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## A phenomenological study of infertility : the couple's perspective

M. Imeson  
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**A PHENOMENOLOGICAL STUDY OF INFERTILITY:  
THE COUPLES' PERSPECTIVE.**

**BY**

**M. Imeson (Bachelor of Nursing)**

**A Thesis Submitted in Partial Fulfilment of the Requirements  
for the Award of**

**Master of Nursing**

**at the School of Nursing, Edith Cowan University**

**Date of Submission: 25. 08. 95**

## USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

## Abstract

The purpose of this phenomenological study was to describe and interpret the experience of infertility from the perspective of infertile couples, in order to gain an in-depth understanding of how it affects their lives. Ten to twenty per cent of the global population share the experience of infertility, however, little is known of their experiences and perceptions related to infertility. Literature to date mainly focuses on the physiological effects of infertility and does not take into account the context in which the experience takes place, or the meanings that people assign to this experience.

To be effective, health carers need to understand the perspective of those experiencing the phenomena in order to provide appropriate information and care.

A phenomenological approach was adopted for the study. A purposive sample of six couples was selected for interview. Data were generated from taped interviews and the researcher's observational field notes. Data analysis was in accordance with the procedure outlined by Colaizzi (1978), which is to describe, interpret, and extrapolate common themes and meanings from the data. Interview responses were categorised by examining the participants' transcripts, and identifying significant statements and meanings. Themes which emerged from the statements were then identified, and cross-case comparisons were made to confirm or modify these themes.

Four key themes emerged from the data: Life Changes; Powerlessness; Hope-Disappointment Cycle; and Social Isolation. All couples undergoing infertility treatment experienced life changes which include: lifestyle changes, various physical and emotional changes, and changes in their

relationships. There was a perceived loss of control over many aspects of their lives. Couples also described a cycle, alternating feelings of hope and disappointment. Most of the couples reported feelings of social isolation associated with being infertile, that were intensified by having to deal with the inappropriate responses of others.

Findings from this study will add to the knowledge base on infertility, and contribute to recommendations for improving the way health care providers guide, counsel, and support infertile couples.

### Declaration

**"I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text."**

### Acknowledgments

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## Chapter One

### Introduction

'and when Rachel saw that she bare Jacob no children,  
Rachel envied her sister; and said unto Jacob, Give me children  
or else I die.' (Genesis 30:1)

This study investigated the experience of infertility from the perspective of the infertile couple. Infertility is defined in medical and nursing texts as the inability to conceive a pregnancy following one year of regular sexual relations in the absence of contraception, or the inability to carry a pregnancy to a live birth (Corson, 1993; Garner, 1991; Menning, 1988; Trepanier, 1985; Woods, Olshansky & Draye, 1991). However, infertility is a phenomenon that is much more complex than its medical definition suggests.

### Background

#### Incidence

Accurate statistics on infertility are not available due to the fact that not all infertile couples present for treatment (Pepperell, Hudson & Wood, 1987). The incidence and prevalence also varies from region to region. The World Health Organization (WHO)(1992) reports that approximately 8-10% of couples (world-wide) experience some form of infertility problem during their reproductive lives. The rates for developed countries, such as the United States, Canada, the United Kingdom, and Australia, are slightly higher. It is estimated that 15-20% of couples within the reproductive age range present for

infertility treatment (Edwards, 1989; S. Dill, personal communication, May 25, 1995; Rowland, 1985).

### Causes

The causes underlying infertility, vary with geographical location and are influenced by socioeconomic factors (Pepperell et al., 1987; Yovich & Grudzinskas, 1990). The main causes of infertility in the developing countries are reported to be tuberculosis (causing ill health and genital tract infections), venereal disease (especially gonorrhoea), post abortal and post partum infections, and malnutrition (WHO, 1992; Yovich & Grudzinskas, 1990). In developed countries, there is a considerable difference in the pattern of underlying causes. Ovulatory dysfunction, spermatozoal disorders, pelvic endometriosis and tubal disease have been cited as the main causes (Corson, 1993; WHO, 1992; Yovich & Grudzinskas, 1990).

There have been numerous factors associated with and related to the causes of infertility. It is estimated that female causes of infertility account for 40% of cases, male causes account for 40% of cases, and 20% of cases are due to combined or unexplained causes (Garner, 1991; Menning, 1982; Shattuck & Schwarz, 1991). Yovich and Grudzinskas (1990) state that approximately 25% or less can be attributed to a single factor. Most cases (75% or more) reveal a multifactorial basis, although often a single dominant condition appears to have importance over other identified factors.

While it is the individual who has the reproductive impairment, it is typically couples who experience infertility (Greil, Leikto, & Porter, 1988). Infertility causes considerable personal suffering, as well as carrying a social stigma in many cultures, as most men and women have strong emotional, social, and cultural reasons for wanting children (Yovich & Grudzinskas, 1990).

In many societies, having children is still the woman's *raison d'être* and establishes the man's identity (Corson, 1993; WHO, 1992).

### Treatment Options

During the last decade, advances in medicine and technology have expanded the range of treatment options available, which has contributed to an increased demand for infertility treatment (Laffont & Edelmann, 1994). Other explanations for this increase include a higher incidence of infertility, more couples actually seeking treatment, increased interest in infertility as a speciality among physicians, and a more pro-family oriented society (Blenner, 1990; Hirsh & Hirsh, 1989). The specific treatment offered to couples falls under the following four broad categories: management of specific conditions, ovarian stimulation, gamete manipulation and substitution (donor), and surrogacy (Pace-Owens, 1988; WHO, 1992; Yovich & Grudzinkas, 1990).

The nature of the infertility experience is also receiving more attention in the infertility literature, although the emphasis still remains on aetiological factors and medical management. The related statistics and the physical aspects of infertility continue to be studied extensively (Corson, 1993; Webb & Holman, 1992; WHO, 1992; Yovich & Grudzinkas, 1990). Blenner (1992) suggests that because of its prolonged, intensive, and highly technical aspects, infertility treatment may focus too much on the physiological side of treatment with little attention given to individuals' emotional responses.

### Significance of the study

Although a great deal is known about the diagnosis and treatment of infertility, less is understood about the human experience and responses to diagnosis and treatment outcomes (Woods et al., 1991). Health carers are often in a unique position to effectively help with the psychological and social aspects, but to intervene effectively, they must understand the meaning of the phenomenon to the couples experiencing it (Draye, Woods, & Mitchell, 1988).

The published literature supports the need for the education, support, and counselling of infertile couples (Blenner, 1992; Clapp, 1985; Mahlstedt, 1985; McCormick, 1980; Menning, 1988). There is a general consensus that the emotional needs of infertile couples are still not being met.

Since previous research has been conducted in North America in the 1970's and 1980's, and has focused on infertile womens' perspectives, it seems pertinent to examine the infertility experience in Australia in the 1990's. In particular, it is important to understand the experience of infertility from the perspective of the couples seeking treatment. Knowing the range of responses to infertility, and how infertility affects the lives of those experiencing it, will enable the health care provider to better understand the nature and meaning of infertility. This, in turn, will lead to the provision of quality guidance and counselling that will assist infertile couples to gain control, develop new insights and coping skills, and tap personal strengths and resources that they will need to move through this critical process.

### Purpose

The purpose of this qualitative study was to describe and interpret the common shared meanings of the infertility experience from the perspective of those couples experiencing it.

### Objectives

1. To examine the infertility experience from the perspective of infertile couples' experiences and needs.
2. To interpret infertile couples' common meanings of infertility.
3. To broaden the knowledge base related to infertility, so health carers can provide improved guidance and support.

### Definition of Terms

#### 1. Infertility

The inability to conceive a pregnancy following one year of sexual relations in the absence of contraception, or the inability to carry a pregnancy to a live birth (Corson, 1993; Garner, 1991; Menning, 1988).

#### 2. Primary infertility

Pregnancy has never been achieved with either partner (Corson, 1993; Garner, 1991).

#### 3. Secondary infertility

Previous pregnancy has been achieved (regardless of outcome) but subsequent pregnancy has not occurred (Corson, 1993; Garner, 1991).

#### 4. *In vitro* fertilisation (IVF)

Medical stimulation of the ovaries to provide multiple ova. Surgical retrieval of the ova to be fertilised by partner's sperm or donor sperm, and implantation of the embryo into the uterus (Yovich & Grudzinkas, 1990).

#### 5. Systemic Lupus Erythematosus (SLE)

This is a chronic inflammatory disease of the collagen or supporting tissues of the body. Connective tissue is found throughout the body, therefore almost any organ or structure can be affected. The overall effect is an alteration in the body's immune response to its own tissues. (Wong, 1993).



#### 6. Intracytoplasmic Sperm Injection (ICSI)

Requires only one sperm which is injected (by microinsemination) into the centre of an ovum in a laboratory setting. When fertilisation occurs, the embryo is transferred to the lining of the female's uterus (ACCESS, 1994).

#### 7. Artificial Insemination by Husband (AIH)

The husband's or partner's sperm is artificially inseminated via the female's cervix or uterus (Yovich & Grudzinkas, 1990).

#### 8. Artificial Insemination by Donor (AID)

Donor sperm is artificially inseminated via the female's cervix or uterus (Yovich & Grudzinkas, 1990).

### Structure of the Thesis

Chapter one introduces the research topic and discusses the background and significance of the problem. Appropriate definitions relating to the experience of infertility are given, and the purpose, objectives, and research question are provided. Chapter two is comprised of a brief literature review which identifies some related studies and gives the reader a broad overview of research interest related infertility. The third chapter provides an explanation of the research method. This section includes a description of the design, research sample, data collection and data analysis. The limitations of the study, validity, and the ethical considerations are addressed. The study's findings are presented in chapter four.

Chapter five includes a discussion of the study's findings, implications, recommendations, and suggestions for further research.

## Chapter Two

### Literature Review

In phenomenological research studies, it is not appropriate to present a comprehensive literature review. According to Oiler (1982), since the researcher's intent is to "bracket" prior explanations about the phenomenon, a comprehensive literature review should be delayed until all the data are collected. However, a brief literature review has been presented to provide some background information for this study, in order to give the reader a broad overview of the work which has been done on infertility to date.

Research on the infertility experience in Australia has been extremely limited. This is surprising, since Australia is considered to be a world leader in the treatment of infertility (Fisher, 1990). In Australia, there is virtually an exclusive focus on the physical factors, such as aetiology (Webb & Holman, 1992), causes and treatment options (Yovich & Grudzinskas, 1990) and related ethical issues (Crowe, 1985; Noble & Bell, 1992; Rowland, 1985).

The literature review will explore several themes that have emerged in relation to the non-physiological components of infertility. These include emotional and behavioural aspects, gender influence, and stage of infertility.

#### Emotional/Behavioural Aspects

There has been a variety of studies relating to the emotional and behavioural responses to infertility. Menning (1977) was one of the earliest to study the human experience of infertility. As a result of her own infertility experience, she founded an infertility support group (RESOLVE) and used the Grief Model as a framework for counselling infertile couples. Although her work was not defined as a research study, and numbers of participants were

not provided, she analysed the content of interviews with infertile men and women in the United States of America (USA). She identified themes of stress and grief throughout the interviews. Menning distinguished the grief response of infertility from the grief response of other losses. Her analysis classified participants' responses into a series of stages (surprise, denial, anger, isolation, guilt, resolution) as a result of their loss. Infertility represented a potential loss rather than an actual loss. Menning suggested that people usually experience difficulty with this type of loss, and have trouble actually discussing a potential loss.

Valentine (1986), also using a qualitative design, conducted semi-structured interviews to explore the emotional impact of 26 persons (12 men and 14 women) experiencing infertility. The study was conducted in Columbia (South Carolina), in the USA. All participants reported multiple sources of loss and stress. The findings revealed both emotional and behavioural reactions to the infertility experience, such as anxiety, disorganisation, distractibility, moodiness, and fatigue. On the basis of these findings, Valentine (1986) suggested that infertility is experienced as a crisis.

Within the context of a larger study, conducted in Boston at the Massachusetts Medical Centre, medical researchers Gurian, Wexler, & Baker (1992) identified delayed behavioural reactions, such as late life paranoia as being attributed to the infertility experience.

These researchers suggest there is an interaction among early trauma, the absence of children, and the appearance of paranoid ideation late in life. Included in this study were 39 research participants (37 of which were women), who were experiencing late life onset of paranoid symptoms. The data were collected from patient records and from semi-structured interviews with a clinician associated with aged care (Positive Aging Services). They reported

that one of the most consistent findings in studies of late onset paranoia is the relatively low number of offspring. The assumption has always been, that as one grows older, the absence of a family or close associate whom one can rely on and talk with, increases the probability that thinking becomes delusional. However, this study highlights that it is not just a question of having a lower than average birthrate. There was only a single live birth among those women identified as late-life delusional disorder patients, even though 27 participants had been married, and eight of those had been in long term marriages. These researchers hypothesised that rather than a constricted social network being responsible for the onset of the paranoia, delusional patients may truly be infertile.

Flemming and Burry (1988) conducted an explorative survey to investigate ways in which infertile people coped with their feelings. These researchers surveyed 83 participants (70 females, and 13 males) who volunteered to complete a questionnaire consisting of both closed and open ended questions. The ages of these participants ranged from 25 to 41 years.

Survey responses suggest that infertility does not appear to be a single, identifiable event which can be resolved, then forgotten. The emotional and behavioural responses to infertility may be more like one's response to a chronic illness (requiring coping strategies for adaptation and adjustment over time), rather than a response to an acute illness (requiring resolution). The researchers concluded that infertile persons may require ongoing support, and counselling throughout the life cycle, rather than short term crisis intervention. This is consistent with the findings from Gurian et al. (1992) study.

### Gender Influence

Although infertility is an unanticipated circumstance that carries both emotional and psychosocial consequences of varying intensity for both individuals and couples, infertility research tends to focus on the woman and her experience (Allison, 1979; Callan, 1987; Sandelowski, 1988). With the exception of Phipps (1993), few studies have addressed the male experience with infertility, or examined the similarities and differences in the infertility experience of partners.

Phipps (1993) conducted a phenomenological study in Tulsa, Oklahoma involving eight infertile couples. The purpose of the study was to identify the common, lived experience of infertility for both males and females. Four couples were receiving low technology treatment (non IVF treatment), and the other four couples were not involved in treatment. Couples involved in IVF treatment were purposely excluded from the study. The couples were interviewed separately, and the interview data were analysed according to Collaizi's (1978) technique. Nine common themes of the male experience were identified and 10 common themes for the female experience. While many of the themes were similar for both men and women, the results of this study also showed that the individual infertility experience is strongly influenced by gender and gender role expectations.

Infertility has traditionally been viewed as a female problem in both the physical and psychological domain. According to a variety of sources, women have been expected to suffer greater psychological repercussions, when infertility occurs (Daniluk, 1988; Draye et al., 1988; Greil et al., 1988; Hirsh & Hirsh, 1989; McEwan, Costello, & Taylor, 1987).

In particular, the study conducted by McEwan et al. (1987) had some very significant findings. These researchers invited clients attending an

infertility clinic in Calgary, Canada to fill out a self report questionnaire. The General Health Questionnaire (GHQ) is a 60 item questionnaire designed to identify cases of nonpsychotic emotional disturbances of recent onset. Sixty two women and 45 men completed the questionnaires. Findings revealed there was more evidence of distress among women than among men. Forty per cent of women, and 13% of men experienced symptoms of clinical severity, and exceeded threshold scores for distress on the GHQ. In particular, women who felt personally responsible for their infertility were more distressed than those who did not. Based on the findings from this study, the researchers suggested that women show poorer adjustment to being infertile than men, and that women tend to view reproduction as a more central component of their gender role identity.

### Stage Effect

The effect that the length of time and the different stages during the infertility process may have on an individual and/or couple has not been thoroughly examined. The limited research in this area seems to indicate that the infertility experience will be affected by the different stage or time in the infertility process.

Berg and Wilson (1991) recruited 104 infertile couples in Lexington, Kentucky, to complete self report questionnaires. These researchers found that psychological functioning across stages of treatment for infertility differed significantly. The general psychological functioning in this study was measured using the Symptom Check List (SCL-90-R) and a summary measure, the Global Severity Index (GSI). The SCL-90-R has nine symptom dimensions and is considered to have sound consistency and test-retest reliability. Results from this study indicated that during the first year couples experienced a

moderate amount of emotional strain. During the second year the amount of emotional strain decreased, and results from the third and subsequent years showed marked increases.

Daniluk (1988) studied infertile couples from the first visit to six weeks post diagnosis and found an increase in psychological symptoms for both men and women at the initial visit. There was also a tendency for infertile women to experience more psychological symptoms after receiving the diagnosis. Results from this study indicated that there were heightened levels of intrapersonal and interpersonal strain, for both men and women, during the more advanced stages of treatment.

On the other hand, McEwan et al. (1987) found that the time attempting conception was unrelated to emotional distress. However, the average time in treatment was just ten months and the sample may not have had a broad enough range of couples to establish an effect.

In summary, the present literature examining infertility and the influence of gender and stage in the infertility population is inconclusive. The infertility literature (world-wide) is predominantly medically oriented and has also focused on the physiological aspects of infertility. Proportionately little attention has been given to the emotional aspects of infertility, and in particular, the emotional responses to IVF. There has also been a tendency to focus on the experience of infertility for women, even though both partners may be affected.

The overall concept of infertility seems to be inadequately documented from the perspective of couples' shared meanings and experiences. A more comprehensive knowledge base is required by all health carers if they are to understand better the phenomenon of infertility, in order to provide the necessary informational and emotional support.

## Chapter Three

### Methodology

A qualitative design within the interpretivist paradigm was selected to explore couples' experiences of infertility.

#### The Paradigm

The purpose of this study was to examine, describe, and interpret the couple's perspective of the experience of infertility. As such, it is concerned with the process of understanding human experience, in context, from the participants' perspective. This type of research is ideally suited to the interpretivist paradigm.

A paradigm is a particular world view, a general perspective, a way of breaking down the complexity of the real world (Patton, 1990). A debate exists as to which inquiry paradigm to use; logical-positivism or interpretativist inquiry. The debate is rooted in philosophical differences about the nature of reality (Patton, 1990).

One paradigm is logical positivism; the view that scientific knowledge is the paragon of rationality, that scientific knowledge must be free of metaphysics, that is, that it must be based on pure observation free of the interests, values, and purposes of individuals (Howe, 1988). Logical positivism uses quantitative and experimental methods to test hypothetical-deductive generalisations (Patton, 1990). The other paradigm is interpretivism (phenomenological) representing the view that, at least as far as social sciences are concerned; metaphysics (in the form of human intentions and beliefs) cannot be eliminated; observation cannot be pure in the sense of altogether



excluding interests, values, purposes; and that investigation must employ empathetic understanding (as opposed to the aims of explanation, prediction, and control that characterise the positivist view point (Howe, 1988).

Interpretivist (phenomenological) inquiry, uses qualitative and naturalistic approaches to inductively and holistically understand human experience in context-specific settings (Patton, 1990).

The interpretivist paradigm supports qualitative methods. Essentially, the goal of qualitative research is to document and interpret as fully as possible, the totality of whatever is being studied in particular contexts from the people's point of view. This includes the identification, study, and analysis of subjective and objective data, in order to know and understand the internal and external world of people. These dimensions of knowing are essential to ascertain quality features of the people's feelings, attitudes, values, and meanings, and their interpretations or explanations (Burns & Grove, 1987; Leininger, 1985). The goal of qualitative research is to gain an in-depth knowledge about human experience in order to improve care.

A qualitative approach is especially appropriate for this study because many experiences and perceptions related to infertility cannot be quantified, but must be understood by health carers, in order to provide quality care and support. According to Field and Morse (1990) interpretive studies are particularly useful in areas where the understanding and meaning of a phenomenon are the central concern, or where there is insufficient information, such as the experience of infertility. Since the researcher does not attempt to control variables, manipulate the data, or predict outcomes, the positivist stance is not appropriate. The interpretivist paradigm presents the approach that is most congruent with a human science, that deals with feelings and perceptions.

### Methodological Approach

Phenomenology is the study of "lived experience", in that it is an attempt to understand a phenomenon from the perspective of the individuals being studied. Phenomenology seeks to understand more fully the structure and meaning of human experience, and to come to a deeper understanding of the nature of every-day experience (Merleau-Ponty, 1964; Oiler, 1982; van Manen, 1990).

Phenomenology is both a philosophical movement and a research method, in which the main objective is to examine and describe phenomena as they are consciously experienced (Oiler, 1982; Omery, 1983). The phenomenological method does not seek to predict or control behaviour, or to reveal causal relationships, but rather to interpret and understand phenomena by intuiting, analysing, and describing (Keen, 1975; Taylor, 1993). It is without theories about causes and as free as possible from unexamined preconceptions and presuppositions (Speigelberg, 1975).

Phenomenological inquiry is usually held to have originated in the work of Edmund Husserl, although it has gone through several changes and revisions since (Beck, 1992; Taylor, 1994). Husserl was the philosophic mentor to subsequent phenomenologists, such as Martin Heidegger (Walters, 1994). Most of the varying interpretations of phenomenology are associated with the diverging perspective of the philosophers, Husserl or Heidegger (Mitchell & Cody, 1993).

By phenomenology, Husserl meant the study of how people describe things and experience them through their senses. His most basic philosophical assumption was that we can only know what we experience by attending to perceptions and meanings that awaken our conscious awareness (Patton, 1990).

These experiences are thought to provide essential truths about reality that are difficult to discover through quantitative methodology (Spiegelberg, 1975).

Husserl developed a phenomenological method for philosophy that would generate essences of pure consciousness. In order to accomplish this extraction of essence, Husserl maintained that pre-suppositions and values must be held in abeyance. This process is known as 'bracketing' or *epoche* (Mitchell & Cody, 1993). Being a philosopher and a mathematician, Husserl modelled this process on the mathematical strategy of bracketing, used for the solution of equations. In other words, the bracketed part of the equation is treated differently while the rest of the equation is investigated (Walters, 1994).

In contrast to Husserl's conviction that one can bracket one's belief about reality was Heidegger's assumption that human beings can never deny the basic actuality that they always exist already in the world. For Heidegger, the human-world interrelationship is a unity. He did not believe that bracketing was possible, or desirable for 'coming to know the world' (Mitchell & Cody, 1993). Heidegger refined and converged Husserl's phenomenology with existentialism, constituting what is known today as existential phenomenology. Heidegger was primarily concerned with 'being' and with time (Mezquita, 1993 cited in Munhall, 1994). His contention was that the meanings we assign to our experiences radiate between, or are extracted from ourselves and particular situations.

According to Taylor (1994) phenomenologists hold diverse views on epistemological and ontological questions. It was this realisation that encouraged historian Herbert Spiegelberg (1975) to suggest that there is no school of phenomenology representing a rigid, uniform view; rather it would more aptly be described as a 'movement'.

Spiegelberg found the common ground within the phenomenological movement by compiling six foundational processes or, types of phenomenology. These six types of phenomenology are not mutually exclusive, and are unified in a common purpose of giving a fuller and deeper grasp of the phenomenon (Spiegelberg, 1975).

Omery (1983) and Taylor (1994) summarise Spiegelberg's six types of phenomenology in the following way:

1. Descriptive Phenomenology

A direct investigation, analysis, and description of phenomena aimed at maximum intuitive content. Aims to be free as possible from preconceived expectations and presuppositions.

2. Essential (Eidetic) Phenomenology

Perception and probing of the phenomena for typical structures or essences. Seeks to explain these essences and their relationships.

3. Phenomenology of Appearances

Attends to the ways in which phenomena appear in different perspectives or modes of clarity. In other words, determining the distinct from the hazy surrounding it.

4. Constitutive Phenomenology

Studies the processes whereby a phenomenon establishes itself, or takes shape in our consciousness.

5. Reductive Phenomenology

Suspending belief in the reality or validity of the phenomena. This process has been implicit since the inception of the method now becomes explicit through the use of 'bracketing'.

6. Hermeneutic phenomenology

Interpreting the concealed or hidden meanings in the phenomena that are

not immediately revealed to direct investigation, analysis, and description.

Each of the six types of phenomenology are related in part, to the others. There are many paths to the same end in phenomenology. The actual modification of the methodology may vary but the overall goal of understanding the phenomenon is the same.

There have been many interpretations and modifications of the phenomenological method. This could be attributed to the fact that phenomenology is considered to be a movement, rather than a rigid method with prescribed steps. The major interpretations have been developed by people working in the human sciences including: Colaizzi (1978), Giorgi (1970), and van Kaam (1969). Most of these modifications include the first three types (or foundational processes) of phenomenology, which are: descriptive phenomenology, essential phenomenology, and phenomenology of appearances (Salsberry, 1989; Taylor, 1994).

Certain principles are observed, that are consistent with the general phenomenological approach. The phenomenological method seeks to describe the essence, and uncover the meaning of humanly experienced phenomena through the analysis of participant's descriptions. This includes the process of comparing, interpreting, and extrapolating meanings (Omery, 1983; Parse, Coyne, & Smith, 1985; Patton, 1990). It is through the analysis of the descriptions that the nature of a phenomenon is revealed, and the meaning of the experience for the participant is understood. This includes not only the phenomenon in itself but also the context of the situation in which it manifests itself. Knowledge about the experience is expanded by allowing a phenomenon to show itself without the predictive descriptions of the quantitative methodologies (Parse et al., 1985; Polit & Hungler, 1991).

The phenomenological method has value in exploring the meaning of any event that affects human beings (Oiler, 1982; Omery, 1983).

Phenomenology, with its focus on human phenomena is a method consistent with the values and beliefs of a humanistic discipline, such as nursing (Leininger, 1985; Lynch-Sauer, 1985; Munhall & Oiler, 1986).

A few examples of recent studies illustrate the similar yet variable phenomenological methodologies being employed to study questions of human experience. Phenomenology has been used to examine areas that have not been amenable to traditional forms of research, such as the experience of grieving (Pilkington, 1993), and perceptions about being a victims of incest (Kondora, 1993). It has been used to explore the meaning that an illness has for its sufferer (Beck, 1992; Coward, 1990; Coward & Lewis, 1993), as opposed to the scientific studies that have only explored the effect of the pathophysiology on the subject. These examples of phenomenological research have facilitated new understandings of the meaning of these experiences for those individuals. Findings from phenomenological research studies can help health carers to develop an improved understanding of behaviour that goes beyond the physical act of providing care (Field & Morse, 1990).

The phenomenological method is an inductive, descriptive research method, whose purpose is to investigate and describe phenomena within human experience in the way they appear 'in their fullest breadth and depth' (Spiegelberg, 1975). As the purpose of this study was to describe and interpret the shared meanings of the infertility experience from the perspective of infertile couples, the phenomenological approach represented the most appropriate method. It was expected that the study would yield rich, descriptive data, in order to come to a deeper understanding about the experience of infertility. This study was influenced by Husserl's traditional

approach to phenomenology by bracketing preconceived ideas about the phenomenon. The Colaizzi (1978) method was used to analysis the data. The type of phenomenological methodology used in this study was based on all of the foundational processes described by Speidelberg (1975), but most closely resembles that of descriptive phenomenology.

### Design

The design for this study was a field study. The researcher used a combination of data sources which included interviews, observations, and observational field notes (memoranda).

### Sample Selection

The sample was drawn from volunteers who responded to an article in the Sunday Times newspaper, during the national Infertility Awareness Week. In this article, the researcher described the emotional aspects of infertility, and outlined the purpose of the study. The following selection criteria was specified: residing in the Perth metropolitan area, currently seeking treatment for infertility problems, available for the required interviews, and the female of the couple aged between 25 and 40. The WHO (1992) identifies this age range as being the ideal fertile period for a female. Infertile couples who met the selection criteria were invited to contact the researcher to participate in the study.

The researcher selected the first eight couples who responded to the invitation, and who met the selection criteria. As is common in phenomenological research, there was a relatively small number of participants, and their selection was purposive, not random. It is appropriate in phenomenological studies to use a small (8-10) homogenous group to elicit

common shared meanings of their lived experience (Field & Morse, 1990). The sample of eight couples (16 participants in total) provides a richness of descriptive data, given the nature of the in-depth study and analysis of data, and the limited time available for the study.

### Procedure

One hundred and eighty six people responded to the newspaper article by phoning the researcher. The calls were all returned, and the first eight couples who met the selection criteria were included in the study.

During the first telephone contact the researcher established that the couple met the selection criteria, explained the purpose of the study including the benefits and estimated time of involvement, and confirmed the couples' willingness to participate in taped interviews. Arrangements were then made for the interviews to be conducted in the home of the participants at a time that was most convenient to them.

Before the interviews were carried out, the researcher familiarised herself with the current infertility assessments and reproductive technologies in order to be able to identify the specific treatments the couples were having. This background knowledge enhanced the understanding and empathy shown to the participants.

An attempt was made to create an empathetic atmosphere where the participants could relate their experiences spontaneously. The prelude to and termination of the interviews varied in time, and typically involved coffee and informal conversation.

The time for interviews ranged from 45 minutes to two hours. A question guide, comprising open ended questions and prompts (see Appendix A) was used during the first interview. The audiotape was turned on (and



tested) and the first opening question was asked specifically to 'break the ice'. This first question asked by the researcher was "When did you first become concerned with your fertility?" The participants were then asked the essential question of "What is like to be living the experience of infertility?" The researcher encouraged the participants to describe their experience as fully and deeply as possible, but did not suggest to them what to say. Subsequent questions from the question guide were only asked when appropriate, or following a pause. Most of the subject matter asked in the questions was brought up during the course of the interview with only minimal prompting, or redirection.

Empathy was conveyed to participants by attending to each couple through maintaining eye contact, an open posture, and responding to their comments with frequent nods and changes in facial expression. Verbal responses from the researcher were kept to a minimum. This was sometimes difficult as participants wanted to hear the views of the researcher as well as share their own. Forrest (1989) comments on the importance of 'the interview attitude' which includes being an interested and sensitive listener, and setting aside one's own judgements and preconceptions in order to focus on the participants' experiences.

While the verbal responses during the interview were kept to a minimum, the direct involvement of the researcher was not. The researcher simultaneously observed the participants' verbal and non-verbal behaviour, the environment, and her own reactions to the situation. The observed behaviours were described rather than evaluated in the form of field notes. The researcher also used the process of intuition where appropriate. Intuiting is the process of coming to know the phenomenon as described by the participant (Parse et al., 1985). Intuiting requires absolute concentration and complete absorption with

the experience being studied (Oiler, 1982). Every attempt was made to be completely focused during the interview, to write memoranda notes as soon as possible, and read to each description in a quiet setting, in order to minimise distractions and to be able to reflect on the whole experience.

Following each interview, observational records (memoranda) (see Appendices B, F) were written by the researcher on the ease of the interaction, non verbal cues, 'off tape' comments, and the impressions of the researcher following reflecting on the data. These observations provided a check on what was reported during the interviews. These observational records also provided insights into the physical, emotional, and social environments of the couples.

### Data analysis

Data collection and analysis occurred in a circular, nonlinear manner. Data analysis started at the time of the first interview. Even as the participants were talking, the researcher was analysing and reflecting on the data. The process of intuiting, analysing, and describing continued throughout each phase of the analysis.

The data were formally analysed according to the procedure outlined by Colaizzi (1978). This analysis consisted of eight steps, which are: transcribing the data, reading all the participant's descriptions, extracting the significant statements, creating formulated meanings, aggregating formulated meanings into clusters of themes, writing an exhaustive description, identifying the fundamental structure of the concept, and returning to the participants for validation (Colaizzi, 1978; Coward & Lewis, 1993; Forrest, 1989; Knaack, 1984; Omery, 1983).

The researcher set aside (in writing) or "bracketed" her personal views, knowledge, and theoretical assumptions about the experience of infertility (See

Appendix C), at the commencement of the study and rigorous attempts were made throughout the research process to not impose this prior knowledge on the emerging data. This was done in order to separate personal bias from interpretations of the interviews and observational data.

The researcher returned several times to the original transcripts to ensure that they were understood. In this way the essential themes were in an emerging state until saturation of themes occurred, and the researcher terminated the analysis and description.

The following eight steps were used for the data analysis:

1. The audiotapes were transcribed verbatim; some by the researcher and others by a professional typist.
2. Each audiotape was listened to by the researcher to verify the completeness of the written transcripts.
3. Audiotapes were then listened to several times to acquire a feeling of familiarity for each participant's expressed or implied meanings, and to sensitise the researcher to the tonality of language and the way in which each participant spoke. The participants' implied meanings and/or the subjective impression of the researcher were written in parenthesis in the written transcripts.
4. The transcripts were read several times to acquire a sense of their total content. The researcher reflected and intuited on each of the transcripts separately to grasp the uniqueness of their description, and to identify any areas for elaboration.
5. The written transcript from the interview with couple number one was read methodically. Verbatim quotes that directly related to the experience of infertility were extracted to identify significant statements. Provisional themes were identified as they emerged from all data sources. Verbatim quotes of the

significant statements and thematic descriptions were clustered around each proposed theme.

6. This procedure (step 5) was repeated for each transcript. Each couple's transcript was then compared with the other couples' transcripts. The essential themes began to emerge as this process continued, until no new themes were identified and the researcher completed the data analysis and description.

There were originally 10 provisional themes identified, and these were collapsed in a series of stages, until the four essential themes remained.

7. A detailed description of the experience of infertility was written by integrating and interpreting all the data sources. This exhaustive description described the structure of infertility.

8. Second interviews were conducted two months following the first interviews to clarify and validate data from the initial interviews. Participants were posted their copy of the interview transcript and invited to make any necessary additions or omissions.

The follow-up interviews were conducted by telephone, and lasted from 20 to 30 minutes. The female and male partners were both addressed separately by the researcher during the phone interview.

Interview questions were based on the themes found in the initial analysis of the data. The researcher summarised these themes for the couples and asked them to fill in any additional information, verify the themes, and comment on how well they fitted with their own infertility experiences. The researcher documented comments made by the participants. Their comments were then analysed and incorporated into the final study report.

### Validity

Guba and Lincoln (1985) developed four major criteria to meet the tests of rigor in qualitative inquiry (truth value, applicability, consistency, and neutrality). They suggest that credibility be the criterion against which the truth value be evaluated, that fittingness be the criterion against which the applicability be evaluated, auditability be the criterion of rigor relating to the consistency of findings, and that confirmability be the criterion of neutrality in qualitative research. Validity issues in this study are based on the guidelines outlined by Sandelowski (1990), which in turn are based on the four criteria proposed by Guba and Lincoln (1985).

### Creditability

The creditability or truth value in this study was based on the confirmed perceptions of couples who are experiencing infertility. Participants were contacted two months after their initial interview. Information from the transcribed interviews was discussed during the second interview to validate and confirm that the themes identified by the researcher were representative of the couples' experiences.

The primary creditability check involved the participants reading a copy of the typed transcript with the invitation to make any additions, deletions, and/or corrections. None of the couples made any changes to their transcripts. They were informed of the themes that evolved from the categorised data in order to check that the researcher captured the essence of their descriptions.

The second creditability check involved sharing the descriptions, emerging themes, and the steps in the analysis with an experienced nurse researcher, who was the researcher's supervisor.

The combination of the different data sources, namely the audiotaped

interviews, and the researcher's observational records (memos), provided the researcher with a means to validate and cross check findings. This process is known as data triangulation (Patton, 1990). In addition to this, the researcher 'bracketed' her assumptions about the experience of infertility in an effort to limit the potential bias.

#### Fittingness

Fittingness (or applicability) of this study was increased by selecting persons who were not only infertile but able to articulate their experiences (Colaizzi, 1978). In phenomenological research, the recounting of past experience is regarded as reliable data, insofar as it is an expression of the feelings, thoughts, and emotions involved in the phenomenon being described (Colaizzi, 1978; Drew, 1986). Sandelowski (1989) states that fittingness is achieved when the findings can fit into contexts outside the study situation, and when its audience views its findings as meaningful and applicable in terms of their own experiences.

#### Auditability

A study and its findings are considered auditable (consistent) when another researcher can clearly follow the method of sample selection, procedure, data collection and analysis, and report comparable findings (Sandelowski, 1989). The auditability of this study was enhanced by including a sample of the coded transcript (See Appendix D), which helps to clarify the transition of formulated meanings to theme clusters.

#### Confirmability

Guba and Lincoln (1985) suggest that confirmability (neutrality) is achieved when credibility (the truth value), fittingness (applicability), and auditability (consistency) are established.

### Limitations

- The sample group was a purposive sample, rather than a random sample therefore the perceptions of the couples interviewed cannot be generalised to other infertile couples. The range of experiences examined was also limited by sample bias. The age of the female participants (25-40 years) was confined to the norm for fertile women as specified by the WHO (1992). In addition, a more racially and culturally mixed population might have developed a greater range of responses.
- The infertile couples who responded to the advertisement, and agreed to the interviews may represent those who feel strongly, or the more motivated and articulate of infertile persons.

### Ethical considerations

Permission to undertake this study was sought and granted from the Committee for Conduct of Ethical Research at Edith Cowan University. Informed consent (see Appendix E) was obtained from each couple prior to commencement of the interview. Both the researcher and the participants kept a copy of the consent form. Couples were also informed of their right to withdraw from the study, at any stage in the proceedings.

All research participants were guaranteed confidentiality and anonymity. The only demographic data that were obtained during the interviews was information that the participants offered about themselves. This included age, ethnicity, marital status, and occupation. Participants were informed that no names would be identified on records, and that pseudonyms and a coding system would be used. Participants were also informed that if the descriptions are published or presented at seminars, no names will be

associated with the data. Only the researcher will have access to the raw data, the audiotapes, transcripts, and computer discs. All these have been stored in a locked filing cabinet in the home of the researcher, and will be destroyed after a five year period.

The researcher recommended referrals to the following agencies if the research participant (s) became distressed during the interview, if it seemed appropriate, or if help was requested. The available referring agencies were: Women's Health Care House, Family Planning Association, Infertility Clinic at King Edward Memorial Hospital, and the Infertility Support Group. Only one participant was referred to Woman's Health Care House for counselling and possible treatment for depression.



## Chapter Four

### Findings

The purpose of this qualitative study was to interpret the common shared meanings of the experience of infertility from the perspective of infertile couples. The research question that guided this study was: what is the experience of couples seeking treatment for infertility?

#### The Sample

The purposive sample consisted of six infertile couples. It was originally intended that eight couples would be interviewed, however two couples decided to withdraw. All participants were white and Caucasian. The female participants' ages ranged from 27 years to 42 years of age. The male participants' ages ranged from 29 years to 39 years of age. One couple were not married but have been in a stable relationship for 10 years, all other couples were in their first marriage.

All the couples were in the middle to upper end of middle class, and based on their standard of living, seemed financially successful. The participants' occupations ranged from trades, to business managers, professional, and civil servants. Some of the participants were university graduates with at least one degree.

The sample was not limited to a particular kind of infertility problem. Couples were infertile due to variety of reasons including; medical problems such as Systemic Lupus Erythematosus (SLE), dysfunctional sperm, and endometriosis. One couple did not know the cause of their infertility. Two of the female participants had been pregnant but had miscarried prior to the first trimester, the others had never been pregnant.

The couples were receiving various types of infertility treatment, including low technology treatments (AIH) to new advanced high technology treatments such as Intracytoplasmic Sperm Injection (ICSI). Time involved in infertility treatment ranged from three years to 10 years.

Most of the participants were extremely open, and intensely emotional in describing their experiences with infertility. All participants commented on how much better they felt by talking about their experiences. Hutchinson, Wilson, and Wilson (1994) report that this is a common response. It can be extremely beneficial to participate in interviews because of the potential to promote self-awareness and sense of purpose, and provide a healing effect.

Two of the male participants were reluctant to share their own feelings but talked freely about the treatment, and their partner's behaviours. One of the female participants was especially 'ill at ease' but was also able to relate her experiences with the specific details of treatment. It was interesting to note that much of the more emotive information was given towards the end of the interview or, in fact, when the tape-recorder was turned off.

Interview responses were categorised by examining the participants' transcripts and identifying significant statements/meanings. Provisional themes that emerged from the statements were then identified and cross-case comparisons made. There were 10 original provisional themes identified, which were collapsed in a series of stages until the four essential themes remained. For example, the sub-headings Stress, Jealousy, Blame, Sorrow, Anger, Guilt, and Inadequacy were collapsed to become the theme Emotional Issues. This theme was then renamed Emotional Changes and became a sub-theme to Life Changes.

The researcher's field notes, were frequently referred to for comparison of the participants' verbal responses against the researcher's subjective

comments. Ideally, the researcher would have liked to have observed the actual treatment process for two of the couples. Unfortunately this was not possible, due to time constraints, and the intrusion it would create for the couple.

### The Experience of Infertility

Final analysis of the data resulted in four key themes: Life Changes, Powerlessness, Hope-Disappointment Cycle, and Social Isolation. The common experiences for this group of infertile couples were considered in terms of how the infertility treatment affected their lives. All couples undergoing infertility treatment experienced life changes which include: lifestyle changes, various physical and emotional changes, and changes in their relationships. There was a perceived loss of control over many aspects of these couples' lives. Couples also expressed feelings of hope and disappointment which were often cyclical. Most of these people reported feelings of social isolation, associated with being infertile, and having to deal with the inappropriate responses of others.

The six couples all contributed information relating to their experience of infertility, which has been coded using the following system. The verbatim statements are followed by a bracket containing the number allocated to the couple, and a letter to represent female or male (for example, 4f or 3m).

### Life Changes

#### Lifestyle Changes

The information provided suggests that the infertile couples participating in this study are highly motivated towards being parents. Couples recounted various examples of their passion and persistence in trying to become parents. For example, one couple's car broke down on their way to a

clinic appointment for artificial insemination. The couple reported hitch-hiking along the freeway in order to get to the clinic in the required thirty minutes. This couple reported that they actually went out and bought a new car the following day so that they wouldn't fail to meet scheduled appointments in the future.

In the broadest sense, the infertility treatment has become a priority, influencing both their current and future lifestyle. Couples felt they were unable to make plans for their lifestyles, careers, and/or, holidays because the infertility treatment or a pregnancy might confine them. The ability to make long, or even short term plans had been affected.

For some couples, infertility treatment was viewed as having a major influence over their current lives, affecting all their decisions. Three couples expressed this in terms of being "in limbo". Others described the magnitude of the lifestyle change as follows:

"...your whole life seems to be just concentrating on getting pregnant."(6f)

"...obviously you have plans in life about what you're going to do but this thing (infertility treatment) takes precedence over everything...And in the meantime everything else has to be put on the backburner until this thing gets sorted out...You can really see how it can destroy peoples' lives and turn them upside down."(6m)

"Your whole life is consumed by it."(2m)

There were also ramifications for career decisions. Career planning for two of the female participants was hampered by the uncertainty of pregnancy.

"You put your career to one side. Everything's been on hold. 'I won't take this job, I'm going to fall pregnant, and then I'll have to leave.'"(4f)

"It's only been this year that I actually applied to do my Masters because all the other years I've just been putting everything on hold."(2f)

Even short term plans, such as holidays were affected by the infertility treatment.

"All my holidays that I have are spent in treatment so I never get a proper holiday."(1f)

Study participants' expressed concern at how their lifestyles were modified by the cost of infertility treatment.

"I feel guilty...All this money, we can't extend the house and we can't buy another house."(6f)

"We'd have to get a loan to do it (infertility treatment). And it all has to be paid back whether you have a baby or not, so you have to be realistic."(6m)

"It (infertility treatment) becomes too financial."(1m)

"I had to go and buy a reliable car (to get his wife to clinic for treatment). As if this isn't costing enough!"(1m)

Being infertile also affected the couples' future plans. One husband commented on the effect that children would have had on their future lives.

"That's what I'm working for (to provide for children). I do a lot of weekend work, I wanted to get it all out the way for when we have a kid so we can spend our free time with the kid."(1m)

Other people expressed sentiments of how children add meaning to their lives. One husband commented on how children give you purpose.

"Last year, I finally had a gutful and said 'bugger this, what's the point of going to work.' I had no goals. When you've got kids you work for your kids, don't you?...Children give you purpose."(3m)

His wife agreed with him and made the following comment:

"We have become different people to how we would have been with children."(3f)

### Physical Changes

Participants reported negative physical effects of the infertility assessments and treatments. These physical changes all have an adverse effect on the couples' quality of life. The women in particular, seemed to make major revisions in their body image and self concept. These treatments also had an impact on the participants' emotional wellbeing, caused by the side-effects of the hormonal injections, and the stress associated with receiving high technology treatment.

"With some of the procedures you get heaps of pimples and you feel awful and you get fat. You're in pain for a long time, getting the needles. Sometimes it's quite a drag putting ourselves through this... I thought I was nuts! My cervix was dilated that much without being pregnant or having a baby (childbirth-contraction pain) or having any medication to help me. So you can imagine the pain!"(4f)

"And the drugs make you more emotional. Clomid is known as the divorce drug it is really bad with mood swings." (4m)

"All the pain and the invasion!"(5f)

"For the first part of the cycle I get headaches on the injections and into the second part of the cycle I just get more and more depressed and bloated and then the grand finale is that you get your period!"(6f)

Some couples were concerned that the physical effects of infertility treatment might have long term lifestyle ramifications.

"Are these drugs going to cause some sort of physical problem later? (6m)

"I have this fear that 10 years down the track. I would hate to jeopardise my health. I'd hate to get cancer or something."(6f)

"We're a bit cautious with all the drugs...frightened what they'll do to you in 20 years time."(4f)

"That's (the drugs) something that worries us and that's why we tend not to take all of the drugs all the time."(4m)

### Emotional Changes

In addition the lifestyle and physical changes, all couples expressed a variety of emotional responses including sorrow, depression, inadequacy, jealousy, guilt, and anger.

One male expressed how sorry he felt for his partner, because of the treatment she underwent and the time involvement.

"She has to go to the clinic all the time...all those needles. It's harder on the woman there's no doubt about it...I feel sorry for her and I feel sorry for me but I probably feel more sorry for her cos she's the one having all the medications and all that...The treatments are harder on her, she has to go the clinic everyday before work."(1m)

Others felt sorry for themselves.

"I found it really hard because this year I've had 13 people telling me they're pregnant and having babies."(6f)

"It's not that I'm not happy for them (friends who are pregnant), It's just that I feel so sorry for myself."(2f)

"It's very hard to go and see somebody who you know can't afford to have a baby that's had their 4th child."(4f)

Feelings of grief and depression were expressed by all the couples. The women's feelings were spoken of more often, and expressed more openly.

"He tends to hide his feelings more than me. I just say whatever I feel. I don't know how much hurt he feels, he just sort of plods along and doesn't really say much."(1f)

"Infertility's like mourning for a death. You don't have anything physical, that's the whole big thing."(4f)

"I think I sometimes get very, very, depressed without knowing it...I don't know whether I'd do it but I often get really, really angry and say I'll kill myself". (3f)

"The first time (treatment failure) I was really devastated but the second time he was."(6f)

There seemed to be a conflict of roles for two of the males. They believed that it was unacceptable to show emotion, and felt it was expected that they should be able to cope, while also attending to their partners' emotional needs.

"I don't think that I have really dealt with it. I've been pushing it down. Recently I've tended to nurture her instead of facing up to it. I do tend to look at my emotions in that way, I suppose because it's painful for me."(5m)

"I sought professional advice because I didn't know the right things to say to comfort her. Like most males I take a more casual approach, and not getting so emotionally wound up. I think she needs a steadying influence because of all her emotional ups and downs. There has to be one partner who is level headed."(2m)

One of the males repeatedly mentioned the feeling of inadequacy, because he had been diagnosed as not having an acrosome sperm reaction; a situation where sperm have a significantly reduced capacity to penetrate and fertilise the ovum.

"I was told there was only really minimal chance that I would get her pregnant through normal procedure. That was absolutely devastating to me! I came home and I just cried my eyes out that I couldn't do it. It was such a big shock to me...There is an underlying feeling of inadequacy there and anger as well. Anger at the fact that I'm not complete and whole...It was those feelings of inadequacy that were worst."(5m).

Jealousy was a very strong emotion expressed by three of the women.

"I was very jealous of a couple of girlfriends who have just had babies. Really, really envious!"(5f)

"I can't stand to be near to pregnant women. I think why can't it be me!"(2f)

"There was a point there where I hated women that were having a baby. He (husband) couldn't understand the way that I felt that I really hated them. Why should they have them when I can't and I've been trying for longer. It's a bitterness, you know you shouldn't but you can't help the way you feel."(1f)



Both male and females, whose physical problems were stated as the cause for the infertility expressed feelings of guilt.

"I feel guilty...because a large portion of the blame lies with me and I think' all this money!...I've tried to scrape up stuff from my background that's maybe caused this."(6f)

"My parents are due shortly (from overseas-for a holiday) and have I got to tell them that I'm infertile, that I can't have children normally? I haven't told them at all. When I first thought of this I just started crying. Imagine telling my parents I can't have children and not being able to deliver grandchildren for them."(5m)

The females tended to feel angry towards women who were able to conceive, whereas it was generally the male participants who expressed anger at those who mistreated children.

"I used to go through periods at a time when I used to find it difficult, especially when a friend of mine was angry because she was pregnant and wanted an abortion. I flew off the handle about that."(4f)

"There's others out there who are dying to have children to look after them and nurture them and these others who pop them out left, right, and centre like rabbits and don't do anything for them. You read about kids who are neglected, left in caravans. It's just terrible."(6m)

"It's a shame because so many people don't want kids. I mean that's when you really get pissed off. When they dump them like that woman in Melbourne, who threw her baby off the bridge and others just dump them in garbage cans."(1m)

"What angers me is parents who deal with their kids badly, who don't appreciate having the child and that makes me angry, I resent them having them."(5m)

### Relationship Changes

The couples' personal lives were all affected by the experience of being infertile. The combination of life style, physical and emotional changes seemed to have both negative and positive implications for the couples' interpersonal relationships.

The negative implications included changes in their sexual relationship, changes in the way they communicated, and the increased pressure it placed on their marital relationship in general.

Many of the couples complained that their sexual relationships were now dominated by 'scheduled or monitored sex'. Sex had now become a means for procreation rather than the outcome of a loving relationship.

"That was very hard too...to have monitored sex. It becomes very hard and very pressured on your relationship having that!"(4f)

One of the females felt that sex had become an unpleasant, mechanical task.

"I went off sex for a long time. I didn't want to be touched for ages...I cringe sometimes when you touch me and I say 'just leave me alone' or I think just get it over with quick."(3f)

The interpersonal and marital implications of being infertile were expressed by couples in the following way:

"I know I probably give him a hard time when I'm going through it (infertility treatment)...It causes a lot of stress and strain on your relationship."(1f)

"It has caused a lot of tension between us."(2f)

One male made the following comment regarding increased arguments with his wife.

"We argue more since we found out we couldn't have kids. It's more an emotional thing."(3m)

This man's wife expressed a particular concern relating to her self worth.

"When we argue I sit down and think nobody else will want me. I can't have a baby, what good am I?"(3f)

For some couples, there was an element of blame towards their partners for being responsible for the infertility.

"You've never actually said to me it's your fault but!"(6f)

"When we have an argument things come up sometimes that shouldn't. You say a lot of things in the heat of the moment."(3m)

His wife responded to this statement by saying...

"He tends to throw things in my face a bit...a lot gets thrown back in your face."(3f)

"I didn't let on that I blamed you. I felt angry cos I thought it was something from football injury that caused it."(1f)

"Your acrosome reaction!" (said in reaction rather heatedly to her partner's comment that they have a problem). Well it's not my problem, I'm fertile!"(5f)

For some of the couples, the experience of infertility has had some positive implications, such as improved communication in their marital relationship.

"It's been interesting because he's not a big communicator but he's able to talk about it (infertility) with other people as well as me. This has really helped! He's been supportive too."(6f)

"We are more effective communicators now."(5m)

"This has brought us a lot closer together...Our relationship has become a lot stronger."(3f)

"The fact we've been through these hard times (infertility treatment) means you grow a lot, you learn a lot."(2f)

Couples all expressed how important it was to support each other, and the various coping strategies they used. One male helped his partner by giving

the injections and being involved in all the assessment procedures and treatments. Others commented on how important it was for partners to be there during any treatments.

"I like him to be physically there for the procedures and treatments. He had a big buzz out of seeing the ultrasound, seeing the egg, the follicles!"(4f)

"It would be better if we attended the clinic together. This keeps the couple together as much as possible. There's issues that come up and I think the more support you can have for keeping the couple together the better."(5m)

Various strategies were used by couples to support one another. One couple pointed out that they need to support each other at different times because situations affect them differently. Couples reported taking control by being positive, indulging themselves between treatments, making action plans, and trying to reduce each other's stress. Some couples found it particularly helpful to talk about their treatments with other couples in the same situation.

All six couples reported changes that affected some aspect of their lives. No cases were found where life changes did not occur.

### Powerlessness

Feelings of powerlessness were a significant element in the experience of these couples. They reported that powerlessness extended into many aspects of their lives, as a result of the enforced changes brought about by being infertile.

"You feel your stress level really rise when you've got to get back into it again (from breaks in the IVF treatment). It's something you can't control, it's like stress is just creeping up and every little thing that happens makes you worse."(1f)

Metaphors were used by some of the males to describe their emotional turmoil. These feelings of powerlessness were expressed as follows:

"Every month the whirlwind begins again"(2m)

"You get into this roller-coaster ride."(6m)

The couples who did not know, or understand, the reason for their infertility, expressed the feeling of unpredictability, and the powerless feeling of not having an answer.

"It's not like if you break something they'd say "we're going to put put in plaster for four weeks. This sort of thing (infertility treatment) is like you go round in circles, continuously, and you don't know where it's going to end."(6m)

"If you could only pinpoint something to say this is the problem! It would be a lot easier then."(4m)

"I'm put in the category of unknown infertility. They tell me I have to have 3 miscarriages before they'll do anything...It's just a guessing game. We were told 'you'll find out eventually what it is.'(3f)

Couples also felt disempowered by health professionals involved in the infertility treatment process. These feelings of being powerless were magnified by the fact that they were imposed by the very system that is supposed to help them - the health care system. One of the males expressed this in the following statement.

"Right from the start (infertility treatment), I felt we had lost control over what is supposed to be a natural event. '(2m)

There were an overwhelming number of comments made by couples relating to the negative responses from health professionals involved with their infertility treatment. The remarks revolved around the amount of information received, the quality of support, and how couples felt they were being treated.

Health professionals failing to provide sufficient information led to couples feeling anxious, confused, as well as powerless.

"I was really frightened because I didn't know what any of those invasive procedures were. They wouldn't explain procedures. I've found that to be a recurring problem all the way through."(5f)

"We'll (the staff from the clinic) take the readings and we'll decide when you go to hospital'. But they don't explain why."(4m)

"They don't tell you anything. They just force fed me what they wanted, and they didn't ask me anything."(3m)

"They didn't want to tell me anything. I actually wanted to know what my levels (hormone levels) were. It was like 'pat, pat, pat,' on the head. 'We'll organise this!'"(6f)

Couple number four reported a slightly different experience. They initially felt powerless to the health professionals, then gradually felt more in control as their knowledge about the infertility treatments increased.

"Having friends in the same position (friends who were also receiving treatment for infertility problems) and everybody finding out things, we learn about the technology much quicker than the doctors do. So we tend to go and do the research and tell the doctors...I feel more capable, and more knowledgeable, when talking to the doctors and to the nurses. You know you gain a kind of respect for being on the programme such a long time."(4f)

Other comments indicated that the couples did not always understand the information provided. In some cases this information actually created misunderstandings.

"The doctor would glibly say 'we'll harvest the eggs'. It's quite a serious operation to harvest eggs-hospital, anaesthetics, etc. This was never spelt out to us clearly...I had a routine pap smear (part of infertility assessment) they phoned me at six o'clock on Friday afternoon to tell me the smear was abnormal, and that I had to come in for a colposcopy. There was no explanation, just to ring on Monday for an appointment and they can't fit me in for 3 months. I spent the whole weekend worrying I might die from cancer."(5f)

Some of the responses made by health professionals left couples feeling unsupported.

"You're supposed to see the doctor every time you have a failed attempt but you don't. You can lose trust in the clinic sometimes."(1f)

"Last time (when receiving intramuscular hormone treatment) I sat down and burst into tears. One of the girls said to me 'Is the needle hurting?' (obviously not the reason for the tears)...You feel you are being brushed off all the time."(6f)

"They'd (infertility clinic staff) say 'if you have any problems just ring', but every time I'd ring I could never get through to anyone. They were never available."(5f)

In addition, all couples felt the health professionals, involved in their infertility treatment, were insensitive to their feelings and needs.

"And there's no closed doors or anything. The things were just discussed with open doors and people coming and going."(6f)

"When they examined me at (the clinic) they said 'you've been messing around long enough, lets get it done. Just get in there and have the whole lot done! They forget about your feelings.'(5f)

"She made me come with her because I didn't believe what she was telling me. I couldn't believe the way they (clinic doctors) talked. They basically treated you like a slab of meat. Some of the comments were not what you'd expect from a doctor 'nice and sloppy' (during a per vaginal examination)...They forget that to the individual it might be their first experience to them it's just a job. It's too rush, rush and hurry get your legs open I've got another one to do in five minutes."(2m)

"Our main doctor's very cold. When she told me our pregnancy (IVF treatment) had failed, she told me over the phone 'Oh well this pregnancy's had it!'"(1f)

Two of the female participants were particularly annoyed that the focus of infertility investigations and treatments were geared towards the female.

"They all assumed it was me! I think that's a very common misconception that society has...I was angry because I'd been having all this invasive treatment for females, and they hadn't even looked at him. They had assumed that it was the woman and they had done all these tests and procedures...I really think they should test the couple together-male and female. It's much easier to test the male, so why is the female always tested first?"(5f)

"What annoyed me most was the big focus on the female and being infertile. I'm not trying to go overboard on feminist issues but it's not fair. They could have tested him earlier."(4f)

### Hope-Disappointment Cycle

According to the study participants, infertility can lead to a cyclical pattern of hope and disappointment. This pattern is exacerbated for couples undergoing infertility treatment. The very nature of the female reproductive cycle can produce a series of hope, expectation, disappointment, and often despair. Couples reported that they feel hopeful as they begin treatment, and then become disappointed each month if the treatment fails, particularly when so much energy, hope, and money has been put into it.

Menstruation was the signal event which precipitated the feelings of hope and disappointment expressed by some of the couples.

"I go to pieces when my period comes"(2f)

"And then the grand finale is that you get your period!"(6f)

"There's more money down the toilet (in reference to menstruation)."(1m)

"You never relax. It's always at the back of your mind. You count the days hoping that something will happen."(6m)

"Even when you're not on the programme it's still like a month to month proposition!"(4m)

Hope, as a fundamental element of infertility treatment, was an overriding theme in many of the interviews.

"You're living with a hope the whole time."(4f)

"It's an emotional roller coaster."(2m)

One male described feeling confident that the treatment would be successful.



"You do build up your hopes a lot. That's probably the worst part of it. I was so confident when we first started (IVF) treatment. I thought it would be a 'piece of cake'. I went off to work thinking I'll be a daddy in a month! (1m)

His wife also stated she was confident that the treatment would be successful.

"I was really confident on the first try of IVF too (as well as AIH). We saw all the eggs fertilised."(1f)

Another couple described similar feelings of hope.

"It's like NASA control giving a count down to a rocket. You know, everything's going well, everything's on target and then you have very high expectations that maybe this could be the month and then it just collapses in front of your eyes."(6m)

"...when you sit in the waiting room and see all those people pour through, you think. What are your chances? I mean someone has to be that one (the one lucky enough to get pregnant)."(6f)

One couple explained how they had planned a new home around the expectation of having children.

"It lost its appeal (the house they had built) because it was built for when we have kids one day...lots of brick paving so the kids could ride their bikes."(3f)

All couples were initially surprised that they were unable to conceive. The surprise of having fertility problems soon led to disappointment as they continued to be unable to conceive.

"I thought I'd fall (pregnant) just like that!"(1f)

"I was very naive when I started trying to have a baby. We just thought I'll be pregnant within a year."(3f)

"I assumed like most people it's just going to happen. One assumes that one is normally fertile. It came as a bit of a surprise that we were (infertile) because we were fit and healthy, we lead a healthy lifestyle and we've both been vegetarians for years. We were both surprised and distressed because we couldn't get pregnant."(5m)

"We never thought we'd have any problem. Once we'd paid off the house we just assumed it would happen soon."(2m)

This man's wife was also surprised that they were unable to conceive.

"All those years taking precautions against a pregnancy, I couldn't believe it!"(2f)

Following the initial surprise at being infertile, couples find themselves in a cycle of expectation, hope, and disappointment. At the start of the infertility treatment, the couple have an expectation that the treatment will work and they will become parents. Each month the couple experience feelings of hope, followed by disappointment when the treatment is unsuccessful.

"I'm sick of being disappointed...And after all the money it had cost us."(5f)

"You just get so disappointed."(1f)

Her husband also expressed the feeling of being disappointed.

"You get disappointed but what can you do?"(1m)

Another response that participants probably did not expect, was having to deal with other peoples' disappointment in their failed infertility treatments.

"A lot of people we know get disappointed if they know I'm on the programme and it hasn't worked. They are more disappointed than me, and I end up consoling them! I mean I can't talk to my Mum for three days because she's in mourning!"(4f)

"Other people can't handle the failure of our treatments."(2f)

Intertwined with this cycle of expectation, hope, and disappointment is the uncertainty of being infertile.

One couple described their feelings of uncertainty in the following ways:

"My other fear is that I'm chasing a dream that might not ever happen...I don't want to wake up in four years time and feel like I've wasted my time. Like chasing a pregnancy that may not happen and become obsessed with it."(6f)

"You don't know where it's all going to end. I've heard stories of people who have been going there for 18 years!"(6m)

There is also an urgency to become pregnant expressed by the older female participants.

"And then it got worse because we got older. Now it's desperate for us to have one quickly or it won't even be an issue anymore."(5f)

"When you're my age you don't have many chances you have to take every chance. I can't wait or I'll be too old."(2f)

"We need to try again before we're too old."(4f)

There is a treadmill of infertility treatment and some participants expressed a strong desire to take a rest with the inherent cycles of hope and disappointment.

"It was just too much, we'd try for 3 months and then take a break, on and off. We thought we might get pregnant by ourselves, but we didn't."(5f)

"We took 2 weeks break and stayed in a hotel room then we got back into it (infertility treatment)."(2m)

One couple in particular, felt it was very important to take a break from infertility treatments.

"I love it when we're having a break cos I don't have to think about it, to worry about it, it's the best time."(1f)

"You just can't do it month after month, you have to have a break otherwise it would drive you mad."(1m)

Many couples felt compelled to attempt all possible avenues to parenthood. These couples felt 'driven' or determined to try whatever they could to conceive.

This sheer determination to become pregnant was expressed by one of the females.

"So we are going through with the extreme step (I.S.C.I) and going to Adelaide. It's the only place we can go to have this treatment...We had 12 attempts (AIH). We just kept on going each month...You tread on eggshells and don't want to do anything to stuff it up."(1f)

Her husband's comment also indicated how important it was for his wife to become pregnant, and to remain pregnant.

"She (his wife) was doing aerobics. She's stopped doing aerobics now. If she does get pregnant I'm going to sit her in bed for the next 8-9 months."(1m)

"We worked through each problem and just kept seeking different doctors to help us and some alternative medicines which cost a lot of money." (4f)

For some couples it was difficult to even think of stopping treatment.

"But you're in an open ended tunnel...you just keep going and going and going."(6m)

"So we went back and had another go and it just went on from there."(5f)

"We will try anything and we will keep on trying until..."(2f)

#### Trying to regain control

Others were able to talk about stopping treatment, and found it important to set themselves limits.

"We discussed this right at the beginning. I mean there has to be a limit. I'm prepared to outlay \$7500 at the most. That would cover the six IVF attempts you can get on HBF."(6f)

"We have a ten year plan and we both agree if we don't have children either through adoption or naturally we'll get the boat and travel around Australia."(3f)

"And that's when I say, that's it! I'll try it once (Couple number one had been unsuccessful with AIH and IVF and are now planning I.C.S.I) and that's it! I reckon there's got to be a limit."(1f)

"We're now in a situation where we've agreed to go back on the programme and give it one last good shot."(5m)

Most couples commented on the importance of 'getting on with life' or 'you still have to have a life' and 'you've got to go on living'. Couples seemed to cope with the infertility investigation/treatment by trying to take control. Various coping strategies were used by couples to assist them in regaining control. For one couple, infertility became a problem to be solved.

"It's like a maze you have to find your way through."(4f)

The hope-disappointment cycle was experienced by all the study participants. There were no exceptions or discrepant cases.

### Social Isolation

All couples commented on the strong, external social pressure to have children. They felt socially isolated from family and friends with children. The women especially, expressed the feeling of being excluded from the social nexus of mothers and couples with children. This exclusion extended from acquaintances through to family and long established friends. Parenthood was perceived to be the common experience around which friendships were initiated and maintained.

"We're starting to realise that you can lose friends and become very isolated because everyone else has children...I find it hard to make friends with women with babies, and I find it hard to make friends with other woman at the clinic."(3f)

"You get left out a lot. They organise to do things, activities that involve children, such as holidays with other couples who have children...Our friends who've had children (even those who had them later) seem to have drifted away from us now." (5f)

Following an in-depth search, one discrepant case was found where the study participant reported how friendships have been therapeutic for her and her husband.

"We have a whole lot of friends who are in the same position (are seeking treatment for infertility problems) and that's been helpful because we can just pick up the phone and say 'I'm having this procedure done.' 'What happened when you had it?'" (4f)

These feelings of isolation even extended into the couples' interpersonal relationships. Feelings of exclusion came up repeatedly in conversations. Couples also commented on how many conversations were related to children.

"I used to hate going to work functions. Some of the women, their whole life revolves around children. It was all they talked about." (4f)

"It was awful. That's all they ever talk about and you just can't join in. It feels really lonely sometimes." (2f)

One of the males described feeling excluded from conversations relating to children.

"I remember one situation at a work function where certain people were talking about their children. We were completely cut out and in particular my wife was cut out." (5m)

His wife agreed, and made the following comment:

"I feel quite devastated sometimes. Seeing all their children, all talking about their children. They talk about them all the time!" (5f)

Pregnant friends and family members were often hesitant about disclosing a pregnancy, and of discussing their experience of pregnancy. This overt avoidance of these topics led to feelings of isolation, exclusion, and of feeling different.

"What really, really peed me off were friends who were falling pregnant and they were trying to be nice by not telling me they were pregnant." (3f)

"The girls at work are reluctant to tell me about anyone who is pregnant, they think I'm too fragile." (2f)

"My brother didn't tell me about (his wife's) last pregnancy for ages but I knew."(5f)

On the other hand, some females perceived any questions relating to their parenting plans as an interrogation. These females preferred not to discuss these issues with others.

"We've even had a bit of pressure from our neighbour. He (the neighbour) always asks 'no babies yet?'"(5f)

"I am sick of people asking 'when are you going to start a family?' I sometimes pretend we don't want one."(1f)

Two other females commented on the attitude of condemnation towards couples without children.

"Are you two going on another holiday!"(a comment made by a friend implying they could afford such a luxury because they did not have children) (4f)

"We often feel that people think of us as selfish yuppies."(2f)

Inappropriate responses from family and friends were also perceived as being isolating. Couples were having to deal with the various reactions from family and friends. The news of their infertility evoked mixed responses which included: a lack understanding and support, avoidance, blame, and embarrassment.

The understanding and support couples wished for was not forthcoming. This lack of understanding towards the couples' infertility often led to family and friends being insensitive to their feelings.

"I don't really think Mum understands. I would like her to understand. I would like her to put her arms around me and say."(6f)

"We don't talk about it much with family, no-one really understands. They think we are typical DINKS (double income no kids)."(2f)

"When I say something about not being able to have children a lot of people don't understand. So I just pretend I'm happy I haven't got any children."(3f)

"People don't really understand, they just don't understand what you're going through and they say stupid things like 'you're trying too hard', 'you're not doing it right', 'take a holiday' or 'just relax it will happen'. It's just not true, they just don't understand."(1f)

Even though one of the study participant's commented on the lack of support from her mother, she did receive support from other family members.

"Both my brothers have been really supportive. They ring up and say 'How's it going?' 'How are you feeling?' Which is really nice."(6f)

Couples also commented on how people often avoided the issue of their infertility.

"No one really lets me talk about it. Even my mum won't let me talk about it!"(3f)

"Some people stick their heads in the sand and not pay any attention to it...A lot of family don't know what to say so they either make a joke of it, ignore it, or say something completely dorkish [stupid-uncool]."(6m)

This man's wife responded by saying:

"Mum I've found a bit hard to talk to. Mum sort of glosses over it. I don't think she knows what to say to me."(6f)

One of the females reported that she was blamed for their infertility problems.

"Your mum (her mother in law) used to blame me a lot of the time, it was just considered my fault. It was just me and if I gave up work, I would fall pregnant. It was blamed on my job!"(4f)

In addition to this, some females commented on how other family members were actually embarrassed about their infertility.

"I think my family, and in particular my sister, found it the hardest to accept. She (sister) was really embarrassed that I would talk about our having problems conceiving...They (husband's family) were more concerned about our infertility and trying to keep it a secret-'don't tell everybody'."(4f)



"I think they're embarrassed for us because we can't have children."(5f)

### Verification Interviews

Follow up interviews were conducted to clarify and validate data from the initial interviews. The study participants were all telephoned and separately asked how they felt about the four themes.

They were asked to comment on the extent to which these themes fitted with their own experiences.

The theme Powerlessness was rated by all participants as being the most pervasive. They were most emphatic about this. The Hope-Disappointment Cycle was seen to be the next most important theme in terms of reflecting the essence of their experience. For two of the females, this was perceived as being equally as important as Powerlessness. Life Changes and Social Isolation were also acknowledged by all study participants as reflecting the essential nature of the infertility experience. The follow up interviews served a second purpose. They were used by the researcher to clarify certain points that were reported in the original findings, such as the reported lack of information from health carers. Study participants were asked if they received information from any other sources. They reported receiving information from other infertile couples undergoing treatment, and from the literature available in the infertility clinics. The study participants all sought information from the health carers but only one couple felt they were successful in their quest.

## Chapter Five

### Discussion

In this chapter, the findings from the study are discussed and the implications and recommendations are presented. The phenomenon of infertility emerged as a multifaceted experience, with numerous meanings, not only for the infertile couple as a group, but also for individual infertile persons. The different aspects of the experience of infertility are discussed under the four key theme headings: Life Changes, Powerlessness, Hope-Disappointment Cycle, and Social Isolation.

#### Life Changes

##### Lifestyle Changes

The findings from this study suggest that the infertile couple experiences some major, enforced life style changes. Physical, emotional, and relationship changes including effect on sexual relationship, all have a significant interactive effect.

These changes include both current and future changes. Most adults have some control over decisions affecting their lifestyle. For the infertile couple involved in high technology treatment, this ability to plan is affected by the financial cost, and the priority placed on the infertility treatment.

Some of the findings were similar to conclusions drawn from other studies of infertility. Three couples in this study expressed the opinion that their life was 'in limbo'. Olshansky (1987a) also reported that infertile persons remain 'in limbo' as they continued unsuccessfully to try to conceive. Intertwined with this is the lack of control, or the feeling of being powerless. This feeling is intensified by the fact that infertile people are highly motivated

(Blenner, 1990), so are more likely to feel the affects of these changes. Mahlstedt (1985) states that people who have been self directed, been in control of their lives, and believed that hard work leads to success in all tasks, are devastated by the infertility experience. Some of the frustration evidenced by these people could stem from the fact that they are used to success in their chosen trades and professions, and accustomed to setting and achieving goals. The monthly treatment failures must be especially distressing for them.

Feelings of helplessness are frequently experienced in many aspects of the couples' lives. The overall effect will change plans for career decisions and even holidays. The time spent on treatment will interfere with daily routines. Further, the couple are unable to make certain short term or long term plans, due to the uncertainty of treatment demands.

One of the males in this study commented on how children 'give you purpose'. Other participants suggested that children would add meaning to their lives. According to medical research, for some infertile couples, the lack of children can make everything they work for seem pointless (Corson, 1993). It seems that material comfort, or attainment of career goals cannot fill the void caused by the absence of a wanted child.

Study findings may be viewed against a background of family studies. The general marital and childbearing trends are changing. Couples are tending to have children at a later age. The contributing factors have been cited as delayed marriage and childbearing, women pursuing advanced educations or careers, and improved contraceptive methods (Edwards, 1989; Garner, 1991; McDonald, 1992).

Australia, as well as most other western societies, has undergone a major structural and cultural shift in the nature of marital and family arrangements (Edgar, 1991). The post war marriage boom, characterised by early marriage,

brought about a prolonged child-bearing period which resulted in the baby boom of the 1960's, and women in full-time home duties.

Since the late 1960's Australia has undergone a dramatic reversal. The total fertility rate has significantly decreased, related to a decrease in the marriage rate. Some people have expressed a strong preference for only two children, while others are choosing voluntary childlessness (Australian Institute of Family Studies [AIFS ] (1983) cited in Edgar, (1991).

In addition to the lifestyle changes, infertile couples experience a variety of physical changes which will contribute to the overall life changes.

#### Physical Changes

The diagnosis and treatment of infertility involves strict adherence to a regimen that requires people to perform tests, administer hormone injections, monitor side effects, and carefully plan coitus. In any given month these people can spend anywhere between 10 and 50 hours attending clinics for tests and treatments (Blenner, 1990). Diagnostic assessment and treatment is expensive, intrusive, and at times painful.

The cumulative effect of this entire process can lead to physical symptoms. Infertile couples commonly experience extreme tension and stress which can contribute to headaches, irritability, and other unpleasant manifestations (Butler & Koraleski, 1990; Valentine, 1986). Reactions to some medications can cause cramps, nausea, and other negative side effects. In particular, the hormones, or hormone stimulators that are frequently used can result in headaches, nausea, moodiness, emotional outbursts, and distractibility (Corson, 1993). Fleming and Burry (1988) have likened ongoing infertility to the crisis of chronic illness or a physical disability.

Goodman and Rothman (1984) dramatically sum up the negative physical effects experienced by infertile couples undergoing diagnostic assessment and treatment.

"...tests, humiliating exams, sex on demand, semen analysis by masturbated sample, painful biopsies, inseminations, daily or sometimes twice a day visits to the doctor for up to 15-20 days during the month, ultrasound several times a month requiring drinking several quarts of water and painfully maintaining a full bladder to determine if one's follicles are maturing. Blood drawn daily for many patients. Hystero-salpingogram, laparoscopy, tubal surgery, D & C (dilatation and curettage of the uterine lining) medications often with considerable side effects, pelvic examinations during one's menstrual cycle-and after all that work, another menstrual period and the same cycle starts all over." (p.80)

The females in this study reported many of these experiences as well as a wide range of other negative effects. These included pain, pimples, increased weight, headaches, bloating, mood swings, and depression. One couple described Clomid (an hormone stimulator) as 'the divorce drug'.

In addition to this, participants expressed fears about what effects these drugs will have in the long term. This seems a genuine and reasonable concern, since this could seriously affect the couple's quality of life in the future. Women in particular, bear most of the burden from reproductive technologies and their possibly detrimental side effects. There are no long term safety guarantees, and it is not known what effects will be found in years to come. Some recent studies have reported a significant association between fertility drugs and ovarian cancer (Darder, 1993; Franceschi et al., 1994; Reynolds, 1993). Other published literature (Jones, 1994; Klein & Rowland, 1988, 1989) suggests that other adverse effects from the fertility drugs should be considered with respect to both the recipient women, and children born through assisted reproductive technologies.

The attitude that reproductive technology is helping the infertile couple has allowed society to accept these medical advances without critical comment. Few question whether this technology does, in fact, help infertile people (Noble & Bell, 1992; Rowland, 1985).

### Emotional Changes

In addition to life-style and physical changes, infertile couples in this study also reported a variety of emotional responses including sorrow, depression, inadequacy, jealousy, guilt, and anger. Laffont and Edelmann, (1994) suggest that emotional consequences may be more pronounced in patients undergoing high technology treatment since these procedures are often considered to be the couple's last chance for a biological child. In addition, infertility is considered to be an acute crisis, and when it is not resolved it becomes a prolonged source of stress or a chronic crisis.

The crisis of infertility, has been documented in previous research as characterised by extensive anxiety, damaged self esteem, grief, uncertainty about the future, and estranged relationships with partners and others (Mahlstedt, 1985; Menning, 1988). For many people the discovery of infertility can provoke a complex biopsychosocial crisis that may take several years to resolve (Cook, 1987; WHO, 1992).

There seems to be a general consensus among the experts in the field about the type and range of feelings experienced by infertile couples. Most of the information presented in the literature was based on repeated clinical observations made by health care providers. The primary framework, to date, for analysing the psychological reactions to infertility has been the Grief Model.

Kubler-Ross (1969) originally formulated the Grief Model to understand the grieving process of people who faced their own death or the death of a significant other person. Loss is the central component of Grief Theory. For

this reason, Grief Theory has been used as a rationale to explain the psychological reactions of individuals to situations other than death in which there may be a perceived loss - such as loss of fertility. Authors who have described similar emotional stages in understanding the response to infertility have differed in their use of terminology, the number of stages used and in the sequence of emotions (Mahlstedt, 1985; Menning, 1977, 1988; Stewart & Glazer, 1986; Wilson, 1979). But they are all clearly based on the original five stages proposed by Kubler-Ross (1969).

The impact of the emotional responses experienced has been variously attributed to the following factors: the couple's ability to communicate, the importance of the child to the couple's identity, the attitude of others involved in the health care team, and the understanding of partner, family and friends (Mahlstedt, 1985; Sandelowski, 1987; Valentine, 1986).

Barbara Menning, a nurse and one of the earliest researchers to study the human experience of infertility, analysed the content of interviews with infertile women and men. She used the Grief Model to help her interpret the experiences of the infertile couples. Infertility represented a potential loss rather than the actual loss of a child who had been born. On the basis of her extensive counselling, Menning identified the following stages of emotional responses: surprise, denial, isolation, guilt, anger, loss, grief, and resolution (Menning, 1977).

These stages of emotional responses associated with infertility tend to be very generalised, and are based on the individual's rather than the couple's experience. They may not capture the experience in the context in which it takes place, or the interactive effects of the emotional responses. There are differences in the way that couples perceive, react to, and resolve the problems that have not been fully understood. The emergent themes of Life Changes,

Powerlessness, Hope-Disappointment Cycle, and Social Isolation in this study present a broader perspective than the traditional Grief Model is able to represent . These themes represent major changes in all aspects of the couple's life, affecting both current and future life styles, and not just a sequence of emotional consequences.

Unruh and McGrath (1985) have also challenged the usefulness of the Grief Model, stating that the Grief Model is limited in its usefulness as a framework for understanding infertility. They state that it is an extremely narrow model concerned with individual emotional reactions and thus may reflect only individual pain rather than provide a contextual model of why the pain exists. According to Unruh and McGrath (1985) it is imperative to understand what causes people to feel such anguish towards a medical condition that is not life threatening, does not compromise activities of daily living, and in most cases, would not require treatment were it not for the desire to have a child.

In this study, all female participants described a diverse range of emotional responses, which included sorrow, depression, jealousy, guilt, and anger. These feelings were expressed openly and intensely by the women. The males were more reluctant to discuss any emotionally personal aspects of being infertile. On the basis of some significant statements from the interview transcripts, and some subjective comments from the observational field notes, the researcher concluded that the male participants tended to experience different emotional responses (such as inadequacy, and anger at people who mistreated children). The men also revealed less emotion in reporting their experiences.

There is a general assumption in both the professional and popular literature that women are more adversely emotionally affected by infertility



than their partners. It seems that women are generally much more vulnerable to the infertility crisis. This is expressed in their significantly lower self-esteem, feelings of anxiety, guilt, and frustration, higher rates of depression, and greater problems in the area of personal life and adjustment (Bernstein, Potts, & Mattox, 1985; Daniluk, 1988; Draye et al., 1988; Greil et al., 1988; Hirsh & Hirsh, 1989; McEwan et al., 1987). Other researchers (Adler & Boxley, 1985; Berg & Wilson, 1991) have failed to find any significant gender differences in emotional distress.

Emotional distress related to infertility has also been related to which partner was the primary cause. (McEwan, et al., 1987). An additional finding from this study was that older women were found to be less distressed. This was attributed to the fact that they had energies invested in their work or careers, and that they have spent a substantial portion of time without children and may have less difficulty adjusting to this. Findings from this current study support the statement that emotional distress can relate to the guilt feelings experienced by the partner whose physical problems have caused the infertility. However, the older females in this study did not report less emotional distress; in fact, they seemed to experience more.

A further issue is the extent to which men and women differ in their response to infertility. Coping with these emotional changes is also likely to differ for men and women. Women have been socialised to express their feelings and concerns regarding their health, whereas men are typically encouraged not to do so (Link & Darling, 1986). Men are expected to accept illness and injury with stoicism and courage, and showing emotional distress is not acceptable. Two of the males in this study experienced a conflict of roles. They were reluctant to show any emotional responses themselves, but felt it

was important for them to be strong emotionally, and to attend to their partner's emotional needs.

Because of the different significance attached to parenting, it is also likely that infertile women are more likely to become depressed than are men (Draye, et al., 1988). Females are not only more conditioned toward the role of parenthood but are also more directly involved in the medical treatment of infertility, which at times can be embarrassing, physically uncomfortable, and frustrating (Link & Darling, 1986).

#### Relationship Changes

There were some important relational changes that affected the couple's personal lives. In particular, a couple's sexual relationship is extremely sensitive to the stress of being infertile. Sexual dysfunction in the form of decreased libido, erectile problems, lack of spontaneity, and failure to achieve orgasm, are all considered to be common consequences of infertility assessment and treatment (Corson, 1993; Daniluk, 1988; Keye, 1984; Mahlstedt, 1985; Seibel & Taymor, 1982).

Infertile couples are told when to have sexual intercourse, in what positions, which days to abstain, and sometimes even need to rush to the clinic before or after sex. Sexual relationships have been reported as deteriorating as the medical interventions progress (McGrade & Tolor, 1981). Sexual response is often affected by infertility and the pressures and embarrassment of the infertility investigations and treatment. Many couples find that sexual pleasure and function can become impaired when they have to 'perform to order' (Elstein, 1975). In addition, sexual response may not always return to pre-infertility function, even when the investigations and treatment ends (Bernstein, et al., 1985).

It is little wonder that most of the couples in this study commented on the negative changes in their sexual relationship. One woman in particular experienced a total abhorrence towards any form of sexual contact with her partner.

Childless couples may feel that being infertile jeopardises their individual sexual identities. Because fertility and virility become intertwined for the infertile, a man who is unable to father a natural child may feel others question his masculinity (Mahlstedt, 1985). For many women, having children is central to their role identity (Corson, 1993; Mahlstedt, 1985; WHO, 1992). This did not seem to be the case for any of the participants in this study. One male actually stated "I never gauge my own masculinity by the number of children I produce." (6m).

The published literature relating to the impact of infertility on the couples' personal relationships are contradictory. Some writers have argued that the stress infertility places on relationships causes major problems (Connolly, Edelman, & Cooke, 1987; Hirsh & Hirsh, 1989; Mahlstedt, 1985; Sandelowski & Jones, 1986; Valentine, 1986), while others have found the adjustment to be a potentially positive experience (Laffont & Edelman, 1994; Mahlstedt, 1985; Menning, 1988; Milne, 1988).

The negative implications of being infertile for couples in this study included an increase in arguments, partners being blamed, and additional stress on the relationship.

Connolly et al. (1987) studied the effect of distress and marital problems associated with infertility. These researchers found the emotional wellbeing of couples were adversely affected by prolonged periods of diagnostic assessment and treatment. An interesting finding from this study was the effect that male infertility had on relationships. Greater emotional and marital difficulties were

reported by both men and women, when the cause of the infertility lay with the man. This may well be associated with the male's loss of self-esteem as a result of the infertility diagnosis, causing intense emotional problems for the man. It has been suggested that infertility and virility become intertwined for the infertile; a man who is unable to father a natural child may feel others will doubt his masculinity (Mahlstedt, 1985).

Sandelowski and Jones (1986) report that both the marriage and the relationship with family and friends can be affected. Further, the financial stress of infertility treatment can be a catalyst to creating additional marital stress (Valentine, 1986). An altered body image and/or lowered self esteem can also affect a person's ability to maintain a sense of self in the relationship (Hirsh & Hirsh, 1989).

The potential benefits of the infertility experience have also been cited in the literature. Menning (1988) and Mahlstedt (1985) have both commented on the increased marital intimacy and personal strength that may result. A study by Laffont and Edelmann (1994) concluded that over 90% of both men and women in their study felt that they were as close or closer, since embarking on IVF, and that communication between them had remained the same or improved.


Milne (1988) also reported positive effects on marital relationships. In this study, 23 out of the 28 couples interviewed found that the experience of being infertile and receiving treatment had a positive effect on their relationship.

The positive implications of the experience for the couples in this study, reported by all but one couple, were improved communication, and the support from their partners.

It is, indeed, heartening to think that being infertile can have some positive implications for the couple's relationship. However, one cannot help but wonder if couples may feel that this is the 'right thing to report', especially if the other partner was present during the interview or survey. This seemed to be the case for one female participant whose responses changed from negative to positive in response to her partner taking offence at some earlier comments. When dealing with a situation that seems so negative, it may also be human nature to report at least something that is positive.

Stanton, Tennen, Afflect, and Mendola (1991) found that infertile couples perceived both threats and challenges in their infertility experience which may represent a more realistic outlook. It seems that a combination of factors will affect the couple's relationship, having both negative and positive implications. Infertility carries the potential for harming an important relationship as well as providing an opportunity for growth. It is interesting to note that the Chinese symbol for crisis is composed of two words; danger and opportunity.


 A handwritten Chinese character, 危 (wēi), which means 'danger' or 'crisis'. It is composed of the radical 厃 (wēi) and the radical 卩 (jié).


 A handwritten Chinese character, 機 (jī), which means 'opportunity' or 'machine'. It is composed of the radical 木 (mù) and the radical 幾 (jǐ).

Infertility can certainly be considered a danger (crisis) which involves

many personal risks, and yet for some infertile couples it becomes an opportunity for growth. According to Clapp (1985), Mahlstedt (1985) and Menning (1982) those who do grow emotionally are probably surrounded by health carers, and family and friends who do what they can to support the couple and help them through the crisis.

### Powerlessness

Some writers have suggested that the loss of control experienced by infertile couples is profound (Cook, 1987; Mahlstedt, 1985; Mathews & Mathews, 1986; Menning, 1988). Although the infertile couple may attempt to control their infertility by seeking diagnostic and therapeutic procedures, only a small percentage of those who undergo such procedures attain a successful pregnancy (ACCESS, 1994). It therefore seems reasonable to proffer that most infertile couples perceive themselves as having little control over their infertility.

In the present study, both the men and the women commented on the powerless feeling of not knowing if they would ever have a baby. This feeling of powerlessness and unpredictability was exacerbated when the couple did not know and/or understand the cause of their infertility. This concurs with the findings of McEwan et al.'s (1987) study, that women who did not receive a diagnosis for their infertility were more distressed, and showed poorer adjustment than those who had.

The males in this study expressed anger and frustration at their inability to change the circumstances, and at their general lack of control. This was directed at the health care providers, especially the doctors. According to Blenner (1990) and Phipps (1993) the treatment experience often makes the couple feel angry and helpless because they perceive they are relinquishing

control to health care providers. This lack of control is also distressing for women because women are more likely to monitor their bodies for signs of pregnancy. When attempts at conception are not successful, the resulting loss of control may be more salient to women, and they may assume greater responsibility for a failed attempt. Women are also more engaged in procedures for diagnosis and treatment, and are more likely to report initiating medical intervention (Draye et al. 1988; Greil et al. 1988). It is interesting to note that in the present study, over 80% of the calls, initiating the contact with the researcher, were made by the female partner. Draye et al. (1988) reported that, in fact, women's difficulties with the health care system exceeded that of their partners. This can be attributed to the fact that women have the greater number of physical interventions regardless of who is responsible (Stanaway, 1986).

It is of concern that couples in this study, without exception, reported negative comments about the clinic and health care providers, especially medical practitioners. This is congruent with the findings of Phipps (1993) who reported that all but one of the eight couples in her study spoke negatively about the health care they were receiving. The medical practitioners, in particular, were perceived as being unsupportive and devaluing of the couple's needs. Communication with the medical practitioners was seen as not meaningful and contributing to frustration, anxiety and anger.

The importance of the therapeutic relationship between clients and health carers has been emphasised by McIver (1993) and Mitchell (1995). These authors contend that as well as desiring effective treatment and cures, clients care about the quality of their relationships with professionals. Clients want good communication, and adequate information to help to allay anxiety, and bring about a feeling of control. They wish for therapeutic encounters with

health carers that they can trust, who convey care and concern, and who will help them cope more effectively.

It is important for health carers to acknowledge feelings of powerlessness, and to discuss with the couple, that the concept of control can pose problems. The couple may have been experiencing a loss of control, but were not able to identify this as a source of anxiety (McCormick, 1980).

Two of the female participants in this study reported their annoyance that their male partners were not investigated at the initial assessment. According to Stanaway (1986), the man and woman jointly consult the doctor in only about a quarter of cases. This may reflect the notion that children are still seen as women's business and that most people assume that difficulties in conceiving are usually women's problems. Services are geared towards the treatment of female infertility rather than male infertility. It is the woman who goes through all major medical and surgical procedures (Stanaway, 1986).

The majority of counsellors advocate keeping the couple together during treatment. Family therapy experts advocate conjoint marital therapy as the preferred modality of treatment. In general, individual therapy for marital problems was actually found to be ineffective, and sometimes harmful (Nichols, 1988).

Since fertility depends on the ability of each partner to reproduce, both partners should be included in treatment from its inception in order to avoid treating a minor physical problem in one partner (usually female) when the other has an irreversible condition that precludes such treatment (ACCESS, 1995). Inclusion of both spouses also enhances treatment by keeping each of them well informed and actively involved in the process (Link & Darling, 1986).



### Hope-Disappointment Cycle

The very nature of the reproduction cycle, produces a series of hope, expectation, disappointment which is commonly referred to as the 'emotional roller coaster' (Link & Darling, 1986). Infertility is a series of crisis events (Butler & Koraleski, 1990). First is the biological fact of the monthly period. For couples trying to conceive, each month is cause for hope, and the onset of the menstrual period dashes that hope. The roller coaster of emotion is further heightened by medical treatments. Each procedure is seen as the possible cure, then each failed treatment is another disappointment. The cycle may be intensified by emotional and physical reactions to these emotional swings (Butler & Koraleski, 1990).

Cultural changes and improved medical care of recent years have contributed to heightened parental expectations for positive pregnancy outcomes. Advancements in technology have contributed to increased positive expectations of pregnancy for couples undergoing infertility treatment. Media reports have tended to heighten these expectations by highlighting the success of high technology treatments without focusing on unsuccessful procedures (Nobel & Bell, 1992; Crowe, 1985; Rowland, 1985).

One of the female participants in this study commented on how positive the staff were at the infertility clinic. She did, in fact, have her doubts as to how realistic this was, and made the following 'tongue in cheek' remark. "They (the clinic staff) all seem to be really positive but they remind me of the oncologists (doctors who specialise in cancer treatment). Oncologists are really positive people too!" (6f)

In spite of all the years of previous failure, many studies found that women had high expectations that IVF would be successful for them. Blenner (1992) and Holmes and Tymstra (1987), in a survey of 29 women who had

received IVF and their partners, found that even though couples had received written information informing them that the success rate for their clinic was between 10% and 20%, 62% of the women and 48% of their partners felt certain that they would be successful. de Zoeten, Tymstra, & Alberda (1987), also reported unrealistic expectations regarding the success of IVF, and amazingly, many women in this study would have even accepted success rates as low as two per cent.

Whatever the chances of success, de Zoeten et al. (1987) contend that once a technology is available there is a compulsion to use it, mainly because of 'anticipated decision regret'. Women want to feel that they have explored every possibility in attempting to have a child, so that in future years they would have nothing to regret.

For many, infertility becomes work (Olshansky, 1985, 1987a) and this work may interfere with their established careers (Olshansky, 1987b). Sandelowski and Pollock (1986) found that women pursued treatment for infertility as if it were a career; to the extent that the pursuit takes on a driven quality. This 'driven' quality of pursuing infertility treatments was evident not only in those couples on IVF treatment but also in infertile persons in general (Olshansky, 1988). High technology options have exacerbated the situation by representing hope to many couples. As new technologies become available, people feel obliged to try them, to assure themselves that they have tried everything possible. Both the sense of 'drivenness' and multiple sources of ambiguity (cause, diagnosis, treatment, identity, life pursuits, and control) can preclude couples' ability to 'get on with life' (Olshansky, 1988; Sandelowski, 1987).

Menstruation can be seen as a summarising symbol which provides a means of reducing the emotional impact of the experience. Some women

believe that it is easier to deal with menstruation than the possibility of never being pregnant (Doty, 1986). Many infertile women experience fluctuations of emotions during their menstrual cycles. They feel hopeful and excited when ovulation approaches. However, when their menses begin they may experience depression and despair (Menning, 1988). Olshansky (1988) described the work of infertility as exacerbated cycles of hope and despair. This is particularly relevant for women in the present study who reported cycles of feeling up and down. Some of the women found the first half of the cycle (during ovarian stimulation) to be the most stressful. During this time, daily injections of drugs and frequent visits to the infertility clinic for monitoring were necessary. They found this to be emotionally and physically draining, as well as stressful. Other women found the second half of the cycle to be the most stressful, as they had to wait and see if the procedure was successful.

There is increased anxiety and excitement as the temperature charts show ovulation is approaching. Sex becomes a carefully timed project. When the period arrives, there is often a feeling of intense disappointment. This feeling may fade as yet another ovulation date appears and the attempt begins again. These feelings of hope and disappointment are renewed and relived every month (cycle). Each month the period is approached with a sense of dread and anticipation, and then crushing disappointment. The physical and emotional aspects of menstruation compound each other.

Some research has shown that men are generally less tolerant of remaining in treatment and more likely to want to terminate treatment before their female partners were ready to quit (Blenner, 1992). It is not surprising that couples sometimes feel the need to take time out from treatments to reassess their feelings or give them a break.

### Social Isolation

Infertile couples also experience social isolation. They may feel out of place at social affairs or family gatherings where other people have children (Menning, 1988). They may also have difficulty sharing their sorrow. Infertile couples often grieve alone because they fear that others do not understand how they feel (Hirsh & Hirsh, 1989).

The couple's personal life inevitably changes. Family gatherings and social events can become traumatic for infertile couples. Without children, they do not share the commonalities that children bring to life events, celebrations, social networks, social events, and parenting experiences. Harris (1992) has described these feelings, and in particular, women's reactions, as being outsiders, and feeling different.

Infertility may lead to a self imposed social isolation. Many couples, especially the male partner, do not speak openly about infertility. They fear any discussions which will elicit pity, or advice based on myths such as 'relax' 'adopt' and 'take a holiday'. They do not want relatives and friends to think their infertility is related to sexual performance. The couple may be extremely sensitive to pregnancy or little children. They may even withdraw from social situations or work situations that involve children (Griffin, 1983).

Daniluk (1988) reported that women experienced greater feeling of isolation than did men. However, Phipps (1993) found that both partners reported a sense of isolation. Men described feeling isolated from others and being physically isolated from their spouses as part of treatment. For the females, isolation also came from feeling that no-one really understood their experience, including their husbands (Phipps, 1993). However, isolation not only increases feelings of inferiority and low self esteem, but also decreases the

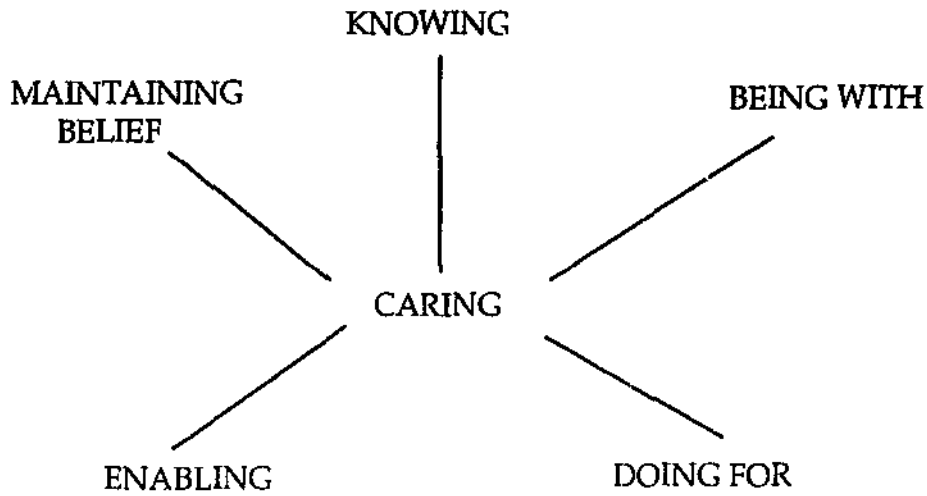
opportunities for couples to interact with others and gain sources of needed emotional support (Link & Darling, 1986).

Another unanimous response from the study participants was that people's comments about their infertility problems did not satisfy the couples' need for support, despite often good intentions. One common thread was people's desire to diminish the grief or to avoid talking about it. Although not a new finding (Bansan & Stevens, 1992; Swanson-Kauffman, 1986), the fact that people interviewed described painful experiences of this sort is evidence that the unique needs of these infertile people are not well understood by the public; not even by their own family.

#### Relationship of the Study Findings to Theory

Although the study was not guided by a designated conceptual or theoretical framework, once the findings emerged, it became clear that Swanson-Kauffman's Model of Caring (1988) (see Figure 1) was relevant to this study and was thus used to provide a second level of analysis for the findings.

It was anticipated that there would be some degree of correspondence with the model's five processes of caring, since the caring needs of women who miscarried, and the caring needs of couples experiencing infertility would be similar.



**Figure 1.** Five Categories of Caring

(Swanson-Kauffman, 1988, p. 59)

Swanson-Kauffman (1986) intended these caring categories to be offered as insights for caring (for both the professional carer and the family carer), rather than a formula of care. Following the analysis, the infertility experiences of couples in this study were further examined using the caring processes from Swanson-Kauffman's Model of Caring.

#### Knowing

This first caring category identifies the couple's desire to be understood for the personal meaning that infertility has in their lives. Most of the participants in this study expressed a desire to be understood. The participants commented on the lack of understanding from not only the health care providers, but also from family and friends.

'Knowing' the meaning that infertility has in each couple's life involves a desire to understand on the health carer's part. It involves a willingness to abandon preconceived ideas, and to see the couple as more than a diagnostic group category. Support for this category can be found in the literature.

Mayeroff (1971) emphasises the importance of knowing another in order to care. Watson (1988) has also focused on the interpersonal aspects of caring. It is equally important for friends and family to try to understand the couple's plight. For friends and family, 'knowing' involves a concerted attempt to understand the experience of infertility as something more than not being able to have a baby (Swanson-Kauffman, 1986, 1988).

### Being with

The next caring category illustrates the couple's need to have others feel with them, and be available to them. 'Being with' goes beyond 'knowing' to actually feeling with the infertile couple, obviously not as deeply as the couple, but with the couple. 'Knowing' and 'being with' are very closely related. Swanson-Kauffman (1986) points out that it seems hard to imagine that one could truly know another's pain without feeling some emotional tugs.

One of the females in this study expressed the need for her mother to understand how she felt.

"...I would like her to understand. I would like her to put her arms around me and say..." (6f).

There have been a number of terms described in the caring literature that capture the essence of 'being with'. These include: compassion, empathy, presence, tenderness, and comfort (Leininger, 1985), and emotional involvement (Travelbee, 1971). Each of these terms involves a relationship that goes beyond 'knowing' and surpasses the bonds of assigned professional or social roles (Swanson-Kauffman, 1988).

'Being with' occurs on different levels depending on the relationship between the people (Swanson-Kauffman, 1988). The caring between a married couple will usually involve a much deeper sense of overall 'being with' than that of the health carer and the infertile couple. A female participant in this

study described how she was comforted by her husband's willingness to be with her and how much this support meant.

For health carers 'being with' may mean dropping the professional facade and willingly entering into an emotional-laden person to person relationship. For friends and family it means recognising and sharing the pain that accompanies infertility (Swanson-Kauffman, 1988).

#### Doing for

The findings from this study did not have any particular relevance to this caring category.

#### Enabling

The next category, 'enabling' is caring that facilitates the couple's capacity to grieve, and to develop coping strategies. 'Enabling' takes a variety of forms, depending on the couple's perception of their infertility, and their usual coping style (Swanson-Kauffman, 1986).

All of the couples in this study commented on the lack of informational and emotional support they received from the health carers. Health carers were described as being 'too busy' 'uninterested', and/or 'insensitive'. One of the females gave an example of how health carers do not acknowledge the person's grief.

"Last time (when receiving intramuscular hormone treatment) I sat down and burst into tears. One of the girls said to me 'Is the needle hurting?' (the tone of participant's voice indicated that this was not the reason for the tears) (6f).

Health carers who are successfully able to assist the couple to grieve, base their care on a thorough assessment of the meaning of infertility to each couple, and are usually able to demonstrate both 'knowing' and 'being with' (Swanson-Kauffman, 1986). Health carers can provide 'enabling' care by providing appropriate information, and emotional support,



discussing/explaining treatment alternatives, and by validation of the couple's responses (Mahlstedt, 1985; Menning, 1988).

### Maintaining belief

The final category 'maintaining belief' focuses on the couple's need to have others believe in their capacity to get through the experience, and ultimately become parents. This caring category takes two forms; if the couple have made a decision to stop treatment or take a break they need others to maintain belief in their capacity to make this decision. If the couple desires another attempt at assisted reproduction, they want to be acknowledged as potential parents (Swanson-Kauffman, 1986).

All of the couples commented on how they were excluded from conversations about children. Some of the females stated they actually preferred to not talk about children, however, the others perceived this exclusion as negative and hurtful. For family and friends to demonstrate 'maintaining belief' they need to include the couple in conversations relating to children, and in all social activities. It is then up to the couple to accept or decline, depending on how they feel.

Watson (1988) states that caring responses accept a person not only as he or she is but as what he or she may become. 'Maintaining belief' involves acknowledging not only a couple's potential to become parents, but also their ability to make the right decision regarding interrupting or ceasing treatment.

According to Swanson-Kauffman (1986) the health care provider, friend, or family member should speak from a basis of 'knowing' and 'being with' so their acknowledgment of 'maintaining belief' will not be interpreted as a means to dismiss the importance of the couple's experience.

Although the caring processes incorporated in the model have been presented and discussed separately, they are not mutually exclusive. Four of

the five caring processes have special relevance to the experience of infertility. Specifically, health care providers should strive to understand those individuals being cared for, in order to know how best to care for them. Understanding people through a phenomenological perspective can shed some light on the meanings people assign to their experiences, and of the health carer-client relationship. Finding ways of caring that are responsive to particular individuals and adding to the theoretical base of the practice discipline are fundamental goals of all health care professionals.

### Implications for Health Care

The findings from this study highlight the fact that the current management of infertility focuses on the physiological, and technological, aspects of treatment. It is clear that the couple's emotional needs are not being met. The findings from this study will enable health care providers to understand more clearly the experience of infertility from the perspective of the couple, and be better able to address their emotional needs.

The findings also suggest that health care providers need to be aware of the importance of their caring role, particularly in light of the powerlessness which is such an important aspect of the infertile couple's experience.

### Recommendations

Health care providers can assist the infertile couple by providing responsive and appropriate reassurance, information, and support. In knowing the broad range of responses to being infertile, health carers can provide anticipatory guidance.

The following recommendations are divided into two categories. First, the recommendations that emerged from this study's findings, and second,

recommendations from other sources. The general strategies that are recommended include: empowering the couple, providing counselling, treating the couple together, providing informational and emotional support, and helping to 'normalise' the experience for the infertile couple.

#### Recommendations from this study

##### 1. Empower the couple.

Help individuals and couples to heighten their feelings of control over their lives. Encourage the couple to increase their knowledge related to the treatment options, to question health carers, and to participate in decision making process.

##### 2. Provide counselling.

The health carer may facilitate understanding and enhance relational support. Health carers can develop close therapeutic relationships and encourage couples to express their feelings and concerns regarding infertility.

##### 3. Treat the couple together.

The couple should be assessed together, no matter whose body ultimately is the source of the problem. The other partner will have a strong interest in the investigations and treatment. Involve both partners in all discussions and planning right from the beginning (Link & Darling, 1986). Two people have twice the ability to take in all the new information, to ask questions, and to clarify certain points. They are also a support for each other.

##### 4. Provide informational support.

Provide couples with clear, accurate, and complete information in language that they understand. This will enable the couple to make informed choices throughout the process and may support their efforts to regain control (Cottle, 1991; McCormick, 1980).

### 5. Provide emotional support.

Probably the most important act the health care provider can perform in caring for infertile couples is to offer support by conveying a compassionate and empathetic attitude (Mahlstedt, 1985; Menning, 1988).

#### Recommendations from other sources

##### 1. Normalise the experience.

Help the couple by acknowledging that their feelings are normal and experienced by others in similar circumstances. Often, it is sufficient for couples to have their feelings validated and they are able to resolve their own problems (Woods et al., 1988).

##### 2. Provide informational support.

Recommend reading material written by other infertile persons, as well as by knowledgeable and empathetic professionals. Inform the couple about local infertility support groups. These groups have the latest information on new treatment techniques, which increases a sense of being in control. Members of support groups discuss the harsh realities of infertility treatments, including the fact that they are not always successful. The acceptance and encouragement offered by others who are experiencing infertility can be valuable in reducing emotional distress, and provide a valuable coping mechanism. (Link & Darling, 1986; Woods et al., 1988).

#### Future Research

There has been limited research relating to the experience of infertility, from the perspective of infertile couples. It is hoped that this study will stimulate interest for continued research in this area. There is a general consensus that the emotional needs of the infertile couple are not being met.

Health care providers need to continue building a knowledge base relating to the experience of infertility.

Other studies using the same approach, with larger sample sizes, and different racial, cultural, and socioeconomic groups are recommended. The couples who participated in this study were part of a selective group. They were all urban, Caucasian, well educated, and from a socio-economically advantaged group. It would be important for future research to compare and examine these findings, to see if there is any relevance for other groups of infertile couples.

The researcher also recommends the following studies:

- An investigation into how health care providers can best provide anticipatory guidance (preventative, primary health care) to infertile couples.
- An investigation comparing the potential differences in perspective of two infertile populations; those who experience primary infertility (never been pregnant), to those who experience secondary infertility (miscarried, still birth, or have one live child).

### Conclusion

Clearly, there are many complex issues, decisions, and emotional consequences associated with being infertile. Infertility affects all aspects of a couple's life. Infertility is usually unanticipated, may be unexplained, and lasts for an indeterminate length of time. Despite the magnitude of the problem, the emotional needs of infertile couples are still not being met. It is important for health care providers to understand the widespread incidence of infertility, and the serious, often devastating effects that invade all aspects of a couple's life. Infertile persons experience additional life stresses that are not always

recognised, and poorly understood. Too often people are unaware of the couple's emotional needs or are unable to offer the time and energy to deal with them successfully (Mahlstedt, 1985; Menning, 1977).

Infertile couples face complex and demanding high technology treatments with a high risk of failure. They deal with major life changes which include life style changes, various physical and emotional changes, and changes in their relationship. They feel powerless when confronted with these enforced changes, and disempowered by health care providers. The emotional roller coaster of feelings is renewed and reinforced with every menstrual period. In addition to this, couples report feeling different and socially isolated.

It is important for health care providers to anticipate and respond to these people's unique needs. The emotional aspects of infertility poses an education problem; to the couple, the family, health care providers, and the community.

"Infertility is like a broken bone, when it heals it will be stronger than ever, but on rainy days it hurts...You may not be proud of breaking your bone, but you can be proud you developed stronger muscles using crutches."  
(Fleming & Burry, 1988, p. 41).

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## Appendix A

Interview Question Guide.

Research participants were asked to share all their thoughts, feelings, and circumstances that they associated with the experience of infertility.

Sample prompts used during the interviews included the following:

- When did you first become concerned with your fertility?
- How does it feel to be living the experience of infertility?
- What is your understanding of the infertility experience?
- Do you think your experiences are typical of the infertility experience?
- Which particular aspects of the infertility experience do you think are typical?
- Does your partner have similar feelings and/or experiences to you?
- Have your feelings or experiences changed at any stage of the infertility process?
- Can you describe any strategies that you use to help you through the infertility experience?

## Appendix B

Memo: Sample of Field Notes-Couple Number Three

The female partner of couple number three responded to the Sunday Times Newspaper article the same day that it was published. She was the fifth person to call.

She spoke at length about her and her husband's experiences in general, and how no-one understood how they felt. She sounded particularly keen to participate; in fact, even anxious that they might not be selected. I got this impression from the way she stated she was available any night, or if this didn't suit me, they could take time off work during the day.

It occurred to me that this interview might prove therapeutic for her, as well as providing a rich data source for me.

On the night of the interview, she seemed anxious, and uptight. The informal interview preliminaries were kept to a minimum as she seemed keen to get started.

Her husband was subdued at the beginning and his wife did most of the talking for at least three quarters of the interview. It surprised me how much information she shared without any prompting required. It was obvious that much of the information she shared was new to her husband. This was interpreted from his facial expressions throughout the interview.

I became concerned towards the end of the taped interview when it became evident she was not coping with her feelings, and talking glibly about suicide. Her husband looked horrified, and was obviously not aware of how badly she felt. I think she even surprised herself at her candid disclosure of these feelings. She seemed to just keep on talking until 'it all came out'.

Her body language was interpreted as being 'closed', or 'guarded' with arms crossed across her chest and sitting on the edge of her chair. There were very few pauses and no periods of silence. Eye contact with her husband was minimal, and even though the conversation involved her husband, it was directed at me.

The tape was turned over, and eventually ran out. I did not use another tape, but chose to continue the interview 'off tape'. The conversation flowed for another 30 minutes. During this time I acknowledged her concerns, and asked her husband how he felt. They both expressed the need for professional help. I recommended some different agencies and left contact names and telephone numbers with them. I phoned three days later and found out that they had contacted one of the agencies for counselling.



## Appendix C

Bracketing Memo: Researcher's Perspective on the Meaning of Infertility

My interest in the topic of infertility started several years ago. The initial interest was due to the fact that two family members had experienced infertility problems. I then became aware of some friends who had been trying to conceive for some time. Due to the fact I was a friend, and a Community Health Nurse, they began asking me questions that I was unable to answer. In fact, most of my Family Planning Nurse Practitioner (Community Nursing) experience was based around prevention of pregnancy, rather than planning a pregnancy.

I started to seek out information relating to assisted reproduction, which I passed on to my friends. There was plenty of information relating to diagnostic assessments and high technology treatments.

The following year, my friends experienced a number of disappointments relating to unsuccessful treatments. Once again I sought out information, this time relating to the emotional aspects of being infertile. Information related to infertility (including the emotional aspects) tended to be focused on the woman. Men seem to have been left on the sidelines. Women seem to receive more support from others because they are the ones who actually physically experience the failed conception. But what about their partner's feelings? Both partner's lives are affected by being infertile. How does infertility affect them as a couple?

I have made a list of some preconceived ideas I had about infertility. Since I am fortunate enough to have my own biological child, my assumptions

about infertility are based on the perspective's of infertile family members, friends, media coverage, and newspaper and magazine articles.

- Infertility will have a profound affect on the lives of both men and women who are trying unsuccessfully to conceive.
- The effects of being infertile will be more pronounced in women in the 25 to 40 year age bracket. Women under 25 years may not feel as emotionally affected since they have at least 15 years to 'keep trying'. Woman over 40 years may not be as emotionally affected because a significant amount of their adult life has already been childfree, and may therefore find it easier to accept and to cope with.
- The partner who is not physically responsible for the cause of the infertility may occasionally feel anger or resentment towards the other partner.
- The partner who is physically responsible for the cause of the infertility may experience feelings of guilt, and find the diagnosis harder to accept or to cope with.
- The label of infertility has negative connotations to terms such as: sterility, impotence, and barren.

It seems to me that the issues relating to infertility are complex and varied. The emotional aspects of infertility are not being adequately addressed by family, friends, and health care providers. Many infertile couples are struggling to cope, without the support and understanding they require.

## Appendix D

Coded Transcript Sample

- The names used are pseudonyms

| Content/verbatim quotes   | Codes/Tentative Themes           |
|---|----------------------------------|
| PAUL  |                                  |
| I'm not concerned about the clinical environment.                   |                                  |
| <u>It's not like if you break something they'd say</u>              | Ambiguity, unpredictability.     |
| <u>"We're going to put you in plaster for 4 weeks".</u>             | Not knowing cause.               |
| <u>I mean this sort of thing is like you go around in circles,</u>  |                                  |
| <u>continuously and you don't know where it's going to end.</u>     | POWERLESSNESS                    |
| <u>And in the meantime everything else has to be put on the</u>     |                                  |
| <u>back burner until this thing gets sorted out.</u>                | Affects decision making          |
| <u>That's the other thing that I find quite frustrating</u>         | and plans.                       |
| <u>because it's gone on for so long and everything that we've</u>   | Time wasted, affects life plans. |
| <u>decided that we were going to do or wanted to do, is that</u>    |                                  |
| <u>Rose says "Oh well I can't do that because I'll be pregnant,</u> | LIFE CHANGES-lifestyle           |
| <u>I'll be pregnant, I'll be pregnant" and it's just gone on</u>    | Continuous, out of control.      |
| <u>and it's just gone on and on and on.</u>                         | POWERLESSNESS                    |
| ROSE  |                                  |
| <u>I mean I feel guilty because I think, well I know that</u>       |                                  |
| <u>a large portion of the blame lies with me and I think</u>        | Guilt, financial costs of        |
| <u>"Oh all this money. We can't extend the house and we</u>         | treatment, future house plans.   |
| <u>can't buy another house, and this money is..." I know that</u>   |                                  |
| <u>Paul wants to do lots of other things as well.</u>               | LIFE CHANGES-life-style          |
| I mean he really wants a child, it's not just me that wants         | -emotional                       |

a child, but it is that you're sort of in limbo really.

You just, nothing else, your whole life seems to be just concentrating on getting pregnant and everything else...

I don't know. Other people say things like "Why don't you go on a holiday" or "Just forget about it"

and I mean that's all very well but particularly now

that we're at Pivot (infertility clinic) it's very hard

to forget about it you know when they say ring up every other day and have injections every other day and that's the only thing you can really think about.

And you have the side effects from the drugs.

It's now our third attempt and I feel a bit more relaxed.

The first day I went in, I went in on Friday and I felt the stress. Just the sight of the place makes me stressed.

But three days down the track and I sort of feel a bit better.

Headachy but better. So it's stressful.

PAUL

I've never liked hospitals or whatever, or doctors rooms

anyway. I shy away from them but it's just everything

else goes on hold while that goes on. So that adds

another stress because you can't plan, every plan

that you like, obviously you have plans in life about

what you're going to do and where, how you're

going to do it, but this thing takes precedence

over everything.

Uncertainty, 'in limbo'.

Life affected, time wasted.

LIFE CHANGES-life-style

Lack of understanding

SOCIAL ISOLATION

Time involvement, physical  
and subconscious.

Negative effects of drugs

LIFE CHANGES-life-style

-physical

Stress.

Physical effects, felt better

later, stress

LIFE CHANGES-emotional

-physical

Affects whole life.

Treatment becomes priority.

Stress, unable to plan

LIFE CHANGES-life-style

-emotional

ROSE

Also too, they said to me the other day that they get  
one pregnancy a day, sometimes two, sometimes three.

Now when you sit in that waiting room and see all those  
people pour through you think what are your chances!

You know what I mean, like it's not very big.

But I suppose somebody has to be that one.

Yes it's hard!

PAUL

You never relax. Its always at the back of your mind.

You count the days hoping that something will  
happen.

Hope, anticipation.

HOPE-DISAPPOINTMENT

CYCLE

Stress, anticipation, hope.

LIFE CHANGES-emotional  
and

HOPE-DISAPPOINTMENT

CYCLE

Appendix E

Consent Form

Ten to twenty per cent of the global population share the experience of infertility, however, different people will have different experiences and perceptions of infertility. This research study seeks to understand the infertility process from the perception of those people experiencing it. The overall aim of the study is to increase the knowledge base relating to the infertility experience in order to improve the counselling and support services for infertile couples. **You have been invited to participate in this study to share your infertility experiences**

.....

In signing this document, I am giving my consent to participate in a research study investigating the infertility experience. The study will be submitted to Edith Cowan University as a requirement for a Master's Thesis.

I understand that I was selected to participate in this study because I am currently experiencing infertility, living in the Perth Metropolitan area, and if female, am aged between 25 and 40 years.

I understand that an audiotaped interview (taking approximately one hour) will be conducted in my home at a time convenient to me. I will be asked to describe feelings, thoughts, and experiences which I relate to the infertility experience. I also understand that the researcher will contact me in 1-2 months for a follow up phone interview.

I have been informed that participation in this study is entirely voluntary. I can refuse to answer any specific questions and I can withdraw from the study at any stage of the proceedings.

I understand that no personally identifying information will be associated with the descriptions I give. Pseudonyms and a coding system will be used instead of names and only the researcher will have access to the original transcripts.

If I have any questions relating to the study, I can contact Margaret Imeson (Master's student) by telephone on 4471431.

Date.....  
Participants' signatures.....  
Researcher's signature.....

## Appendix F

Memo: Reflections on theme Powerlessness

Powerlessness was identified as one of the key themes that emerged from the data. Powerlessness has been defined by (Kim, McFarlane, & McLane, 1991) as "Perception that one's own action will not significantly affect an outcome; a perceived lack of control over a current situation or immediate happening."

The theme powerlessness is interrelated to the other themes; Life Changes, Hope-Disappointment Cycle, and Social Isolation. Being powerless, extended into many aspects of the couple's lives as a result of the enforced changes brought about by being infertile. Being powerless can affect a person's self esteem, which in turn has negative effects on their emotional wellbeing, and personal relationships.

The males, in particular, seemed to be more affected by powerlessness. In general, men have been socialised to be independent, in control, and to suppress or deny their emotions (Phipps, 1993). The reality of being unable to change circumstances or outcomes was extremely frustrating for the males in this study. This was expressed as anger, and directed towards the health care providers, especially the doctors. The males also expressed a greater desire to try to regain control of the situation by making plans, and setting limits. This included the expressed need to take a break from treatment, and stating how long they would continue with the treatment, and how much money they would spend on the treatment.

Both the males and the females in the study commented on the powerless feeling of not knowing if they would ever have a baby. This feeling

of powerlessness and unpredictability was exacerbated when the couple did not know and/or understand the cause of their infertility.

Couples were extremely disappointed with, and felt disempowered by health care providers. They reported a variety of negative responses that contributed to the powerless feelings. These included: insufficient information, lack of explanation, lack of support, and insensitivity to their feelings and needs.

Couples seeking infertility treatment are indeed relinquishing control over various aspects of their lives; physical, personal, and sexual). The health care providers (usually the doctor), make decisions relating to which treatment is appropriate, when the treatment and the associated appointments will be scheduled, and even when the couple will have sex and how often. They may not take into account, the emotional and financial capabilities of the couple, and their combined professional and social commitments. This will almost certainly have adverse affects for the couple, and significantly contribute to the enforced and unwanted life style changes, emotional changes, and relationship changes.

Powerlessness is something the couple can do something about. Couples can empower themselves by increasing their knowledge about infertility, take an active role in understanding assessment and diagnostic procedures, and select appointment/treatment times to suit their life style, jobs, and financial circumstances. These strategies will not only enhance communication between the couple, but may also have a positive effect on the couple's marital relationship and emotional well being.

The couple cannot change the fact that they are infertile but they can set some realistic short term, and long term goals, which will assist them to regain some control in a situation where they feel so out of control.