)*

6 – 4.37 It felt as if on the film the woman experiences more emotion, you know a fuller spectrum compared to men, but I wonder if that's true, I'm not sure *(Male)*

5.6 - 0.52 We did think that it didn't perhaps verbally emphasise enough that it wasn't woman's fault. You showed it but I am not sure that you explicitly said it. But it was unexplained infertility so perhaps you could have said it as the couple seemed to be assuming her as the one to blame. *(Male)*

3.4 – 10.36 I believe that the general message that you are trying to convey is that its good to talk and I suppose that it does comes over, but for me perhaps in a rather too obvious way, by this I mean that it's a little corny, its what you would expect you know a male who is not interested and a female that is in tears. *(Male)*

3.4 – 3.25 You definitely say all the right things in all the right places and it felt like you were really there with the couple, but I am not sure that a real couple would fit that much into a 25 minute session *(Female)*

3.4 – 6.11 You're using too often the word painful. Especially when you talk to the woman. I don't think you should remind them this is painful, you are meant to make them want to talk about it, don't send the message out it's painful they know that, they want help, not compassion. *(Female)*

3.4 – 6.32 You tend to come to conclusions too quickly because in less than 20 minutes you might try to pack several sessions of counselling. As a general rule, you're talking too much, you should perhaps show that you're leading them to their own conclusion, *(Male)*

4 – 8.02 For me there is a lot of information crammed into a short space of time, which could perhaps be a bit overwhelming for some people *(Male)*

CATEGORY: VALUE OF AN AUDIO VISUAL MEDIUM

The audio visual medium was viewed positively. Couples and individuals expressed that it was a user friendly medium that they would choose over other mediums e.g. books, leaflets, talk. Factors contributing to this included privacy, convenience, being able to see a 'live couple' and limited effort on behalf of the viewer.

Comments:-

3 – 12.03 I think as a starter a film is a preferable option, you know I would be more likely to watch this then decide what I wanted to do to find out more *(Female)*

5.6 – 14.21 We found it great because there is always so much to read that you tend to get bogged down, so it was good to see a 'live couple' as it were, it kind of brings it to life you know *(Male)*

4 – 9.15 If I wanted to have something I think a film is good start, I would

still want to read stuff but this is easy to fit in around everything else, not too much effort I could say *(Male)*

5- 11.13 I liked the privacy of being able to watch it in our own home when we wanted to. We could also turn if off between sections to talk about it. *(Female)*

6 – 10.12 I liked the fact that we both saw the same thing at the same time so we could talk about it together. So often 'x' tells me she has read something that she would like me to read and if I don't get round to it we don't discuss it so this helps from that point of view *(Male)*

18 – 11.21 I think that being able to watch a film is great, as I said before I wouldn't read a book and I don't want to talk to my mates about it really so this is the best way to get information *(Male)*

17.18 – 13.12 We liked that you could sit down together and watch something that affects both of us, it was something we could in private and that is important *(Female)*

APPENDIX 38

Approved MSc Research Proposal

Counselling Psychology MSc Research Proposal – Jo Perkins

Supervisor – Don Rawson

November 2003

The Infertile Couple –

An exploration of how the process of the infertility experience contributes to the changing identity of the couple and of the individuals within the couple

Summary

This study will explore how the process of the infertility experience contributes to the changing identity of the couple and individuals within the couple.

In total 18 interviews will be conducted and analysed using a Grounded Theory (Strauss 1987) framework.

The aim of the exploration is to build a theory that explains how the process of the infertility experience contributes to the changing identity of the couple and individuals within the couple over time.

It is hoped that the theory can be used to promote understanding of what the different psychological and emotional needs of the couple and the individuals within the couple experiencing infertility, might be at any given stage of their infertility process.

It is hoped that the findings will contribute to the practice of counselling in the field of infertility.

General Background

In the United States, 'infertility' is defined by the failure to conceive after 1 year of engaging in sexual intercourse without contraception (Mosher & Pratt, 1982).

According to The Human Fertilisation and Embryology Authority (HFEA, 1999) 1 in 6 couples experience fertility problems. Amongst these couples, female infertility accounts for 40% of all cases with 30% being accounted for by male infertility. The remaining 30% of infertility is due to infertility in both partners and unexplained infertility.

Infertility is not a new problem. It has been present through the ages, although traditionally it has been a taboo subject (Marsh & Ronner 1996; Pfeffer, 1993). However, medical and technical developments over the last 30 years have meant that the possibilities for the individual/couple experiencing infertility have grown considerably. Furthermore, social and economic change over this period has made these possibilities more accessible to a wider range of people. Statistics confirm that the incidence of infertility has not increased but that the numbers presenting with fertility issues have increased (Read, 1995).

This year saw the 25th anniversary of the birth of the first baby through In Vitro Fertilisation (IVF) in 1978. Since 1978, more than 68,000 children have been born through IVF in Britain. Over 8,000 of these babies were born in the 12-month period between 1st April 2000 and 31st March 2001. This figure makes up 12% of the total number of babies born through IVF in the last 25 years. However, whilst the number of babies born through IVF is increasing, the success (live birth) rate for patients of all ages is still only 22%.

The experience of infertility is made up of many layers and is a complex phenomenon. There are a number of issues involved for the individual/couple experiencing infertility e.g. biological, emotional, physical, relational, social financial and psychological. The pain and loss that they face can be immense.

Not only do the individuals within the couple have to come to terms with the idea that they may not be able to conceive children naturally, they also face decisions about what to do next. For example, whether to embark on the process if In Vitro Fertilisation (IVF), or decide not to have any treatment and begin to face their future without children, or consider using a donor, finding a surrogate mother or try to adopt/foster a child/ren (Read, 1995).

The couple that do decide to proceed with IVF are then faced with understanding the medical and biological factors involved. The process of IVF can be anxiety provoking for the couple and exert extreme stress on their relationship (Salvatore, Gariboldi, Offidani, Coppola, Amore & Maggini, 2001; Levin & Sher, 2000; Greil, 1997; Ow, Kumar & Leo, 2003).

The decisions do not stop here. If a couple do decide to start a cycle of IVF, given the success rate of IVF (22%) many couples are faced with a further decision about whether to 'try again'. In addition, if there is are egg/sperm donor/s involved, this throws up even more issues for consideration. For example, the couple will need to consider the implications on them as a couple and for the potential child amongst other things. There is a growing body of research looking into identity issues for donor-conceived children (Hewitt, 2002; Turner & Coyle, 2000).

There are a number of other factors that can contribute to the individual/couple's distress. For example pressure from family, friends and work colleagues can contribute to feelings of inadequacy and loss. This can also contribute to secrecy around the issue (Bor & Scher, 1995), which can add to the couple's feelings of isolation.

In light of the complexities of infertility, the HFEA state in their Code of Practice (1990) that three distinct types of counselling must be available at licensed treatment centres. These include implications counselling, support counselling and therapeutic counselling. However, the Code also states that 'no-one is obliged to accept counselling' (p. 28, HFEA Guide). These 3 types of counselling will be briefly outlined in the following.

Implications counselling is concerned with enabling the clients to consider the implications of treatment for themselves, their families and any children born as a result of treatment.

Support counselling is concerned with providing emotional support at particularly stressful times e.g. when treatment fails.

Therapeutic counselling aims to help people cope with the consequences of infertility and treatment. It aims to help the couple/ individual work towards a resolution of the problems incurred as a result of infertility and treatment. It also aims to help the couple come to terms with their situation and adjust their expectations for their future (p.29, HFEA Guide).

The Code states (p.29) that centres *must* make implications counselling available to everyone. It also states that they also need to provide support or therapeutic counselling in appropriate cases or refer individuals on to those with more specialised training outside centres. The emphasis placed on the provision of implications counselling by the HFEA, ties in with the HFEA Guide description of infertility counselling. This is any counselling that relates specifically to the infertility itself.

Therefore, it is important to bear in mind that many couples experiencing infertility will only be offered counselling once they embark on treatment. Furthermore, whilst many people may be offered counselling for issues involved in the treatment and support for failed attempts, they may not be offered any therapeutic counselling.

In light of this there are likely to be a high number of individuals experiencing issues in relation to their experience of infertility who are not having their emotional and psychological needs met, for one reason or another. As a result, these factors will continue to contribute to the distress experienced by many individuals and couples.

Specific Research Focus

A number of people close to me have gone through the experience of discovering that they are unable to conceive naturally. Through their experience, I have witnessed the impact on both of the individuals within that couple and on the couple as a unit.

As discussed earlier, there are a number of decisions facing the couple experiencing difficulties conceiving. Running parallel to these joint decisions is the process that each individual within the couple goes through. Their assumptions, beliefs, expectations and dreams are challenged. What they held to be true about being a male / female in relation to conceiving / bearing a child, over time becomes uncertain (Mason, 1993; Crawshaw, 1995).

Therefore, it is not surprising that in my observations of these friends the concerns and feelings disclosed or discussed tend to vary depending whether the couple are talking in the presence of each other as a 'couple' or whether they are talking alone, as an 'individual'. For example, when the couple talk in the presence of each other, the focus tends to be more about the loss of dreams for the couple e.g. children and how it changes their vision for the future. Thus implicitly alluding to their changing identity as a couple e.g. from couple who might have children 'one day' to a potentially childless couple.

However, when talking alone the feelings and concerns expressed, tend to focus on what it means to them as a female/male. This highlights the 3 identities inextricably linked to any couple - those of the 2 two individuals and that of the couple.

Greil, (1997) reviews the literature on the social psychological impact of infertility, with particular reference to the relationship between gender and the infertility experience. Amongst the findings, it is concluded that more attention needs to be paid to the way in which social structural realties condition the experience of infertility. It is also argued that ways of accounting for the processual nature of the infertility experience need to be developed.

Our identity is shaped through experience and is continually evolving through the lifespan as we move through different experiences. I am interested in exploring how the ongoing experience of infertility contributes to the 3 changing identities linked to a couple. In short I am interested in looking at how the process of the infertility experience shapes identity.

Rationale for conducting this research:-

- To consider how social structural realties condition the experience of infertility and impact on identity.
- To build a theory that explains how the process of the infertility experience contributes to the changing identity of the couple and individuals within the couple.
- Use the theory to understand what the different psychological and emotional needs of the couple and the individuals within the couple experiencing infertility might be at any given stage of the infertility process.
- Use the findings to raise practitioners awareness of these emotional and psychological needs, particularly those working in the area of 'therapeutic' counselling.
- Provide a platform for further research into the psychological and emotional needs of the couple and individuals experiencing infertility and its consequences.

Research Methodology

I have decided that the research paradigm that fits best with this research topic is a qualitative research paradigm. I feel that it is a compatible methodology because the epistemological assumptions underlying qualitative research have many parallels with the theory and practice of counselling psychology. Central to the practice of counselling psychology is its humanistic value base (Duffy, 1990). This value base emphasises that each human being is separate and that their subjective experience, feelings and meanings are unique (Woolfe, 1996). This highlights the value of employing a research strategy that reflects this value base when searching for meanings constructed by individuals about their unique experience of infertility. The purpose of my research is to build a theory based on

the exploration of feelings, perceptions and experience – issues central to the practice of counselling psychology.

Another strength of utilising this approach for my MSc dissertation in counselling psychology is that doing qualitative research is similar to doing therapy in that a skilled qualitative researcher uses empathy, genuineness and acceptance in the development of the relationship with informants (Mearns & McLeod, 1984). I am hoping that my reflective skills as a counselling psychologist in training will provide me with a firm base to work from in the interview process as a relative newcomer to qualitative research.

There are at least 26 different qualitative research frameworks (Tesch, 1990) and I have chosen to adopt a Grounded Theory framework, as taught by Strauss (1987).

Grounded theories are derived from data that has been systematically gathered and analysed. Strauss & Corbin (1998) argue that because these theories are drawn from data, they are likely to offer insight, promote understanding and provide a meaningful guide to action. They also argue that theories derived from data are more likely to resemble "reality" (p.12).

Therefore adopting a grounded theory framework is considered appropriate because the aim of this study is to build a theory. A theory of how the process of infertility shapes identity.

Firstly semi-structured interviews will be conducted. The accounts or stories that interviewees provide about their personal experience of the infertility process will be systematically analysed. This search for and clarification of the meanings that surround or are attached to the issue of infertility and how these meanings consequently shape identity will provide the basis for the developing theory.

This theory will hopefully form the basis for more serious scientific investigation, which would employ quantitative methods at a later date.

Sample

My aim is to gain a broad perspective of the experience of infertility at different stages. Therefore, I am going to interview 6 couples and each of the individuals, resulting in 18 interviews in total. The sample will be made up of 3 couples who have had a successful IVF cycle and 3 who have not.

At present I have access to 4 couples through my own personal network who have expressed interest in taking part. To make up the complete sample, I intend to ask friends and colleagues if they know anybody who would be willing to take part in my research.

Ethical Considerations

The topic of infertility is a sensitive one. I realise that this may be the first time that the individuals/couples taking part have spoken to anyone outside their relationship or very close friends about their experience. Therefore talking about their experience is likely to evoke new or underlying feelings for each of the individuals and between them as a couple. They may also disclose more than they intend to. It is my responsibility to be transparent and manage participants' expectations. Thus, I need to make sure that participants are made aware of this and that these issues are highlighted before they agree to take part.

In line with this, all clients will receive a cover sheet with their consent form. The cover sheet acknowledges the fact that feelings may be evoked either during and/or following the interview. It states that the interview is not the appropriate place or time to deal with these feelings. To prepare participants, it explicitly states that should I feel that the interview is drifting into counselling then I will shift the focus back to the interview. Sticking to the interview should serve to protect the participants from disclosing more than they want to.

All participants will receive a sheet of contact details of different organisations offering counselling and support with the cover sheet.

It is my ethical responsibility to manage the boundaries and be aware of interviewees' feelings at all times. Should the line between the interview and counselling be crossed, I will sensitively but firmly change the focus back to the interview.

I will need to be mindful of my position in the role of interviewer and be aware of falling into the trap of wanting to counsel. This is likely to be especially difficult for a counselling psychologist in training whose role is to 'counsel'.

In light of this difficulty, I will need to make time for reflection following each interview. I will need to consider how I managed the boundaries. However, it is vital that I reflect on the role that I played in the interview and how this impacted on the responses given and the direction of the interview. I will also need to be aware of the process when interviewing couples. For example, what is the effect of my being there, what dynamics are created between the couple and myself and how are these exerting their effects on the interview (Lee, 1993). This process of reflection can inform my practice as an interviewer in future interviews. It will also form part of the discussion section in the write up. There will also be an informed debate in the full write up considering the issues involved when researching sensitive topics.

Support

I have become a member of the British Infertility Counselling Association (BICA). Membership gives me access to a network of individuals currently working in the field. I have already contacted a couple of different members who have expressed their interest in my area of research. My intention is to take up their offer to discuss my ideas with them at different stages of the research process.

I am aware that conducting research in this area will be difficult emotionally at times. With this in mind, I have considered working with my personal therapist again.

I have a close network on the course with whom I speak regularly about the research process. We support each other and exchange ideas on a regular basis.

Presentation of Findings

My aim on completion of this research is to publish the findings. The intention is to raise awareness of the how the couple / individual identity changes with the experience of infertility. This will have implications for the area of therapeutic counselling currently offered at clinics and in private practice.

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APPENDIX 39

Conversion of MSc to DPsych - Research Proposal

Research Proposal in respect of my application for the Counselling Psychology DPsych Transfer

Joanne Perkins

April 2004

Overview

I intend to conduct my doctoral research in the area of infertility, building and extending on the findings from my current MSc research in this area. A background to the topic of infertility is provided in the following before addressing the specific focus of the intended research. After this the choice of methodology is addressed.

Infertility – a definition

A widely held expectation is that should those who choose to have children will be able to. This assumption is not challenged until such a time prolonged difficulties in conceiving are experienced. 'Infertility' is defined as the failure to conceive after one year of engaging in sexual intercourse without contraception (Mosher & Pratt, 1982).

Infertility – facts and figures

Infertility affects over 80 million people worldwide (World Health Organisation, 2003). According to The Human Fertilisation and Embryology Authority (HFEA, 1999) 1 in 6 couples experience fertility problems. Amongst these couples, female infertility accounts for 40% of all cases with 30% being accounted for by male infertility. The remaining 30% of infertility is due to infertility in both partners and unexplained infertility (HFEA, 1999).

Infertility is not a new problem. It has been prevalent through the ages, however traditionally it has been a taboo subject (Marsh & Ronner 1996; Pfeffer, 1993). Statistics confirm that the incidence of infertility has not increased over time but that the number of people presenting with fertility issues have increased (Read, 1995). This is largely due to medical and technical advance during the last 30 years which have meant that the possibilities available to the individual/couple experiencing infertility have grown considerably. Moreover, social and economic change over this time has made advances in technology such as in vitro fertilization (IVF) more accessible to a wider range of people. These possibilities are about to be extended to a broader population, with guidelines from the National Institute of Clinical Excellence (NICE, 2004) stating that the NHS will provide 1 free cycle of IVF for all females aged between 23 and 39 who meet certain clinical criteria from April 2005.

2004 saw the 25th anniversary of the birth of the first baby through IVF. Since then, more than 68,000 children have been born through IVF in Britain. Over 8,000 of these babies were born in the 12-month period between 1st April 2000 and 31st March 2001. This figure makes up 12% of the total number of babies born through IVF in the last 25 years. However, whilst the number of babies born through IVF is increasing, the success (live birth) rate for patients of all ages is still only 22% (HFEA, 1999).

The infertility experience

The experience of infertility is a multi-layered and complex phenomenon. There are a number of issues involved for the individual/couple experiencing infertility, e.g. biological, emotional, physical, relational, social, financial and psychological and the pain and loss that they face can be immense. Gibson & Myers (2000) found that the infertility experience can cause serious emotional, psychological & social distress. The experience can also have a significant negative impact on marital and sexual relationships (Leiblum, Aviv & Hamer, 1998).

Infertility counselling
In light of the complexities of infertility, the HFEA state in their Code of Practice (1990) that three distinct types of counselling must be available at licensed treatment centres. These include implications counselling, support counselling and therapeutic counselling. However, the HFEA Code of Practice also states that 'no-one is obliged to accept counselling' (p. 28, HFEA, 1999).

It is important to bear in mind that many couples experiencing infertility will only be offered counselling once they embark on treatment. Even then only be 1 session they are offered. In addition, it cannot be assumed that because counselling is offered, it will be taken up.

In light of this there are likely to be a high number of individuals experiencing issues in relation to their experience of infertility whose emotional and psychological needs are not met. As a result, these emotional and psychological issues can contribute to the distress experienced by many individuals and couples.

Relevance to counselling psychology
The role of counselling psychologists is to work 'therapeutically with clients with a variety of problems, difficulties and life issues and crises' (BPS Division of Counselling Psychology, 2002). Furthermore, given that there is a focus on the wide range of 'human psychological functioning across the lifespan' (BPS Training Committee in Counselling Psychology, 2003. p.3) within counselling psychology, we need to understand how psychological functioning can be affected by issues encountered during the pivotal childbearing period of our lives.

So counselling psychologists not only need to be able to work therapeutically with this growing client group and their specific needs, they also need to ensure that the appropriate services are developed and made accessible to these clients.

Specific Research Focus
My current MSc research explored the nature of the infertility experience for males and females and how this experience impacts on the couple relationship. A model of the overall infertility experience was developed (Figure 1). It was found that the infertility experience is emotionally and psychologically more distressing for females than males, which is in line with the findings of Gibson & Myers (2000) and Leiblum et al. (1998). It also identified that the infertility experience is qualitatively different for the female compared to the male, with the female experience being more emotionally and psychologically distressing than for the male.

I am still discussing ideas for building and extending my MSc research for my doctoral research with my supervisor Dr Don Rawson. A firm direction has not been established at this stage however I am very interested in exploring the factors involved for couples and /

TEXT BOUND INTO

THE SPINE

Figure 1. Overall Model of the Infertility Experience

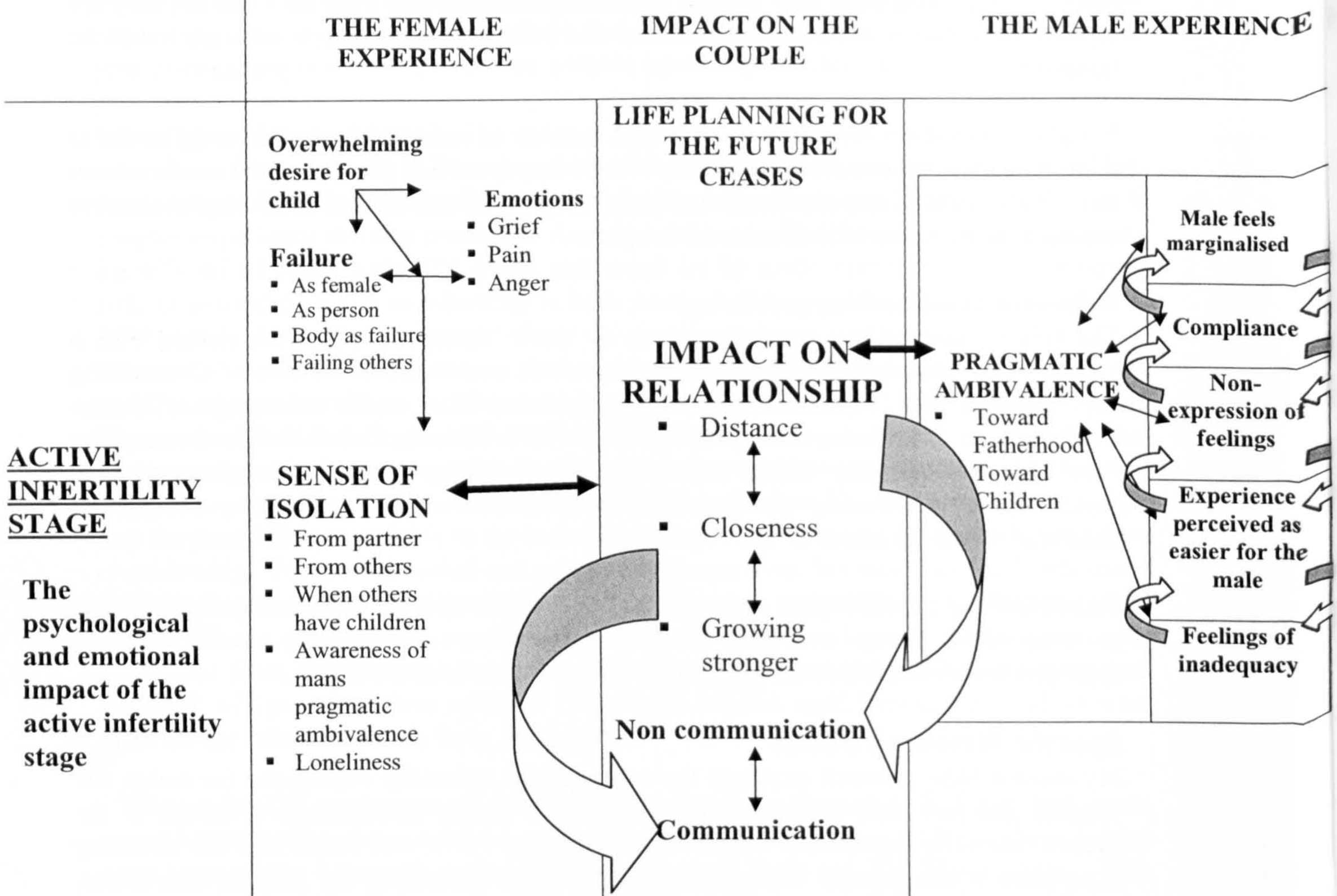
PRE ACTIVE INFERTILITY STAGE

Planning a family

- Decision to have a child
- Actively trying to conceive
- Not falling pregnant – female goes to GP

ACTIVE INFERTILITY STAGE

The psychological and emotional impact of the active infertility stage



POST ACTIVE INFERTILITY

Active infertility stage ends with:-

- Pregnancy
- End of treatment
- The decision to face future without children
- Adoption

Becoming a mother	Facing future without children	Whether becoming a family or facing a future without children	Fatherhood	Facing future with children
▪ Happy ▪ Complete ▪ Normal	▪ Process of acceptance ▪ Grieving ▪ New direction for future	▪ If couple stay together they emerge stronger **LIFE PLANNING FOR THE FUTURE RECOMMENCES**	▪ Satisfaction	▪ Acceptance

or individuals when choosing whether or not to have counselling for fertility issues. Another option is to explore different aspects of the model in more detail. The ultimate aim with the research would be to gain knowledge that I can apply to counselling practice as I intend to develop a counselling service for this particular client group.

Research Methodology and analysis

The choice of research methodology will be dependent on the best fit with the research aim. Given that at present the specific research aim is under discussion I am not able to confirm which research methodology I will employ.

However, I have found the richness of data gathered when adopting a qualitative approach very useful in understanding the complex topic of infertility. In particular I have enjoyed using a grounded theory approach to data collection and analysis. I am very keen to develop my knowledge of this particular research approach further at doctoral level.

However, I do recognise the value of expanding my skills base as a researcher and I anticipate that this can be achieved with Doctoral level research. As such I would welcome the opportunity to utilise a quantitative approach either alone or in conjunction with a qualitative approach if appropriate.

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APPENDIX 40

Copy of approved ethics release form

Appendix 4: Ethics Release Form

All students planning to undertake research in the Department of Psychology for degree or other purposes are required to complete this Ethics Release Form and have it signed by their supervisor and one other member of staff **prior to commencing the investigation**. Please note the following:

- An understanding of ethical considerations is central to planning and conducting research.
- The published Code of Ethics of the British Psychological Society (1997) Code of Conduct, Ethical Principles and Guidelines. BPS. Leicester and American Psychological Society (1992) Ethical Principles of Psychologists and Code of Conduct. American Psychologist, 47, no 12, 1597-1611 should be referred to when planning your research.
- Approval to carry out research does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, eg: Hospitals, NHS Trusts, HM Prisons Service, etc.
- Completed and signed ethics release forms must be submitted as an appendix in the final dissertation

Please answer all of the following questions:

1.	Has a research proposal been completed and submitted to the supervisor?	Yes ☑	No ☐
2.	Will the research involve either or both of the following:		
	2.1 A survey of human subjects/participants	Yes ☑	No ☐
	2.2 An intervention with a cohort of human subjects/ participants, and/or an evaluation of outcome of an intervention?	Yes ☐	No ☑
3.	Is there any risk of physical or psychological harm to participants (in either a control or experimental group)?	Yes ☐	No ☑
4.	Will all participants receive an information sheet describing the aims, procedure and possible risks involved, in easily understood language? (Attach a copy of the participants information sheet)	Yes ☑	No ☐
5.	Will any person's treatment or care be in any way prejudiced if they choose not to participate in the study?	Yes ☐	No ☑
6.	Will all participants be required to sign a consent form, stating that they understand the purpose of the study and possible risks ie will informed consent be given?	Yes ☑	No ☐
7.	Can participants freely withdraw from the study at any stage without risk of harm or prejudice?	Yes ☑	No ☐
8.	Will the study involve working with or studying minors (ie <16 years)?	Yes ☐	No ☑
	If yes, will signed parental consent be obtained? N/A	Yes ☐	No ☐

9. Are any questions or procedures likely to be considered in any way offensive or indecent? Yes [ ] No [✓]

10. Will all necessary steps be taken to protect the privacy of participants and the need for anonymity? Yes [✓] No [ ]

Is there provision for the safe-keeping of video/audio recordings of participants? Yes [✓] No [ ]

11. If applicable, is there provision for de-briefing participants after the intervention or study? Yes [✓] No [ ]

12. If any psychometric instruments are to be employed, will their use be controlled and supervised by a qualified psychologist? N/A Yes [ ] No [ ]

If you have placed an X in any of the double boxes [X], please provide further information below:

- SEMI-STRUCTURED INTERVIEWS WILL BE CONDUCTED WITH COUPLES TOGETHER PRIOR TO INTERVIEWING INDIVIDUALLY
- THE FOCUS OF INTERVIEWS WILL BE THEIR EXPERIENCE OF INFERTILITY / DIFFICULTIES CONCEIVING AS A MALE / FEMALE / COUPLE. INTERVIEWS WILL ALSO EXPLORE EXPERIENCES OF COUNSELLING.
- ALL PARTICIPANTS WILL BE PROVIDED WITH AN INFORMATION SHEET CONSISTING OF A LIST OF ORGANISATIONS THAT THEY MAY FIND USEFULL eg SUPPORT GROUPS, ORGANISATIONS, COUNSELLING SERVICES
- PARTICIPANTS WILL ALSO RECEIVE AN INFORMATION SHEET OUTLINING THE RESEARCH AND EXPLICITLY STATING CONFIDENTIALITY.

APPENDIX 41

Summary of the key theoretical concepts used in the work with Sarah

1.1 Core conditions of the person-centred model

The core conditions of the person-centred model provided the foundations of the work, particularly in the 'beginning stage' of the work where the focus is on establishing strong therapeutic alliance (Culley & Bond, 2004). My aim was to form a strong therapeutic alliance with Sarah. To facilitate this I was keen to establish the core conditions of the person-centred approach.

Rogers (1957) stated that there are six conditions that are fundamental to the helping relationship that when combined, are both 'necessary' and 'sufficient' for clients to experience therapeutic change. The first condition is that two people must be in a relationship. The five remaining conditions relate to the characteristics of this relationship. These include the 'core conditions'. As a therapist my goal was to demonstrate empathic understanding of Sarah's frame of reference, convey unconditional positive regard for her and be congruent and integrated as a person. In contrast Rogers (1957) posits that clients, being vulnerable, are in a state of 'incongruence'. Further, whilst therapists aim to convey empathy and acceptance Rogers (1957) argues that clients need to be able to perceive this empathy and acceptance at some level for change to occur. He also argued that the therapeutic relationship is central to the change process. Hence competent practitioners are defined by their level of self awareness and capacity to engage in a meaningful helping relationship rather than any technical knowledge of person-centred counselling (Rawson, 2003).

1.2 Psychodynamic approach

Psychodynamic theory played a central role in the assessment and treatment process with Sarah. In line with a brief psychodynamic approach the key techniques used in the work were transference and interpretation (Malan, 1963).

The psychodynamic model is derived from the psychoanalytic tradition initiated by Freud. A central tenet of the model is the role played by the 'unconscious' in the development and maintenance of conflict and disturbance (McLoughlin, 1995). Material is banished to the unconscious when it is too threatening for the individual to endure (Smith, 1996). In short the material is 'repressed'.

Defences serve the protective role of keeping unconscious material from creeping into consciousness. One of the primary aims of the psychodynamic model is to work carefully with these defences, through acknowledging and analysing 'resistance'. A key technique used in this analysis is 'interpretation'. Therapists formulate hypotheses (interpretations) about defences and the functions they serve for the client. This process alters the structure of defences and brings unconscious processes into consciousness, thereby eliminating symptoms (Smith, 1996). This is a function of gaining a clearer understanding of their past, and present patterns of relating to both themselves and others, then paving the way for future patterns of relating.

In contrast with traditional long-term psychodynamic work interpretations are made more directly and regularly in short-term therapy and tend to relate specifically to the focus and goals of the therapy (Malan, 1963).

The core of psychodynamic counselling is what Jacobs, (1999 p.14) calls a 'many-layered way of understanding the client' and helping the client to reach an understanding of her/him self. In short it is a search for meaning.

The 'transference relationship' (Smith, 1996) that develops between the client and counsellor is a core element of the psychodynamic approach. Clients past patterns of relating are present in the therapeutic encounter, with the use of the therapist as a 'surrogate' for significant others in their past (Smith, 1996); the emotional release that ensues is a function of 'transference'. For example, clients will experience their therapist as frustrating, because of their inability to meet the client's needs. It is the process of partially meeting the client's wishes that unconscious material starts to enter the session. This results from a loosening of the repressed material.

Just as there is a meeting at the conscious level between client and therapist, so there is at the, deeper unconscious level (McLoughlin, 1995). The therapist in response to the transference will experience feelings, fantasies and impulses. These feelings, referred to as counter transference, need to be carefully considered as to whether they are meaningful in the communication between client and therapist. Counter transference can be considered as communication at a deeper level.

1.3 Cognitive-behavioural approach

The theory behind CBT has developed from Beck's (1976) cognitive theory of emotional disorder assessing the relationship between negative early learning experiences, maladaptive core beliefs and assumptions that make a person vulnerable to psychological distress. CBT is a collaborative, proactive process between client and therapist.

Schemata have been defined by Beck (1967, 1976) as core beliefs about oneself, other people and the world. These are applied in life in an attempt to interpret and attach meaning to events. Core beliefs are formulated and developed early in life as a means of organising and making sense of the world. Early childhood experiences such as trauma, separation, rejection and parenting style result in core beliefs that are related to 'lovability' or 'competence' (Beck, 1983). In turn, core beliefs give rise to the formation of stable underlying dysfunctional attitudes and assumptions such as ''I can only be happy if I am totally successful''. Core beliefs, attitudes and assumptions in and of themselves do not give rise to psychological disturbance. They are always there but may not be salient until an event is encountered that is congruent with the schemata held by an individual (Moorey, 1996). This is when they are susceptible to activation.

Once schemata are activated they are responsible for causing systematic biases and distortions when the individual is processing information regarding situations and experiences, defined as 'logical errors'. The anxious patient makes different logical errors that contribute to the anxious state. Cognitive distortions include - *arbitrary inference,* which refers to the act of reaching a conclusion in the absence of any evidence to support it. *Selective abstraction* is characterised by extracting one detail from a situation, focusing on it and in turn, using this one small aspect of the situation as a basis for summarising the whole experience. *Overgeneralisation,* refers to the universal application of one fact drawn from one experience, to all other situations whether or not it is valid. *Magnification and minimization,* are gross errors that are made when interpreting the significance of a situation, minimising success and magnifying mistakes.

Three main goals of CBT are to 1) relieve symptoms and resolve problems 2) provide the client with coping skills and 3) help the client challenge underlying negative schemas to prevent relapse (Moorey 1996). The cognitive model views cognitive processes as influencing and determining behaviour and mood. Cognitions, emotions and behaviour are thought to interact reciprocally (Scott & Dryden, 2001). Since cognition is allegedly learned, the model assumes that maladaptive thinking can be challenged and new modes of thinking adopted, thereby alleviating symptoms. Based on the cognitive model it follows that the primary emphasis in treatment of emotional disorders is on breaking out of the negative chains via cognitive and behavioural ports of entry. A number of behavioural and cognitive techniques can be utilised in therapy including verbal challenging, reality testing, decatastrophising, relaxation, problem solving and thought monitoring amongst others (Moorey, 1996).

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