

**Premature menopause – the experiences of women and their
partners**

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A thesis submitted in partial fulfilment
of the requirements for the degree of
Doctor of Psychology (Counselling Psychology)

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2012

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Abstract

Premature menopause – the experiences of women and their partners

This study aimed to investigate the experience of spontaneous premature menopause for women and their partners. Eighteen women who had become menopausal before the age of 40 and their husbands were involved in the study. Participants were sought by advertisements in local newspapers and other forums including websites relating to women's health. The men and women participated in open ended, semi structured interviews. Hermeneutic phenomenology was used as a theoretical foundation and as a basis for analysis. Common themes and patterns of responding were identified from the interview transcripts. The findings varied with regard to the women's physical symptoms and psychological responses experienced by the women and their partners. Themes included being shocked at the diagnosis, facing infertility, confusion about feeling older and what the condition meant for their long term health, a sense of not fitting in to a social group and perceived professional confusion about the condition. The men tended to offer both practical and emotional support to their wives. Impacts on the marital relationship are also discussed.

Acknowledgements

Thank you to the women and men who kindly and generously shared their stories for this study. Thanks also to my supervisor Dr Roger Cook who gave me guidance and relevant critique throughout this work. My gratitude also goes to my family, Tony, Luke, Tim and Lily for their love and support.

Declaration

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere from a thesis for any other degree or diploma.

No other person's work has been used without due acknowledgment in the text of the thesis.

Geraldine Lockley
September 2012

Chapter 1 Introduction

Preamble

The choice of this thesis topic comes in part from personal experience and part from curiosity. At the time of beginning this research I was aged 39 and not menopausal. In fact to date I have not experienced any peri menopausal symptoms. The curiosity about menopause came from the realisation that it was a stage I would be facing, presumably in the next 15 years or so, and awareness that it was something I knew very little about.

Apart from some basic reading, my only understanding of menopause came from earlier conversations with my mother about her experience. My mother went through a sudden menopause, over 20 years ago, in her early 40s as a result of an oophorectomy (hysterectomy and removal of ovaries) as treatment for ovarian cysts. At that time, being a teenager myself and busy in my own world, I didn't think too much about what happened to my mother, I only knew she had an operation which meant she wouldn't get any more periods and couldn't have any more babies. It is only in recent years, as I approached the age she was when she had that operation that I wondered what it would have been like for her. My mother's answers to those questions interested me. She said that although she was pleased to be rid of her physical discomfort, she had a sense that 'something was taken' from her, that in ways she felt less womanly, that she missed her periods and the repetition of her monthly cycle and that she 'grieved what was gone.' Although she hadn't planned on having more children (I have two younger brothers), she felt her fertility had ended too early. I found her recollections intriguing and they raised the question, 'what is it like to reach menopause too soon?' I assumed I had many years before my own menopause, but what is it like to not have those years? What does it mean to experience menopause early?

I should also note my mother's references to loss, of her body image, her fertility, her womanliness, her sense of identity and her choices incited my general interest in themes and experiences of loss. My predilection toward an awareness of loss stems from my

personal encounters with assisted reproductive technologies, miscarriage and reproductive loss. Since then, I have paid more attention to how others interpret and incorporate losses, both tangible and intangible, into their own lives.

This doctoral research also has links to my MA (Counselling Psychology) studies, completed in 2005, for which my research was titled 'women's' experience of miscarriage after assisted reproductive technology'. This earlier work incorporated my six month study placement as a psychologist in a Melbourne IVF clinic, with my interests in women's health, fertility, and themes of loss.

The current research topic connects these ongoing interests with my own life stage and family experience as well as my practice as a psychologist in which I work with my clients to explore and understand the ways in which they respond to and cope with life events.

Research goals

The term 'menopause' today will have different meanings for different people, but many will have a general view that menopause is something that happens to 'older women', 'later in life', when they have finished the reproductive years, and that with menopause comes a perhaps rather mysterious range of physical and emotional symptoms, mostly which are unwelcome.

But what happens when menopause comes early, before it is expected, before a woman has had the chance to finish or even start the childbearing phase of her life? How does premature menopause affect a woman and in what ways does it impact her partner, her relationships, her plans for the future and feelings about herself?

Premature menopause affects around one in one hundred women in Australia and is largely a poorly understood condition (Nippita & Baber, 2007). Although medical research into the causes of premature menopause continues to advance, the ways in

which this condition impacts women psychologically and emotionally is relatively unexplored (Groff et al., 2005, Orshan et al., 2001, Singer & Hunter, 1999).

This study aims to explore psychological aspects of spontaneous premature menopause, in particular, the ways in which the experience has impacted women and their partners. The sorts of questions which have framed the research include the ways the experience affected the women and their partners individually and as a couple, as well as what was helpful and unhelpful over this time. It is hoped that this study will provide valuable information, not only for people working in the area of women's health and fertility, but also for other women, and their partners, who may experience premature menopause in the future.

Outline of this thesis

For the remainder of this first introductory chapter I will describe what we know about 'normal' menopause and ovarian functioning. I will describe a range of common menopausal symptoms and set menopause in a historical and psychological context.

Chapter 2 of this introduction will discuss premature menopause, its causes and some recognised management options. I will also offer some opinions on why the condition of premature menopause presents women with unique challenges. Current knowledge about psychological aspects of premature menopause, and infertility – an outcome of the condition in question will be addressed.

The methodology for this research is explained in Chapter 3. Chapters 4 to 10 each present and discuss a key theme from the findings of the study. Finally, Chapter 11 draws conclusions from this research and offers implications for counselling practice.

What is menopause?

Menopause is defined as 'permanent cessation of the menses: termination of menstrual life' (Stedman's Medical Dictionary, 2000). Menopause is the stage of a female's reproductive life that occurs when the ovaries are depleted of eggs and stop producing estrogen, causing the reproductive system to shut down. It is commonly thought of as the last menstrual period in a woman's life. Menopause is said to have occurred, and the term postmenopausal is used, when there has been amenorrhea (no periods) for 12 months.

In studying the age of menopause in ancient times, Amundsen (1970) suggests in classical times, the average age of menopause was in the 40s, and in medieval times, age 50. Ginsburg (1991) agrees with an average age of 50 for twentieth century women and notes that despite reported studies on the age of menopause being wrought with methodological problems, it would seem there has been little change in this average age over the last century.

Most women today reach menopause somewhere between the ages of 48 and 55, the average being around 50 years in western industrialised societies (McKinlay & Thompson, 1972).

The term peri menopause is often mentioned in discussions about menopause. Peri menopause is referred to as the transition time between experiencing some menopausal symptoms, usually in the mid to late 40s and the time periods actually stop. Different studies report differing lengths of time for peri menopause, but the range appears to be between 4 and 7 years (Dell & Stewart, 2000). During the peri menopausal phase ovarian function is declining and fluctuating, causing a range of menopausal symptoms. This transition phase, during which the body is undergoing changes occurs gradually over the years around the last menstrual period and is medically termed 'the climacteric'. (DeGraff – Bender, 1998)

Historical perspectives on menopause

Views on menopause have changed over time. As the roles of women in society have changed and medical knowledge has developed, medical approaches to menopause and the way society views menopause have also changed. In past centuries many women did not live to menopause. A girl born in 1789 would be expected to live only to her mid 30s, and by 1890 this had increased only to age 44 (Foxcroft, 2009). Aristotle referred to menopause being at age 40. The ancient Greeks thought menopause was attributed to an excess of 'humours' (which related to the four seasons and were the basis of all disease). They believed the cessation of menstruation was because the humours were not balanced out each month. In ancient Greek times, a remedy was to apply leeches to a woman's legs to let out excess blood in order to rebalance the humours (Houck, 2008). In 1777, John Leake wrote in 'Chronic or Slow Diseases Peculiar to Women' that menopause caused 'pain and giddiness of the head, hysteric disorders, colic pain, and a mid-life female weakness.'

The word 'menopause' itself was coined in the 1870s and came from the Greek words 'meno' for month, and 'pause' for cessation, the end of the monthly courses, or menstruation. Before the 1870s, this time of a woman's life was referred to as 'the change', 'Indian summer', or other euphemistic terms (Formanek, 1990). In the 1880s one recommendation for women to avoid the 'evil effects' of menopause was to avoid too much education, concern with fashion or too much sexual activity and they were encouraged to devote themselves to the care of their husbands and children (Foxcroft, 2009).

In the 1930s estrogen started being used by doctors to treat the symptoms of menopause. By the 1960s it was decided that menopause was a disease, the cause of which was a deficiency of estrogen. As such, the deficiency could be addressed and the disease prevented (Formanek, 1990).

Only in March 2005 did the US's National Institute of Health issue a statement saying menopause was not a disease to be treated, but a natural phase in the life of women.

A turning point in understanding and managing menopause came in 1977 in a paper which linked hormone replacement therapy (HRT) to an increased risk of breast cancer, blood clots and stroke; but the first wide scale studies to test this were not conducted until the 1990s (Houck, 2008). In 2002, and with the release of the results of the Women's Health Initiative study from the US National Institute of Health, attitudes about HRT for menopause changed. The study suggested that the combination of progestin and estrogen had increased risk of heart disease and breast cancer (Houck, 2008). However research on the risks of HRT is highly controversial. The Women's Health Initiative study has since been widely criticised for its sample and methodology.

In a major review of the use of HRT for menopause, Santen, Allred et al (2010) report conclusions relating to the overall benefits and risks of menopause hormone treatment (MHT). They expressed their findings as the number of women per 1000 taking MHT for 5 years who would experience benefit or harm. The use of MHT was found to be beneficial for relief of hot flashes and symptoms of urogenital atrophy, as well as prevention of bone fractures and diabetes. Risks of using MHT were found to include venothrombotic episodes, stroke, and cholecystitis. In the subgroup of women starting MHT between ages 50 and 59 or less than 10 years after onset of menopause, congruent trends suggested additional benefit including reduction of overall mortality and coronary artery disease. In this subgroup, use of estrogen plus some progestogens increased the risk of breast cancer, whereas estrogen alone did not. Beneficial effects on colorectal and endometrial cancer and harmful effects on ovarian cancer occurred but affected only a small number of women.

Data from the various Women's Health Initiative studies, which involved women of average age 63 cannot be appropriately applied to calculate risks and benefits of MHT in women starting shortly after menopause, (Santen, Allred et al, 2010). At the present time, assessments of benefit and risk in these younger women are based on lower levels of evidence while the risks of taking HRT from a young age and over an extended period of time are largely unknown.

Santen and Allred et al suggest use of HRT should be an individual choice based on symptomatology and health and family history. While many women choose to use varying types of HRT, to manage menopause symptoms, others look to dietary and lifestyle changes as well as alternatives such as acupuncture (De Graff – Bender, 1998).

Menopause paradigms

Over the centuries, as discussed, menopause has been viewed as a psychological problem, a physical disease, and a natural life phase. Today there remain three main paradigms in which menopause is commonly presented; menopause as a medical issue, a loss, and as a stage of life.

Perhaps still the predominant discourse on menopause is the biomedical view which sees menopause as a medical issue or as a hormone ‘deficiency disease’, the suggestion being that an aspect of health has diminished and that menopausal women require treatment (Ussher, 1989). From this perspective, hormone replacement therapy becomes ‘almost obligatory’ to fix the ‘problem’ (Ussher, 1989).

Menopause can also be seen as a loss; of youth, of health, of fertility, of womanhood. A widespread public view of menopause today remains one in which ‘menopause is associated with ageing, ill health, distress and social undesirability’ (Singer & Hunter, 1999). Komesaroff, Rothfield and Daly (1997) suggest this negative view is reinforced by media representations of women and through marketing of youth, fitness, health sexuality and medicine. Such stereotypes link menopause to emotional and physical decline (Dillaway, 2005; Komesaroff et al,1997). Dillaway suggests negative prejudices about menopause exist, especially perhaps amongst younger women who are usually without direct experience, and who tend to have more negative attitudes towards it.

Others (e.g. Greer, 1991), offer less negative perspectives on menopause by framing menopause as a natural developmental stage of a woman’s life which presents new opportunities, wisdom and an opportunity to reflect back and look forward (Hvas, 2006,

Sommer et al., 1999, Utian, 1997). Positive aspects of menopause may include relief at no longer menstruating and feeling calm (Dennerstein, 1996). Deeks and McCabe (2004) has suggested menopause may indicate to women that their role in life is changing as they move into a new stage in their lives.

Cross-cultural studies indicate that there are differences in the experience of menopause among women within and across cultures in terms of the types of symptoms they experience and the degree to which they find menopause troublesome (Robinson, 1996). It would seem there is no one model through which to view menopause, rather the experience of menopause and menopausal symptoms seem to be caused by a combination of physical changes, cultural influences, and individual perceptions and expectations (Cheung, 2004). Deeks (2003) also suggests menopause must be viewed in light of a range of perspectives including social interpretations and psychological changes occurring in a woman's life at the same time.

These views all assume menopause happens in mid life, around age 50. But that is not always the case. How do we view menopause when it happens much earlier? The focus of this thesis is premature menopause. However in order to understand what premature menopause is, it is necessary to first briefly review what is known about 'normal' menopause, why does it occur? To do that, the basics of ovarian function, ovulation and hormone production have been summarised.

Ovaries, ovulation and hormones

The ovaries are the organs relevant to menopause. Ovaries are two nut sized organs located within the female pelvis. They are attached either side of the uterus near the opening of the fallopian tube. Ovaries have two main functions; to store and release oocytes (eggs) and to produce hormones.

The ovaries contain follicles which are fluid-filled sacs in which eggs grow to maturity. At approximately 20 weeks gestation females have their maximum number of follicles containing eggs and are not capable of making any more. From this time on, the number

of follicles begins to naturally reduce in a process called atresia so that at birth, the number of eggs a female baby has is reduced from around 2 million to around 700,000. As a girl grows, the number of eggs in her ovarian follicles continues to reduce. Around 400,000 follicles will remain at puberty and this number continues to decrease with age. Over the next 30-40 years of a female's reproductive life, the entire egg supply will be depleted (Johnson and Everitt, 2000).

From puberty, if ovarian function is normal, either the left or right ovary will release an egg to be fertilised each month. This process is called ovulation and is linked to the menstrual cycle. Even though hundreds of eggs begin to mature each month, ordinarily only one egg (sometimes two) will become dominant during each menstrual cycle, and reach its fully mature state, capable of ovulation and fertilisation. The dominant egg develops, relying on hormones for growth and stimulation. When it becomes fully mature, the follicle surrounding the egg bursts, and releases the mature egg which travels through the fallopian tube toward the uterus. If the egg becomes fertilised, it plants itself into the womb lining and the follicle it came from continues to produce progesterone to 'feed' the fertilised egg.

The remaining eggs will waste away. The large number of eggs that are used each month account for the steady decline in the female's total egg pool that occurs from birth to menopause. If fertilisation does not occur, the follicle starts to break down and slowly stops producing hormones. When the follicle has broken down completely and is no longer releasing any hormones, the womb sheds its lining (endometrium) and menstrual bleeding (a period) occurs. The start of a period is considered the first day of a new menstrual cycle (day one). Women's menstrual cycles range from 21 to 40 days or more, with an average of around 28 days.

Although ovulation occurs in most cycles, it is possible to have a cycle, and a period, without ovulating. This is called an anovulatory cycle and may happen in young women who have just started menstruating, women who are breastfeeding, women nearing the menopause, and women whose cycles are longer than 35 days (Johnson & Everitt, 2000).

As well as producing eggs, the ovaries serve an important hormonal function. The regularity of the menstrual cycle is controlled by the balance of four hormones; estrogen, progesterone, follicle stimulating hormone (FSH) and luteinizing hormone (LH).

Estrogen and progesterone are two of the primary female sex hormones. During a normal menstrual cycle, they take turns managing the process of maturing and releasing an egg and preparing the uterus for possible pregnancy: estrogen rises in the first half of the cycle, peaks at ovulation, then falls in the second half as progesterone rises. Progesterone is released by the rupturing of the egg follicle during ovulation. Testosterone too is secreted in surges around the time of ovulation. How much or how little of each hormone is made at any one time relies on a complicated feedback system between the brain: specifically the hypothalamus and the pituitary gland, which release LH (luteinizing hormone) and FSH (follicle stimulating hormone), the ovaries, and the adrenal glands (Carrell & Peterson, 2010).

In order to begin the ovulation process the ovaries begin to produce less estrogen. The drop in estrogen signals the brain to release a hormone called gonadotropin releasing hormone (GnRH). The release of this hormone triggers the production of follicle stimulating hormone (FSH) which helps the eggs to mature in the ovaries (Lebovic et al, 2005).

Like all parts of the body, ovaries age. The size of the ovaries declines with age, as does their function (Lebovic, Gordon & Taylor, 2005). The quality of eggs inside the ovaries diminishes with age and they become older and more difficult to fertilise (Carrell & Peterson, 2010). As mentioned, the number of eggs in the ovarian store also diminishes with age. With age, the ovaries also start to produce less of the female sex hormones estrogen and progesterone. Eventually ovulation and hormone production will stop and this is generally referred to as menopause.

Menopause symptoms

A range of symptoms can come with naturally occurring menopause and these symptoms are generally referred to similarly in discussions of premature menopause. Symptoms can be divided into early and late onset. Early symptoms include abnormal menstrual cycles which may be longer, shorter or less regular than usual. Bleeding patterns may change by becoming lighter or heavier. Other common early occurring menopausal complaints include hot flushes and night sweats. These body temperature changes are referred to as vasomotor instability and can result in irritability, insomnia, anxiety, embarrassment and related mood disturbance (Utian, 2005; Dell & Stewart, 2000). Hot flushes cause sudden extreme rises in skin temperature and an onset of heat, sweating, flushing, anxiety and chills (Williams, Kalilani et al., (2008). They can cause a woman to become quite red on the face and neck. Hot flushes can last for several minutes and be unpleasant and uncomfortable. Hot flushes have been associated with higher levels of distress than other menopausal symptoms (Ford, Sowers et al., 2005). Hot flushes and night sweats were the symptoms about which menopausal women most commonly sought advice from GPs (Lind-Astrand et al., 2005).

Ratka, Miller & Brown, (2006) report hot flushes being experienced by 65–80% of menopausal women in Western cultures. Similarly, Williams, Kalilani et al., (2008) found the prevalence of vasomotor symptoms was 79% in peri- and 65% in postmenopausal women. Daire & Fairall (2005) report rates of hot flushes and night sweats as high as 85 – 90% in perimenopausal women.

A variation of the hot flush is night sweats which may cause night waking due to increased body heat and perspiration. While the prevalence rates of night sweats have been reported as lower than hot flushes, their association with disturbed sleep may result in lethargy, irritability and diminished concentration (Stubbs, Cohen & Carr, 2005).

Hot flushes and night sweats are thought to be related to the decrease in oestrogen which occurs at menopause (Overlie, Moen et al., 1999). In more recent research, Andrikoula and Prelevic (2009) suggest levels of estrogens do not appear to correlate well with hot flushes and argue it is more likely that the rate of change of estrogen concentrations influences the body's thermoregulatory system via the hypothalamus. Other early

symptoms that may be experienced during perimenopause include an increase in body weight and headaches. (DeGraff- Bender, 1998).

Later effects of menopause due to decreasing oestrogen can include vaginal dryness and irritation, osteoporosis and heart disease. Natural vaginal secretions decrease which can lead to vaginal dryness, and as a result discomfort can be felt during sexual intercourse. The pubic hair may thin and the interior of the vagina changes with a thinning of the walls. The chemical changes in the vagina may increase susceptibility to infection, particularly cystitis. Some stress incontinence may also be experienced when small amounts of urine are leaked during sneezing or coughing (Sigelman & Rider, 2008).

Experience of menopausal symptoms and their intensity varies between women. Many find that the menopause is no problem to them whatsoever, with little or no symptoms manifesting themselves. Some however can suffer quite badly and the ability to function normally in daily life can be affected (Stewart, 2005).

One survey of 6096 women aged 45 to 54 years found that 84% had experienced at least one of the classic menopausal symptoms, with 45% finding one or more symptoms a problem (Porter et al,1996). Chedraui, Aguire, Hidulgo & Fayad (2007) in measuring frequency and intensity of menopausal symptoms in menopausal women found the 5 most frequent menopausal symptoms were muscle and joint problems (77%), depressive mood (74.6%), sexual problems (69.6%), hot flushes (65.5%) and sleeping disorders (45.6%).

The Greene Climacteric Scale is a common measure of the extent to which a woman is affected by a list of 21 menopausal symptoms. Greene (1998) found that psychomotor, psychological and vasomotor symptoms were common categorisations of symptoms and the scale was developed on this basis. The scale was constructed so that symptoms measured psychological aspects, somatic conditions, vasomotor symptoms and assessed loss of sexual interest (Barentsen et al, 2001).

Symptoms of menopause are often summarised as vasomotor, psychological, urogenital, and sexual symptoms (Stewart, 2005). These groupings are represented below;

Vasomotor	Hot-flushes, night sweats, palpitations
Psychological	Loss of confidence, depressed mood, panic attacks, difficulty concentrating
Urogenital	Vaginal dryness, urinary problems (frequency, urgency, dysuria)
Sexual	Changes in desire and sexual response

Psychological aspects of menopause

Many studies have investigated how women respond psychologically to menopause. A lot of this work has focused on anxiety and depression in relation to menopause (e.g, Avis, 2003, Dennerstein, 1987). The nature of this relationship is often unclear (Dennerstein, 1996). In her article, ‘Psychological aspects of menopause management’, Deeks (2003) summarises the literature on menopause, depression and anxiety and maintains that these problems should not be attributed to menopause alone; reactions to menopause must also be considered in the light of a range of psychosocial factors including personal psychological vulnerability, lifestyle, body image, interpersonal relationships, role, social factors and culture. Of particular relevance to my work, Deeks notes the importance of interpersonal relationships with partners as they relate to menopause and dedicates a small section of her paper to the limited research in this area. She frames my research questions by remarking,

‘Whether women are in a relationship with a partner, heterosexual, or homosexual, or whether they are single, widowed or divorced may also influence the experience of menopause. It is not clear whether the quality of a woman’s relationship with her partner changes during the menopausal transition, or whether her feelings about her interpersonal relationships influence the experience of menopause, (p.26).

The author makes it clear that reactions to premature menopause and its link to psychosocial factors, including relationships, are not well understood and require more investigation.

Other researchers have sought to investigate positive aspects of menopause. For example Hvas (2001) suggested that for some women, a sense of wellbeing, the relief of finishing menstruation, an end to premenstrual symptoms and an end to the fear of pregnancy came with menopause. Hvas also suggested the possibility of personal growth and a new freedom to concentrate on their own requirements for some women after menopause.

Deeks and McCabe (2004) further investigated well-being and menopause, focusing on purpose in life, self-acceptance and social role in premenopausal, perimenopausal and postmenopausal women. This study looked at the psychological aspects of women who were pre, peri, and postmenopausal. The authors began by noting that most studies on the psychological aspects of menopause consider anxiety and depression during the menopausal transition and say there is little understanding of the positive aspects of well being among menopausal women. The authors' aim was to expand on previous studies of menopause and wellbeing, which tended to look at measures of happiness and health to include a more multidimensional psychological approach that incorporated a wider range of quality of life factors. The paper reported on two studies which aimed to examine how women who are pre, peri, and post menopause felt about wellbeing factors of self acceptance, purpose in life and social roles. The first study investigated purpose in life and self acceptance of 304 women. The second study further investigated purpose in life by examining the roles occupied by 203 women from Study 1 and how they felt about those roles.

The findings of Deeks and McCabe's (2004) research suggested menopause may signify a new life stage for women and that with these changes come changes to their roles. They suggest that some measures of quality of life including wellbeing appear to change with menopausal stage. Menopausal women perceived their future purpose in life and self acceptance less positively than pre menopausal women. However all women in the study, irrespective of their menopausal stage, felt more positive about their future

purpose in life and feelings of self acceptance than for the present time or the past. Additionally, the less positive feelings experienced by women in the present time seemed to be related to women's' feelings about their roles in life.

Overall the relationship between menopause and psychological factors is complex. Although it may be a commonly held belief that hormonal changes including menopause contribute to depressed mood, this is not a clear cut relationship. There is some evidence for estrogen deficiency increasing susceptibility to depression (Birkhauser, 2002). Dell and Stewart (2000) suggest that in women who become depressed, mood symptoms tend to decrease at the end of menopause. Other research, (eg Kornstein et al, 2010) suggests that depression in women is most prevalent not at menopause but in the childbearing years. Kornstein notes however depression in mid life women should take into account the possible influence of both menopausal status and hormone replacement therapy.

Chapter 2 Premature Menopause

Explanation of terminology

A brief discussion of terminology is required here to clarify the focus of the current study. The terms premature menopause and premature ovarian failure (POF) are the most commonly referenced terms to describe this condition and are often used interchangeably. Other medical terms used include hypergonadotropic amenorrhea and hypergonadotropic hypogonadism and ovarian insufficiency (Nelson, Covington & Rebar, 2005). The term ‘early menopause’ is generally used to describe menopause that occurs before the age of 45 (*Jean Hailes Foundation website, 2009*) and affects approximately 5% of the female population.

The terms ‘premature menopause’ and ‘premature ovarian failure’ are neither clear nor lacking debate about definition. Recent reviews (eg Nelson, 2009, Panay & Kalu, 2009, Welt, 2008) have discussed appropriate terminology for this condition. The main issues with terminology are that although the terms ‘premature menopause’ and ‘premature ovarian failure’ are used as synonyms, they are not equivalent. Also, the term premature ovarian failure is problematic as it incorrectly implies cessation of ovarian functioning is permanent.

Both terms imply the ending of ovarian function, and it could be assumed that women who have been told they have reached menopause prematurely or have been diagnosed with POF would not ovulate and can not conceive, although this is not necessarily the case. As mentioned, menopause refers to complete cessation of ovarian function and is an irreversible condition (Stedman’s Medical Dictionary, 2000). However, the ‘failure’ of the ovaries is not permanent in all women with this condition, and they may still have irregular periods and ovulate at times (Welt, 2008; Rebar & Connolly, 1990). Unlike menopause, approximately 50% of women with premature ovarian failure still experience intermittent ovarian function, produce some estrogen and may ovulate even after their periods seem to have stopped and even if their hormone levels appear post menopausal (Popat and Nelson, 2007, Rebar and Connolly, 1990, van Karseren &

Schoemaker, 1990). In fact it has been suggested that up to 5% to 10% of women have conceived after being diagnosed with premature ovarian failure (Dragojevic-Dikic et al., 2009, Nelson, Covington & Rebar, 2005, van Karseren & Schoemaker, 1999).

Several authors, for example, Welt (2008) and Popat & Nelson (2007) argue the term spontaneous POF is inaccurate and suggest the term premature ovarian insufficiency (POI) is more appropriate as it can be modified to describe the state and level of ovarian function. POI is a term first used by Albright, Smith & Fraser (1942) in an early article discussing eleven cases of females presenting with 'lack of sexual development' and generalised pituitary deficiencies where he suggests 'primary ovarian lack' rather than primary pituitary disease may be the cause.

Another terminology issue is that the term 'failure' may make a diagnosis harder to accept as it implies some fault on the part of the women and may in fact make emotional resolution problematic. Kalu and Panay (2008) in their discussion of management challenges in spontaneous premature ovarian failure also suggest the term POF should be reappraised as its suggestion of irreversible ovarian failure is medically inaccurate and the term 'failure' may be offensive to some patients. More recently, the term premature ovarian dysfunction (POD) has been suggested, (Panay & Kalu, 2009).

The women in the current study all identified with the term 'premature menopause'. Usually this was the term used by their GPs to describe their lack of or diminished ovulation even though POF or POI may have been technically more accurate. The women in the current study had been told they were either not ovulating at all or had been advised it was highly unlikely they would conceive a pregnancy with their own eggs. Reasons for this varied amongst the group but were largely unknown. Shelling (2010) suggests that while premature menopause may not accurately describe the condition in all patients, it is a 'simple and understandable term that can be explained to friends and family' (p. 140). Shelling adds that many patients and doctors prefer to use the term premature menopause as do relevant support groups.

The choice of terminology in this thesis

From here on in this thesis, when discussing the experience of the women in the current study, this thesis will use the broad term ‘premature menopause’. That is, naturally occurring premature ovarian dysfunction (not induced by surgery, radiation, or chemotherapy) before the age of 40, and encompassing spontaneous POI, POF and POD. The term ‘premature menopause’ has been chosen for this work as it covers the range of conditions the women in the current study faced. As this thesis takes a psychological rather than a medical perspective, the less medicalised term seems fitting. When describing research other than the present study, the term used in the original research will be used.

What is premature menopause?

Having reviewed the essentials of ‘normal’ menopause, this thesis will now draw attention to premature menopause - the focus of the current study. Why does menopause sometimes happen early, and what are the psychological consequences for a woman of facing a change in her 20s, 30s or 40s that is meant to happen in her 50s?

Premature menopause is commonly thought of as menopause before the age of 40. It refers to the medical condition where a woman’s ovarian function slows or stops the production of mature eggs and reproductive hormones before the age of 40 (Goswami, 2005). It is characterised by irregular menstrual cycles and eventual cessation of menstruation (amenorrhea) and leaves women with the possibility of infertility and a range of complicated menopausal symptoms due to lowered estrogen levels (hypoestrogenism) (Graziottin, 2004). Premature menopause can result from a decreased number of follicles formed when the ovaries are developing, by an increased rate of follicle loss or by follicles which are unresponsive to hormonal stimulation. (Petras, 1999).

Approximately 1% of women younger than 40 years will experience spontaneous premature menopause (Woad, Watkins, Prendergast & Shelling, 2006). This figure has been suggested as rising up to 8-10% where premature menopause results from surgery or chemotherapy and or radiation therapy. Nippita and Baber (2007) cite the prevalence as between 0.9 and 1.2% in women 40 years or younger. 0.1% of women under 30 and 0.01% of women under the age of 20 will experience primary ovarian failure (Coulam, Adamson & Annegers, 1986). In a multiethnic population study of premature ovarian failure in the USA, Luborsky et al., (2003) found premature ovarian failure was reported by 1.1% of women. Ethnic differences included 1.0% of Caucasian, 1.4% of African American, 1.4% of Hispanic, 0.5% of Chinese and 0.1% of Japanese women. They suggested varying health factors by ethnicity may have played a part in the results.

With improved survival rates of cancer patients treated with chemotherapy and radiation, the incidence of premature menopause is increasing (Abdullah & Muasher, 2006).

The symptoms of premature menopause are usually described as including the same range of indicators as normal menopause and may be more severe than those experienced by typical age menopausal women (Kalantaridou & Nelson, 2000).

Causes of premature menopause

The main bases of premature menopause are a genetically predetermined lowered number of ovarian follicles at birth, follicular dysfunction or accelerated follicular atresia (Nelson, Covington & Rebar, 2005). The two main categories of premature menopause can be grouped as spontaneous and induced (iatrogenic). Although the focus of this work is spontaneous premature menopause, a brief discussion of induced premature menopause is first offered.

Induced menopause occurs when the ovaries are surgically removed (bilateral oophorectomy) to medically treat conditions such as endometriosis or uterine cancer (Speroff & Fritz, 2005). In the case of a hysterectomy where the uterus is removed but

the ovaries remain, menstrual periods will stop but other menopausal symptoms will generally occur at the same time as they would naturally, although some women who have a hysterectomy will experience menopausal symptoms younger than they would expect (Lebovic, Gordon & Taylor, 2005). Menopause will happen most dramatically as a result of a hysterectomy and bilateral oophorectomy. This operation is known as TAH/BSO, or total abdominal hysterectomy with bilateral salpingo-oophorectomy (Speroff & Fritz, 2005).

Induced menopause can also result from damage to the ovaries caused by chemotherapy and radiation for treatment of cancer. Chemotherapy and radiation are the most common known causes of premature menopause (Nippita & Baber, 2007). The ovaries are sensitive to the effects of radiation and therefore radiotherapy of the pelvis and chemotherapy impact ovarian function and can lead to premature menopause. The level of radiation which will cause complete ovarian failure seems to be determined by the number of eggs present in the ovaries – this is largely a factor of the woman's age at the time of treatment (Speroff & Fritz, 2005). In women over 40 years of age, a radiation dose greater than 600Rads will usually result in ovarian failure. Younger women however who have had doses of radiation up to 3000 Rads have later conceived. Prepubertal ovaries are relatively resistant to radiation (Beerendonk & Braat, 2005). The position of the ovaries in relation to the radiation field is a factor in the development of premature menopause. As such, the ovaries can sometimes be moved surgically to distance them from the radiation field area (Meirow & Nugent, 2001). Radiation is more toxic to the ovaries than chemotherapy (Sklar, 2005). The impact of chemotherapy on the chances of developing premature menopause depend on the age at treatment, drug type, dose and duration of treatment (Meirow & Nugent, 2001). In general, younger women are more resistant to the effects of chemotherapy than older women.

Knobf (2002) describes the experience of chemotherapy induced premature menopause as complex and points to gaps in the knowledge about menopausal symptom distress and factors influencing symptom management and outcomes in this population. The meaning of menopause in this group may be subsumed by concerns about the broader health challenges their disease presents.

In an ethnographic study by Pasquali (1999), narratives of eleven women who experienced early menopause as a result of surgery or chemotherapy were examined. The study focused on early menopause in relation to the women's concept of self and discussed findings in terms of the physical self, the psychological self, the social self and the spiritual self. Three consecutive themes emerged in the findings; change/loss, connectedness/disconnectedness, and transcendence/transformation. Although similar themes may well be fundamental to my study, the sample group is different in that it involves women whose early menopause is 'spontaneous' rather than as a result of therapeutic intervention. In Pasquali's study, menopause may have been initially overshadowed by the more immediate health threat or intervention. The author notes, 'the experience of cancer had tempered their outlook about premature menopause' (p.360). It cannot be clear to what extent anxieties and shifts in self concepts related to early menopause or the health condition that underpinned it. The women may have been advised of and prepared for some of the symptoms and treatments associated with menopause as a result of their medical treatments.

Spontaneous premature menopause

Nippita and Baber (2007) suggest in up to 90% of cases, the etiology of premature menopause is unknown and it is classified as idiopathic or karyotypically normal spontaneous premature menopause. Other causes include genetic abnormalities and autoimmune disorders.

According to Shelling (2010) a genetic basis for the disease can be identified in around 20-30% of cases of premature menopause, but the figure is difficult to specify as family history of premature menopause is not easy to confirm. Shelling suggests it would be helpful to develop wider family awareness of this issue. Genetic disorders related to premature menopause usually involve problems with the X chromosome but there are currently no genetic markers for premature menopause (Rebar, 2009). X linked genetic abnormalities include Turner Syndrome, 47XXX and Fragile X Syndrome (Simpson, 2008). Autosomal abnormalities, that is, genetic conditions caused by a defective gene

carried on a chromosome other than a sex chromosome, for example, the functionality of FSH/LH receptors, have also been identified as possible causes of premature menopause (Simpson, 2008).

Approximately 10-20% of women with premature menopause will have an autoimmune disease such as Addison's disease or hypothyroidism (Rebar, 2009). Metabolic disorders such as galactosaemia (where the body's transformation of galactose to glucose is blocked) are rare causes of premature menopause (Nelson, 2009). Infections, such as mumps, which may result in the destruction of oocytes have also been linked to premature menopause in rare cases (Nelson, 2009).

Why is premature menopause different?

Whether the cause of premature menopause is known or not, the usually unexpected nature of the condition, and the fact that it occurs during a life period when women are generally likely to be considering reproduction, make it a unique and troublesome condition.

Most books and general reading about menopause tend to suggest that menopausal experience can be generalised. However, it is important to understand and account for individual women's experience of menopause, and the timing of it must be seen as a major factor in how it is experienced. Deeks (2003) notes the impact of timing of menopause for women should always be taken into consideration, especially when menopause may occur early.

In considering the timing of menopause, Lennon (1982) argues that its timing as a life stage is an important element in its psychological impact. She argues that if menopause occurs during midlife, when expected, it is not generally associated with psychological distress, but when it occurs at an earlier or later stage in a woman's life it is more likely to be a psychologically stressful event. This relates to the idea of developmental stages being potentially problematic if they occur 'off time' as opposed to 'on time'. The

concept of having one's physical development 'off time' relative to one's same age peers has been explored in research into early and late sexual maturation in adolescence and is discussed further in chapter 5. Essentially, off time menopause, in this case premature menopause leaves women experiencing something that much older women usually face. Neither do they necessarily relate to older menopausal women, who may well be at a different life stage, usually having older children or even grandchildren, nor to women their own age who are not menopausal and who are likely to still be family building or raising young children.

Boughton (2002) describes this sense of 'not fitting in' as 'social-self identity disruption'. Drawing on feminist philosophy in her work, Boughton provides an interesting phenomenological study involving thirty-five women who had menopause before the age of forty. The concept of social-self identity disruption outlines the difficulty of socially identifying with a group of women which was not congruent with the image of menopausal women; a group to which prematurely menopausal women now also belonged.

Premature menopause is a very different proposition for women than 'normal' menopause also for the reason that it can challenge a woman's sense of herself, her body and her age in unique ways. Boughton's (2002) study explores women's relationships with their own bodies. The author argues that menopause is experienced not only as a biological experience, but also the way a woman relates to her body (the lived body), and discusses findings in these terms. Findings included the concept that women who have premature menopause suffered a sense of alienation; that is they experienced a sense of their body as being alien, where the body the woman feels she is in, is different to the one she sees in the mirror. Boughton describes 'the conspicuous symptomatic body,' whereby premature menopause brought women to become conscious of their bodies' physical restrictions and aware of their limits. Experiencing 'a different body' was another finding; the changes attributed to menopause caused a sense that the body a woman has lived in is no longer recognised as her own. Experiencing 'menopause stereotype discordance' described how women did not relate their bodies to the stereotype of what a menopausal woman is – an older woman.

In terms of psychological well being, premature menopause has been found to be very distressing for women. Liao, Wood and Conway (2000) investigated the psychological wellbeing of 64 women who experienced menopause before age 40. Compared with the general population, these women reported high levels of perceived stress and depression and low levels of life satisfaction and self esteem. The authors suggested that life factors such as whether they were in a long term relationship and whether they had children may also have impacted their levels of depression. Self reports on dimensions of sexuality were also more negative. It was argued that premature menopause could pose significant psychological difficulties for many who have the condition. The findings suggest that several factors could affect the degree of reported distress in women with early menopause; age, age at diagnosis, time since diagnosis, already having children, being in a long term relationship, or having psychological treatment presently or in the past.

Groff, Covington et al, (2005) also found premature menopause to be distressing for women. They used telephone interviews based on findings from focus groups to examine women's emotional responses to learning the diagnosis of premature ovarian failure (POF). One hundred women previously diagnosed with POF with a median age of 28 years at diagnosis were included. Of interest to the researchers was the manner in which the women were informed of their diagnosis, their emotional responses to the diagnosis and their forms of emotional support. The study found that the women diagnosed with premature ovarian failure reported significant emotional distress on learning their diagnoses, with 89% reporting moderate to severe emotional stress at the time. Feelings associated with the diagnosis included anger, depression, feeling less healthy, empty, older, confused and anxious.

In a study of 21 women with premature ovarian failure, de Taraciuk, Nolting, et al., (2008) administered a battery of psychological measures with the aim of studying personality traits and assessing anxiety, depression and psychological stress. The study found anxiety, but not depressive symptoms in the women studied. A range of scales on personality tests were found to stand out in menopausal women and the authors suggest the varied tests indicated the women had difficulty with reaching female identification and suggested conflictive bonds with mother figures. Although this is an interesting

attempt to understand the psychological aspects of premature ovarian failure, half of the measures used for the assessment were projective (drawing tests and Rorschach Inkblot Test) and open to varied interpretation. It can not be clear whether the stress and anxiety identified related to POF or broader underlying health concerns, as premature ovarian failure was secondary to a range of serious diseases in many of the women assessed in this study.

Most of the research on premature menopause and psychology has been quantitative (e.g, de Taraciuk, Nolting, et al., 2008, Ventura, Fitzgerald, et al., 2007, Liao, Wood et al., 2000). One of the qualitative studies is by Orshan, Furniss et al., (2001) who used phenomenological methodology, similar to that used in the current study, to examine the lived experience of six women with premature ovarian failure. The ovarian failure in this study group was idiopathic. It could be presumed that this lack of explanation for the condition may have added to the women's frustrations. Four main themes resulted including; being treated like a diagnosis instead of a person, grieving the death of a dreamed future, existing in a world of fertile people, and being too young to be so old. Of the six women interviewed, only three were in relationships and the findings did not specifically discuss the ways in which spousal relationships were affected.

Pasquali's (1999) earlier mentioned study titled 'The impact of premature menopause on women's experience of self' utilised an ethnographic methodology, generating narratives of eleven women who experienced early menopause as a result of surgery or chemotherapy.

To date the research on psychological aspects of premature menopause is limited and it is hoped that more insight into the lived experience of spontaneously occurring premature menopause will be useful to those working in the area of women's health and wellbeing, as well as to women who have the condition, and their partners.

Premature menopause and infertility

The incidence of infertility in our population is difficult to measure because it is not always discovered or reported; however, it is often quoted that around one in six couples will experience some degree of infertility at some point in their lives (Fertility Society of Australia, 2009). Infertility is usually defined as the inability to conceive a pregnancy after one year of engaging in sexual intercourse without contraception (Fertility Society of Australia). In the case of all the couples in this study, they had been told they were either unable to, or highly unlikely to be able to use their own eggs for reproduction and would need to find donor eggs in order to attempt IVF.

Infertility can relate to many different factors. In approximately 35% of cases, problems with fertility are attributable to the male. These problems can relate to a low sperm count or various abnormalities in sperm including formation, movement and size. Testicular injury, presence of varicocele, or other disease may affect male fertility. In another 40% of cases, fertility issues are related to the woman. Abnormal ovulation, endometriosis, polycystic ovarian syndrome, fibroids and problematic fallopian tubes are among the more common problems affecting female fertility. Around 15% of the time fertility problems are linked to both partners, and in another 10% of cases, infertility is unexplained (Speroff, Glass & Kase, 1994.) In this study no couples mentioned male factors and all couples related their infertility challenges to the women's menopausal status.

As mentioned, one of the biggest impacts of premature menopause is the resultant infertility or significantly reduced fertility; only between 5 percent and 10 percent of women with premature ovarian failure become pregnant without fertility treatment. At this time there is no proven treatment to improve a woman's ability to have a baby naturally if she has premature ovarian failure. Therefore the condition can cut short a woman's childbearing years and interrupt her plans for having children. The ways in which women and men experience infertility is an important aspect of the experience of premature menopause.

The desire for children and the suffering involved in not being able to have them has been chronicled throughout time by religious accounts, myths, legends, art and literature (Hammer Burns & Covington, 1999). In colonial times for example, children were an economic necessity as they were required for labour. After the industrial revolution and the introduction of child labour laws, children were displaced from the workforce and became valued for their affectionate ties. Thus children became 'functionally worthless, but emotionally priceless' (Hammer Burns & Covington, 1999). Reasons for wanting children today are broad and varied but commonly include motherhood as a 'natural instinct', as a 'stage in the development of a relationship, and as a 'social expectation'. (Ulrich & Weatherall, 2000).

Just as historical perspectives on menopause have changed, so too have views about infertility. Early models of infertility painted it as a psychosomatic illness. Fischer (1958) described two personality styles in women contributing to infertility: the 'weak, emotionally immature type and the ambitious, aggressive, dominating career type.' Also of the view that infertility was caused by psychological factors, Sandler, (1968) described 'evidence of the causal relationship between stress and infertility' (p.51). This type of 'psychogenic' model of infertility became less accepted as reproductive science about diagnosis and treatment of infertility advanced. The psychological theoretical view of infertility has evolved over time from a psychogenic model, to a psychological sequelae model, based on work by Menning (1980), in which heightened psychological distress was seen as a consequence of, and not the cause of infertility (Greil, 1997). The idea that infertility was an emotionally difficult experience was derived from this perspective. The psychological sequelae model of infertility integrates different psychological theories, of which a crisis model, a grief and loss model, and a stress and coping model have received the most attention.

Whether infertility is due to premature menopause or other causes, there is a wealth of research about women's psychological reactions to it (e.g. Kopitzke, 2002, Daniluk, 2001, Hammer Burns & Covington, 1999, Greil, 1997, Dunkel-Schetter & Lobel, 1991, Mahlstedt, 1985, Kraft et al., 1980). The research differs on whether or not infertility causes adverse psychological reactions. Some empirical studies have found negative

psychological effects of infertility (e.g. Matasubayashi et al., 2001, Lukse & Vacc, 1999, Mc Ewan et al., 1987, and Freeman et al., 1983).

Stanton and Dunkel-Schetter (1991) summarise the most common psychological effects of infertility in women as mentioned in the descriptive literature as emotional reactions including grief, depression, anger, frustration, guilt, shock and anxiety. In a key study of emotional reactions to infertility, Mahlstedt (1985) reported that grief and depression are common reactions in women to a diagnosis of infertility and suggested that depression is due to both the loss that infertile women feel as well as the strains that infertility diagnosis and treatment put on their lives. In this same study Mahlstedt also reported high levels of anger relating to infertility being unfair. Others, e.g. Kraft et al., (1980) have also found infertile women to respond with anger which at times was found to be intense. Other studies on infertile women have looked for pathology but have tended not to find significant differences between infertile and fertile women (Greil, 1997, Dunkel-Schetter & Lobel 1991). For example, Paulson et al., (1988) found no differences between 150 infertile women and 50 control women on measures of anxiety, depression, personality, self concept and locus of control. In a study of 103 infertile men and women and 61 fertile men and women, no significant differences were found relating to measures of marital adjustment, self esteem, psychiatric symptoms, body image or sex roles (Adler & Boxley, 1985).

Whether infertility causes pathological responses or not, there appears to be an accepted view that the experience can place couples under varying levels of stress. Men and women are both affected by infertility. Wright et al., (1991) looked at men's and women's responses to infertility. They suggested that infertile women show greater, but not clinically significant, distress than their partners on measures of anxiety, depression, hostility, cognitive disturbances, stress and self esteem. When compared with population norms, men and women patients were more distressed overall than average.

Research on gender differences in psychological responses to infertility tends to be descriptive and suggests a greater level of distress is experienced by women than men in response to infertility (Berg et al., 1991, Link & Darling 1986, Wright et al., 1991).

Cook (2002) described the way men coped with a diagnosis of infertility as different to women in that they tended to become stressed and anxious rather than depressed.

Collins et al., (1992) showed that the intensity of emotional responses to infertility was the same in men and women, but coping strategies in dealing with the related stress differed between the sexes.

Social effects of infertility, including marital, sexual functioning and changes to social groups and interactions are also reported frequently in qualitative literature (Stanton & Dunkel-Schetter, 1991). Wilson & Kopitzke (2002) emphasised effects of infertility on social, interpersonal and identity aspects of quality of life in infertile women. Daniluk (1988) in an exploratory study of 43 infertile couples found significant distress in couples during infertility diagnosis. Although the couples didn't report impaired relationship quality as a result of the investigation into their infertility, questions were raised about how satisfactory their sexual relationships were. Some studies, e.g. Woolett (1985) and Mahlstedt (1985) suggest marital relationships become strained due to reasons such as one partner blaming the other for the problem, or not feeling the required amount of support from the partner, or sensing a lack of equal commitment to having a child.

Other reported psychological effects of infertility on women include effects of loss of self esteem, identity and beliefs about the world. For example, Woolett (1985) suggested that infertility involves 'rethinking one's purpose and overall sense of reality and suggested infertile women can go through a challenging and painful path of examining their motives for being a parent and may even be led to question broader societal views of children.

In a study of couple's experiences of infertility using a phenomenological method similar to this one, Imeson & McMurray (1996) found themes of life changes, powerlessness, and social isolation and hope-disappointment cycles in a group of six interviewed infertile couples.

In summary, quantitative and qualitative findings on infertility and its psychological impact are varied and generally not well aligned. Dunkel-Schetter & Lobel (1991), in a review of studies into psychological responses to infertility, concluded there is a discrepancy between the empirical research literature and anecdotal-descriptive work on infertility. Whereas overall, empirical research does not clearly indicate that severe or clinically significant negative effects accompany infertility, the descriptive literature tends to portray infertile people as being in a great deal of distress. Greil (1997) described this difference in a later review of the psychological impact of infertility,

“The descriptive literature....presents infertility as a devastating experience especially for women.....In general, studies which look for psychopathology have not found significant differences between the infertile and others.....studies which employ measures of stress and self esteem have found significant measures...” (p.1679).

Overall, both the qualitative and quantitative research into responses to infertility, whilst not being conclusive, suggest that whether the responses are pathological and clinically significant or not, a diagnosis of infertility brought about by premature menopause or other causes brings a range of challenges, including stress, difficult emotions and decisions for women and their partners.

Turning to forms of assisted reproductive technology (ART), including in vitro fertilisation (IVF) is the usual way to attempt to address infertility. At this stage, egg (ova) donation is the main treatment for women with premature ovarian failure who wish to have a child. Egg donation is the process by which a woman provides one or several eggs to a woman who can not produce her own for purposes of assisted reproduction. Egg donation involves the process of (IVF) as the eggs are fertilised in a fertility clinic laboratory then transferred to the woman with premature menopause.

Psychological Aspects of IVF

IVF has been found to bring its own stresses. It is widely acknowledged that the process can be emotionally challenging. Some researchers, including Alesi (2005) have described infertility treatment as an 'emotional roller coaster'. According to Alesi,

'Once the treatment process begins, the roller coaster of emotions also begins. From the outset there is a mixture of excitement and anticipatory anxiety about the whole medical process; excitement about the hope the treatment presents and anxiety about the potential for failure.' (p136).

Alesi further describes how these mixed emotions of hope and anxiety fluctuate over the course of a treatment cycle. In line with this 'emotional rollercoaster' analogy, studies have shown that mood and emotions including anxiety, depression, and loss of control as well as positive feelings fluctuate over the course of an ART cycle. For example anxiety can rise before egg pick up, decrease on embryo transfer day and rise again at the time of pregnancy testing. Depression can also fluctuate over a treatment cycle, increasing after unsuccessful egg pick ups or embryo transfers (Newman & Zouves, 1991). Although some investigators (e.g, Boivin et al., 1995, Merari, Feldberg & Elizur, 1992, Beaurepaire, Jones & Thierring, 1994) have suggested the intensity of these responses diminishes with repeated cycles, the unusually difficult fluctuation in feelings and reactions is likely to continue throughout treatment.

Several studies looking at reactions to ART have focused on the reaction to failed IVF cycles. For example, Newton, Hearn & Yuzpe (1990) studied the immediate psychological impact of failed IVF as well as emotional status and marital functioning prior to IVF. They found that although most participants coped adequately with IVF and group means were not clinically elevated, both males and females showed increased levels of anxiety and depressive symptoms, particularly after a failed cycle. Women without children were found to be particularly vulnerable to the stress of failure.

Predisposition toward anxiety, pre IVF depression and fertility history were the most important predictors of emotional response.

Weaver, Clifford, Hay & Robinson (1997) followed up couples for whom ART treatment had been successful and unsuccessful and assessed them on a number of standardised measures. Questionnaire results suggested unsuccessful program recipients could not be distinguished from general population norms on clinical measures of depression; however they suffered more emotional distress including grief and sadness than couples for who treatment had worked. Boivin et al., (1995) found two different factors that contributed to a strong grief reaction following unsuccessful ART. They were a pre-existing psychological condition and the belief that the treatment is the last chance to have a biological child.

It appears that although women undertaking assisted reproductive technologies (ART) may be at greater risk of anxiety, distress and grief than women not on ART, especially if the procedure is unsuccessful, they are at no greater risk for significant psychological disturbance (Downey, Yingling & Mc Kinney, 1989, Boivin et al., 1995). Ardeni et al., (1999) also found that in a sample of 200 patients that although undergoing IVF significantly increased state anxiety, perceptive functioning was normal, even after a long duration of failed attempts.

In an interesting study looking at motives for parenthood in relation to responses to failed IVF, Newton, Hearn, Yuzpe & Houle (1992) investigated motives for parenthood then the relationship between motives, pre-treatment emotional adjustment, and reaction to treatment failure. Women as a group placed greatest emphasis on fulfilling gender role requirements as a motivation for parenthood. Women who felt strongest about this motive showed poorest adjustment pre IVF and the most negative reactions after first cycle failure.

Link and Darling (1986) looked at the perceived life, marital and sexual satisfaction of married couples undergoing treatment for infertility. Their study indicated that wives undergoing ART had a significantly lower level of satisfaction with life than their

husbands. The wives of men who did not respond to the survey were the most dissatisfied and were more likely to be clinically depressed. This suggests women who had involved and supportive spouses coped better with the stresses of ART.

In a qualitative study of 281 infertile women awaiting assisted reproduction treatment, Oddens, den Tonkelaar and Nieuwenhuijse (1999) found infertile women reported more changes in inter-partner relationships (positive and negative). Sexuality was negatively affected in the infertile women. At the time of IVF consultation, patients had less favourable reports of depressed mood memory/concentration, anxiety and fears, as well as for self perceived attractiveness.

In summary, although the vast amount of research into psychological responses to ART shows that women undergoing ART are at no greater risk of major psychological disturbance, trauma or psychopathology than other women, the use of assisted reproductive technology has been widely reported to involve a plethora of additional stressors and to increase psychological distress including anxiety, depression and grief, and especially if the procedure is unsuccessful.

Issues with diagnosis

One of the common problems with premature menopause is recognising when it is happening. One of the most common signs of premature ovarian failure is having irregular periods (Kim, 1997). However, not all women necessarily pay close attention to their menstrual cycles and may not recognise potentially problematic changes, nor do they always alert their health care provider when changes occur in their periods.

It has been suggested that women under age 40 with irregular periods, or who miss periods altogether for three months or more, should see a health care provider who may measure the level of FSH in the blood, to check for primary ovarian insufficiency in its early stages, or possibly even fully developed premature ovarian failure. As discussed earlier, FSH signals the ovaries to make estrogen. If the ovaries are not working properly, as is the case in premature ovarian failure, the level of FSH in the blood increases. A higher level of FSH in

the blood is a strong sign of premature ovarian failure. But, irregular periods alone are not a sure sign of premature ovarian failure - research shows that fewer than 10 percent of women who have irregular or skipped periods have high FSH levels and premature ovarian failure (Kim, 1997, Aiman, 1985).

The difficulty in diagnosis seems to be one of the factors complicating the experience of premature menopause. This is partly because definitive diagnostic criteria have not been reached (Nelson, Covington & Rebar, 2005). It is generally accepted that premature menopause can be confirmed by blood tests to measure levels of follicle stimulating hormone (FSH) and luteinizing hormone (LH). The levels of these hormones will be raised if menopause has occurred. Most authors describe at least four months of amenorrhea as well as raised menopausal level serum FSH concentrations on two occasions (Rebar & Connolly, 1990, Anasti, 1998). Conway (2000) bases diagnosis on elevated FSH levels in menopausal range detected on at least two occasions a few weeks apart.

The path to diagnosis can take a long time as patients and doctors consider a range of reasons for menstrual pattern changes and delay in pregnancy. Any delay in diagnosis to a woman wanting to become pregnant could be seen as 'essential lost time' in their fertility.

In an attempt to understand the experience of diagnosis of premature ovarian failure, Alzubaidi, Chapin et al., (2002) studied 50 patients with spontaneous premature ovarian failure in relation to their initial presenting problems, promptness of diagnosis and education received about the diagnosis. Initial symptoms in over 90% of cases were menstrual disturbance. Over half visited a GP three or four times about this before laboratory testing was conducted to reach a diagnosis. 25% of the women took more than five years after initial inquiries for a diagnosis of premature ovarian failure to be determined. The authors advocate more aggressive evaluation of young women with amenorrhea as the resultant ovarian insufficiency and associated estrogen deficiency is a well established risk factor for osteoporosis. They noted that a challenge for clinicians is to efficiently distinguish the relatively few patients with amenorrhea who have a serious disorder from the many who present with what is a fairly common symptom in

reproductive age women; they cite 3-4% of reproductive age women having three months of amenorrhea each year. The authors supported an earlier recommendation by Rebar & Connolly (1990) that a measurement of basal levels in all women with amenorrhea should be taken to promptly identify those with spontaneous premature ovarian failure.

Coping with premature menopause

There are a number of ways women and their partners cope with the disruption to their lives and potentially their plans for family building that premature menopause brings.

Groff, Covington et al., (2005), found factors perceived to be helpful in coping with premature menopause were thorough and accurate medical information, support of others and spirituality. The helpful social support described included mothers and husbands. There was a general sense that women supporters could relate better than men to the emotional aspects of premature menopause. Interestingly, the results included the finding that some interpersonal relationships were strained after the diagnosis and others were improved by bringing the women closer to those who were supportive of their needs. This finding was not elaborated on and is central to the questions in the current study. I am interested in knowing more about the ways in which relationships with partners were changed as a result of this diagnosis.

Key review articles on premature menopause usually refer to the need for emotional support and counselling in managing premature menopause. For example, in their review Nippita & Baber (2007) refer to psychological health as one of the three critical issues the condition raises, in addition to infertility and effects of estrogen deficiency. They suggest sensitive and sympathetic counselling of patients, referral to support groups or other sources of information and potentially a mental health assessment. Kalu & Panay (2008) suggest that management of premature ovarian failure should include, 'counselling and emotional support,' and that 'professional help should be offered to help patients deal with emotional sequelae of the condition.' (p. 276). Popat and Nelson

(2007), in their detailed review of the condition for e-medicine online note briefly that, the diagnosis of POF/POI may have a deleterious psychological impact. They allude to a 'baseline psychological evaluation' and 'appropriate counselling' as being of potential benefit but do not go in to more detail. In another review, Goswami and Conway (2005) also suggest women with a diagnosis of premature ovarian failure should have psychological support to deal with the impact of the condition on their health and relationships, although these potential impacts are not elaborated on. In another key article, Welt (2008) agrees that psychosocial support is critical for women facing premature ovarian failure. These articles however tend not to elaborate on the psychological aspects or emotional sequelae of the condition and other than referring to counselling or psychological assessment and support tend to not expand upon these concepts.

'Spiritual wellbeing' has also been suggested to be important in coping with premature menopause. By analysis of a range of validated self reporting tools, Ventura, Fitzgerald, et al., (2007) examined the relationship between spiritual and functional wellbeing in 138 women with spontaneous POF. The findings suggested that overall spiritual wellbeing, particularly a sense of peace and meaning, to be positively correlated with functional wellbeing. The authors advocated strategies which enhance spiritual wellbeing as important in any therapy aimed at supporting women with premature menopause.

Premature menopause and relationships

The impact of premature menopause on relationships with partners is not well understood. Often studies in this area provide the marital or relationship status of the study participants but do not discuss the nature of the relationship in terms of the condition in question. For example, in Liao, Wood et al.'s, (2000) study, over 70% of the women were described as being married or in long term relationships, however the impact on the partner or the relationship was not addressed.

In Boughton's (2002) study of premature menopause, of the thirty five women who were interviewed, twenty five were married, but 'not necessarily to the person they were married to at the time of their menopause,' (p 425.) Interestingly, 'some of the women identified their menopause as a major contributing factor in their divorce,' (p 425.)

Singer and Hunter (1999) note that feelings of isolation and social withdrawal as a result of early menopause were found to be particularly difficult when there was no 'intimate and confiding relationship to act as a protective buffer,' (p.76). Even when there was a supportive person in the woman's life that support was experienced as 'more apparent than real', and it was not until the woman had shared her experience in a therapeutic group did she feel that she could share her true feelings with her partner. Although there was a limited sample size, this study provided an early attempt to discuss women's experiences as they related to premature menopause and how it impacts spousal partnerships.

Pasquali's (1999) study did not directly address relationships with partners but noted that, '...even though the women had described their husbands as supportive, they had never confided in or discussed with their husbands the physical and emotional changes that they were experiencing or their husband's feelings, attitudes, and beliefs about menopause. Even in these relationships, which the women described as supportive, there was an element of disconnectedness.' (p. 354.) This is an interesting finding and the notion of the 'supportive partner' is one that I hope to explore.

Social support has been shown to affect stress and health (Uchino, Cacioppo & Kiecolt-Glaser, 1996) and could be assumed to be a factor in easing women's menopausal transition. Social support can be described as assistance from others that is intended to meet the emotional and practical needs of another person (Flaherty & Richman, 1989). Emotional support expressed as encouragement or empathy seems to be more effective than practical or instrumental aid such as helping with tasks in mitigating stress for women, but not for men (Cohen & Wills, 1985).

People in marriages and other significant relationships are likely to want to support each other through difficult times. Having a close, confiding and intimate relationship with another has been shown to be effective in buffering against life stresses and close relationships with partners are seen as important in reducing psychological distress (Cohen & Wills, 1985). Husbands have been found to assist their wives with managing stress and distress by supporting them through what has been described as potentially challenging life stages, for example during pregnancy and after the birth of a baby (Goldberg, Michaels & Lamb, 1985). However there is a scarcity of research into the central role of husbands during menopause and even less with premature menopause.

Mansfield, Koch, & Gierachs' (2003) article is perhaps the only published work to date which directly considers husbands support in relation to menopausal women. This study investigated the social support provided by 96 husbands to their perimenopausal wives. Survey questions asked how supportive the men considered themselves to be, what information about menopause they had, and what kinds of stress they were experiencing in their own lives. Findings included that one third of the men thought they had not been supportive, but most said they provided mainly emotional support. However, the study looked at perimenopause, not premature menopause. As perimenopause is usually not unexpected (like premature menopause usually is), it could be assumed that the findings would be different if the study considered husbands' support of their prematurely menopausal wives, especially in relation to the impact of infertility and disruption to family building.

It is hoped that obtaining a deeper understanding of both husbands' and wives' responses together will add to the field of understanding about the experience of premature menopause.

The following chapter will discuss the choice of methodology for this research, including the sample group, procedure and data analysis.

Chapter 3 Methodology

This chapter describes the choice of my research approach including the research paradigm and its philosophical assumptions and framework, the methodology, and the strategies used to gather data and derive meaning from the data. Criteria chosen to ensure quality in interpretive research; rigor (Lincoln & Guba, 2000) and credibility (Denzin & Lincoln, 2000; Koch & Harrington, 1998) are outlined. In addition, I describe the ethical conduct of the research.

Why a qualitative research methodology?

The key issue in choosing a methodological approach must always be the relevance of the approach to the goals of the research (Denzin & Lincoln, 2008). The merits and applicability of quantitative and qualitative research methodologies have been much discussed (e.g. Denzin & Lincoln, 2008; Willig & Stainton-Rogers, 2008; Patton, 1990). In the current study, a qualitative methodology was considered more fitting than a quantitative methodology for seeking to understand and describe a complex life experience and to interpret its meaning as perceived by those involved.

The goal of this research was to explore a psychological response to a life experience, in particular, the experience of premature menopause for women and their partners. I wanted to discover how the women and men in my sample felt about their experience and the ways in which it affected them personally and as a couple. I also wanted to report the results for others to read. My aim therefore, was to gather a body of personal, descriptive, detailed and rich information representing the participants' lived experiences which could be interpreted and discussed and which could allow the reader to develop an understanding of the psychological and emotional impact of premature menopause. I was interested in a depth and richness of data and in exploring the subtleties of the women's and men's responses. For these reasons, I deemed that quantitative methods, which utilise statistical

techniques, approximations and averages and tend to subsume individual data within that of the group were not in line with the research question.

Studies of premature menopause have largely been of a quantitative nature as discussed in earlier chapters. I wanted to add to this existing body of knowledge by presenting a new depth of information about common themes in the lived experience of the phenomenon. Of all the qualitative approaches available, I selected hermeneutic phenomenology as fitting the research aims and this approach will be explained further in this chapter.

The interpretive paradigm

The goal of this research involves understanding a human phenomenon and the participants' experiences of this phenomenon (premature menopause). This goal fits with the philosophy, strategies, and intentions of the interpretive research paradigm. The interpretive research paradigm is based on the epistemology of idealism (in idealism, knowledge is viewed as a social construction) and encompasses a number of research approaches, which have a central goal of seeking to interpret the social world (Higgs, 2001). The investigative approaches of Dilthey (1833-1911) and Weber (1864-1920) focused on interpretive understanding (or *Verstehen*), to access the meanings of participants' experiences as opposed to explaining or predicting their behaviour, which is the goal of empirico-analytical paradigm (or quantitative) research (Willig & Stainton-Rogers, 2008). According to the interpretive paradigm, meanings are constructed by human beings in unique ways, depending on their context and personal frames of reference as they engage with the world they are interpreting (Crotty, 1998). This is the notion of multiple constructed realities (Crotty, 1998). In this type of research, findings emerge from the interactions between the researcher and the participants as the research progresses (Denzin & Lincoln, 2000). Therefore, subjectivity is valued; there is acknowledgement that humans are incapable of total objectivity because they are situated in a reality constructed by subjective experiences. Further, the research is value-bound by the nature of the questions being asked, the values held by the researcher, and the ways findings are

generated and interpreted.

In choosing a particular paradigm for this research, certain assumptions and perspectives were accepted. Premature menopause was seen as a complex phenomenon, psychological reactions to which may in part be subconscious and occur in context. Such a phenomenon cannot maintain its essential and embedded features if reduced or measured as in quantitative research. Attempting to isolate or measure a contextual process as specific, ignores the complexity, reality, and consequences of this experience in life context.

The interpretive paradigm was viewed as the most suitable for this research because of its potential to generate new understandings of complex multidimensional human phenomena, such as that investigated in this research.

The phenomenological component

The research methodology chosen depends on the research questions and the philosophical perspectives from which the questions are to be investigated (Shepard, Jensen, Schmoll, Hack, & Gwyer, 1993). Research devised to understand the nature of the phenomenon of premature menopause lends itself to phenomenological research. Phenomenology is a school of thought that emphasises a focus on people's subjective experiences and interpretations of the world (Willig & Stainton-Rogers, 2008). The phenomenologist wants to understand how the world appears to others in detail in order to gain an understanding of the phenomenon in general (Van Manen, 1990). Van Manen describes phenomenology as an exploration of 'the essence of lived experience'. With its origins in the thinking of the German philosopher Husserl and the French phenomenologist Merleau-Ponty, phenomenology's core philosophical position is the primacy of experiences and how individuals put together phenomena they experience in order to make sense of events, objects and happenings. Smith (2007) describes phenomenological analysis as 'seeking the psychological meanings that constitute the phenomenon through investigating and analysing lived examples within the context of the participants' lives'. I saw this approach as particularly suited to my research aims. Additionally, having worked for

over ten years as a psychologist in a general counselling setting, the phenomenological approach, which involves seeking to hear and understand a client's subjective experience and meaning of that experience, fits naturally with my own training in counselling psychology, my theoretical interests and work style. Phenomenology is concerned with lived experience, and is thus ideal for investigating the current research question. Other researchers (eg Boughton & Halliday, 2008, Boughton, 2002; Orshan, Furniss, Forst & Santoro, 2001) have seen the efficacy of phenomenology for researching aspects of premature menopause.

The hermeneutic research methodology

The phenomenological methodology utilised in the current study is hermeneutic in its nature. Hermeneutics is a form of phenomenological inquiry that takes into account the personal experience and insights of the researcher as valuable and meaningful to the study (Smith, 2007). The researcher assumes an interpretative role in which he or she attempts to make sense of the participants' world and construct meaning from the research findings. To undertake these interpretations effectively, the researcher needs to be aware of his or her preconceptions, expectations and theoretical ideas about the subject matter in the study (Smith, 2007). In this case, the researcher's personal experience of premature menopause, reproductive loss and infertility treatment is referred to in the preamble.

Central to the discussion of hermeneutic phenomenology is the work of Gadamer and Heidegger (Denzin & Lincoln, 2008). Martin Heidegger (1889–1976) was a German philosopher known for his existential and phenomenological explorations of the 'question of being.' Heidegger believed this question defines our central nature. He argued that humans are practical agents, caring and concerned about our projects in the world, and allowing the world to reveal, or 'unconceal' itself to us. He also said that our manipulation of reality can be harmful and may hide our true being as essentially limited participants, not masters, of the world which we discover. Heidegger wrote about these issues in his best-known book, 'Being and Time'(1927).

Hans-Georg Gadamer's philosophical project was to elaborate on 'philosophical hermeneutics', a concept which Heidegger has been described as initiating (Coltman, 1998). Gadamer was interested in the nature of human understanding. In his central writing, 'Truth and Method' (1960) he argued that 'truth' and 'method' were at odds with one another. He was critical of the then two main approaches to the human sciences. The modern approaches to humanities which modeled themselves on the natural sciences (and thus on rigorous scientific methods) as well as the traditional German approach to the humanities which believed that correctly interpreting a text meant recovering the original intention of the author who wrote it (Coltman, 1998).

In contrast to both of these positions, Gadamer argued that people have a 'historically effected consciousness' and that they are embedded in the particular history and culture that shaped them. Thus interpreting a text involves a 'fusion of horizons' where the scholar finds the ways that the text's history articulates with their own background. Gadamer intended 'Truth and Method' to be a description of what we (usually unknowingly) do when we interpret things: "My real concern was and is philosophic: not what we do or what we ought to do, but what happens to us over and above our wanting and doing" (in Sheed & Ward, 1989).

Hermeneutic phenomenology has been described as a "research methodology aimed at producing rich textual descriptions of the experiencing of selected phenomenon in the lifeworld of individuals that are able to connect with the experience of all of us collectively" (Smith, 1997, p. 80). From identification of the experience of phenomenon, a deeper understanding of the meaning of that experience is sought (Smith, 1997). This occurs through increasingly deeper and layered reflection by the use of rich descriptive language.

The use of hermeneutic phenomenology enabled the exploration of participants' experiences with further abstraction and interpretation by the researcher based on the researchers' theoretical and personal knowledge. Hermeneutics adds the interpretive element to explicate meanings and assumptions in the participants' interviews that participants themselves may have difficulty in articulating, for example, tacit practice knowledge (Crotty, 1998). Communication and language are intertwined and hermeneutics offers a way of understanding such human experiences captured

through language and in context (van Manen, 1997). In sum, the use of hermeneutic phenomenology enabled the exploration of participants' experiences of premature menopause with further interpretation by the researcher based on the researcher's theoretical background and personal knowledge.

Ethics

Prior to commencing data collection, ethical approval was given by the Swinburne Human Research Ethics Committee.

Recruiting participants

The selection method was chosen, in order to select information-rich cases for detailed study (Denzin & Lincoln, 2000; Patton, 2002). The approach taken to promote the study and recruit participants was purposefully wide and varied. An attempt was made to find participants from as many sources as possible. The following list shows the range of initial points of contact for participant recruitment;

- Article in several suburban local newspapers.
- A letter, 'flyer' and discussion with four GPs to discuss and promote the study.
- Article in an IVF clinic newsletter.
- Letters to two endocrinologists to describe and promote the study.
- Meeting and discussion about the study with a local endocrinologist specialising in premature menopause.
- 'Flyer' in endocrinologist's waiting room.
- Article in Swinburne Psychology Clinic Newsletter.
- Postings on two parenting websites.
- Posting on Australasian Menopause Society website.
- Posting on an egg donor website.

- Article in ‘Mothers Matter’ magazine.
- Advertisement for participants in a parenting magazine.
- Approach made to two hospital based menopause clinics by phone and letter.
- Word of mouth (to researcher’s social and professional contacts.)

The range of contact points was chosen so as to ‘cast a wide net’ in participant recruitment. Some of the publications used in this strategy had readerships who were likely to be parents (e.g. parenting magazines), some who were likely to be having fertility challenges (e.g. IVF newsletter), some who were seeking or had experience with egg donors (e.g. egg donor chat rooms), whereas others targeted a more general population (e.g. local newspapers). Most of these avenues generated enquiries and/or participants. Two participants were recruited via word of mouth, four via a medical specialist, eight from online sources and four via printed media.

The Australasian Menopause Society website posting yielded an enquiry from the convenor of the New Zealand Premature Menopause Support Group. Five of their members participated in the research. These interviews were conducted via telephone and the interviews were digitally recorded using the same method as face to face interviews, which is described later in this chapter. Amendments to the original University Human Research Ethics Committee ethical approval was sought and received to allow for inclusion of non Australian residents and the use of telephone interviews. Although some writers, for example, Hill, Thompson and Williams (1997) raise the question of whether varying interview modes might yield different results, the researcher found the telephone participants in this study to be equally forthcoming and open and the telephone mode to be similarly productive in eliciting descriptions of personal experience. Telephone interviews have been found to be useful ways to elicit personal information in psychological research (eg; Groves, 1990, Aneshensel et al, 1982).

Participant demographics

In total, 18 couples were included in the study. See Appendix 1 for further details on participant demographics.

The sample group

The sample consisted of volunteers who responded to advertisements or expressions of interest via one of the approaches listed above.

Inclusion criteria were:

- Women who had experienced spontaneous premature ovarian failure or menopause before the age of 40 but not as a result of chemotherapy or surgery.
- Women who were in a relationship with a partner who was available to comment.
- Couples who lived within 30km from Melbourne city and were willing to participate in a face to face interview, or lived outside Melbourne and were willing to participate in a telephone interview.

There were two enquiries from women who did not meet the selection criteria. One had premature menopause induced by a hysterectomy and one had premature menopause related to cancer treatment. Two others expressed an initial interest but did not participate, one because she was going to be overseas for six months and would not be available to interview during the data collection phase of the study, and the other agreed and then withdrew due to her partner developing health problems.

In all, eighteen couples were interviewed for the study. All initial enquiries about the research came from the women. The couples lived in Melbourne, Australia or in the north island of New Zealand. All of them were in heterosexual marriages and had been together as couples before diagnosis of premature menopause. The women

were between 30 and 65 years of age at the time of the interview. The time between original diagnosis and interview ranged from six months to twenty nine years. All of the husbands were within eight years of their wife's age. Eight of the couples had children at the time of the interview. Five of the women had conceived prior to diagnosis and three since diagnosis. The three couples who had conceived since diagnosis had used donor eggs from known donors. Of the couples, six were still actively trying to conceive another child and were undergoing in-vitro fertilisation (IVF) or seeking an egg donor. Five of the couples described their family as complete and seven couples were undecided or unresolved as to whether they wanted to have more children.

Procedure

The nature and purpose of the study was explained to all participants over the telephone and the researcher arranged to meet with each couple at a mutually suitable time and location for a one to two hour audio recorded interview. Thirteen of the interviews took place at the participants' homes, and five were conducted by telephone. Prior to the interview, in addition to the phone conversation, participants were posted a written description of the aims of the study and an explanation of what was being asked of them. The nature of the study was again discussed and questions answered before turning on the sound recorder.

Maintaining participants' confidentiality is often a major ethical concern of interpretive research because of the personal nature of the research and the type of questions the participants are asked. Confidentiality was maintained through the use of pseudonyms in the research reporting and by changing specific contextual details that could have revealed the identity of the participant. Any records, listing of code names or any other potentially identifying data was kept in a password protected computer file. All participants were assured both in writing and verbally that anonymity and confidentiality would be maintained and that they could refuse to

participate or withdraw from the study at any time. All participants signed a form consenting to participate and being audio recorded.

Data collection

Interviews were conducted between July 2009 and February 2010 and recorded on a digital voice recorder. They were later transcribed verbatim with the assistance of an experienced transcriber.

Semi structured interviews

In hermeneutic phenomenology the interview serves very specific purposes. First, it is used as a means for exploring and gathering of narratives (or stories) of lived experiences. Second, it is a vehicle by which to develop a conversational relationship with the participant about the meaning of an experience. This may be achieved through reflection with the participant on the topic at hand (van Manen, 1997).

There are various ways of conducting research interviews, including structured, semi-structured, and unstructured interviews (Willig & Stainton-Rogers, 2008). Semi structured interviews were chosen as the method of data collection for this research. Semi structured interviews have advantages over structured interviews in phenomenology as they allow for a freer exchange between researcher and respondent, facilitating rapport and empathy and allowing flexibility to look into novel areas, which ultimately tends to produce richer data (Smith & Osborn, 2003). In semi structured interviewing, the researcher is able to probe into unexpected information and the respondent determines more of the direction of the interview (Smith & Osborn, 2003). Semi-structured interviews provide greater breadth or richness in data compared with structured interviews, and allow participants freedom to respond to questions and probes, and to narrate their experiences without being tied down to specific answers (Morse & Field, 1995). A further advantage over unstructured interviews is the ability to compare across interviews because some of

the questions are standard (Minichiello et al, 1995).

Interview guide

Although the interview took the form of a conversation, an interview topic guide (Appendix 2) was prepared to refer to during the interview to ensure certain pertinent topic areas were addressed. The interview topic guide consisted of eleven points of interest; health background, experience of diagnosis, prior understanding of menopause, impact on family building, support, changes, losses, symptoms, relationships, marital relationship and husbands. These points of interest were derived from background reading, supervision discussions about research design and initial informal discussions with two women who had experienced premature menopause. Specifically worded questions regarding these issues were not defined prior to the initial interviews, allowing me to remain 'free to word questions spontaneously' and 'to establish a conversational style contributory to the nature of the interaction between interviewer and participant, still maintaining focus on the topics under discussion' (Patton, 1990, p. 283). The interview questions were asked in an open-ended fashion in order to 'minimize the imposition of predetermined responses when gathering data' (Patton, 1990, p. 295). Each interview began with the question, 'can you start by telling me about your experience of premature menopause?' In all cases the woman spoke first. In the course of each interview, new questions emerged, requesting either elaboration or further exploration of events, feelings, or perspectives. A conversational style allowed me to present the new questions while maintaining the flow of the interview. Examples of these types of questions included; 'please tell me more about that', 'how did that feel for you?' and 'can you tell me more about what that was like for you?' All interviews concluded with a final question inviting participants to comment on any area of importance regarding their experience that the interview had not addressed.

The interview duration was approximately one and a half to two hours. When the procedure was initially described in the set up phase, both partners were requested to be present at the same time. In most cases the husband and wife were in the room

together and heard each others' responses. In two of the interviews, because they were otherwise busy in the home, the husbands came into the room after the woman had spoken and participated with her remaining in the room. With the telephone interviews, the husband and wife could not hear the questions their partner was responding to. All of the participants were forthcoming and open in their responses.

In every interview the women seemed comfortable with recalling their experiences, and were very forthcoming with their stories. Inevitably, in recalling their stories, the women touched on all of the topic areas in which I was interested. The areas of interest I had in mind were covered in the natural flow of the recollection of the story. At times I had to steer the conversation away from details of assisted reproductive technologies, egg donation issues and fertility challenges and back onto the experience of menopause, as this was my primary interest.

Appendix 2 summarises broad interview topics and samples of questions used to generate discussion.

The role of the researcher in data collection

During this research I was the sole data collector. It was important for me to facilitate trust and confidence in the researcher- participant relationship and establish rapport with the participants early in the data gathering process, providing access into their personal world and thoughts. Having already conducted Masters level research into aspects of infertility and assisted reproductive technologies I was already familiar with some of the medical and technical terms and language the participants used, which provided greater access to their world without the need to constantly ask for clarification. However, this may be a disadvantage if researchers ascribe meanings to certain words or jargon, behaviors, and decisions, with which participants differ (Minichiello et al., 1995). Being aware of this possibility I attempted to maintain what van Manen (1997) referred to as *hermeneutic alertness*, which occurs in situations where researchers step back to reflect on the meanings of situations rather than accepting their pre-conceptions and interpretations at face value. Thus,

reflexivity was viewed as an important dimension in designing and implementing this research. Throughout the research, opportunities for thoughtful analysis of the research experience, and the relationship between the researcher, participants, and the research (e.g., research questions, methods) were built into the research process. Using the phenomenological technique of ‘bracketing’ (Van Manen, 1990), I was able to suspend my own beliefs as far as possible in order to focus on the respondent’s worldview and ‘understand the meaning of what the person was saying, rather than what the researcher expected that person to say’ (Hycner, 1985, p.281).

Data analysis

My objective in analysing the interviews was to describe the essence of the phenomenon of premature menopause in the fullest breadth and depth possible without preconceptions or presuppositions. In keeping with the methodology adopted in this research, data analysis methods were developed from phenomenological and hermeneutic principles and from guidelines in the literature about systematic ways of interpreting qualitative research data. Therefore, the data analysis methods used were specific to this research, but also drew on the experience and knowledge of experts in the field of interpretive research.

Of the various phenomenological approaches available, Interpretive Phenomenological Analysis (IPA) has been chosen as the general approach for making meaning of the data. This is a systematic approach which provided a sense of structure from which to approach data analysis.

IPA is a useful approach to qualitative phenomenological psychology, with theoretical origins in phenomenology and hermeneutics and emerges from ideas by Merleau-Ponty and Heidegger. With IPA, data collection does not set out to test a hypothesis; rather it is inductive, with a focus on enquiry and meaning making (Smith, Flowers & Larkin, 2009). IPA involves ‘coding’ transcriptions for insights, cataloging emerging themes and looking for patterns in the codes. Themes are recurring patterns of meaning (ideas, thoughts and feelings) throughout a text. In

IPA final themes are summarised and described using quotes from the text. This process took several main phases, and was based on Colaizzi's (1978) model of qualitative data analysis.

Colaizzi's (1978) method of analysis is often drawn on in phenomenological research in psychology, (Denzin & Lincoln, 2008, Willig & Stainton Rogers, 2008). This provided me with a helpful approach to work with my data. In his article, 'psychological research as the phenomenologist sees it', Colaizzi (1978) describes seven key steps as summarised;

1. Each research informant's verbatim transcript is read to acquire a sense of the whole.
2. Significant statements and phrases pertaining to the phenomenon being studied are extracted from each transcript.
3. Meanings are formulated from the significant statements.
4. Meanings are organised into themes and these themes evolve into theme clusters, and eventually into theme categories.
5. These results are integrated into a rich description of the lived experience.
6. The essential structure of the phenomenon is formulated.
7. Authentication is sought from the research informants to compare the researcher's descriptive results with their lived experiences. If necessary the researcher's description is modified to achieve congruence with the research informants' experience.

The following section explains the specifics of how I have drawn on and adapted Colaizzi's steps in my data analysis;

Initially I listened to the recordings of the interviews again. This assisted in what Colaizzi describes as ‘acquiring a sense of the whole’ or immersing in the story. I then read and re-read the typed transcripts for transcribing errors and made corrections as I listened to the recordings a second time. Once I was confident the transcripts were verbatim they were summarised page by page, becoming about one quarter of their original length. In formulating the summaries information that departed significantly from the central question was left out of the summary. Examples include introductory content and explanations about the study, reflections on holidays, career history, or digressions into talking about other people or detailed family history. Several women went into a lot of detail about the stages of their egg donor search and these extended explanations were abridged at this stage. Also at this stage, the men’s comments were highlighted with a unique colour so as to distinguish them from the women’s’ comments. Each couple was sent the summary of their interview in late February 2010 with a cover letter asking them to identify any additional thoughts or reflections to what had been summarised and to check for authenticity and fittingness with their experience. They were also asked to note any significant life changes since the time of the interview. Five of the 18 couples wrote back, largely confirming the applicability and credibility of the summaries.

The next phase involved returning to the original transcripts and working closely with them again in entirety. Every paragraph was scrutinised for significant statements that were seen as related to the phenomenon under study. Small phrases, statements or sentences which reflected a single, specific thought were highlighted. Colaizzi (1978) calls this process ‘extracting significant statements’ or ‘coding’. This ‘coding’ marked insights into participants’ experiences and perspectives on their world. To assist coding, each interview was numbered 1 to 18 and each highlighted phrase was numbered. A statement made by a husband was noted with an asterisk. For example the code 3(29) refers to the twenty ninth highlighted phrase in interview three, and code 7(12*) refers to the twelfth highlighted phrase in interview seven, which was made by the husband. Examples of a piece of text that was coded include, ‘...I was just floored...’, ‘...I was really concerned about my

skin...’, ‘...I had no idea what she meant when she was using those words...’, ‘...I just felt lost...’. ‘...she just didn’t seem like herself for ages, it was like she was ‘somewhere else’ and I couldn’t really get through to her...’ Out of all the 18 transcripts, 2327 phrases, statements or comments were highlighted, or on average, about 125 phrases per interview.

In the Results and Discussion chapters where quotes are given, quotes are written in italics and followed by the page number of the transcript on which that quote was found. Eg (p.21) means the particular quote written in italics was found on page 21 of the written transcript from the quoted interview.

A next stage involved ‘formulating meanings’ (Colaizzi, 1978). Colaizzi describes formulating meanings as expressing statements as more general formulations which make sense of the statement in the participants’ own terms (1978). Forrest (1989) describes this step as ‘moving from what the participants said to what they meant’ (p.817) and it can be a ‘precarious leap’ (Colaizzi, 1978, p59). In order to remain true to the data, two important steps were taken. First, each formulated meaning was coded with the same code as the significant statement from which it was derived. My highlighted codes and phrases were submitted for checking to another experienced researcher familiar with phenomenological analysis. This resulted in a high level of consistency in the selection of phrases between us.

Some examples of coded significant statements with their formulated meanings are below:

Coded significant statement 1(9): ‘...it’s not how it’s supposed to be. It is something bizarre and something not...I wouldn’t say socially unacceptable, but just not the norm. It’s not how it’s supposed to be’.

Formulated meaning: Premature menopause was seen as unexpected and outside the norm for women of that age.

Coded significant statement 12 (114):* ‘...and throughout the whole process we were being bombarded with terminology left right and centre and I was on the Net trying to work out what the hell it was all about, trying to understand it.’

Formulated meaning: Unfamiliar terminology was used and she tried to understand this terminology and what she was being told by using the internet.

Coded significant statement 11(45):* ‘...it was something we had always taken for granted and just thought it would happen and hadn’t really thought about, should we have children or shouldn’t we? It was just a given.’

Formulated meaning: The couple had assumed they would have children.

Coded significant statement 16(35): ‘...they don’t seem to know...like the other doctor I went to see said, ‘are they sure? Why can’t you try IVF?’ It’s like they don’t really understand it themselves.’

Formulated meaning: She felt like one of the doctors did not understand her situation as he had asked her why she couldn’t do normal IVF.

The next phase involved grouping these coded formulated meanings into emerging themes (theme clusters) that reflected the various meanings or aspects of the experiential phenomenon of premature menopause. Common patterns in the data began to emerge at this stage. New codes were assigned to the emerging themes and the formulated meanings that formed part of the emerging theme were listed beneath it. The clusters of emerging themes were taken back to the original data by referencing them back to the initial codes and this process was repeated until all meanings were accounted for. Themes which were unique to individual interviews and extrinsic to the area of study were not discarded but were isolated and retained for discussion purposes and potentially confounding factors.

Examples of theme clusters included, ‘feeling like her husband might want to leave her’, ‘having a diagnosis was helpful in making sense of the symptoms’ and ‘feeling cheated of her fertility’. The emerging themes, with example statements were then shared with another experienced researcher in relation to meeting the methodological criteria of applicability and trustworthiness. This served to further increase credibility of the data.

In total 32 theme clusters were elicited during this phase. For example, below are three theme clusters with a small selection of their associated coded formulated meanings;

Theme cluster: Feeling like her husband might want to leave her.

- It crossed her mind that her husband was still young enough to have a child with another woman.
- At one point thought that she wasn’t good enough for him and that he deserved better.
- She asked her husband if he was considering leaving the relationship.
- She told her husband she would understand if he wanted to find another, fertile woman.
- She expressed the idea that as she wasn’t fulfilling what they had expected when getting married, she would understand if he wanted to review the wedding vows.

Theme cluster: Having a diagnosis was an important stage.

- Finally feeling like she wasn’t making up the feelings she had been having.
- Although it was not what she wanted to hear, she felt that she now knew what she was dealing with.
- They thought that if there was a name for it there must be a known course of treatment.
- Having a diagnosis was good as she realised she wasn’t ‘going mad’.

Theme cluster: Having questions and concerns about longer term health implications

- She had heard about menopause being linked to cancer but wasn't sure if this was true.
- She had questions about longer term health consequences.
- She remembered being worried that she would get osteoporosis.
- She wondered if premature menopause was related to shortened life expectancy.

The 32 theme clusters were then organised into groupings on the basis of having related content. For example, the cluster themes of 'not relating to my peers', 'not relating to older, menopausal women', 'feeling like my friends didn't understand what I was going through', and 'not identifying with my mother's story', were all seen to describe aspects of not relating to others and were clustered under the name of 'being in no woman's land', a term coined by one of the participants, which was then labelled as the theme 'social void', to which a results chapter is dedicated. Occasionally clustered themes were conceptually related to more than one overall theme. Where this occurred, they were assigned to the theme they best represented and were cross checked with an independent researcher check for plausibility of the interpretation of the grouping. This stage resulted in seven overall themes.

The final phase of data analysis involved constructing an overall description of the phenomenon as the participants experienced it from the resultant themes. According to Patton (1990), such a description should communicate the 'voices, feelings, actions and meanings' of those involved. The overall themes are addressed in the results and discussion chapters of this work. A final credibility check was undertaken by writing to each of the couples and including brief descriptions of the overall themes. They were asked to comment on the precision of the themes and add anything that they felt had been missed. The feedback was that the themes were fitting and reflected the participants' experiences.

Rigor in the research

For qualitative research to be credible the process must be rigorous. Lincoln and Guba, (2000) suggest ensuring quality in qualitative research requires the rigorous use of systematic methods of data collection and analysis, transparency in documenting these methods, and consistency in operating within the philosophical assumptions and traditions of the research paradigm and approach. Several strategies have been used in the current research to enhance rigor. These include a congruence between the adopted paradigm and chosen method, prolonged engagement with the participants, and auditable records.

The nature and background to the research was discussed with participants before the interviews took place. This informal communication assisted in establishing some rapport with the participants and helped in gaining their trust. This aimed to give participants the comfort and freedom to discuss their views and experiences, increasing the rigor and trustworthiness of the research findings.

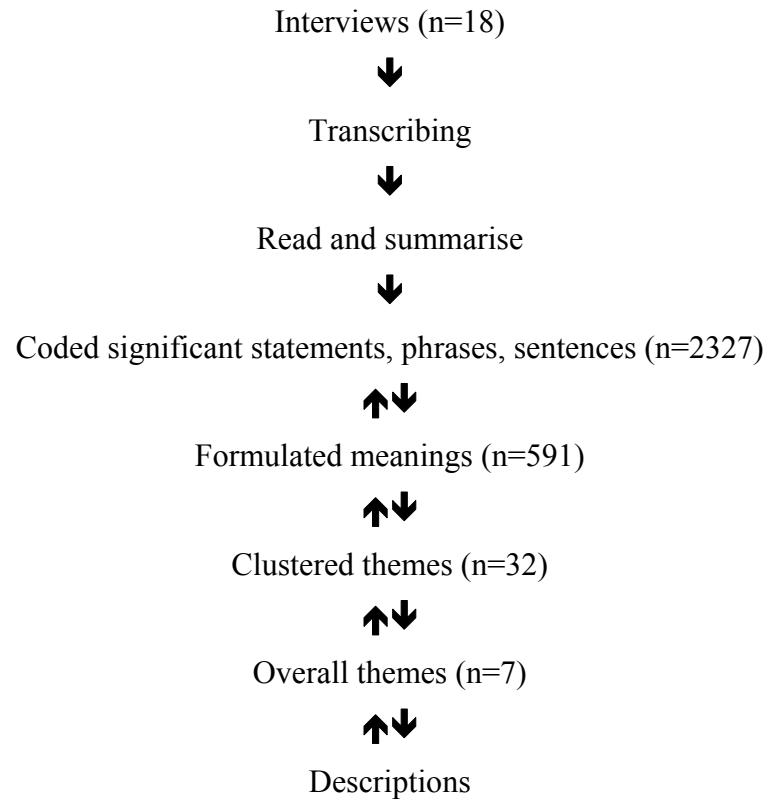
Throughout all stages of the data analysis there was ongoing interpretation of the interviews and transcripts. In addition, I continually tested my pre-research assumptions about the phenomenon of premature menopause by comparing and contrasting these assumptions with the findings in the emerging data. In this way, I was able to address any prejudices developed from the literature and personal experience. By constantly cross-checking my interpretations with the original transcripts I sought to maintain closeness (or faithfulness) to the participants' constructs, grounding interpretations in the data. This strategy to maintain authenticity was suggested by Lincoln and Guba (2000). Dialogue between me as principal researcher and my supervisor about emerging findings served to further check the faithfulness and authenticity of the data. Checking for fittingness of summaries and of the emerging themes with the participants assisted in achieving rigor, and transparency of the research process.

Credibility

Credibility refers to the vividness and faithfulness of the description to the phenomenon (Koch & Harrington, 1998), or trustworthiness of the findings of the research (Denzin & Lincoln, 2000). Authenticity is demonstrated if researchers show a range of different realities in a fair and balanced manner (Denzin & Lincoln, 1994). Using both phone, face to face and written communication as sources of data, and allowing the flow of communication to be open (participants were able to contact me directly if they wanted to) strengthens my claim for fair dealing in illuminating the phenomenon. Multiple constructions and interpretations of events and experiences are consistent with the philosophical underpinnings of the interpretive paradigm (Crotty, 1998). Ensuring that the voices of both the participants and the researcher are evident in the text also enhances authenticity (Lincoln & Guba, 2000). This was achieved by the use of rich description and, where possible, the use of participants' words to allow them to speak for themselves.

Summary of data analysis process

Figure 1



Six key themes were drawn from the analysis of the interview transcripts. The themes were a disrupted sense of ageing, a social void, dealing with infertility, the men's voice, perceived professional confusion, and the marital relationship.

The results and discussion section that now follows will report and discuss these themes. Each of the following seven chapters will present a major theme and its subthemes and will include a discussion on these findings. Each chapter will be briefly summarised before the next theme is presented.

The direct chapter (Chapter 4) discusses the responses the couples had in the immediate period after they received confirmation of their menopausal status. The next six chapters will present the major themes. Chapter 5 reports findings associated with the ways in which the condition changed how the women felt about their age. Chapter 6 discusses the ways in which premature menopause affected the women's sense of belonging to a social group. Chapter 7 discusses associated aspects of infertility for the men and women involved. Chapter 8 presents the men's perspective on premature menopause. Chapter 9 discusses a perception of professional confusion around the condition, and Chapter 10 reports impacts on the couple's relationship as a result of premature menopause.

Initial reactions to a diagnosis of premature menopause

The first theme centres on the participants' initial reactions to premature menopause. The ways in which the women in the study responded in the early days and weeks after learning that they were facing premature menopause are discussed. Just as each woman in the study had a unique health and fertility history, so did they have unique and individual responses to finding out they were prematurely menopausal. There are however, some more common thoughts and feelings which formed salient themes amongst the early reactions to this diagnosis.

These reactions were influenced largely by the level of pre-diagnosis awareness of premature menopause the participants had. In this study, only three of the 18 women interviewed said they were aware of premature menopause as a condition prior to their own diagnosis, supporting views that it is a relatively unheard of problem. Two of these three had some family history of the condition. As such, 15 of the 18 women in the study had never heard of premature menopause and were therefore not aware the condition existed prior to their own lived experience of it.

Reactions of shock and devastation

Learning that menopause was even a possibility before age 40 was a surprise in itself. Learning that this was a possibility for women *and* that they were experiencing it themselves can be described as a ‘double shock’. Janette sums up the double shock of this first reaction ;

It was a massive shock to me. I didn't even know you could be menopausal at that age. It was news to me. So finding out I was menopausal was unbelievable. (p.3)

As chosen by Janette, the word ‘shock’ was the most used adjective to describe initial reactions to the realisation of premature menopause. In fact three quarters of the women used the word ‘shock’ when describing their own diagnosis. It appears the shock came from learning they were facing a condition that was previously unheard of to them. Marli describes the shock of learning about her menopausal status having gone to her GP with an irregular menstrual cycle, and seeking assistance with having a second child;

I was sent to the gynaecologist to see if there was any way to regulate my cycle and have a child....and instead we did blood tests and he said...you need to go on HRT but because of your age you should just

go on the pill. I went 'what?! That's not what I want to hear!' I was blown away. (p.3)

Arielle recalls, '*It was absolute shock. Crying. Terror.*' (p.2).

A reaction of shock, or an otherwise described acute stress reaction is an understandable response to traumatic or highly stressful news, especially if it is not expected. Shock is often associated with initial diagnosis of an unwelcome medical condition, for example multiple sclerosis (Johnson, 2003), or childhood disease (Ablon, 2000). Consistent with an emotional shock reaction came a range of related immediate responses such as inability to take action or think clearly, fear and anxiety. Herbert, one of the husbands, described his shock coupled with a feeling of denial, *I remember experiencing shock and disbelief and dissociation from the present.* (p. 4). Herbert's comments are consistent with views of infertility as a crisis to which initial reactions of shock, surprise, disbelief, and denial are common (Lalos, 1999).

That the women and their partners were shocked is not surprising given they were mostly emotionally unprepared for such a diagnosis. As mentioned in the introductory chapter, women who experience a natural menopause in their 50s often struggle with emotional issues related to body image, ageing, the end of fertility, sexuality and the long term health implications of lowered estrogen. In natural menopause, however, the preceding perimenopausal stage provides a period of preparation and transition into menopausal status. However women who are prematurely menopausal like those in the current study, do not have such an adjustment period or time to prepare themselves emotionally for the changes menopause brings.

A related and often simultaneous feeling of devastation came with the shock of the confirmation of premature menopause. 'Shock' and 'devastation' were the terms most commonly used to describe what was universally seen as a negative and

stressful situation. In Mary's words, *I was devastated at first, I just couldn't believe it and I just cried.* (p.4).

Patricia described the overwhelming blow of the news this way,

I just sat in the car and burst into tears. As a woman, I've got no children. I was devastated and a bit confused. I went back to work and I was at work for five minutes and I just couldn't control myself. I had to go home. I got a bus and just cried the whole way home. I would say it was devastating. (p.4).

Sophie remembered how for her and her husband their initial reactions left them feeling numb, *We were gutted...just devastated....shell shocked...we walked out like zombies* (p.5).

In all cases the women and men who used this term related 'devastation' to the connection they made between menopause and infertility. The couples described being devastated by the new knowledge the women were menopausal because they realised this meant their dreams and plans for family building were suddenly threatened. These shock and devastation reactions indicated the high levels of distress the couples were expressing in the early responses. Such reactions have been found to relate to infertility more generally by many authors (eg Lalos, 1999, Stanton & Dunkel Schetter, 1991, Covington, 1988, Valentine, 1986, Clapp, 1985). The ways in which the couples responded to the infertility associated with premature menopause are discussed further in Chapter 7.

That they were shocked suggests the couples had an assumption of health and fertility and a belief that pregnancy would be achievable at a time more or less of their choosing. These assumptions of health and fertility and an ideology of curability prevail in our modern society. It could be argued that in times of increasing education, personal career success, financial security and advanced medical technology, there is a tendency for women to assume that pregnancy can be achieved

within their chosen timeframe. It could be argued that developments of medical interventions for infertility has left us open to greater disappointment when infertility can not be 'fixed'.

The shock was unrelated to menopausal type symptoms

Interestingly, comments about being shocked seemed to be unrelated to whether or not the women had experienced menopausal type symptoms prior to diagnosis. Just under half of the group could be described as not having noticed symptoms generally associated with menopause prior to diagnosis. For this group of women, the path to diagnosis began by visiting a GP with concerns that it was taking 'too long' to conceive. Although they may have recalled some irregularities in their menstrual pattern, these women had not noticed vasomotor upsets such as hot flushes or night sweats or other symptoms commonly associated with menopause. These women described visiting a GP to discuss ways to increase fertility. As Janette recalls;

It (pregnancy) was taking a while and I thought maybe I needed help to ovulate or regulate my cycle. A friend had gone on Clomid to speed things up. I thought because my periods were a bit irregular, that might help. (p.5).

Even though they had acknowledged some concerns about their fertility, these women had not considered their delays in conceiving could be related to menopause. For this group perhaps, the term 'shock' applied the most. Anne describes how not having any noticeable menopausal symptoms made her situation harder to believe,

It feels a bit unbelievable because my body isn't actually doing anything. If I was having sweats or if my taste in food had changed or if there was some physical symptom then I might be more connected to the experience, but nothing is happening. (p.3).

To make it worse, a lack of any noticeable symptoms was misconstrued by her stepmother,

She said, 'if you've gone through menopause and you haven't had any symptoms then consider your self lucky.' I was thinking, I don't consider myself lucky to have gone through menopause at age 36 (p.4).

By comparison, on reflecting on the discovery of their diagnosis, half of the women described having acknowledged some physical or emotional symptoms commonly associated with menopause. Often this group of women went to discuss with their GP various menopause type symptoms such as night sweats as well as less tangible ailments such as what Marli described as '*just not feeling like myself.*' However, when seeking medical advice on these symptoms they had not consciously considered they may be menopausal. Marli recalled,

Looking back, I had been feeling really moody and up and down, hot and cold, just not right. Now I know that it was menopause, but then I didn't make that connection. (p.12).

Several women described having a vague idea or a feeling that 'something was wrong;' but had not really considered menopause. Janette recalled feeling '*out of whack*', and said,

In the back of my mind I thought something might be wrong, but hadn't thought of that (menopause). (p.9).

Recalling her experience in her interview, Roberta told of having hot flushes, sweats and mood swings, but didn't consider menopause. Rather, she put the physical and emotional changes down to other factors. As she explained;

I had started having all these hot feelings in my body.....and I went to the doctor. I thought I had pituitary cancer because that's one of the

symptoms.....I had never even thought about that, that it could be that (menopause). (p.1).

It was only on reflection, post diagnosis that this symptomatic group of women related symptoms like flushes and mood swings to menopause. Having been told she was prematurely menopausal, Lucy recalled looking back on how she had been feeling and ‘making sense’ of her symptoms,

I thought, ‘oh that explains everything’. ‘Cause you tend to look back and think about being moody and having vaginal dryness and all that. So I’d noticed changes but just hadn’t really thought about them. (p.1).

Ari and his wife Sophie had a similar discussion. Ari remembered ‘*piecing together*’ what Sophie had described as feeling ‘*unusually moody*’ and the test results that revealed she had gone through menopause. He said,

When we came to think about it, I thought, ‘in a lot of ways that makes sense.’ (p.3).

Sophie added,

Certainly, at the back of my mind I was thinking that this was what my mum and aunty and everyone else had talked about. I guess you don’t really ‘go there’. (p.1).

It appeared that some of the women had a vague idea that they were experiencing physical and/or emotional menopausal type symptoms but didn’t consciously consider they were menopausal or investigate it as a possibility. It is interesting that this group of women were shocked with the diagnosis of premature menopause, despite having symptoms commonly related to menopause. Perhaps they were in some sort of denial, not ready to accept a dawning thought that they may have been menopausal. The more likely reason for them not associating their symptomatic changes with menopause is the prevailing understanding that menopause happens at

a later age. This is likely because they were not aware of the possibility of menopause occurring early, had assumed they were 'too young' for menopause and had associated it with an older age group.

'But I'm not old enough!'

Following immediate reactions of shock and devastation usually came a short period of trying to 'make sense' of what they were being told about their menopausal status. This involved struggling to reconcile their current age with the word 'menopause'. Learning that menopause could happen at an early age was clearly a revelation to the women and they expressed in a range of ways the idea that they were not old enough to be menopausal. Lucy who was 32 years old when she found out she was menopausal said,

It's the sort of thing that happens to women in their 50s and 60s, maybe 40s. For me it just wasn't on the radar. (p.9).

Lucy described her assumptions,

To me it's thinking of an older woman going through the change of life, where they stop having periods and get grumpy and sweat. That's only from what I'd seen from other people. (p.10).

Mary also described having thought she was not old enough for menopause,

The only thing I really knew about it was that it happened to you when you were in your 50s. And the only other thing I'd heard about was HRT, so that was all I knew. Until you're kind of at an age when it affects you, you don't take much notice of it. (p.11).

Roberta, Mary and Sophie agreed,

I had thought the average age was about 50 or 52 or something so I felt I had about 15 years, but it was like no, 15 minutes. (Roberta, p.3).

We were thinking, no that's not right because I'm nowhere near 50... (Mary, p.2).

I went, this is ridiculous, I'm too young for this! I thought maybe late 40s, 50 or 55? (Sophie, p.3).

Like many phenomenon, views on menopause were founded on personal experience and observation. Thoughts about being too young to be menopausal were based on prior experience of menopause drawn from observations of women they knew or had heard about. For many of the women in the study, and certainly for most of the men, opinions about menopause more generally had been influenced largely by their observations of their mothers or older female family members dealing with it. This experience had taught them menopause was something that happened to 'older women.' Anne recalls how she formed her opinions about menopause,

My step mother had gone through menopause a few years earlier and the whole family had gone through hell....so my expectation of menopause was that you go a bit mad and people around you suffer. (p.2).

Karen remembered,

I remembered my Mum going through menopause...driving us places and putting the window up and down, up and down because she was getting hot flushes. Then I thought I was going to have hot flushes too. (p.5).

Sasha also said her views on menopause were largely formed from observing her mother,

I had watched my Mum go through it. She'd be sitting on the couch watching TV and you'd turn around to talk to her and she'd have taken her top off because she was sweating. (p.5).

Dave recalled how his father sometimes reacted to his mother's, 'moods', *He used to say, 'just ignore her' (his mother), 'it's the menopause' (p.5).*

Two of the women in the group were aware of premature menopause because their sisters or mothers had experienced it, in these cases, in their 30s. In Marie's case, even though both her sister and mother had had an early menopause, her doctor had told her 'not to worry' because it 'probably wouldn't happen' to her. This advice would seem to contradict an established genetic connection with the condition.

It would appear that the described reactions of shock and views that they were too young for menopause are rooted in a lack of widespread understanding about the condition. The general lack of awareness about premature menopause found in this study was greater than what was expected given a growing public awareness that infertility declines as a woman ages. The last 25 years has seen a trend of delaying child bearing in educated women until they are past 30 years of age. With this trend, the incidence of age related infertility has increased (Dunson, Baird & Colombo, 2004). The current generation's women are more knowledgeable than previous generations about the problem of infertility and of the increase in its likelihood as they reach their mid 30s than earlier generations. It would seem that despite this knowledge, the reasons for infertility are not widely known amongst women. The current group of women were largely unaware of premature menopause as one of the causes of infertility and so were shocked when diagnosed.

An assumption that menopause symptoms were due to stress

Menopausal type symptoms were often attributed by the women in the study to factors other than menopause. Many of the women in the group who in retrospect

had menopause like symptoms, recalled relating their symptoms to stress. Most of them described busy lives including varying combinations of raising young children, maintaining work, challenging relationships, worry about relationships and fertility amongst other things and assumed these pressures were causing their varying emotional and physical changes. Bernadette explained,

I just assumed that with everything that was going on, missing the odd period and feeling edgy was just the stress of my life. (p.12).

Sophie had a similar explanation for the changes to her menstrual cycle,

I just thought I was exhausted. I'm tired. I'm irritable. I thought it was hormonally linked because my cycle was all over the place. But I just kept going. We had a house move, I was working two nights a week and my husband was working all hours and the kids were young and I was tired. (p.2).

Some women were actually told by their doctors that their changes to their periods were probably related to stress, as in the case of Emma,

He said, 'oh you're too young for menopause.' I said, 'not necessarily, I started (menstruating) pretty young.' And he (jokingly) said, 'it's just stress and that rotten relationship of yours, that's all. Get rid of him and you'll be all right.' (p.3).

Whether stress causes amenorrhea is unclear. The relationship between stress and the reproductive cycle is complex (Ferin, 1996), as is the relationship between stress and premature menopause. It is difficult to conclusively describe the ways in which stress may contribute to premature menopause. Gindoff (1989) puts forward that that the central issue in considering the influence of psychogenic stress on the menstrual cycle is the appropriate definition of 'stress' or 'emotional trauma' and that interpretations of stress should be done on an individual basis although he argues psychogenic stimuli lead to amenorrhea in direct proportion to the intensity of the

stress. It has been suggested by Berga (1996) that stress induced metabolic changes may cause hormonal imbalances which may in turn speed up signs of premature menopause. Berga argues that if severe enough, stress caused by activating the hypothalamic-pituitary-adrenal axis may lead to the suppression of the normal menstrual cycle in a condition known as functional hypothalamic amenorrhea or functional hypothalamic chronic anovulation and when fully established, the syndrome is characterized by ovarian quiescence, amenorrhea and infertility (p. 1768). Ferin (1999) in reviewing stress and the reproductive system suggests that although it is impossible to identify a threshold at which stress will interfere with a normal menstrual cycle, it appears that stress causing metabolic changes cause hormone imbalances which may in turn speed up signs of early menopause. Fries (1974) reported psychological stress was more frequently experienced by women with secondary amenorrhea than by age matched control subjects. He notes that environmental change is an example of stress, and found for example, travel abroad was nearly twice as common in an amenorrhoeic group as among controls. It appears the directional effects of stress on premature menopause are unclear and we can not be certain to what extent stress preceded or followed premature menopause in the current study group.

Some women had suggestions other than stress as to what was causing them to feel different. For example, Mary said;

I recalled I had started to get hot flushes after I'd had my daughter which was quite new for me but I thought it was hormonal, trying to get back to normal after having a baby. (p.11)

Confusion about what the condition meant

Another common and often simultaneous early reaction to the diagnosis of premature menopause was confusion. The women and the men in the study almost universally described being flooded with questions about what this diagnosis meant. Karen and

Mike talked of being ‘*confused and bewildered*’ about the diagnosis and needing to understand it. Mike said,

...throughout the whole process we were being bombarded by terminology and we had all these questions left, right and centre and I was on the ‘Net trying to work out what the hell it’s all about, trying to understand it. (p.9)

Janette, who was 32 when she was told she was ‘postmenopausal’ also remembered being very confused,

We didn’t understand how I could have ‘45 year old eggs’ as we were told....just so many questions about what that meant. What it meant for us. (p.8)

The main types of initial questions the couples had were about what premature menopause meant in terms of fertility. Of all the psychological reactions to premature menopause, issues around the resultant infertility were amongst the most significant to the women and men in this study. Chapter 9 of this results and discussion section is devoted to addressing the psychological responses to infertility caused by premature menopause and the ways in which the couples dealt and coped with it.

Other initial questions centred on what premature menopause meant in terms of ageing, long term health and well being and the types of options available for managing the condition. Wanting to understand a phenomenon and looking for answers is a known coping mechanism. In this case, searching for information and answers about premature menopause was one way couples used to cope with their new diagnosis. The most common way for the study group of dealing with the early questions was to turn to the internet for answers. Although this was often helpful as a starting point, several couples described this leading them to feeling overwhelmed with information. Many couples despaired that it was hard to know how to translate

information available about menopause generally to their own age and life situation. For example, Sasha said,

It was like most of the literature assumed you were older and so it's hard to know whether the advice related to me or not. Like what parts of this are relevant when you are 36? (p.2).

Arielle added,

All the info about menopause and HRT and stuff was confusing because it didn't talk about what happens if you take that stuff for 30 years...and it's all about the change of life and being positive about it, which it wasn't for us...(p.15).

These women were referring to the problem of initially finding information about 'normal' menopause trying to apply this to themselves. They often found themselves trying to do what Patricia described as '*adapting normal menopause knowledge to a younger person, which just led to more questions*'. (p.7).

Or as her husband, Germaine said,

We looked up menopause on the Internet, but we didn't know if it was the same for us, because it assumed the woman was older. There wasn't much around about what we had...we had to dig deeper into the Internet I suppose. (p.12).

It is not clear whether the initial shock of the diagnosis meant that early explanations and definitions of the condition by their medical practitioners were not taken in by the participants, or whether they were not provided with the sort of information they needed in the early stages. It would seem that there was room for improvement in terms of the sorts of information, and the way it was given to the current study group

at diagnosis. In particular, a clear and simple explanation of the ways in which what they were facing differed from 'normal menopause' would have been useful.

Related to a sense of confusion and a need to understand the condition often came the question, 'why me?' Associated feelings of anger and frustration about facing a premature menopause were commonly described as another early response. This was often conveyed by comments about feeling their situation was unfair. Searching for reasons for being prematurely menopausal was a way of finding meaning in their situation. Several of the women recalled asking their doctors if premature menopause was caused by something they had done or not done. Karen remembers asking,

Was it something I had done? Was it because I smoked a few years ago? Was it because my mother smoked when she was pregnant? (p.2).

Finding some relief in having a diagnosis

Amongst all the questions and confusion they faced, some women including Lucy and Anya both offered the view that having a diagnosis, shocking as it was, was in some ways a positive development. Having a medically recognised condition was better than not knowing what was causing their symptoms. They were hopeful that a diagnosis meant there was a corresponding course of management or treatment. As Lucy said,

It's good to have an explanation. I probably feel a bit better knowing I'm menopausal. At least I know what's wrong with me. (p.4).

Anya said,

You're short tempered, you're down, I wouldn't say depressed, just down, but you don't know why and then it all falls into place. In a way having that diagnosis, being told you're menopausal is a good thing, it

explains what's going on. I was going nuts, thinking, 'what's wrong with me?' (p.4).

For some, the label seemed to legitimise the symptoms they had been experiencing. Emma described how it was good to know there was a physical basis for what she was experiencing and that it was not all '*in my head*',

By this stage the arthritis had set in, the teeth were falling out, the hair was thinning, what else? You name it, everything collapsing. And me going around the twist. I went to see him (the GP) this day and said, 'I'm going crazy!' (p.3).

Summary

In summary, the existing level of awareness about the condition of premature menopause and assumptions about menopause more generally seemed to be major influencers on how the women and men in this study reacted to the diagnosis in the very early stages. Generally, awareness of premature menopause as a condition was very low. Consistent with other work on premature menopause, (e.g. Groff, Covington et al., 2005., Alzubaidi, Chapin et al., 2002., Liao, Wood & Conway, 2000), common initial responses to a diagnosis of premature menopause were shock, devastation, stress, confusion, anger and frustration. In the current study, such early reactions were found to be common across nearly all couples irrespective of their medical history, their reasons for seeking medical advice and the level or types of menopausal symptoms they had experienced.

Chapter 5 A disrupted sense of ageing

A clear theme around ageing emerged early in the data analysis. All of the interviews contained comments and reflections on aspects of age and ageing. The women described in a range of ways how a diagnosis of premature menopause led to a sense that their body was ageing out of time with their chronological age. They discussed ideas of feeling older, being concerned about looking older, being confused about what the condition meant for their ageing process and generally feeling the natural ageing process had been disrupted. These findings are discussed in this chapter.

Feeling suddenly aged

All of the women associated menopause with ageing. The common response was that they felt being prematurely menopausal meant they had in some way prematurely aged. Marie described her assumptions that she would age quickly, *For me it was like, I thought I would suddenly get really old. Menopause meant you are an old woman.* (p.9). Marli explained this assumption by saying, *I feel like I have missed a whole 20 years of ageing* (p.11), and Sasha said, *I felt I had aged 20 years in a split second* (p.3). Roberta told how she also suddenly felt older, *I'd look in the mirror and it's like I'm 36 but suddenly I see myself as 50. I wasn't ready for that.* (p.12).

Normally ageing is a process that happens gradually over time. In this case the suddenness of perceived change was what was distressing for the women. Although ageing itself was not expressed negatively by those who took part, the idea that it may occur prematurely was alarming and distressing. As Marli said, *I am terrified of the whole middle age spread coming early* (p.9).

Terminology of ageing

The idea of ageing quickly was reinforced by the words their medical professionals chose to describe the condition. Several women commented that the diagnosis of premature menopause had been explained to them by doctors in terms of ageing, for example having ‘aged ovaries’ or ovaries that are ‘acting like a much older woman’s. As Anya said, *‘It was explained like my eggs were too old to be of use.’* Bernadette had a similar experience; *‘He (the fertility specialist) told me my ovaries were acting like a 60 year olds. To me, I took it that my age was 32 but my body is 60’.* Fran interpreted her doctor’s explanations this way; *‘I understood it to mean my body was ageing really fast’.* And Janette summarised the explanation she had been given this way; *‘I sort of took what I had been told by him (the GP) as my insides are ageing faster than my outsides’* (p.16)

It would seem that despite the preconceptions of menopause they may have had prior to their own diagnosis, the condition was commonly described by their doctors using a medical view of menopause as an estrogen deficiency problem. Boughton (2002) suggests the pervasive biomedical model of menopause as an oestrogen deficiency disease inextricably links menopause with ageing and contributes to a confused view of one’s body and sense of self.

A disrupted sense of self

The idea that their reproductive system was functioning like a much older woman’s was hard to reconcile with their age at time of diagnosis. The notion of ‘being 30 in a 50 year olds body’ caused confusion and a sense of being disconnected. Anya describes this feeling,

My body is older than I am! I still find it hard to deal with. Even now I wonder...how can this part of me be older than the rest of me? Am I old or am I young? (p.13).

The women were widely perplexed as they understood menopause happened to older women and they associated it with ageing and middle age. Being prematurely menopausal created an unusual and puzzling perception of themselves and they struggled to make sense of mismatched biological, chronological and physical ages. Some of the women in the current study weren't sure whether ageing was obvious or all in their mind. They described how this was very puzzling and at times led to feelings of 'going mad', as Patricia said, *I look in the mirror and get confused. Am I meant to look like this, if I didn't have this problem? Sometimes I feel like I'm going mad.* (p.3). Ann's perspective was similar,

It's like you look in the mirror and wonder whether what I see is what others see. It's hard to explain, but I'm not sure how old I am in a way, or am meant to be. I probably sound mental...(p.14).

These perplexing changes to the women's sense of themselves suggest a disruption to their self identity. Halliday & Boughton (2009) also found the women in their study reported feeling older and losing their sense of identity. In the current study Janette described it this way,

I just felt like I didn't know myself anymore. You sort of assume if you are 35, your fertility will be like a 35 year olds, not like an older woman. A 35 year old should age like a 35 year old. I just felt weird about myself and it was hard to come to terms with being out of line like that. (p.19).

Boughton (2002) uses the term 'menopause stereotype discordance' to describe such confusion around ageing. This is a description for when the biological body is ahead of the 'embodied self' resulting in being 'out of synchrony' (p. 427). Because they receive cultural messages that menopause signifies a decline physically, emotionally and sexually women with premature menopause experience a 'split' where they feel they are 'something within and something else without' (p.426).

Increased focus on physical appearance

The women in this study described trying to reconcile this confusion about their sense of themselves and their age by paying increased attention to the way they looked. They scrutinised their physical appearance for tangible signs of ageing. It was as if they were seeking to understand whether they were 'old' or 'young' by looking for tangible evidence. Many described how they became vigilant about checking in the mirror for visible signs of ageing. As Mary described, '*I look in the mirror and think, 'Oh My God, I do look older!'*' (p.10). Natalie said,

Sometimes I look in the mirror and wonder if I look my age. I've been through menopause so do I have more wrinkles that I should have? If I hadn't been through menopause would I have this many wrinkles? (p.12).

Patricia and Mary describe seeking evidence of ageing this way,

I look at myself and try and reconcile that image with being post menopausal which is something you associate with being old. I can get a bit obsessive about looking at myself and wondering if I am ageing quicker. (p.6).

I didn't look older really, but I'd look in the mirror and think, oh, I notice more lines around my eyes. (p.10).

Many of the women in this study discussed their concerns about ageing in terms of what it meant for their outward appearance. As is perhaps our prevailing societal view, there was a general view in this group of women that beauty is associated with youth. They expressed their fears that they would be seen as less attractive because of ageing quicker. Patricia struggled with this,

I felt I had gone from being a young, energetic, lively woman to being old. I associated being menopausal with being in the 50s or 60s and losing attractiveness. Women can look beautiful obviously in their 60s but they don't have that young sexy vibrant attractiveness. (p.6).

Some women said they understood that a reduction in oestrogen associated with their condition could affect the quality of their skin and hair and expressed concerns about this. In particular, they worried about hair loss and dry or wrinkled skin. The women in their earlier 30s were particularly concerned about suddenly looking older. This suggested outwardly observable body changes posed a threat to their identity as a 'young' woman. Roberta explained,

Now I'm 40 and ever since I was 20 I loved the fact that everyone said I look young for my age. I still feel like I look younger but that was quite a struggle (changing shape around the waist line) because all of a sudden, something I was really proud of and I found really flattering had changed and I was scared people wouldn't say that any more. (p.12)

Some of the women in the group who were over age 40 described being confused as to whether the changes they noticed were normal for their age or accelerated as a result of menopause. Some questioned the differentiation between menopause itself and the stress of menopause as a cause of ageing. As Bernadette wondered,

I'm not losing hair like a lot of menopausal women. I think I have more wrinkles but that could be due to stress. (p.5)

In describing the impact of premature menopause Anya suggested the 'trauma' of her diagnosis led to her feeling older,

I think the whole thing has aged me in ways I may not have aged...because of the trauma of it. I guess it's like any trauma

situation, it's going to make you feel older than you are. It's not so much the condition itself, but the trauma of it. (p.19)

There was a differentiation between those who were concerned about looking older and those who despite having no outward signs of looking older, still 'felt older'. Some of the women construed ageing as a more internal process and they raised questions about the extent to which their body was ageing 'internally'. Marie explained this feeling,

I didn't feel old before I became menopausal. But now I feel like an old woman. I mean, it's just a feeling, not a physical one, it's just how I feel. (p.17).

Marli said, *I just immediately felt aged. Like I was over basically'* (p.4). Patricia agreed, *I felt like an old woman. Not a young, sexually attractive woman* (p.8). And Arielle explained,

When I look in the mirror I feel old and heavy and really uncomfortable in my own skin. I can't explain it. I feel horrible. I feel old, fat, just awful. And my husband says I'm not. But how do I explain it's just a feeling. You may look fine but it's just a feeling and you just feel that way. (p.13).

These findings are consistent with Boughton's (2002) who in describing 'body confusion' explained some of the women in her premature menopause study felt older even though 'on an intellectual level they knew they were still 'young' according to social categorisation by age'. (p.426) This idea of feeling the body one has as being different to the one reflected in the mirror follows Boughton's earlier (1997) work on the experience of the body in which she describes how premature menopause results in 'a split, where women feel they are something within and something else without; a sense of the body as an 'alien thing' arises out of the symptomatic physical body experience of premature menopause' (p.170).

Fran described an attempt to balance these feelings out by ‘bringing on’ the menopausal changes in order to align her sense of herself with her post menopausal body,

Physically I am the same, but I think that physically I am different. It’s hard to make sense but I am waiting for my physical changes to happen because that’s what happens to menopausal women. Their metabolism slows down, they put on weight. I’ve stopped going to the gym and I am eating rubbish food so I’m sort of psychologically wishing the changes on even though I don’t want them. (p.12).

Just as their own views of themselves were confusing, concerns about what others might think about their age was mentioned as a common worry. It was important to some of the women in this study that others didn’t see them as significantly older than their actual age. These women explained,

I felt I would be judged as old. I thought they (people generally) would look at me differently and think I was wrinkly or something. (Marie, p.10).

I picture myself as rather than being 41 now, I’m looked at like I’m 50 or 60. I am old before I really am. (Marie, p.16).

I guess I’m not young and feminine and virile anymore. When I picture women with premature menopause I see old grandmothers with grey hair and I don’t want others to see me like that. (Lucy, p.19).

A concern about people seeing them as ‘older’ was one of the factors considered in whether or not the women told others about their condition. This may have been one of the reasons why in most cases in this study, participants had shared their condition

only with close friends and/or family. Lucy added, *I pretty much kept it to myself. I didn't want people to see me as old.* (p.19).

Use of hormone replacement therapy

Just over half of the women in this study said they were taking forms of hormone replacement therapy (HRT) as prescribed by doctors. They explained this in terms of, as one woman said, *correcting the ageing process*. They felt HRT helped counteract this 'split' or feeling of age discrepancy by as Natalie said, *putting things back into alignment*. Although most of them took HRT because they were as Mary said, *following doctor's orders*, others described using HRT to, in Grant's words, *readjust the ageing process*. Pam described how she hoped HRT would put her body, *'back where it's meant to be, age wise'*. (p.18).

On the other hand, Patricia described how wearing a transdermal HRT patch made her feel old. She described trying to explain this to her doctor,

I said I can't bear wearing this thing on my bum. It makes me feel old and it looks like I'm wearing an ovary on my arse....whereas if I took a tablet I wouldn't have to see it....I told him I am too young to walk around with a patch. I want to be young and wear a bikini and walk around in my knickers. He said it would stay on if I went swimming. But he didn't get it. I didn't want a visible sign of this old person's condition and a reminder that made me feel old. (p.15).

Halliday & Boughton (2009) similarly found that prematurely menopausal women in their study described feeling older, not feeling 'normal' and tried using HRT to make them 'feel normal again' or 'put them back to their old self,' (p. 20). Other women in the current study reported mixed feelings about using HRT as they understood their bodies '*need the estrogen,*' but were confused about what Buick, Crook & Horne (2005) describes as the 'double edged sword' of HRT and its sometimes discussed possible links with cancer. Some couples expressed concerns about long

term use of HRT. Several referred to hearing what Phil described as *mixed reports about HRT and it's link to cancer*. (p.6) It seemed the impact of long term HRT use for younger women was not well understood by the group. Pam spoke for many when she said,

It's all very well giving me HRT, but that is usually for women 30 years older, so who knows how that is going to affect us younger ones in the long term. The Dr just gives it to you but it's not as if I am your typical menopausal woman. I know I have to protect my bones, but is it just the same stuff in lower doses, or will it build up in my system?
(p.4).

Buick et al., (2005) suggest a review of the published studies relating to 'typical' menopausal women and HRT use revealed the usage of HRT seems to be influenced by the short term relief of symptoms rather than the awareness of the long term benefits. The results of the current study suggest that even if women had an interest in using HRT to assist with short term symptoms they were concerned about how long term use may affect them, '*given I am starting it 20 years earlier than most menopausal women using it,*' as Janette said (p.12). These concerns are understandable given that research exploring the long term risk of HRT in younger women is very limited (Salpeter, 2005). The younger menopausal women in this study needed information about the ways in which the concerning issues of HRT use for menopausal woman of typical age may or may not apply to them.

Questions about long term health

Another aspect of premature menopause and it's perceived relationship with ageing was that the women had the idea that they were ageing but didn't really know what that meant in terms of their longer term health consequences. As Anne said, *What 36 year old woman is worried about her bones?* (p.4) Karen, Sophie and Anne described similar concerns;

I am concerned about the impact on my skin on my bones, osteoporosis, the ageing process because I think that once you don't have the oestrogen I think you age more. I am concerned about the impact of that on my life span. (Karen, p.12) .

It's not just the external physical ageing but the whole idea of ageing and oestrogen being the feminising hormone and what does that mean? (Sophie, p.7).

I see it that I have a 20 year lead on calcium deficiency and my reproductive system and eggs are that of a 52 year old. (Anne, p.5).

Marie (who had a baby using donated eggs) however, said she had never been worried about the long term effects of premature menopause as her whole focus had been on having a baby,

Basically nothing else much matters now we have him. I hadn't been worried about what it might mean for me other than having a baby. I think I blocked out what it might mean for my health. Nothing else is as important as him. I guess I might think about those things down the track, but I haven't yet. (p.7).

Largely, the women wanted to understand how menopause occurring early would affect their health later in life and universally felt this was not made clear to them by their treating doctors. Several of the men also expressed concern over long term health implications for their partners and described not feeling well informed about this.

Summary

In summary, premature menopause disrupted the women's sense of their own age. Their concepts of biological and chronological age were upset. These findings

relating to an upset in the understanding and sense of ageing are consistent with earlier work on psychological reactions to premature menopause (e.g, Boughton, 2002., Orshan, Furniss et al., 2001., Pasquali, 1999, Lennon, 1982). Of particular concern to the women in this study was the possibility that they might be ‘ageing too quickly.’ They felt premature menopause aged them in sometimes vague and confusing ways and this was at times distressing. One way of coping with this was by looking for visible signs of physical ageing, in particular by paying extra attention to the way they looked. Women who were using HRT to manage menopause described this as a means of rectifying advanced aging. The women were widely confused and often worried about what the condition and the use of HRT meant for their long term health.

Chapter 6 **A social void**

A diagnosis of premature menopause and its associated disruptions to their sense of ageing had social implications for the women in this study. A theme around premature menopause launching the women into a ‘social void’ emerged. This theme derived from the participants’ descriptions of feeling that they were living between two age ranges. Findings about the impact of premature menopause on social and peer groupings are discussed in this chapter.

No woman’s land

The women described in various ways how menopause set them apart from their same age peers, yet they felt they didn’t relate to menopausal women of the ‘normal’ age; leaving them, as Anne described, in ‘no woman’s land’,

I am somewhere in between, in a no man’s land. I’m not like my mates because they are all dealing with normal 30 and 40 year old stuff like getting pregnant, and I’m not like menopausal women, because they are older and dealing with their stuff, like teenagers or grandchildren. I’m on some island of my own. I really feel like I am in no man’s land, or should I say, no woman’s land! (p.14).

Marli’s comments described a similar view,

I am not in one group or the other. I’m not like someone who shouldn’t yet be post menopausal because I am, but I’m not like someone who is post menopausal, because I’m too young. It’s like I’m in some little category of my own. (Marli, p.35).

This finding, that there was an awareness of not quite fitting with their peers, but also not quite fitting with older women fits with that of Boughton (1997) who described 'social identity disruption' as 'belonging yet not belonging to two very different social groups of women: 1) the young, the energetic, their friends with small children or some embarking on motherhood; and 2) the older, less attractive, more mature women with older children, possibly grandchildren' (p.428).

One of the reasons Patricia gave for feeling separate from her friends was a concern that her same age peers would somehow see discussing menopause as distasteful,

If I mentioned it to someone my age that I'm menopausal I think they would look at me like, 'oh yuck, that's horrible', like they would think less of me. They might think I wasn't as attractive, that my body wasn't working well, wonder how I go having sex, that sort of stuff. Older women probably get it, but I can't relate to them either. (p.16).

Emma also felt her same age group friends found menopause distasteful and distanced themselves from her because they couldn't relate to her anymore,

The women in my group would go, "we don't know her, we're nothing to do with her, and we are nowhere near that, we're different, she's old". And actually I was younger than most of them. It was just awful. (p.2).

She added this unique view,

The other women didn't want the men in the group to think that was what women were like. They didn't understand it and they didn't want it to reflect on them. (p.15).

As mentioned, others too expressed reluctance to discussing their menopausal status with their peers and most tended to avoid the topic. Perhaps this was a sign of not wanting to be outside the group or not 'fitting in' with the social norm.

A major factor contributing to the feeling of being in 'no woman's land' was that the women in the study were dealing with menopause while many of their friends were having babies. In 2008, the average age of Australian women having their first baby was 28 years, with the median age being 30 (Australian Bureau of Statistics, 2008). The majority of the women were diagnosed between 24 and 40 years, which is the age group with the highest fertility rate in Australia. Part of their sense of 'not relating' was not being able to share stories of pregnancy, childbirth and children at the same time as their friends were experiencing these things. Several women commented it was especially hard when friends were announcing their pregnancies or having babies as it reinforced their own trials and losses. As Sasha said,

Amongst my friends of my age, that year when we went through all this, finding out I had gone through menopause, there were 14 babies born in my circle of friends. All that was incredibly tough. (p.10).

Roberta had the same problem,

Friends my age are all about finding a man or having babies, normal menopausal women are in a different age group, so I fall between. (p.22).

Even some of the women who had finished their families or who did not necessarily want more children alluded to this,

It wasn't like I was trying for a baby, but just knowing I couldn't have one sort of put me on a different plain to my mates. I guess they could if they wanted to, or they would always talk about 'do you want another one?', or the pros and cons of 2 versus 3 and I felt left out. (p.28).

Singer & Hunter (1999) described how premature menopause changed the way women in their study felt about themselves in relation to others by saying they entered a 'no woman's land - partly because perhaps menopause occupies a place in between discourses of what being a woman is all about,' (p.64). They found the prematurely menopausal women in their study experienced a 'painful preoccupation with not being understood' and that 'knowing friends or family with premature menopause moderated the experience'. The women in Singer & Hunter's study felt that 'being menopausal was like becoming a member of a particular social group or community'. This was problematic for them because the group they identified with socially was not congruent with the social image of menopausal women.

Descriptions of being in 'no woman's land' were also offered in the current study and were amplified in part because although the women had at times shared their stories of infertility challenges with friends, none of their friend's infertility, as far as they knew, was due to premature menopause. Bernadette explained,

They (similar aged friends) talk about being worried about their biological clock and fertility. They know that their eggs aren't so good after 36. They think, because of my condition, I can relate to fertility fears with them. The difference is, although they are getting older, as far as they know, there is nothing wrong with them. Whereas, I've had tests and I know something's wrong. I'm not having periods. I am abnormal. As far as they know, their bodies are working normally. (p.12).

Sasha seemed to sum up the unique and complex challenge of premature menopause for many women who hope to have children by adding,

I could talk about some of their issues. I've tried IVF, so I can talk about the ups and downs of that. I was potentially pregnant for 12 days, so I can offer that. But my issues are about menopause, and

none of my age group friends comprehend that. Normally menopausal women aren't trying to get pregnant. (p.15).

Feeling lonely

A salient subtheme of falling between two age groups was isolation. Despite all having partners, family and friends, the effect of premature menopause left the women in this study feeling alone. This was in part because they felt that the significance of the condition was not really understood by those around them. Sasha explained, *I felt so out of place amongst women. Like an alien. On the wrong planet. No one got it. (p.16)* Patricia had a similar experience, *I was really happy to talk about it, but women aren't interested in other women's menopause unless they are going through it themselves, so I ended up pretty lonely (p.17).*

Arielle expanded on her sense of loneliness,

It's not an easy thing to go through and I've got no one to talk to because none of my friends have menopause. They have no idea. They just sit there and sympathise with me but they have no idea what it is like because they have different issues that 30 year olds normally have. At 36 my body is really ageing. I'm going through things they don't have to worry about for 15 years. I can talk to them till I'm blue in the face, but they have no idea. So I would describe it as a lonely feeling. They're there but I'm still lonely in my menopausal way. (p.12).

Feelings of isolation and loneliness have previously been associated with premature ovarian failure, (Schmidt, 2006). Alder (1999) points out that a feeling of being lonely, withdrawal from social relationships and growing social isolation are major features in many illness, especially chronic ones. Although premature

menopause for these women was not an illness, the 'condition' had a similar impact.

Several women in the current study actively tried to overcome loneliness by seeking out older menopausal women to talk to, however, this was generally not helpful. Patricia and Anne described unsatisfactory attempts,

One 50 something woman I see is always fanning herself and I asked her if she was having hot flushes and she said, 'Oh God, it's terrible', and I said, 'I know', and she said, 'no you don't', and I said, 'yes I do,' and she said, 'no you can't, you're too young.' (Patricia, p.4).

I found the older women I knew who were going through menopause naturally seemed to be having their own sets of issues relating to that stage in their life. They didn't seem to be able to relate to a 32 year old who might be going through the same thing. (Anne, p.15).

There was one woman however who commented she found talking to older menopausal women pleasantly surprising. Mary said,

There were three women at work in their 60s. One was over it, one was always getting hot sweats at work, and the other was just starting to and was feeling off. We all used to talk about it. I found myself for the first time really identifying with the generation ahead of me. Quite strange, but it was good to have the same things going on. I suppose I mightn't have got to know them otherwise... (p.11).

Contrary to most, Roberta commented she felt she related to older menopausal women,

I have a new respect for all women who go through menopause. I now appreciate what all those older ladies in the street have been through. (p.15).

Some of the women described falling in between these age groups in terms of lacking a 'peer group'. Pam said, '*There is no peer group for me, I'm somewhere between my friends' age and oldies. In some kind of group of my own*'. (p.31).

Karen and Sasha had similar comments,

I feel like I don't have peers. I'm different from women who are the normal age going through menopause. They can't see I'm there too. A lady at work in her 50s for example said, 'even if you get hot flushes, it can't be the same.' So I don't relate to her at her age and she doesn't relate to me. There is no one for me to relate to. My friends my age are all getting periods and I don't relate to that either. (Karen, p.16).

I'm out of my peer group and plonked right in the middle of nowhere. I felt removed from my peer group. Sometimes it makes it hard for me to relate to them. (Sasha, p.14).

Fran extended the concept of missing a peer group to describing the lack of a similar aged role model,

I thought, God I'm 30, should I be packing up and going around Australia in a caravan? That's what menopausal women do! I had all these sort of weird thoughts because I didn't have a role model. I didn't know anyone else going through it at my age. I didn't know what was expected of me. Who is 30 and menopausal? If they are, they don't shout it from the roof tops. (p.3).

Sasha described how frustrations in relating to her same age peers sometimes caused conflict,

It's hard at my age when you go out for drinks with friends your own age and they are all going on about period hassles. I have actually screamed at them and said, "Guys, at least you're still getting it. You should be thankful." They all just shut up and I felt like the odd one out, like I should go and talk to the HRT ladies. (p.15).

Lesser et al., (2004) and Teaff & Wiley (1999) suggest peers provide an important source of support and information for midlife menopausal women. Many of the women in the current study said they thought their feelings of being isolated in 'no woman's land' would be eased if they could speak to others with premature menopause. Demand for support groups was high. However it seemed it was difficult for prematurely menopausal women to access peers who had similar experiences. They desperately wanted information and were particularly interested in talking to others with the same experience. Several women commented that other's experiences, such as what this thesis aims to produce, would be of particular interest to them.

The 13 prematurely menopausal women in Singer & Hunter's (1999) study expressed a theme of seeking support from other women of the same age and stage of family building as themselves. It has been widely recommended, e.g, Nelson (2009) that women with premature menopause should be directed to support groups and be encouraged to become better informed about their condition. Some of the Melbourne women in the current study had unsuccessfully tried to find a local support group for premature menopause. They thought a support group would be very helpful in easing their sense of loneliness and anxiety. All of the New Zealand participants were members of a support group and all described it in very positive terms, including one woman who said it was the only thing that was keeping her 'sane'.

A lack of easily obtainable information specific to women in their 30s was major contributor to feeling lost. As mentioned earlier, it seems that most of the literature about menopause presumes an older audience and comes with advice about managing midlife changes. The feeling of being in ‘no woman’s land’ was reinforced by the participant’s experience that the majority of information they found on menopause related to women aged 50 to 60. As such, information specifically aimed at younger women was most in demand amongst this group. As Pam explained it,

You look up menopause on the Net and it is all about older women. I wasn’t sure how that related to me. It was like I had fallen between the cracks of my age group and some other age group (p.21).

Arielle added,

Most of the stuff available to read about menopause is aimed at women aged 50 plus. I don’t know if I should read it and try and adapt it to myself, or just try and remember it is for old people. I can’t explain it; it’s just like, I’m neither here nor there.’ (p.14).

‘Off time’ development

The feeling of being in ‘no woman’s land’ in this study arose from being in a stage of physical development which was ahead of their same age peers. The notion of having one’s physical development ‘off time’ relative to one’s same age peers has been explored in research into early and late sexual maturation in adolescence. Most research on maturational timing was completed in the 1950s and 1960s and sought to understand how early or late maturation influenced young people’s peer relations, personality and social adjustment (Santrock & Bartlett, 1986). Most of this research suggests that early maturation has overall positive effects for boys, but mixed effects for girls (Santrock & Bartlett, 1986). It could be argued that the physical changes

that come with puberty are likely to be more overt and observable to others than the physical changes that come with menopause. Prematurely menopausal women do not necessarily look older than their same age friends. The current study's findings suggest that the experience of falling between two groups of women and feeling in 'no woman's land' was more to do with feeling different and facing different life challenges than to looking different to their peers as in the case of adolescence.

Sociologically, Elder (1975) argues that life events and stages are socially defined and that we assign age expectations around such life course changes, evaluating our experiences against 'normative standards'. Menopause is generally an expected occurrence and perceived as appropriate for mid life women and is not 'the norm' for younger women. Neugarten & Hagestad (1976) says "most life transition changes are not generally traumatic if they occur on time, or in the age range expected because they have been anticipated and rehearsed", and, "major stresses are caused by life events that upset the expected sequences and rhythms of life, as when the death of a parent comes in adolescence rather than middle age" (Neugarten & Hagestad, 1976). Other examples of life events which have been shown to have negative psychological consequences when occurring earlier than the norm include early widowhood (Kalu, 1990, Anderson, 1984). Neugarten & Hagestad, (1976) explain becoming a grandparent at a young age can be stressful. Also having children leave home earlier than expected, leaving an early empty nest (White & Edwards, 1990). Early unexpected retirement has also been shown to have negative psychological consequences (Beck, 1982).

Lennon (1982) suggests one explanation for the stressfulness of 'off schedule' events concerns social relationships and support systems (p.362). She argues on time events occur within a context in which their associated changes are normative and for which social supports are probably readily available (p.362). Women who experience menopause 'on time' are likely to receive more assistance in terms of advice, information and emotional support since they will tend to know others undergoing the same thing. In relation to premature menopause Lennon contends 'psychological

distress is regarded as a consequence of deviation from age norms and not as the result of menopausal losses, whether physiological or social' (p. 354).

An older person's concern

Just as menopause is usually associated with a certain age range, other medical conditions too are generally related to older age groups. Some researchers have sought to establish the psychological impact of medical conditions usually associated with older age on young people. Packham (2004) evaluated the impact of arthritis, a condition most commonly associated with those over age 60, on the quality of life of a group of young people aged 19-26 and found it to create unique difficulties for younger people. Chad, Deal et al., (2005) found 21% of young people with arthritis were clinically depressed with the rate of depression increasing with the degree of disability. Only 38% felt the condition had no effect on their ability to have satisfying relationships. Although having the condition impacted relationships with peers, this effect seems to have diminished by later adulthood. In a another study by Packham & Hall et al., (2002), 246 adults who had juvenile arthritis were followed up to assess their social function, relationships and sexual activity. The authors found juvenile arthritis had detrimental effects on body image in 50% of the participants but relationships were affected in only 28%. The authors recommended counselling for young people with the condition to help them address any psychosocial issues and impacts on relationships.

Early arthritis obviously comes with different physical effects and limitations than early menopause; nevertheless both are conditions usually associated with old age and seem to impact social relationships. As the New South Wales Young Adults with Arthritis support web page advises, 'it is hard enough to live with the pain and fatigue associated with many forms of arthritis without having to face laughter, ridicule or being told you are crazy for claiming to have a disease that you are seen as being 'too young' to have. (Website accessed 25/5/2010).

Summary

In summary, discrepancies brought on by disruptions between chronological, social and physical age impacted relationships with friends by leaving the women feeling they did not fit in. The women felt neither old nor young, and this left many feeling they no longer related to their peers. Feelings of loneliness were common. The women in the study expressed a strong desire to talk to other women with similar conditions. It would seem the lack of information, advice, support, and opportunity to share made the experience of premature menopause more isolating and therefore difficult than could be expected of 'normal' menopause.

Chapter 7 Dealing with infertility

Issues of infertility were salient in all of the interviews. All of the interviewees associated premature menopause with infertility as its main meaning. Infertility had varying levels of relevance to them as individuals and couples depending on their family circumstances and wishes regarding children. The women were divided between those for whom infertility was of major concern and those for whom infertility was not their main focus. Aspects of infertility and its impact as a result of premature menopause are discussed in this chapter.

As discussed in the chapter 2, infertility is one result of premature menopause. At the time of the interviews, 6 of the 18 couples were actively trying to have their first child or additional children with the assistance of egg donation. For these women and their husbands, premature menopause represented primarily infertility. The infertility associated with premature menopause was their immediate and foremost concern. As Karen said, *'to me it (premature menopause) was about fertility, not being able to have a family. Nothing else really mattered'*. (p.6). Bernadette's reaction was the same, *'the first thing I thought about was kids, you know, we didn't have any'*. (p.2).

As discussed earlier, none of the women in this study had contemplated being prematurely menopausal and this was a shock for all of them. Although several of the women described thoughts that 'something was wrong', largely because they had a troubling delay in conceiving, menstrual irregularities or hot flushes, in nearly all cases the news about being menopausal was not anticipated. The idea of infertility was not something they had really considered and if they had, there was an assumption that technology could help. One couple who had been trying to conceive for several months described,

We thought it might be hard for us for whatever reason but we always assumed we would have IVF as a backup, so the whole idea of menopause and not having good eggs was off our radar. (Dave, p.9).

At the time of the interviews, some of these 6 couples were undergoing IVF with donor eggs, some were actively seeking egg donors and others were in discussions with potential egg donors. Sasha, who had not had children and who was trying to find an egg donor said,

It (premature menopause) just meant we are infertile and we probably can't have children... Nothing else about it really bothers me compared to that. (p.21)

Sophie and Ari had a daughter and had planned more children. Menopause for them too meant infertility,

Obviously I was desperate to know whether we were able to have more children which was my main concern, which was obviously where the bad news came about. (Sophie, p.2)

Arielle, who had unsuccessfully used donated eggs in an attempt to have a child recalled how to her,

Premature menopause meant infertility...it was just, 'Oh my God, this means we can't have a baby'. Children were always a given. With the diagnosis, nothing else mattered. I didn't really care about my body or what was going on with my bones or whatever; I would do anything I was told in order to have a child. (p.21)

Some of the women who wanted more children acknowledged health implications of premature menopause other than infertility but said these were of secondary concern. Marie said,

I knew it had implications for bones and so on but I was so focussed on finding out if I had at least any useful eggs left that all that was

just in the background somewhere. Like who cares if my bones are soft, we just want a baby. (p.12)

And Sasha said,

I just thought, 'I'm not going to have children'. I didn't even worry about all the hormones and bones and heart and all the rest of it. The first thing I thought was children. We have just focussed on trying to have a family. Maybe later I will worry about my health. (p.11)

Infertility - a crisis model

For these couples wanting to grow their families, infertility was a crisis in their life. It was something they were desperately trying to get around, by trying everything they could to have a child. Researchers have often conceptualised the emotional distress infertility can cause as a major life crisis (e.g. Cook, 1987, Menning, 1980). Crisis theory considers how individuals adapt to a crisis in which they are thrown into a state of helplessness and where previous coping strategies no longer work. In this light, infertility is seen as a new, enforced and unwanted situation that stretches one's ability to cope. According to Menning (1980), the crisis of infertility is developmental in that it may impede generativity, which is a concern with establishing and developing the next generation. Erikson (1950) asserts generativity is a central developmental task of adulthood. Menning (1980) contended that infertility and the emotional challenges it brings, present a life crisis for infertile women, pushing them toward resolution and homeostasis and providing the possibility for either maladjustment or positive growth (Hammer Burns & Covington, 1999). Stanton & Dunkel Schetter (1991) say the conceptualisation of infertility as a life crisis has been helpful in that it has helped to stimulate the development of support groups for infertile couples, it increased awareness by health professionals of infertile patients concerns, and generated research into adjustment to infertility (p9).

Infertility - a grief and loss model

Others described what they felt as a strong sense of grief and loss in not being able to have a biological child of their own. For Bernadette, infertility seemed, *like a death* (p.16). She described feelings of loss about fertility combined with emotional changes of menopause as an ‘emotional overload’,

It's the end of it (fertility) kind of thing. Basically it was just a massive loss I felt. Loss and grief and emotional overload. You go through a lot of emotions, anger and frustration and coming through those emotions and going through menopause having mood swings left, right and centre, makes everything harder to deal with. (p.5).

A grief and loss model of infertility is another perspective on infertility which applies Kübler-Ross's (1958) five stages of death and dying model (shock, denial, anger, bargain, acceptance) to describing the typical feelings relating to being infertile (Hammer Burns & Covington, 1999). Hammer Burns & Covington list a myriad of losses involved in infertility including the loss of hopes, dreams, future plans, marital satisfaction, self esteem, sense of control, belief in the fairness of life, health and wellbeing, and most importantly, the ‘dream child’ (p12). Anne spoke this way, ‘*It was just total grief. A loss of that whole idea of what my life would be.*’ (p.22). Fran added, ‘*It was like this massive sense of losing something... my fertility, I'm still not ready to say good bye to my eggs.*’ (p.9).

Menning (1980) in describing the losses associated with infertility contended that these losses evoke a predictable pattern of feelings that need acknowledgement, working through and overcoming in order to attain effective resolution. Stanton & Dunkel-Schetter (1991) suggest that through the experience and expression of emotions involved in the grieving process, the infertile woman can move toward accepting her infertility, exploring alternatives to a biological child or more biological children and beginning to move forward in her life.

Most of the women in the current study who were primarily concerned about the infertility associated with premature menopause had been diagnosed within the last 4 years and were still actively trying to get pregnant at the time of interviewing. It seemed the focus on infertility and its associated losses did change with time and reflection. Patricia, who was the oldest woman in the group and who had discovered her premature menopause 8 years earlier said once she had ‘dealt with the grief’ of infertility, she had space to consider other aspects of premature menopause and what it meant to her,

It's only as the years have gone on and we have probably run out of options (to have a child) that I've done my own research and I've seen other professionals that deal with this that I have a more rounded perspective of what it means. I am actually getting to the point where the fertility thing, I'm sort of moving on from that now. Automatically after being diagnosed I got caught up in having to find an egg donor and that went on for years. (p.4).

Karen, who had an 18 month baby by egg donor, had a similar view,

It's only as time has gone on and I've gotten over the grief thing - after we had our baby (by egg donor) it was only then I really started thinking about the impact on my skin, my bones, osteoporosis, the ageing process cause once you don't have estrogen I think everything starts to age. I started worrying about the impact on my life span. Will I die earlier because I'm not ovulating – that sort of thing. But I had to have the baby before I got to that side of it. (p.12).

Others have suggested grief in infertility presents additional complexities. For example, Anderson & Alesi (1997) suggest that the grief response in infertility is complicated by the fact that there is no tangible loss or discrete event upon which to focus the experience of the loss. Because the loss of fertility is difficult for others who have not experienced it to understand, women experiencing infertility may miss out on much needed social support. Anderson & Alesi (1997) also argue that because

infertility treatments are improving and becoming more widely available and accepted, 'the loss is uncertain and the grieving cannot proceed' (p.49).

The egg donor world

At this time there is no proven medical treatment for premature menopause and some medical therapies for infertility have proven ineffective, including high dose estrogen therapy, gonadotropin releasing hormone (GnRH) agonist therapy and corticosteroid therapy (Medicinenet ; accessed 28 April 2011). Adoption and egg donation are the main options for couples with premature menopause who want a family. Challenges associated with egg and embryo donation have been widely investigated (e.g. Purewal & van den Akker, 2009, Ahuja, 1997). For the women in the current study who were looking to find an egg donor or who had unsuccessfully tried donor eggs, the search for an egg donor was all encompassing. These women had a lot to say about their experiences sourcing and working with egg donors whether they were known to them or not. They were very eager in the interviews to share their frustrations with what was sometimes referred to as 'the egg donor world'. The interviews with these women were often easily diverted onto the topic of their experience with egg donors and all that involved. As Bernadette said, *I think menopause and I think egg donation*. Janette said, *I could spend weeks telling you about the egg donor world. It has a political scene of its own* (p.6). And Karen said, *it's been all about the struggle to have a child for us. We have been totally focussed on finding our donors and all that involves* (p.2). It was at times necessary for the interviewer to steer the conversation away from details of the egg donation process and its associated challenges and frustrations, toward the more general and relevant line of discussion, 'what did premature menopause mean to you?'

Anya and Herbert described how their fertility specialist told them they would need to find an egg donor. They felt there was an assumption that this would be a preferred way of becoming parents. They had found the process of finding an egg donor difficult and disappointing. They said they were dissatisfied with the amount of

information available about alternative family building options such as adoption or permanent care;

It was just assumed with my ovaries when we finally understood it that we should go down that path (egg donation) and so we did. If we had known it was going to be so bloody hard and that half of them were nutters (egg donors) we might have gone for other options, but they were not really discussed with us by anyone so we have wasted all that time in that area. (p.31).

Overall, those who were, or had been involved in the egg donation route described it as stressful and overwhelming and a process which over rode most other aspects of premature menopause for them.

‘Our family was complete so it wasn’t an issue’

As well as those desperately wanting children, a second group of 5 couples described having ‘complete families’ and did not have plans to add to their family. For this group, the infertility which came from premature menopause was not a chief concern. Natalie was in her early 20s and not thinking about having a family when she learnt she was not ovulating. She went into her 30s knowing she would not be able to have her own biological child,

When I was diagnosed I wasn’t really thinking about wanting a family as I was pretty young, so it didn’t mean much. The doctors were giving me the pills I needed and I didn’t really think about it. All I cared about was having periods and being normal like that. It (premature menopause) has never really been much of an issue to me. I just sort of got on with my work, adjusted to it, and I’ve always had good medical advice about my hormones so I’ve never known any different. (p.3).

Lucy and Dave had also completed their children and were not concerned about infertility. As Lucy said,

Had I been trying for a child I would have been devastated. Partly because the kids were little and I was so exhausted, maybe because I didn't realise I was menopausal, having another child was out of the question. It was more medical stuff – like what does PM mean? Questions about my health and should I take HRT – that's what I was more worried about. (p. 6).

Lucy and Dave were the only couple to mention what they saw as a positive aspect of infertility; not needing to use contraception,

We thought great, no more kids, no more contraception, but apparently we still have to use something for a while just in case...(p.12).

These women discussed being more troubled by the symptoms of menopause than women who were primarily focussed on fertility. *I'd say I can cope with the infertility; it's the menopause that has really thrown me. (Lucy, p.10).*

It wasn't so much about that though (infertility), it was more about the bloody hot sweats and aches and pains and feeling awful about myself – not so much about the baby thing. (Roberta, p.10).

We had made the decision years ago not to have more kids, so I went though all of that years ago. My only concern was not wanting the flushes to go on for too long. I just thought, 'God, I hope this doesn't go on till I'm 55'. (Roberta. P.11).

Mary explained that

I deal with not being able to have more children separately to being menopausal. I'm now 44 so my fertility would be virtually gone now anyway. I was 39 when I was told so my fertility was probably in the lower end at the best of times. Now I am 44, it's like I am now where I'm supposed to be with my fertility. It's easier now, but it was hard having that choice taken from me. (p.10).

'Our family was complete but infertility still had meaning'

The third reaction to infertility was from a mixed group including couples who had decided not to have more children and couples who were undecided about whether or not they wanted more children. Those in this group described a less tangible sense of loss and a feeling that their fertility was gone too soon,

It wasn't that we couldn't have more kids, the loss was more knowing we couldn't if we wanted to if that makes sense...(Nick. p.11).

I guess I felt my 'womaness' had gone in a way. Even though I wouldn't have had more kids, it was like that part of my life was over before I was ready. (Fran. p.13).

I wasn't really looking at having kids, but just knowing we couldn't was quite hard anyway. I sort of thought I had lost something, the option I guess. (Karen, p.7).

Several women and some men expressed resentment that the choice of having more children or not had been 'taken' from them. For example, Arielle who was 33 when she was told she had 'gone through menopause' said she knew she was *less fertile than in my 20s but still thought I had some time left – I felt robbed of my ability to make decisions* (p.9).

I'd never been 100% sure I wanted children, but taking away that possibility is extreme. (Marli, p.4).

Just having the options taken from us was what made me sort of feel ripped off...you like to think these things are in your control and I remember feeling a bit angry about that. (Nick, p.12)

It has been suggested that infertility threatens the ability to feel some sense of control over the future by challenging assumptions, in particular the ability to predict or plan the future and meet life goals. Stanton & Dunkel-Schetter, in Covington & Hammer Burns (2006) describe loss of control, including loss of control over activities and one's body, as well as the loss of the ability to predict and plan the future as other common psychological reactions to infertility in women. Mahlstedt (1985) and McCormick (1980) suggest that this challenge to life plans creates a negative feeling of loss of control. McCormick (1980) extends this loss of control to losing the ability to control emotions and being prone to emotional outbursts.

Infertility – stress and coping

The views of this group in the current study, that infertility was imposed on them, seem to relate to the view of infertility as an unwanted stress and can be seen in light of a stress and coping model of infertility. Stanton & Dunkel-Schetter (1995) suggest that infertility represents the dimensions that individuals usually find most stressful: unpredictability, negativity, uncontrollability and ambiguity. As such, they say, infertility is a stressor that extends over time, is beyond control of the individuals involved, entails negative consequences, and outcomes that are unknown and unpredictable. Stanton & Dunkel-Schetter suggest that the application of a stress and coping theory to infertility can provide a greater understanding of 1) the conditions under which infertility is likely to be perceived as stressful, 2) factors which might facilitate or impede adjustment in infertile individuals and 3) guidance in defining what constitutes successful psychological adjustment to infertility.

Notwithstanding their family situation, several participants mentioned that they thought premature menopause would be less of an issue if a couple had completed their family and were not hoping to have their first or an additional child. Marie said,

I think if we hadn't had the earlier miscarriages, it (premature menopause) wouldn't bother me because we would have had children and I never would have known my eggs were finished until I got menopausal symptoms, but by then it wouldn't matter. (p.6).

Anya, who was persisting in trying to find an egg donor having had negative experiences with one said,

It's been about not being able to have children. If I'd had a child – for me there's a big difference between someone who's got this problem that's had children earlier and someone who hasn't. There's probably a difference between someone who has early menopause and had success with an egg donor and someone like me who hasn't. (p.16)

Summary

In summary, the infertility that came with premature menopause was the foremost consideration for many couples, especially those who wanted children or more children. In line with models presented in this chapter, infertility as a result of premature menopause was described both in terms of a life crisis and a loss. Losses included the ability to conceive (whether they were planning to or not), the loss of femininity and of a sense of control. Some couples were angry that their choice to extend their family had been taken from them. There was no data to suggest the condition caused pathological responses. No participants in the current study talked of having a clinical diagnosis of depression or other mental health concerns before or after becoming aware of their condition. Couples put primary focus on coping with

infertility by trying to 'get around' it, most commonly by seeking egg donors. As one woman said, 'premature menopause equals egg donors'. Experiences with egg donors were largely described as frustrating and those involved very much wanted to share their stories.

Chapter 8 The men's voice

Eighteen men whose wives had experienced premature menopause were interviewed for this study. Sixteen of these interviews took place with the wives present in the interview room. Two men were interviewed separate to their wives and five interviews took place over the phone (with the wives within earshot). The intention was to gain a picture of the men's experience, with the overall question being, 'what was it like for you when your wife went through premature menopause?'

As discussed in the method chapter the interviews were free flowing and open but at times specific questions were put to the men in context with the discussion in order to draw out their views. Examples of specific questions included, 'what did you know about menopause prior to this? What do you understand about it now? What changes, if any, did you notice in your wife? What was your reaction to premature menopause? Did it change the way you felt about your partner? Did it impact your relationship? In what way? How did you respond? What would you tell other men in your shoes?'

Some men had more to say than others and a couple of them initially said they didn't think they had much to add. Nevertheless, all the men who contributed were forthcoming with their input to the interviews.

This chapter outlines and discusses the main findings from the men's point of view.

What did the men know about menopause?

The interviews revealed that the men had varying levels of knowledge about menopause. Four of the 18 men interviewed offered that they knew nothing about menopause, '*I was totally ignorant about it*' said Dave. Patrick commented that menopause was not a topic he had taken interest in as aged in his 30s, he had

assumed it wasn't yet relevant to his and his wife's stage of life. He said, '*I hadn't thought about it and hadn't been interested. I might have got interested if was 50, but at our age it's not on your radar so I hadn't paid attention.*' (p.4).

The other 14 men had some understanding about menopause. The level of knowledge however was quite general. The most common perceptions were that periods stopped and fertility ended. Germaine explained his understanding as; '*their body is changing and getting ready to stop reproduction.*' (p. 9). Two of the men made reference to hormones, Martin noting, '*it's when the estrogen drops and that can cause a range of changes in the woman's body that are generally unpleasant for her.*' (p. 5).

Over half the men expressed ideas that women got 'moody and/or emotional' during menopause. Frank said, '*to be honest, the take on it I had was that women get really moody for a few years, like a really bad case of PMT*'. (p.17).

Rueben's wife Catherine, aged 37, had only recently mentioned to him that she was post menopausal, although she had known for six weeks that she had gone through menopause. She had been advised by a nurse at her medical practice, over the phone. For her, it wasn't of such great significance as they had three children and didn't want more. When Catherine asked him what he had thought about menopause Rueben said, '*Isn't that when women get grumpy? Isn't it normally about age 50? I don't know. I really haven't thought about it.*' (p.8).

The current finding, that men related menopause to being 'emotional' sits with findings of Mansfield, Koch and Gierach, (2003). In their study titled, 'husbands' support of their perimenopausal wives,' one third of the 96 men surveyed believed 'mood swings and heightened emotionality were characteristic of the transition.'

The majority of the men in the current study understood that menopause was a period of change for women, four of them specifically mentioning the term, 'change of life.'

One third of the men made comments relating to ageing. As Andy said, ' *I guess old age sets in...*' (p.2)

Frank also saw menopause as an ageing process and added, '*I thought it was sort of that time when women started getting into an older age bracket. I thought they got upset about getting older and losing their youth.*' (p. 12). This comment about perceived ageing reflects many of the women's own views of premature menopause. However Frank was the only husband to mention such a concept, supporting the finding that 'ageing' is one particular aspect of the experience of premature menopause in which women feel misunderstood.

The finding that most of the men knew something about menopause is similar to that of Mansfield, Koch and Gierach, (2003) who found that approximately three quarters of the 96 men they surveyed knew something about menopause. This is interesting given that the men in their survey were on average around 10 years older than those in the current study and may have therefore had more exposure to the topic of menopause. Some of the husbands in Mansfield, Koch and Gierach's study gave 'detailed biomedical descriptions' of menopause however these men were health professionals and may be expected to have a better understanding. None of the men in the current study worked in the health field.

The general perception amongst the men in the current study was that menopause was a challenging time for women. It would seem the men's views of menopause as a negative experience reflects the pervasive societal view. Descriptors such as 'tricky', 'hard time', 'difficult', and 'unpleasant' were offered amongst the men's opinions. None of the men offered a positive view on menopause. Scott did offer though that one advantage for the couple was that they no longer need to use contraception.

Where did the men learn about menopause?

Over half of the men in the current study mainly learnt what they knew about menopause from their wives. As Robert said, *'it's not something guys really talk about. Especially at our age.'* (p.5). This is consistent with Mansfield, Koch and Gierach's, (2003) findings that most men learnt about menopause from their wives. Six of the men in the current study referred to 'the media' as a source of knowledge about menopause but didn't mention any specific media source. In addition to wives and the media, three of the men mentioned that observing or talking to family members or work colleagues had further formed their views about menopause. As Bernard said,

'I remember Mum having a rough trot and always complaining about sweating and being exhausted. I think she milked it a bit. Dad kept a wide berth and we never really asked what was going on.' (p.10).

These views relate to men's understanding of 'normal' menopause. Interestingly, none of the men in this study were aware that menopause could happen at their wife's age, before age 40. Like the women, the men almost universally expressed shock at learning such a condition existed. Phil recalled,

'I was aware of menopause. You have this perception about what menopause is going to be like. So when she came back from the doctor and said she'd been through menopause it was just...we couldn't believe it. It wasn't what we thought it would be like really.' (p.16).

As they became aware of the condition of premature menopause, one quarter of the men personally sought further information about it. The most common source of information on premature menopause was the internet. Two men wrote lists of specific questions to ask doctors or specialists during appointments. None of the men mentioned friends or family as a source of information about premature

menopause, probably because they didn't know any others who could share their experiences. As Nick said,

'I had a lot of questions, especially after looking online. But I didn't know anyone who could give me answers so we had to rely on the doctors. Arielle talked to her friends, but none of mine were really in that zone.' (p.22).

How did premature menopause affect the men?

Their partners' premature menopause affected the men to varying degrees and in a range of ways. The majority of the reflections the men offered during the interviews centred on the observations they made of their wives and comments on the ways in which they supported their wives emotionally. Compared to the women, few men spoke in depth or with detail of the emotional impact the condition had on them personally. One third of the men described not noticing a personal impact from the condition and their wife's experience and two thirds described their personal responses in other ways.

'I wasn't really fazed'

One third of the men felt that the experience had little or no noteworthy affect on them. For example, Patrick commented,

'It really hasn't been anything I've paid much attention to. I wouldn't say it has meant anything to me.' (p.16).

Two of the men in this 'not fazed' group felt that menopause had little impact on them because the busy pace of life in their late 30s called their attention to other issues. As Herbert said,

'I think I was so distracted by other things through the time she was in menopause. The house, moving, building, kids, work. I imagine in your 50s you wouldn't be so distracted by that sort of stuff in life so you might sort of notice it more.' (p.17).

Shane described how the focus on continuing to undergo IVF meant *'the menopause wasn't at the forefront of our minds because the IVF thing kept us focussing on something other than that.'* (p.21).

In Grant's opinion also, premature menopause had little impact, especially in light of other life challenges such as having a daughter with serious health concerns, *'to be perfectly honest, I wasn't really fazed about it. It's just life. We've had a fair bit on in the last few years.'* (p.14).

Tony thought one of the reasons menopause had little meaning for him was because the couple didn't want more children, *'we had finished having children. It would be a bigger deal if we didn't have that choice any more because of her menopause.'* (p.18).

Although dealing with their partners' 'moodiness' was sometimes mentioned by the third of the group who were 'not fazed', their wives emotional changes were not described as of concern to them. Ian remembers his wife's moods being changeable but didn't recall being overly affected or concerned,

'I never thought, 'oh God what has she turned into?' or anything. I never thought, 'oh no, what's going on here?' I just thought, 'it's one of those days' when she was a bit upset. Like, 'here she goes,' sort of thing.' (p.17).

‘It was a pretty tough time’

Contrary to the men above who described being unaffected by premature menopause, the other two thirds of the men referred to premature menopause as being personally challenging for them in various ways. The main two ways the condition upset these men was the resultant infertility and seeing their wives in distress.

Phil described his feelings of being upset and confused,

‘I’ve gone to bed crying at times too because the whole thing is doing my head in. How could this happen so young?’ (p.17).

Andy described being worried about his wife’s health,

‘It was worrying for me and I guess it brought on the whole question of why, and what was going on inside her to make that happen so soon’.
(p.20).

He added that seeing his wife suffering menopausal symptoms was distressing,

‘It was fairly hard. The mood swings. It was physically quite tough on her with feeling so hot and cramping and so on.’ (p.20).

Andy was not alone in finding it difficult to see his wife suffer. Martin said,

‘She did it hard. She didn’t sleep, she felt itchy all the time, and she had to keep getting changed at work. I really felt for her actually....it was pretty hard now I think of it.’ (p.17).

Several of these men expressed their distress at the prospect of not having children or more children because of the condition. Shane spoke for many in saying the hardest part of premature menopause was,

'...the realisation that we weren't going to have kids. That was my main thought because we were going through the whole fertility thing at the time. I have to say, that was pretty hard for me to come to terms with.' (p.20).

Men and infertility

As we know, infertility, whether it is due to male, female or unknown factors, is a stress to men as well as women (Cook, 2003). It has been suggested that men respond to infertility in ways that are similar to women. For example, Wright et al., (1991) looked at men's and women's responses to infertility. They suggested that infertile women showed greater, but not clinically significant, distress than their partners on measures of anxiety, depression, hostility, cognitive disturbances, stress and self esteem. When compared with population norms, men and women patients were slightly more distressed overall than non-patients. Cook (2003), using similar phenomenological techniques to this study explored men's psychological responses to their infertility. He suggested a grief and bereavement model of infertility, which has been used widely to describe women's psychological responses was not appropriate for men who were more likely to find their own infertility to be stressful and disturbing. He summarised men's responses to infertility as a threat to their sense of themselves and their inability to be fathers, rather than as an experience of grief. He also found that while some men also experienced their infertility as a shock, it was also common for others to immediately adopt a problem solving approach.

Despite whether or not the men in the present study described being personally threatened, stressed or saddened by premature menopause, and regardless of the reasons for their distress, the men generally felt that their wives suffered more than they did. This finding was also similar to Cook (2003) who found men tended to put their own needs and feelings in relation to infertility second to their wives and partners.

Some of the men who said menopause did not have significant bearing on them said this was because they were not experiencing the physical or emotional changes first hand. Tony spoke for others when he said, *'it affects her more than me. She's the one going through the changes. It doesn't really affect me at all'*. (p.17). As Shane said, *'I'm not the one who is 30 and physically going through it so I'm not experiencing it'* (p.21). It seemed as if these men took a literal view of 'experiencing menopause' – it was not them physically changing, so they were not having the experience. Perhaps these men tended to put their own feelings 'on hold' to support their wives whom they considered were having a worse time than them. Nick alluded to this,

'I would say it was a rough time for me, dealing her moods and not knowing what to do, but she was doing it worse as a woman.' (p. 19).

He continued,

'I had to deal with the having no more kids which was a bit sad but not the end of the world. I think she was more upset about that than me, but also, she's dealing with the sweaty nights and the anxiety and the forgetfulness. It's her body that changing not mine, so she's really the one coping it.' (p.21).

Germaine agreed with this perspective, *'what I thought didn't really weigh in because I wasn't the one going through it.'* (p.20).

These thoughts suggest the men felt their experience of premature menopause was secondary because it was their wife who was 'going through' it physically. We know that men also have significant reactions to other life changes such as pregnancy and childbirth in which it is the women whose body physically changes. Men have been shown to have significant emotional responses to their wives early pregnancy, which are generally overlooked in place of focus on the woman (Draper, 2002). Paternal prenatal and postpartum depression is much overshadowed in place of

maternal depression at these times (Paulson & Bazemore, 2010) and yet these researchers found up to about 10% of men suffered depression when adjusting to having a child.

In reflecting on his feelings about his wife's premature menopause, Dave made a comparison to how he felt when his wife was pregnant. He recalled how his experience of this significant life event was *overlooked* because it was her body which was changing,

'It (pregnancy) was exciting for me, a big deal in fact, but it was really all about her because it was her body that was doing all the work. I was a bit of a bystander' (p.21).

The concept of focusing on the wife's condition and care and 'putting themselves on hold' was also a major theme in Hilton, Crawford and Tarko's (2000) study (2000) which described men's perspectives of having a wife with breast cancer.

Men's frustrations

Feeling frustrated about premature menopause was a common response amongst the men in this study. Frustration was described and expressed in a number of ways. Scott explained his frustrations at feeling he couldn't do enough to make his wife feel better,

'It's very hard to know if you are doing the right thing. You try and be there and support your partner, but nothing was good enough. I felt a bit on the back foot and that I couldn't do anything right'. (p.15).

He explained how his frustration was in part because he couldn't change the situation and felt helpless. As he said, *'I couldn't fix it (premature menopause)'*. (p.15).

Others described the frustration of feeling helpless to make a difference to the situation. Robert continued,

'It's not like something you can change or do anything about. Usually I like to try and make things better, but I couldn't fix her eggs you know...' (p.25).

Scott also felt he couldn't do anything to help, *'what do you do? I just didn't know what to do or say.'* (p.15).

In a slightly different view, not being able to change the situation led to Shane's acceptance of it. As he said, *'there's no point worrying about things you can't change'*. (p. 21).

Some men felt frustrated that the attempts they made to support their partners didn't seem to be good enough. For example, Ian said,

'I was trying to bend over backwards to support her but she was still upset, thought she was fat, thought all these negative things. From a partner point of view you think, 'what else can I do to support her?' (p.15).

And Robert said,

'She is very moody. Extremely moody to be honest. Very emotional. Little things upset her. We might be going out for dinner and she looks lovely and I say, honey you look great and she can't see that and she'll start crying. I'm going, pull yourself together. I don't say that of course. But you know, what do you do? I just don't know what to do or say.' (p.16).

There was a tendency for some of the men to wonder if it was them who was upsetting their wives. This suggested the possibility that the men took their wives distress personally. As Scott said,

'Sometimes when she was lying in bed and crying I was just going, oh no, what have I done? What else should I do? I knew we had to talk, but she didn't always want to. It was really hard on me at times.'

(p.15).

Gavin too, wondered if he had done something to upset his wife;

'It's hard because you think you've done something wrong or it's your fault, have I upset her? But I haven't, it's just the menopause. I hope it's just the menopause!' (p.16).

Husbands' support of their wives

The topic of what the men did to support their wives inevitably came up in the interviews. Four of the men said they did nothing special to support their wife. Either they didn't see that what she was going through was their business or they didn't think she needed any particular support. Patrick said he was aware he probably should have done something but didn't,

'I didn't really know much about it, I probably wasn't interested to tell the truth and I kept out of her way. I probably should have paid more attention, but you don't really talk about that sort of thing' (p.25).

This comment reflects Mansfield, Koch, & Gierach's (2003) finding that one third of the 96 men they surveyed said they did nothing special or were not supportive to their perimenopausal wives.

The rest of the men in the current study described conscious attempts to support their wives during premature menopause. Most of this help was described as ‘emotional support’. ‘Listening’ was widely offered as the major form of emotional support. Scott’s views were shared amongst the men, *‘I just listen and try and be there for her for whatever she is going through.’* (p. 19). Martin agreed,

‘I just try and support her. There’s not much else I can do. I just try and help her get herself right. I can’t always go to the appointments so I just listen to her telling me about them and everything she has learnt about it on the internet.’ (p.16).

Hilton, Crawford and Tarko (2000) named a similar theme, ‘being there’, to describe how men supported, by listening to, their wives with breast cancer.

In another form of support, Bernard described how he noticed his wife’s feelings of insecurity about her physical appearance and interpreted this as a need for more affection. He tried to offer that;

‘She is more self conscious now and worried about ageing more than before this happened. She needs more affection and assurance from me which I’m not great at but I try and adjust to that – give her a bit more security.’ (p.15).

Others too, tried to show emotional support by reassuring their wives that they were still attractive to them.

Chapter 2 of this results and discussion considered how women were confused about whether or not menopause had prematurely visibly aged them. Some men felt it was important to reassure their partners that they didn’t look older. They often offered external objectivity to the woman. *‘I can tell you, I see you every day and you look the same, even if you feel like you look older,’* said Rueben (p.15). In his efforts to be what he called the ‘voice of reason’ on this topic Murray offered, *‘its hard to*

judge because you have to remember you haven't had a good nights sleep for seven months because of the baby'. (p.6).

Arnold couldn't really understand the concerns about ageing and tried to introduce reason, *'I thought, they're just insecurities, be above that, be greater than that, there are bigger things going on.'* (p. 8).

Working on 'Plan B'

Whereas the women had a range of psychological responses to premature menopause, the salient view the men had was that the condition was something to 'get around'. The questions the condition raised for them included, 'how can we get around this (premature menopause) and still get pregnant? If this means we can't have children, what else should we do with our lives?'

In couples still wanting children, the men usually tried to find ways to 'get around' the condition in order to build or continue building a family. Usually the men took a practical, problem solving approach to the situation they faced with their wives. With a focus on having a child or more children the men commonly talked about needing a 'Plan B'.

Following the still birth of naturally conceived twins and later years of trying unsuccessfully to conceive again, Arnold recalled at one stage realising that there was a very real possibility that he and his wife would be unable to have children. He remembers having to *'rethink the life plans'* without children. The idea of having to 'rethink the life plans' and come up with 'plan B' were most common amongst the men in families with no children. Arnold remembered he wanted to *'try everything possible to get pregnant again, so as not to have any regrets at age 50'*. (p.14).

In some cases, plan B meant considering alternative ways of having children. In Arnold and Marie's case it was Arnold who suggested they pursue the possibility of

finding an egg donor, describing how he would be prepared to do *'whatever it took'* to have a child. He described encouraging his wife to explore egg donation even though she was *'exhausted and over it (IVF), and ready to give up'*. (p.11).

Arnold described viewing his wife's initial reluctance to pursue egg donation as *'getting in the way of our options for success.'* (p.12). He went on,

I know she was upset and everything...we had been through a lot. But there was a time she wanted to give up (IVF) because it was emotionally too hard. I said 'you have to keep going, just because it's hard, it's a means to an end for us'. We had to get around it (premature menopause) and try the egg donor IVF. Being upset was just an annoyance to me, but at the same time I could see how it was hard for her. It was like, 'can't you put those emotions to the side and just keep going to get around this because there is a really small window of time here.' (p.12).

Some men discussed the way infertility from premature menopause changed their views on what a family could look like, describing changing from the traditional ideology of biological children to broader views of family including children from egg donors, fostering and adopting.

Dan for example, discussed an expanding view of family plans,

'When egg donation came up it wasn't part of our plan, but then I thought we have to have an open mind and just see what the options are. It's not what I had imagined, but your plans have to change. I thought it would be another way of having the family we wanted.' (p.14)

Other men discussed optimistically considering fostering or adopting as part of 'Plan B'. Other studies have found men to be more reluctant than their wives to consider such options. Tyebee (2003) explored attitudes to adoption and found that American

men were more sceptical about adoption than women. As did Williams (1988), who found that amongst a group of Canadian couples undergoing IVF, wives were more in favour of adoption than husbands.

The men's broadening views of 'family' sits with findings of Parry (2005) who discussed how conceptualisations of family were found to be fluid amongst IVF couples. Parry's interviews revealed couples undergoing IVF originally had traditional ideologies of family. Those who conceived biological children through IVF expressed a broader conceptualisation of family through a greater appreciation for their children and family life in general. Those who did not conceive despite assisted reproductive techniques, such as the case with many in the current study, discussed broadening their conceptualisations so that 'family' took on new meanings, structures and/or significance.

Women too saw premature menopause as something to 'get around', but tended to talk about a range of other emotional reactions and responses to it, whereas the men were more likely to talk about the ways they sought to get around what they saw as a hurdle in their life plans. They often took a practical role of working on 'Plan B' while their wife seemed to be reacting to the condition at a more emotional level. This response has been reported elsewhere (e.g, Thompson & Walker, 1989) and supports a general idea of men seeing their role in marriage and family as providing solutions to problems and challenges.

'You see, I'm in my prime!'

Like women, men's sexual lives are important to them and some of the men raised concerns about whether premature menopause would affect their sexual relationship with their wives. Just less than a third of the men raised issues of sex or libido, but only a couple of women offered views on this. It is not clear whether the men were aware that loss of libido is often associated with menopause, whether they hadn't

noticed this in their wives, or whether their sexual relationship had in fact changed but they chose not to discuss it in the interview.

Reuben's preconceptions were that menopause meant '*no more children and also I guess I thought it meant the woman was no longer interested in sex*'. (p.6).

He was quick to add that he was not overly concerned about the prospect of Catherine's interest in sex diminishing, '*I wasn't looking forward to it, but I wasn't really worried about it*'. (p.6).

Others clearly were more troubled by the change to their sex life, '*Her not wanting to have sex was difficult for both of us*', said Bernard. (p.15).

Scott expressed some sadness about the changes to the couple's sex life,

'She isn't really interested in the sexual side of things. I think she tries to make an effort but it's meant to be about the two of you enjoying it. I'm hoping that the menopause will settle down to the point where she's interested again but I'm not sure if that happens.' (p.15).

A couple of the men who did discuss sex did this mostly in a humorous way, probably to deflect any embarrassment they may have felt about the topic, or about discussing it with a female researcher they hadn't before met. As Frank tentatively joked,

'I don't know how she can resist me, but recently she has. I'm hoping she'll come to her senses once this (menopause) all settles down and we can get it going again!' (p.12).

Martin also used humour, '*I thought, well she might not be interested, but I'm still in my prime*'. (p. 13).

Others put changes in their sex life down to stresses of the broader context of their lives. Gary commented that he had noticed a reduction in his wife's libido but had assumed it was related to the stresses of infertility and trying to find an egg donor rather than menopause itself.

Undergoing IVF treatment has been associated with diminished sexual satisfaction in couples, (Oddens, den Tonkelaar & Nieuwenhuys, 1999, Leiblum, Aviv & Hamer, 1998). Some of the men in this group put reduced sexual intimacy down to the pressures of trying to conceive or the grief over realising they couldn't. Gary added the couples' sexual spontaneity had been disrupted for years due to 'regulated sex' in an attempt to conceive,

'We went for ages just having sex as a means to get pregnant, when the temperature was right and then it was IVF which is such a passion killer.' (p.20).

Robert saw the decline in the couples' sex life as a result of being busy and tired with a young baby but admitted to a quiet concern that menopause may have changed this aspect of their lives for ever, *'I don't know if we will ever get back to where we were now she has gone through menopause.'* (p.21)

Consistent with the men's focus on 'getting around' a problem, Arnold saw a reduction in sexual activity in the marriage as something that he would attempt to overcome, *'I will just have to lift my game so to speak, get a bit more romantic or put a bit more effort in. Do what it takes.'* (p. 10)

It is hard to say if and in what way the men's responses may have been different in the interviews if their wives were not present while they spoke. Would their responses have been different if the wives weren't there? Perhaps they would have been more inclined to speak openly about sensitive personal issues including their sex lives. Then again, the men who were spoken to with their wives not present did not reveal more in terms of depth or detail than those whose wives were present.

Summary

The findings in relations to men's experiences support the idea that men are not well informed about menopause generally (e.g, Mansfield and Koch, 2003). Men in the current study had limited understanding of menopause, with their views formed largely from their wives telling them about it. None of the men in the current study had known that menopause could occur before age 40, all seeing it as happening 'later in life.' Like their wives, they were shocked by the diagnosis of premature menopause. Consistent with research about men's responses to their own infertility (e.g, Cook, 2003), the men were commonly upset and stressed to learn their wife was infertile. Men were often unsure how to respond and what role to take when it came to dealing with premature menopause. They often took an active role in seeking solutions or a 'Plan B' by looking into ways of conceiving through assisted reproductive technologies or making life plans without children. In addition to practical approaches, most of the men tried to offer emotional support, primarily by listening to their wives. Other than often feeling very frustrated at not being able to help or change the situation, the men did not indicate any major negative emotional responses to their wives' premature menopause.

Chapter 9 **Perceived professional confusion**

Another theme in the findings was that women in this study, as well as many of their husbands described feeling like they were dealing with the ‘unknown’ in relation to premature menopause. The terms ‘uncharted territory,’ and ‘uncharted waters’ were used in this context, reflecting that little is known about the condition in the general community and a perception that medical professionals they dealt with were sometimes unsure how to respond to their problems.

Emma, aged 32 said her own ignorance about menopause was what made her feel she was sailing into ‘unknown waters’,

Because I really hadn't thought about it (menopause). I just thought I'd come out the other side, be barren, have no periods and an easier life. I'd be free as a bird, terrific. But then all the symptoms of it and side effects started in really early, they were horrendous and I thought, God what is going on? I'm in unknown waters here!’ (p. 4)

For others, it was a sense that the medical professional they went to for advice and help weren’t familiar with their particular problems. Bernard’s words represented this perspective,

It was like sailing into uncharted territory...just with everything that happened, we, and to be honest everyone including two GPs and the infertility clinic, didn't really seem to know much about what was going on...we felt a bit like a science experiment. (p.20).

Marlee, then Janette said,

I remember feeling so scared. What was this weird thing? Was I some freak of nature? It was like you imagine being told you had cancer.
(p.3).

It's not like you're being told you can't get pregnant because of low sperm or PCOS (polycystic ovarian syndrome) or something. It's like, what's that? (premature menopause). It's like some unknown thing, so it felt terrifying in that sense. (Janette, p.7).

Their fear of the 'unknown' was amplified by the couple's impressions that their GPs and other doctors were not familiar with how to identify or best to manage the condition.

Mike and Karen had a 7 month old child via egg donor at the time of interview. Karen had struggled with ovarian cysts on one ovary from age 20 and had had several laparoscopies. The couple had been told that the cysts would not affect her fertility. However several attempts of IVF were unsuccessful.

Mike explained how the doctors he and Karen saw about their fertility challenges worked to a 'formula' with couples trying to conceive. He felt that they were used to dealing with 'common fertility problems' and were therefore slow to identify Karen's specific ovulation problem. He felt that premature menopause was an area '*they (the doctors they saw) knew little about.*' Mike explained it this way,

I think a lot of these professionals, they see a lot of people and really they've got a formula that they use constantly with people and they see you over and over again for appointments but then they'll realise, 'hang on, this person is outside the usual formula,' hence our situation, and then they start looking closer at you. But it takes a while, several visits and several periods of anguish and frustration before they start considering you outside the norm and say, 'let's have a really good look at what's going on with you.' (p. 2).

Karen described how the gynaecologist who had treated her for ovarian cysts in one ovary had not detected irregularities in her other ovary. She described how she felt she was in ‘*uncharted waters*,’

It was like no one had dealt with a case like mine and so no one was really sure. We did the usual tests and I told him (fertility specialist) about my history with the cysts on the left ovary and all. He said there was nothing wrong with me. So we did IVF and I got another cyst and then they couldn't see my other ovary on the ultrasound. And he asked, 'what have you done with your ovary?' My other gyno had been in there twice with operations and never checked my right ovary. And then he said, 'oh well it looks like that right one has probably never functioned properly and you've probably gone through menopause. And I'm like, 'what?!' (p. 3)

Dealing with what Emma described as something ‘*not widely understood by the professionals*’ often contributed to feelings of fear and anxiety. The women explained how they felt scared and worried about what premature menopause might mean for them and their future. Fran described,

'panicking about the unknown....when I'm dealing with the unknown I usually assume the worst, so I was panicking. We both felt like premature menopause was the end of the world...just something no one really understood it seemed...it was as if it was a mystery cancer.' (p.2).

The participants on the whole sensed a degree of professional confusion surrounding the condition of premature menopause. They referred to perceived knowledge gaps and inconsistent advice from the medical professionals they had dealt with. Adding to their trepidation, half the couples specifically mentioned receiving conflicting advice about how to manage premature menopause.

Anne explained how she thought her GP was ‘*unsure*’ about how best to manage her condition,

To be honest I thought she (the GP) made it up as she went along or was Googling it all like I was. Half the time I seemed to be telling her what I thought I needed (regarding HRT). (p.13).

On reflection, Bernadette, said she felt both she and her doctor were in ‘new territory’,

It was all new for him too. Trying to figure out what HRT to give you, what advice. These days having internet and stuff like that, they tend to Google it and say these are some of the websites you can look at. But 10 or 11 years ago, for me, it was a lot harder’ (p.16).

One woman described how her feeling of being in unknown territory was rooted in her view that management of premature menopause with HRT was ‘*trial and error*’. The sense that treatment options were ‘trial and error’ was also found amongst women in Halliday & Boughton’s (2009) study. Some clinicians in the area (e.g., Nelson, 2009) recommend stated doses of replacement hormones, however no randomised trials have been conducted to determine the ideal dose, regimen or delivery system for women with premature menopause receiving HRT (Nippita & Baber, 2007).

Sophie described feeling ‘*insecure about anyone knowing what to do*’ and spoke for many in describing the feeling of dealing with a condition that she assumed was not well understood,

There is all this stuff about easing menopause and what medications or herbs or whatever to take but then when it comes to women our age there seems to be a gap in the options about what to do – like it’s an unknown area really. Do I take hormones, do I not? For how long?

Do I go for bog standard stuff off the shelf or will that not be right for a 31 year old? It seems to depend who you talk to. It's like a void in the knowledge and no one really knows what's going on with you. I mean, I'm sure there are doctors who are on top of it, but probably most aren't really, so you feel you are left as a bit of an experiment. (p.7).

In this quote Sophie was alluding to what her husband had called 'the luck of the draw' of having a doctor who was informed about premature menopause. Anne also spoke of this,

It seems you are lucky if you have a doctor who investigates your menstrual issues thoroughly. Like me, you might get one who tells you it's stress or don't worry or whatever...what about if you live in the woop woops and there aren't doctors who've seen this stuff? You could be left totally in the dark thinking you are going mad....a lot to do with the medical support you have at the time you get suspicious...(p.19).

Sasha shared her frustrations about conflicting medical advice she had received,

One doctor questioned the first one, which I thought you weren't meant to do, and said to me, 'that can't be right, are you sure? Why don't you go on IVF?' But we had been told they won't do IVF with my (hormone) levels. Another one said to try India as they do it there. And no one can tell me how to deal with what's going on. So I am self medicating, keeping notes of what I am taking, now it's just progesterone and calcium, and telling my GP. But she is hopeless; she is going off what I tell her I'm doing. So I am trying to get in to see an endocrinologist. (p.6)

About conflicting medical advice, Gavin said,

I sort of got the idea the bloke (GP) we saw had no idea. He gave her really high doses of HRT and when we saw the other doctor she said that was wrong, that it was the wrong mixture or something. (p.21)

Some women, including Bernadette, who became menopausal 10 years ago age 33, expressed anger at conflicting or lack of information from doctors,

I was referred to a fertility clinic. At that stage I had an elderly male doctor. We went on a waiting list for egg donors. Then two years later I had a meeting with another specialist and he told me no one had tested to see if I had any eggs reserves and it had just been presumed that my test results meant there were no eggs. So there were probably tests I could have done back when I was 29 if I had had a doctor who was a bit more up with it. (p.3).

These issues led some women to comment that they didn't have confidence in the doctors they had dealt with or were seeing at the time of the interviews. Sasha who had suddenly stopped having periods at age 29 explained,

She (fertility doctor) didn't mention the 'M' word in that first meeting when she gave me my test results. But I sort of knew and I thought, 'she doesn't really know what to make of me' and I wanted a second opinion. I wasn't confident she knew what she was talking about. I mean I knew those hormone levels were a real problem but she didn't say anything. What if she was wrong, or was an idiot? So I went back to my GP and asked for another doctor. (p. 4).

Sasha described what she thought was 'ignorance' amongst GPs about early menopause, creating a risk that 'many girls might be going undiagnosed and wasting time trying to get pregnant'. She described what she encountered as 'a lack of awareness' amongst the doctors she dealt with,

They (doctors) just put it down to stress. Even if like me, girls say, 'please test me, check me out properly, I think something is wrong with me', doctors don't really think it can happen this young and they don't follow up. Girls like me could have been getting better help rather than wasting time. (p. 11).

Like those in the current study, the women in Halliday & Boughton's (2009) study of prematurely menopausal women reported doctors being 'dismissive' of their 'often vague' symptoms and a 'general lack of confidence in their doctor's knowledge about premature menopause/POF' (p. 19).

Reduced confidence in their doctors was a particularly concerning aspect of the experience of premature menopause for many couples because it led them to feel no one really understood the condition and this made them helpless. It was also one of the main reasons couples gave for doing their own research on the internet. Low confidence in doctors was also a reason given for wanting to be able to share experiences with other women. Several women mentioned they would have found it helpful to 'swap notes' and 'compare advice' with others who were going through it.

Not all those involved in the study lacked faith in their doctors. One couple made a point of saying they thought highly of the specialists they had seen. As mentioned in an earlier results chapter, others felt that a doctor giving them a 'medical label' for their problems helped them feel the doctor knew what was wrong and accordingly would know what to do to help. Bogduk (2000) suggested the labelling of medical problems improved faith in their doctors for patients with back pain and also helped them maintain a sense of control.

Several couples perceived that their doctors were unsure about or confused by their symptoms in terms of whether a diagnosable condition existed and how best to help them with their physical problems. Consequently, the couples were also confused at times about how much faith they should place in their doctor's advice.

It seemed the sense of ‘professional confusion’ around premature menopause extended to other health professionals including counsellors. Only one of the women in this study had spoken to a counsellor specifically about her condition. Two others said they had considered talking to a counsellor, but assumed counsellors wouldn’t understand enough about premature menopause to be of help. Patricia said she had a ‘*fantastic counsellor*’ who she had seen prior to menopause but didn’t think she would be appropriate for her current concerns, ‘*she doesn’t know anything about menopause really so I haven’t really talked about it with her even though I would have liked to talk to someone*’ (p.10). Two other women who had psychologists prior to menopause chose not to discuss it with them because they assumed as Rose said, ‘*she wouldn’t have really known anything about it.*’ This finding suggests there is a place for counsellors who have some understanding of the causes of and common experiences involved with premature menopause.

Delay in diagnosis

In discussing aspects of dealing with the ‘unknown’ the women and some men tended to reflect on their experience of receiving the diagnosis of premature menopause. A delay in diagnosis was problematic for most couples and sometimes construed by them as professional incompetence or lack of quality care.

The course to diagnosis was varied amongst the current group. Time to diagnosis was not specifically explored in this study but ranged from days to several years. Initial symptoms raised with GPs included missed or irregular periods in quarter of the women and delay in getting pregnant for another quarter. This was more than in Alzubaidi et al.’s, (2002) work in which only 2 women (4%) presented initially with infertility and the diagnosis of POF was established after failed attempts at ovulation induction.

The difficulty diagnosing premature menopause has been much discussed in the research. Alzubaidi et al., (2002) outlined the problems and frustrations associated with reaching a diagnosis of spontaneous premature ovarian failure. Over half the

women in their study reported visiting a doctor's office three or more times before laboratory testing was conducted to determine a diagnosis. In 25% of women it took longer than 5 years from original doctor's appointment to reach a diagnosis, with an average time of 2 years from initially seeking help. Consistent with Alzubaidi et al., the majority of women in the current study perceived delays in diagnosis as a lack of quality care. Consistent with Alzubaidi et al.'s, (2002) findings, the women in this study commonly expressed what they saw as a need for 'more aggressive evaluation of secondary amenorrhea', or delays with conceiving.

It would seem the challenge facing clinicians is to distinguish between the 3-4 % of women of reproductive age who experience amenorrhea each year from the much smaller number who have a potentially more serious disorder such as POF (Speroff & Fritz, 2005). Some researchers have recommended routine testing for all women with altered menstrual patterns, e.g, Rebar & Connolly (1990) recommend all women with amenorrhea have basal gonadotropin concentrations measured to promptly identify whether POF is occurring.

As mentioned in the first results chapter, most women in the study recalled quite vividly the way in which the diagnosis of menopause was given to them. Three quarters described it in negative terms. Arielle recalled being '*traumatised*' by the way she was advised she was menopausal,

So he was going through my blood test results and he said, 'this one is ok and this one is ok, but this one looks like you are going through menopause', and I was 33. He said, 'I don't know much about that. You need to go and see someone else, or go to the hospital.' Then he gave me a referral and walked out the door. (p.3).

Arielle continued,

After that I called up the surgery and got my records moved straight away and never went back there. (p. 3).

Others recalled how receiving a diagnosis over the phone was distressing. Rose felt this was,

...totally inappropriate. For him (GP) it was a quick phone call, but for me it was a bombshell. You just don't do that stuff over the phone no matter how busy you are. (p.1).

Arielle raised the important issue of GP and patient rapport and she thought it problematic that she didn't have a rapport with the GP she saw,

If I'd seen the GP I have now then, she would have been totally different and I wouldn't have felt so alone like I was stepping into a world of unknown at that point. (p.4).

Summary

In summary, the path to a diagnosis of premature menopause was often difficult and a long time coming. This finding supports other research into the condition, (e.g, Nippita & Baber, 2007., Goswami & Conway, 2005). Consistent with findings of Groff, Covington et al., (2005) and Alzubaidi, Chapin et al., (2002), general satisfaction with the time taken to reach a diagnosis, the way in which the diagnosis was given and related support was low. The time doctors spent listening to their concerns, discussing the condition with them and doctor/patient rapport seemed to be factors in this dissatisfaction. The women in the study perceived a general lack of understanding of the condition amongst the doctors they dealt with, often struggling with conflicting advice from health professionals. This at times led to low confidence in doctors and a perceived general lack of care.

The primary piece of advice to other women experiencing menstrual changes or trouble conceiving by those in this study was to become more knowledgeable about

their menstrual health and to be proactive in seeking to find causes of menstrual and/or fertility disturbance.

Chapter 10 The marital relationship

The experience of premature menopause had implications for the marital relationship. This chapter presents and discusses those findings.

Two different views regarding the impact of premature menopause on the couples' relationship emerged from this study. One view conveyed there was no discernable detrimental difference to the way the couple felt about each other or related to each other as a result of premature menopause. The second view is that the experience made the couples stronger, meaning they felt closer to each other, more supportive of each other and more of a team than they had before the experience.

'It didn't change us as a couple'

Gavin's comments represent this first perspective. He mentioned how he didn't feel premature menopause had a noticeable impact on his relationship with his wife,

It hasn't changed us. We've been together a while now and it's just one of those things. She's still the same, I'm still the same, and we're still the same. (p.4).

Bernard agreed with this view,

I wouldn't say anything changed between us, you just deal with what comes up and get on with it. We're still the same people. (p.19).

Ian also commented he didn't see premature menopause in particular as impacting his relationship. He described his marriage as something that was constantly evolving as he and Anne faced numerous challenges together. He expressed how as a couple, they continued to adapt to the challenges and situations their busy lives brought them,

We are going through that time in our life where we have little children and work is hard...life is changing all the time for a lot of reasons. We just change with it. Our relationship hasn't changed. We just keep changing to the situation we are in. (p.16).

It is interesting that despite acknowledging effects such as increased moodiness and neediness, reduced sleep and loss of libido, these couples did not describe these effects as negatively impacting the quality of the relationship overall. Bernard further described this,

Sure she was cranky at times and our sex life probably went off the boil a bit but that's life, you just deal with it. We're still together and still love each other. (p.19).

One explanation for this finding could be that premature menopause had meaning to the individuals, but this meaning wasn't manifested in a way that impacted their relationship. Perhaps these couples lived 'parallel' lives and didn't share much about their personal experiences or feelings. The relationship may have existed outside their individual, personal experience.

This rationale relates to social exchange theory, which describes views that relationships can exist as an entity in themselves, separate to the individuals in the relationship. Wilmot (1995) describes three differing orientations people may hold toward the concepts of self, other and relationship. 'Paradigm one', 'emphasizes the self, deemphasizes the other, and reduces the relationship to a fragile connecting mechanism' (p.37). Such a view puts emphasis on self and the impact of events on ones' self above the other or the relationship. Perhaps study participants who didn't see any impact on the relationship didn't have such an emphasis on relationship as an entity in itself, but were more focussed on their own responses, needs and outcomes. Wilmot's 'paradigm two' sees self as not a separate entity, but to be examined within the context of the relationship. Gudykunst and Kim (1997) suggest paradigm two views are more common in collectivist cultures where relationships and family take

precedence over an individual's goals. Couples who questioned, 'what does this mean for our relationship' could be assuming a paradigm two view. Wilmot (1995) argues that communication problems between men and women can arise when they have differing paradigm preferences, suggesting males are more likely to rely on a paradigm one view and women on a paradigm two view. Supporting this notion, it was the case in the current study that the men were more likely to say premature menopause had no impact on the marital relationship, suggesting they were not so attuned to the state of the relationship as an entity.

'It made us stronger'

The other, quite different theme in the current study was that the experience of premature menopause led to the strengthening of some of the couple's relationships. These couples saw premature menopause as something they were going through together, not alone, and seemed to consider each others' thoughts and feelings about premature menopause as well as being able to discuss how it impacted 'the relationship.' As Roberta said, *I think it's made us stronger if anything. We are probably tighter than ever.* (p. 21).

Nick spoke of becoming closer to his wife through dealing with premature menopause,

Nothing sharpens your focus more than someone you really care about going through something. You think you have problems with your job or whatever but when you have something real to worry about, it brings you back in to focus on your relationship and what really matters. (p.28).

This theme seems to relate to Nietzsche's famous quote 'what doesn't kill us makes us stronger' (in Kaufman, 2000). Moreover, theories of resilience suggest relationships have the ability to withstand, survive and become stronger after a crisis

(e.g, Walsh, 1996). Studies have suggested such crises as new parenthood (Feldman & Nash, 1984), birth of a disabled child (Fortier & Wanlass, 1984), and serious illness, including breast cancer, (Bolger et al., 1996) can strengthen marital relationships.

As discussed earlier, there can be a range of psychological responses to infertility. It would seem that contrary to expectation, infertility does not always have a negative impact on marital cohesion or satisfaction. Some studies report that coping with infertility results in increased couple commitment and closeness (eg Ravel et al, 1987), while others studies suggest the reverse (eg, Lukse & Vacc, 1999). In a recent study of infertile Danish couples, Peterson et al. (2011) found approximately one third of participants undergoing unsuccessful fertility treatments for five years reported high marital benefit as a positive consequence of the infertility experience. They described ‘meaning based coping’ where the men and women found their own meaning in the experience was a positive factor for marital benefit.

It would be reasonable to assume that high or increased marital satisfaction after premature menopause would relate to those couples who had a positive view of their relationship before premature menopause. A similar finding was reached by Lichtman, Taylor and Wood (2008) in a study of social support and marital adjustment after breast cancer. They found successful marital adjustment after a cancer episode was more likely when the partners expressed satisfaction with the relationship before the episode. Lichtman, Taylor and Wood used self reports to rate the level of marital satisfaction before and after cancer. In the current study, no assessment was made of marital satisfaction before or after premature menopause. The interview question, ‘in what way, if any, has your relationship changed as a result of premature menopause?’ elicited comments about the nature of the relationship. Consistent with the patients and husbands in Lichtman, Taylor and Wood’s study who expressed satisfaction with their marital relationship, those in the current study tended to view the marriage as a partnership, and to describe their partner in idealised terms such as ‘amazing’.

Another process that assisted strengthening the relationship in some cases was the reassessing together of life goals together without children or more children. Arnold described this,

We had to really focus in on us and what we really wanted. After all the adoption and fostering stuff went by the by we talked a lot about what else we wanted to achieve, where we wanted to go...sort of brought us together more. It seemed a bit empty so we had to fill that hole. (p.9).

Importance of communication

All couples that said the experience made them stronger gave 'communication' as the key to relationship success. Communication for the couples involved was commonly described as talking to each other about their feelings and making decisions together.

Phil explained how communication during the time of premature menopause was central to making his marriage stronger,,

It has certainly made us stronger. We always have been. We are open. Nothing is not talked about. We just talk openly with each other about whatever. (p.16).

Gavin added,

I think it is just the communication. Just talk and have a cry and things like that. We had to put our heads together and we went through it together. It is certainly not going to tear us apart, put it that way. (p.16).

And Mary also said talking was important in helping her and Phil strengthen their relationship,

Just talking really. We just talked or listened or whatever. You just couldn't cope on your own, or I couldn't anyway. Just going over it with him and talking or whatever probably felt like we were in it together or something. You wouldn't wish it, but the upside is we stuck together. (p.2).

Arnold mentioned talking was not always easy, but worth it for the resultant relational benefits,

Sometimes you don't want to talk about stuff. We've been through a bit. We talk about it, hash it all out, have a bit of a cry and a drink and then move on. Move on to the next battle pretty much. You've got to stick together. (p. 21).

Dave mentioned that his initial response was to 'bottle up' his feelings, but realised this was not helpful,

....tend to bottle up, go in the old 'man cave' as they say, but she wanted to know what I thought about the kids and all that...she was leaning on me a bit so I had to tell her what I thought and that...was probably the best thing for us really...not that you have to always be talking. (p.30).

Most books on menopause (e.g, Teaff & Wiley, 1999) include a section for women on the importance of talking to your partner about what you are experiencing. For example Teaff and Wiley stress, 'being open with your partner about your symptoms, energy level, and sexual interest', noting the importance of early communication, 'just as many women wait to see their doctors until the symptoms have become unbearable, they often wait to broach the subject with their partners

until they are at emotional breaking point'. (p.187). Petras (1999) offers the following tips to women on communicating with their partners about premature menopause:

- Talk it out
- Teach him about premature menopause
- Give concrete suggestions for helping you cope
- Don't let him feel left out
- Keep him aware of your mood changes and physical symptoms

All of these ideas were mentioned by women in the current study as being key communication points which assisted with relationship strengthening.

Another aspect to strengthening the relationship brought about by premature menopause was the couples' reassessment of what they meant to each other. Mike spoke of this,

I think it affected us by making us stronger. I didn't marry her for her inside parts, I married her for who she is and it gave us the opportunity to express that strength in our relationship. We've been through a lot and come out stronger. All the IVF cycles and stuff, I guess most couples skip over that. (p.16).

Karen confirmed this view when she said, *I guess he saw I am more than my ovaries. (p.9).*

Marli agreed the experience of premature menopause made them reassess their priorities as a couple,

It really made us focus on what's important and that we really were committed to each other. He saw me at my worst. I saw him in a

different way. It made us feel stronger when we realised what is really important is us and our future. (p.12).

Two of the women raised the question of whether their husband might want to leave them as a result of premature menopause. Karen questioned,

I thought will he leave me? Should he leave me? I told him, if he wanted someone he could have kids with, I would understand. I felt he deserved to be happy. (p.4).

But her husband Mike was quick to dispel that idea, *I told her that I was in for the long term. It was her I wanted (p.5).*

Questioning whether a partner would remain committed to a relationship after learning about infertility has been explored in women and men. Cook (2003) found that infertile men also questioned whether their partners would choose to leave them when they learnt they were unable to have their own biological children, but this proved to be an anxious over reaction.

Although no marriages were described as being significantly threatened as a result of premature menopause, some couples said the condition put strain on their relationship. An example was Rupert who said, *yeah sure it was tough on us as a couple*, and Oscar who said, *I wouldn't say it was good that we are dealing with this, sometimes we get the shits with each other.*

Other than these, and a few similar comments referring to generally minor relationship stress, not one of the participants mentioned major conflict or disharmony in the marital relationship over the period of time premature menopause was most relevant to them. This does not mean however that premature menopause does not put significant strain on relationships or even couldn't be a catalyst for marital breakdown. As mentioned earlier, Boughton (2002) found some women identified premature menopause as a contributing factor in their divorce.

No man or woman whose relationship had been significantly stressed or broken as a response to premature menopause offered to be in the current study. It is likely they were not available to respond together or didn't want to reflect on such a difficult time. This may represent a bias in the results as it could also be expected that difficult times could break a couple.

Phil raised this point; that couples whose relationship was faltering prior to premature menopause may have not survived the strain premature menopause can present, *I'm sure there are marriages out there that wouldn't survive this if they had been struggling.* (p.16).

The sexual relationship

Another impact on couples related to their sexual relationship. It is likely that symptoms such as low mood, reduced libido, and increased worry would affect physical intimacy. Research links a satisfying sexual relationship, characterised by satisfaction with the quality and frequency of sex and by the absence of sexual dysfunction, with greater feelings of love (e.g., Hendrick & Hendrick, 2002), marital happiness (e.g., Brezsnayak & Whisman, 2004), and lower levels of marital conflict (Metz & Epstein, 2002). Studies also show that stress within the marital relationship, in the form of marital tension and conflict, covaries with lower sexual satisfaction and greater likelihood of sexual dysfunction (e.g., Hurlbert, Apt, Hurlbert, & Pierce, 2000).

Surprisingly, Morokoff and Gilliland (1993) showed that desired frequency of sexual intercourse *increased* with daily hassles for husbands and for wives. This is consistent with McCarthy's (2003) view that sexual activity may often serve to reduce tension as couples contend with stressors in everyday life or marriage. Acute life events in the past 6 months, in contrast, were unrelated to sexual functioning (after controlling for age) in the Morokoff and Gilliland study, though unemployed

men experienced more difficulties in sexual performance compared to employed men.

Women with premature menopause have been reported to have diminished general and sexual wellbeing and were less satisfied with their sex lives (van der Steege et al., 2008). Premature menopause has shown to affect sexual identity, sexual function, and sexual relationships (Graziottin & Bassoon, 2004).

Graziottin (2007) notes that premature menopause can have varying impacts depending on whether it is the only major health issue a woman is facing or is associated with other medical or psychological troubles. Graziottin suggests factors such as age, personal factors and relational and sociocultural context modulate sexual problems associated with premature menopause.

The topic of sexuality was not specifically raised by the interviewer in the current study. Interestingly, relatively little content was offered in this area by the participants. This may have been because they were embarrassed, didn't want to discuss such a personal topic in front of each other, or were not comfortable sharing such issues with the interviewer.

However some participants did make reference to sexual matters. As discussed in chapter 9, some of the men offered their views on sexual matters. Comments about sexuality related mainly to women's reduced libido and the impact on their sexual relationship. Fran mentioned she had '*come to terms with infertility,*' but struggled mainly with the changes to her libido brought about by menopause. She mentioned missing her monthly cycle as she explained,

We certainly have had a very cyclic sex life and now that's changed and the game is very different now. I miss that. I have no interest (in sex) at all now. We used to have a great sex life and now we don't and I feel that is what menopause has taken from me. (p.6).

Bernadette also gave lack of libido as the most problematic symptom of menopause. She described the physical and emotional components of this change as, *just not feeling physically like it, like I used to*, and by describing,

When I first found out I thought, God how's my husband going to want to have sex with an old woman? And I just didn't have that inclination, which put pressure on him, and then he put pressure on me. It's hard to know if the libido thing is menopause or other things like sadness. (p.11).

Fran said her libido had changed and this had impacted her marriage, but could not put that directly down to menopause. She also described confusion between what was going on in her mind and body,

Since menopause I don't feel like having sex so we don't have sex then I don't feel sexually attractive, then I reflect on whether I am suddenly old. So it's weird like that. You don't know what is the hormones and what is the mind. (p.12).

Marie and Arnold together discussed a reduction in her libido since menopause,

You know how you get drier when you go through menopause? I think that has already started? Don't you think? I think so? But I can't remember when it happened. Maybe it was gradual but I think that has happened. And I don't feel like it as much. (Marie, p.21).

Arnold noted that the frequency of their sexual interactions had dropped off over the last couple of years but both agreed they couldn't put it down to menopause specifically as other factors had contributed, including IVF, 'diarised conception sex', miscarriage and a reluctance to have intercourse when pregnant. Marie said

...IVF and everything is such a passion killer. And after the miscarriage I was sort of scared about not wanting to lose the baby so...(p.21).

Sasha also noted changes to her interest in sex but similar to Marie, couldn't isolate the cause as menopause because of other changes at the time,

I had endometriosis anyway, it was painful, I'm not sure if it was that or more a psychological thing, having problems...and of course it was probably the low estrogen affecting it as well. (p.12).

Mary said,

There was a loss of sex drive which did affect my relationship with Phil...we are trying to deal with that as well...so it goes from being a fertility thing to a relationship thing as well. (p.7).

She continued,

So the menopause has brought vaginal dryness which makes it quite painful and because we are still getting tests and other things going on I didn't know that was part of it at the time....I obviously wasn't very keen (on sex) and that put a strain on us. Then I felt I wasn't a good enough wife, so you've got all that guilt going on too...(p.7).

Bernadette also noted menopause changed her sex life but put this largely down to the couple no longer associating sex with conception,

I suppose most of our cues for sex was to try for kids and when you've been trying for so long and it's not just why you're doing it but generally, and then it doesn't matter how often you do it you're still not going to have kids. That put a dampener on it I suppose. (p.11).

These findings fit with the prevailing view that the effect of premature menopause on sexuality is complex. The couples in this study describe changes relating to hormonal fluctuations during menopause as affecting their sexual response. Also, adjusted

feelings towards their partner, the partners own sexual health and the women's own overall feelings of contentment and wellbeing seemed to play a part.

Summary

Despite sometimes distressing symptoms, premature menopause was not found to be detrimental overall to the marriages of those in this study. Some couples described how premature menopause placed a strain on the quality of their relationship, in particular by impacting the level of satisfaction with the sexual relationship. In noting challenges and changes brought about by certain symptoms, in particular loss of libido, no one in the study indicated that the overall quality of their marital relationship suffered directly as a response to premature menopause. Rather, such symptoms were seen as issues to be overcome, endured or incorporated into and dealt with within the relationship.

Communication by sharing feelings and concerns and making joint decisions, as well as the benefits of 'surviving a tough time' were seen to be factors bolstering the couple's marital relationships. It is important to note the current study results do not cover couples for whom the experience had a negative effect on their marriage or for whom the experience contributed to a breakdown in or end of the marital relationship.

Chapter 11 **Conclusion**

This study has addressed a gap in the research about the psychology of premature menopause by providing a depth of description about the experience of both women and their partners. The exploration of the experience of these couples has been through the evaluation of detailed qualitative information about their psychological, emotional and behavioural responses to premature menopause.

While a small number of earlier studies have investigated women with premature menopause, most have included menopause prematurely brought about by surgical intervention, potentially contaminating the findings with issues more likely to be associated with a disease prognosis and associated treatments. This study has attempted to generate more ‘pure’ data, concentrating on the experience of spontaneous premature menopause only.

Hermeneutic phenomenology proved to be an appropriate methodology to investigate the experience of premature menopause in this study. The focus that phenomenology provided on lived experience was congruent with the aim of exploring participants’ experience of premature menopause. Hermeneutics allowed for an added layer of abstraction and interpretation through the lens of the researcher to make meaning of the phenomenon in a way that is credible and maintains faithfulness to the participants and their interpretations. Using the interpretive paradigm enabled understanding of premature menopause in context from the experiences of the participants. Rigor and credibility were the criteria used to ensure quality in this research.

In addition to adding to the body of knowledge concerned with premature menopause, the chosen research strategy, through its reflexive nature enabled me as a researcher to engage in my own learning journey towards a deeper understanding of the phenomenon being researched, the strategies adopted, and myself as a researcher.

In this concluding chapter I attempt to integrate the findings of the study and point to the more salient response themes and patterns which have emerged from the interviews that formed the basis of this research. I also comment on some implications of these results for those interested in women's health and the wider community.

Main findings

The study sought to investigate the experience of premature menopause for women and their partners. The most important finding was that women and men are not generally aware of the possibility of premature menopause. Not unexpectedly, they were widely shocked to discover the condition existed. In line with my original prediction, premature menopause was found to be a profound experience affecting many facets of a woman's life. Although there was natural variation in the way the women experienced this, it was widely seen as a 'devastating' event. The infertility that came with premature menopause was the foremost consideration for many couples. This finding is not unexpected as six couples were highly motivated to have a child at the time of interview and the resultant fertility challenges were seen as a major setback to achieving a much wanted baby. Couples who described themselves as 'undecided' about wanting more children also found premature menopause upsetting as it 'took away' their choice.

As discussed earlier, many studies of infertility have reported women's psychological responses in terms of grief or bereavement. Many women in this study expressed feelings of grief and loss for their fertility, whether or not they had or wanted children or more children. Losses were described as the ability to conceive (whether they were planning to or not), the loss of femininity and of a sense of control. Grief however was not the predominant reaction. Other reactions to infertility included stress, worry, anxiety, frustration and anger. There was no evidence of depressed or pathological functioning more typical of descriptions of significant grief or loss. Rather, responses were more in the nature of stress and anxiety, with participants attempting various

strategies to alleviate these feelings. The anxiety related less to the medium and long term effects of lowered estrogen, but more to the immediate challenge facing them – a threat to their fertility, and how they would overcome that.

Trying to ‘get around’ premature menopause was the most widely used coping strategy. After diagnosis participants often turned their attention quickly to finding ‘ways around’ the infertility, mostly by attempting to find egg donors. Experiences with egg donors were largely described as frustrating and those involved very much wanted to share their stories.

However not everyone reported being devastated by premature menopause, and there were some women who showed little emotionality and those for whom the experience held little meaning. These were mostly women who did not want to have children or more children.

It is important to acknowledge that both women and men had feelings and reactions to the condition. The findings suggest that perhaps not surprisingly the men had less understanding of menopause than their wives, and none of them had known that menopause could occur before age 40, all seeing it as happening ‘later in life.’ Other than often feeling frustrated by not being able to help or change the situation, and confused about what it meant for their wives’ longer term health, the men tended to be less affected by premature menopause than their wives and considered their own needs as secondary to their wives in this respect. Having said that, a few men acknowledged being upset at the prospect of not being able to have their own biological children. Men took two approaches to coping with their situation. One common coping strategy for men was taking an active role in looking into ways of conceiving with donor eggs. They described this as working on ‘Plan B’ by investigating or showing an active interest in assisted reproductive technologies and other ways of building a family. Men were more likely than their wives to consider making life plans without children as part of a Plan B. Another, often simultaneous approach was offering increased emotional support, primarily by listening to their wives.

Although secondary to issues of infertility, another main finding was that premature menopause disrupted the way women felt about their age. Their concepts of biological and chronological age were disrupted. They felt the experience aged them in ways that were hard to describe. Often they tried to make sense of this by paying extra attention to the way they looked or by using HRT to rectify what they understood to be advanced aging. The women were widely confused and often worried about what the condition and the use of HRT meant for their long term health.

Discrepancies brought on by disruptions between chronological, social and physical age impacted relationships with friends by leaving the women feeling they did not fit in. The women felt neither old (like menopausal women) nor young (like other women of their own age group), and many were left feeling lonely and that they no longer related to their peers. They very much wanted to be able to ‘hear stories’ about women with similar conditions. It would seem a perceived lack of information, advice, support, and opportunity to share made the experience of premature menopause more isolating and therefore difficult than could be expected of ‘normal’ menopause.

A developing field of research considers positive aspects of menopause. In the current study no specific interview questions sought positive views. Premature menopause was described in negative terms overall by women and men, however there were some rare positives offered, including a woman who said she felt she related better to older women having experienced menopause herself prematurely. Another positive interpretation was that having supported each other through a very difficult time, some women and men reported the experience had strengthened their marital relationship. This relates to another finding about the impact of premature menopause on the participants’ marital relationships. The overall impact of premature menopause was either neutral or positive for the couples' marital relationship. There was evidence for concluding that some marriages were enhanced by the process of acknowledging and coping with premature menopause. In this

respect, the condition was viewed similarly to a range of other life challenges, that although difficult, ultimately brought couples closer by having them reaffirm their commitment to each other. Improved communication involving more actively sharing feelings and concerns and making joint decisions was another factor seen to bolster couples' relationships.

Central to the difficulty of the experience of premature menopause was the finding that the path to a diagnosis was often difficult and a long time coming. General dissatisfaction with the time taken to reach a diagnosis and the way in which the information was given was high. The women perceived a general lack of understanding of the condition amongst the doctors they dealt with, and they sometimes grappled with conflicting advice from medical professionals. The primary piece of advice from the women in this study to other women experiencing menstrual changes or trouble conceiving was to become more knowledgeable about their menstrual health and to be proactive in seeking to understand any cause of their menstrual disturbance.

Limitations of the study

As in many phenomenological studies this research examined a small number of information rich cases, 18 men and 18 women. The sample was adequate in number for the aim of this work, but like most research it is usually better to include more participants. Including more participants may have made it possible to get a deeper understanding of the experience. The aim of the study was to understand the personal experiences of the participants. This intention and the moderate sample size means caution should be taken in making generalisations about premature menopause for women and their partners in general. As the data was gathered from individual interviews there is always the potential for the investigator, especially one with a personal emotional investment in the topic, to interpret the participants' meanings in a manner not representative of others. This potential was reduced by sending participants summaries of their interview transcripts to check that they

agreed with the interpretation taken from the interviews. Other potential limitations relate to the representativeness of the sample. First, all of the women in the study volunteered to tell their story and were eager to participate. The self selected nature of the participant group could indicate a sampling bias as the findings did not cover those who had no particular concerns or feelings about the experience, or those for whom the topic was too upsetting to talk about. It is noted that only couples who were still together were included in the study. Those couples for whom premature menopause placed insurmountable stresses on the relationship were not included in the study. Another sampling issue concerns the homogeneous nature of the group of women in the study which had limited socio demographic diversity. As such we can not say how the experience may vary as a function of ethnicity or other sociological factors. None of this, of course, diminishes the complexity and richness of detail which this research has been able to obtain.

Implications and recommendations for intervention

Nurses, counsellors, doctors and other health care providers could use this knowledge to develop sensitive guidance for couples facing premature menopause. The findings from this study could be a useful resource to add to their clinical experience in helping them understand how the relatively infrequent, yet often intense experience of premature menopause can impact women and their partners.

The diagnosis can be overwhelming, confusing and particularly upsetting to women wanting first or subsequent biological children. Care should be taken to inform women of the diagnosis in a supportive and sensitive way, ideally in person, and allowing time for questions. As the initial reaction is likely to be shock, follow up meetings may be required for further discussion about treatment options, once the initial shock has subsided and the patient has had a little time to accept the diagnosis. At this time, family planning decisions may be discussed after the patient has had some time to come to terms with her condition. In addition to clear and relevant

information, women mostly wanted more time spent with them to explain the diagnosis and fertility and treatment options.

Women with premature menopause have very different needs to those with normal menopause. As such, their special needs should be acknowledged and addressed. Relevant information, specifically aimed at women under 40 should be provided when giving the diagnosis of premature menopause. In particular, the ways in which their condition differs from a natural menopause should be discussed. It would seem that it is not uncommon for women to misinterpret a diagnosis of premature menopause by thinking they are ageing too quickly. This should be explained.

Clinicians should acknowledge any concerns prematurely menopausal women have and clarify where appropriate any unnecessary concerns they may have based on their presumptions of naturally occurring, later stage menopause. These women and their partners may feel overwhelmed by the amount of potentially conflicting information they have collected on the internet and elsewhere regarding menopause and importantly, medical professionals may help by assisting with 'making sense' of this information in a practical way.

Prematurely menopausal women and their partners are likely to want information to help them explain their infertility. Realistic chances of conceiving a natural pregnancy and alternatives should be made as clear as possible. Other implications of the ongoing medical condition and decisions about further treatment should be provided.

For anyone relating to women who have become prematurely menopausal, it would seem helpful foremost to listen to them and acknowledge their experience. This expression should be allowed without offering advice. Common reactions are shock, devastation, loss and frustration. It would be important to let women express these feelings, to acknowledge and validate them as real and appropriate for their situation. They may want to talk a lot and repeat their story over and over.

Feelings related to not fitting in to a peer group, about the reliance on assisted reproductive technologies including egg donation or concerns about 'feeling old' may arise. Listening without trying to find a 'bright side' is advised. Such well intended comments are likely to be poorly received. It may be helpful to acknowledge that men too have a range of reactions to this condition. It should not be assumed that male partners don't have emotional reactions to the condition as they may also be stressed by news of infertility and feel helpless in knowing how best to support their wife.

In some cases it may be helpful for women facing premature menopause to be offered additional support by referring them to an appropriate counsellor and/or support group as these women are likely to feel isolated and alone and may not feel strong enough to, or know how to make contact with support services. It should not be assumed that men are not feeling anxious or confused. They too may benefit from discussing coping strategies such as talking to a confidante about their own responses. Contact details of support groups, counsellors or help lines, websites or other sources of information may be useful.

Any counselling should primarily validate emotional concerns. Because women and men often describe feeling out of control when facing premature menopause, helping them find ways to maintain a sense of control of their emotional and physical health will be helpful.

Further research

There are many complex issues, decisions, and emotional consequences embedded in the lived experience of premature menopause for women and their partners.

Although the findings of this study may illuminate some important issues, future studies should extend this work to see if the findings are transferable across settings, cultures and age groups and whether perspectives change with time. Issues such as

whether the women already or subsequently had children, age, marital satisfaction, support systems, predisposition to depression and other mental health issues may all be factors to include in future research.

Final Comment

This thesis provides a significant contribution to the knowledge of the impact of premature menopause on both women and their partners. Women, partners and health professionals will be beneficiaries of this work.

Appendix 1

Participant Demographic Information.

<i>Category</i>		<i>Frequency</i>
Women interviewed		18
Men interviewed		18
Age of woman at time of interview	30-35	3
	36-41	11
	42-47	3
	48-53	0
	54+	1
Age of woman at diagnosis	18-23	1
	24-29	3
	30-35	7
	36-40	7
Time elapsed since diagnosis	0-2 years	6
	2-4 years	6
	5 years+	6
Etiology	Unspecified	18
	Known	0
Did the woman have living children at time of interview?	Yes	8
	No	10
Number of living children at time of interview	1 or 2	7
	More than 2	1
Number of women with children born prior to diagnosis		5
Number of women with children born since diagnosis		3
Egg donor used?	Yes	3
Has the couple finished building their family?	Yes	5
	No	6
	Undecided	7
Undergoing ART (incl. looking for an egg donor) at time of interview		6
Interview format	Face to face	13
	Telephone	5

Appendix 2

Summary of interview topics and sample questions.

Health background	Can you tell me a bit about your health history?
Experience of diagnosis	What was your experience of being diagnosed? What was helpful and unhelpful about the way this happened? What were your initial reactions?
Prior understanding of menopause	Did you know much about menopause before this happened to you? What was your understanding about when menopause happened and what you could expect?
Impact on family building	What impact did this news have on your plans for having children/more children? How are you dealing with this now?
Support	Did you have any support around this time? What was helpful/unhelpful?
Changes	In what way did premature menopause change the way you felt about yourself? What impact did premature menopause have on your self image? What were your feelings associated with premature menopause? Did premature menopause change your views or feelings about your role in life?

Losses	Did you feel any sense of loss related to premature menopause?
Symptoms	Did you experience any menopausal symptoms? What were they like? How are you managing any symptoms/ongoing health implications?
Relationships	Did this have any impact on relationships such as family or friends?
Marital relationship	How much did you share with your partner? Was your relationship impacted in any way? What did your partner do that was helpful/unhelpful?
Husbands	What did you know about menopause prior to this? What do you understand about it now? What changes, if any, did you notice in your wife? What was your reaction? Did it change the way you felt about your partner? Did it impact your relationship? In what way? How did you respond? What would you tell other men in your shoes?

Appendix 3

Useful sources of information about premature menopause.

New Zealand Early Menopause Support Group website:

<http://www.earlymenopause.org.nz>

ACCESS: Australia's National Infertility Network website:

<http://www.access.org.au>

The Daisy Network Premature Menopause Support Group website:

<http://www.daisynetwork.org.uk>

The Jean Hailes Foundation website:

<http://www.jeanhailes.org.au>

Australasian Menopause Society website:

<http://www.menopause.org.au/>

The International Premature Ovarian Failure Association (IPOFA) website:

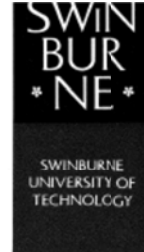
<http://www.pofsupport.org;>

Turner Syndrome Association of Australia website:

<http://www.turnersyndrome.org.au>

Appendix 4

Certificate of Ethics Clearance



Swinburne University of Technology
Human Research Ethics Committee (SUHREC)
Certificate of Ethics Clearance

SUHREC Project 2009/023

Psychological Experiences of Premature Menopause in women and their partners

Chief Investigator/Supervisor: A/Prof Roger Cook
Main Student Investigator(s): Ms Geraldine S Lockley
Duration Approved: 11/05/2009 To 30/04/2010

This is to certify that the above project has been given ethics clearance in accordance with the current *National Statement on Ethical Conduct in Human Research*. The standard conditions and any special conditions for on-going ethics clearance are here printed.

All human research activity undertaken under Swinburne auspices must conform to Swinburne and external regulatory standards, including the above-mentioned *National Statement* and with respect to secure data use, retention and disposal.

The named Swinburne Chief Investigator/Supervisor remains responsible for any personnel appointed to or associated with the project being made aware of ethics clearance conditions, including research and consent procedures or instruments approved. Any change in chief investigator/supervisor requires timely notification and SUHREC endorsement.

The above project has been approved as submitted to date for ethical review by or on behalf of SUHREC. Amendments to approved procedures or instruments ordinarily require prior ethical appraisal/ clearance. SUHREC must be notified immediately or as soon as possible thereafter of (a) any serious or unexpected adverse effects on participants and any redress measures; (b) proposed changes in protocols; and (c) unforeseen events which might affect continued ethical acceptability of the project.

At a minimum, an annual report on the progress of the project is required as well as at the conclusion (or abandonment) of the project.

A duly authorised external or internal audit of the project may be undertaken at any time.

The SUHREC project number and title should be cited in any communication.


Keith Wilkins
Secretary, SUHREC and Research Ethics Officer
07/07/2009



References

- Abdullah, R. T. & Muasher, S.J. (2006). Surviving cancer, saving fertility: the promise of cryopreservation. *Sexuality, Reproduction and Menopause* 4(1), 7-12.
- Ablon, J. (2000). Parents' responses to their child's diagnosis of neurofibromatosis 1. *American Journal of Medical Genetics*, 93(2), 136-142.
- Adler, J. D. & Boxley, R.L. (1985). The psychological reactions to infertility: Sex roles and coping styles. *Sex Roles*, 12, 271-279.
- Ahuja, K. K., Mostyn, B. J., & Simons, E. G. (1997). Egg sharing and egg donation: attitudes of British egg donors and recipients. *Human Reproduction*, 12(12), 2845-2852.
- Aiman, J. & Smentek, C. (1985). Premature ovarian failure. *Obstetrics and Gynecology*. 66 (1)
- Albright, F., Smith, P.H. & Fraser, R. (1942). A syndrome characterised by primary ovarian insufficiency and decreased stature. *American Journal of the Medical Sciences*, 204, 625-648
- Alder, B. (1999). *Psychology of Health: Applications of Psychology for Health Professionals*. Amsterdam: Gordon and Breach Publishers.
- Alesi, R. (2005). Infertility and its treatment: An emotional rollercoaster. *Australian Family Physician*, 3, 135-138.
- Alzubaidi, N. H. M. D., Chapin, H. L., Vanderhoof, V. H., Rn, Crnp, Calis, K. A. (2002). Meeting the needs of young women with secondary amenorrhea and

spontaneous premature ovarian failure. *Obstetrics and Gynecology*, 99(5), 720-725.

Amundsen, D. C. (1970). The age of the menopause in classical Greece and Rome. *Human Biology*, 42, 79-86.

Anderson, J. & Alesi, R. . (1997). Infertility Counselling. In G. Kovacs (Ed.), *The subfertility handbook: A clinicians guide*. Cambridge, UK: Cambridge University Press.

Anderson, T. B. (1984). Widowhood as a Life Transition: Its Impact on Kinship Ties. *Journal of Marriage and Family*, 46(1), 105-114.

Andrikoula, M. & Prelevic, G. (2009). Menopausal hot flushes revisited. *Climacteric*, 12(1), 3-15.

Aneshensel, C, Frerichs, R., Clark, V. & Yokopenic, Y. (1982). Measuring depression in the community: A comparison of telephone and personal interviews: *Public Opinion Quarterly*. 46 (1): 110-121.

Ardenti, R., Campari, C., Agazzi, L., La Sala, G. (1999). Anxiety and perceptive functioning in infertile women during IVF: Exploratory survey of an Italian sample. *Human Reproduction*, 14, 3126-3132.

Australian Bureau of Statistics (2008). Fertility rate statistics. Retrieved from www.abs.gov.au/ausstats/abs. (10 May 2011).

Avis, N. E. (2003). Depression During The Menopausal Transition. *Psychology of Women Quarterly*, 27(2), 91-100.

- Barentsen, R., van de Weijer, P. H. M., van Gend, S., & Foekema, H. (2001). Climacteric symptoms in a representative Dutch population sample as measured with the Greene Climacteric Scale. *Maturitas*, 38(2), 123-128.
- Beaurepaire, J., Jones M., Thierring, P. & Saunders. A (1994). Psychosocial adjustment in infertility and its treatment: Male and female responses at different stages of IVF/ET treatment. *Journal of Psychosomatic Research*, 38, 229-240.
- Beck, S. H. (1982). Adjustment to and Satisfaction With Retirement. *Journal of Gerontology*, 37(5), 616-624.
- Beerendonk, C. & Braat, D. (2005). Present and Future Options for the Preservation of Fertility in Female Adolescents with Cancer. *Endocrine Development*, 8, 166-175.
- Berg, B. J., Wilson, J.F., Weingartner, P.J. (1991). Psychological sequelae of infertility treatment: The role of gender and sex role identification. *Social Science Medicine*, 33, 1071-1080.
- Berga, S. L. (1996). Stress and ovarian function. *American Journal of Sports Medicine*, 24(6), 36-37.
- Birkhauser, M. (2002). Depression, menopause and estrogens: is there a correlation? *Maturitas*, 41, 3-8.
- Bogduk, N. (2000). What's in a name? The labelling of back pain. *Medical Journal of Australia* 173(8), 400-401.
- Boivin, J., Takefman, J.E., Tulandi, T., Brender, W. (1995). Reactions to infertility based on extent of treatment failure. *Fertility and Sterility*, 63, 801-807.

- Bolger, N. F., M.; Vinokur, A. D.; Ng, Rosanna. . (1996). Close relationships and adjustments to a life crisis: The case of breast cancer. *Journal of Personality and Social Psychology*, 70(2), 283-294.
- Boughton, M. A .(1997) Embodied self, human biology, and human experience, in Lawler J (ed.) *The Body in Nursing: A Collection of Views*, Churchill Livingstone, Melbourne
- Boughton, M. A. (2002). Premature menopause: multiple disruptions between the woman's biological body experience and her lived body. *Journal of Advanced Nursing*, 37(5), 423-430.
- Brezsnyak. M., & Whisman, M.A. (2004) Sexual Desire and Relationship Functioning: The Effects of Marital Satisfaction and Power. *Journal of Sex & Marital Therapy*, 30(3).199-217.
- Buick, D. L., Crook, D., & Horne, R. (2005). Women's perceptions of hormone replacement therapy: risks and benefits (1980â€“2002). A literature review. *Climacteric*, 8(1), 24-35.
- Carell, D. T., Peterson, C.M. (2010). *Reproduction and infertility: Integrating modern clinical and laboratory practice*. London: Springer.
- Chad. P.C., Deal. A.L., Alaylia.G., Durmus.H.R. (2005). Arthritis and depression in younger people. *Rheumatology International*. 2 (1).
- Chedraui, P., Aguirre, W., Hidalgo, L., & Fayad, L. (2007). Assessing menopausal symptoms among healthy middle aged women with the Menopause Rating Scale. *Maturitas*, 57(3), 271-278.

- Cheung, A., Chaudhry, R., Kapral, M., Jackevicius, C., & Robinson, G. (2004). Perimenopausal and Postmenopausal Health. *BMC Women's Health*, 4(Suppl 1), S23.
- Clapp, D. (1985). Emotional Responses to Infertility. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 14, 32s-35s
- Cohen, S., Wills, T.A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98(2), 310-357.
- Colaizzi, P. (1978). Psychological research as the phenomenologist views it. In K. M. Valle. R. (Ed.), *Existential Phenomenological Alternative for Psychology*. New York: Oxford University Press.
- Collins, A., Freeman, E., Boxer, A., Tureck, R (1992). Perceptions of infertility stress in females as compared with males entering IVF treatment. *Fertility and Sterility*, 57 (2), , 57(2), 350-356.
- Coltman, Robert . (1998). *The Language of Hermeneutics: Gadamer and Heidegger in Dialogue*. Albany: State University Press,
- Conway.G.S. (2000). Premature ovarian failure. *British Medical Bulletin*. 56(3). 643-649.
- Cook, E. (1987). Characteristics of the bio-psychosocial crisis of infertility. *Journal of Counselling and Development*, 65, 465-470.
- Cook, R. H. (2002). The psychosocial effects on men of their infertility. Unpublished PhD dissertation. La Trobe University.
- Coulam.G.S., Adamson.S.C., Annegers.J.F. (1986). Incidence of premature ovarian failure. *Obstetric Gynecology*. 67(4). 604-606.

- Covington, S. N. (1988). Psychosocial Evaluation of the Infertile Couple: Implications for Social Work Practice. *Journal of Social Work & Human Sexuality*, 6(6).
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Sydney, New South Wales, Australia: Allen & Unwin.
- Daire, A. P., & Fairall, H. (2005). Sexuality and Perimenopause: What Counselors Need to Know. *Adultspan: Theory Research & Practice*, 4(2), 105-115.
- Daniluk, J. (1988). Infertility: intrapersonal and interpersonal impact. *Fertility and Sterility*, 49(6), 982-990.
- Daniluk, J. (2001). Reconstructing their lives: a longitudinal, qualitative analysis of the transition to biological childlessness for infertile couples. *Journal of Counselling and Development*, 79(4), 439-450.
- de Taraciuk, M. B., Nolting, M., Fernandez, G., Colela, D., Onetto, C., & Straminsky, V. (2008). Psychological assessment of patients with premature ovarian failure. *Gynecological Endocrinology*, 24(1), 44-53.
- Deeks, A. A. (2003). Psychological aspects of menopause management. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 17(1), 17-31.
- Deeks, A. A., & McCabe, M. P. (2004). Well-being and menopause: An investigation of purpose in life, self-acceptance and social role in premenopausal, perimenopausal and postmenopausal women. *Quality of Life Research*, 13(2), 389-398.

- Degraff - Bender, S. (1998). *The power of perimenopause: a woman's guide to physical and emotional health during the transitional decade* (1 ed.). New York: Harmony Books.
- Dell, D. L., Stewart, D.E. (2000). Menopause and mood: is depression linked with hormone changes? *Postgraduate Medicine*, 1(108), 34-36.
- Dennerstein, L. (1987). Depression in the menopause. *Obstet Gynecol Clin North Am*, 14(1), 33-48.
- Dennerstein, L. (1996). Well-being, symptoms and the menopausal transition. *Maturitas*, 23(2), 147-157.
- Denzin, N. K., Lincoln Y. S. (2008). *Collecting and Interpreting Qualitative Materials* (3 ed.). Thousand Oaks, CA: Sage.
- Denzin, N. K., & Lincoln, Y. S. (2000). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed). Thousand Oaks, CA: Sage.
- Dillaway, H. E. (2005). Menopause is the 'Good Old'. *Gender & Society*, 19(3), 398-417.
- Dostal, Robert J. "Gadamer's Relation to Heidegger and Phenomenology." *The Cambridge Companion to Gadamer*. Ed. Robert J. Dostal. Cambridge University Press, 2002. Cambridge Collections Online. Cambridge University Press. (21 May 2012)
- Downey, J., Yingling, S., McKinney, M (1989). Mood disorders, psychiatric symptoms and distress in women presenting for infertility treatment. *Fertility and Sterility*, 52, 425-432.

- Dragojec.S., Rakic.C.S., Nikolic.B.,Popovac.S. (2009). Hormone replacement therapy and successful pregnancy in a patient with premature ovarian failure. *Gynecological Endocrinology*. 25(12). 769-772.
- Draper, B. (2002). 'It's the first scientific evidence': men's experience of pregnancy confirmation. *Journal of Advanced Nursing*, 39(6), 563-570.
- Dunkel-Schetter, C., Lobel, M. . (1991). Psychological reactions to infertility. In A. L. Stanton, Dunkel-Schetter, C. (Ed.), *Infertility: Perspectives from stress and coping research*. New York: Plenum Press.
- Dunson, D. B., Baird, D. D., & Colombo, B. (2004). Increased Infertility With Age in Men and Women. *Obstetrics & Gynecology*, 103(1), 51-56.
- Elder, G. H. (1975). Age Differentiation and the Life Course. *Annual Review of Sociology*, 1, 165-190.
- Erikson, E. (1950). *Childhood and Society*. New York: W. W. Norton & Company.
- Feldman, S. S., & Nash, S. C. (1984). The transition from expectancy to parenthood: Impact of the firstborn child on men and women. *Sex Roles*, 11(1), 61-78.
- Ferin, M. (1996). Stress and hypothalamic amenorrhea. *Gynecological Endocrinology*, 10(0), 42-43.
- Ferin, M. (1999). Stress and the Reproductive Cycle. *Journal of Clinical Endocrinology & Metabolism*, 84(6), 1768-1774.
- Fertility Society of Australia website. <http://www.fsa.au.com/>. (Accessed 21 May 2010).

- Fischer, I. C. (1958). Psychogenic aspects of infertility. *Fertility and Sterility*, 4, 446-471.
- Flaherty, J., Richman, J. (1989). Gender differences in the perception and utilization of social support: Theoretical perspectives and an empirical test *Social Science Medicine*, 28(12), 1221-1228.
- Ford, K., Sowers, M., Crutchfield, M., Wilson, A., & Jannausch, M. (2005). A longitudinal study of the predictors of prevalence and severity of symptoms commonly associated with menopause. *Menopause*, 12(3), 308-317.
- Formanek, R. (1990). *The meanings of menopause: historical, medical and clinical perspectives*. Hillsdale, NJ: Analytic Press.
- Forrest, D. (1989). The experience of caring. *Journal of Advanced Nursing*, 14, 815-823.
- Fortier, L. M. W., R. L. . (1984). Family crisis following the diagnosis of a handicapped child. *Family Relations: An Interdisciplinary Journal of Applied Family Studies*, 33(1), 13-24.
- Foxcroft, L. (2009). *Hot flushes, cold science: A history of the modern menopause*. London: Granta Books.
- Freeman, E. W., Garcia, C.R., Rickels, K. (1983). Behavioural and emotional factors: Comparisons of anovulatory infertile women with fertile and other infertile women. *Fertility and Sterility*, 40, 195-201.
- Fries, H. (1974). Secondary amenorrhoea, self-induced weight reduction and anorexia nervosa. *Acta Psychiatr Scand Suppl*, 248, 1-70.

- Gadamer, H.-G. (1976). *Philosophical hermeneutics*. Berkeley: University of California Press.
- Gadamer, H. (1983). *Hermeneutics as practical philosophy*. In F. G. Lawrence (Trans.), *Reason in the age of science*. (pp. 88-138). Cambridge: The MIT Press.
- Gadamer, H.-G. (1998). *Truth and method* (2nd ed.). New York: Continuum. (Original work published 1960.)
- Gindoff, P. R. (1989). Menstrual function and its relationship to stress, exercise, and body weight. *Bulletin of the New York Academy of Medicine*, 65(7), 774-786.
- Ginsburg, F., & Rapp, R. (1991). The Politics of Reproduction. *Annual Review of Anthropology*, 20(1), 311-343.
- Goldberg, W. A., Michaels, G. Y., & Lamb, M. E. (1985). Husbands' and wives' adjustment to pregnancy and first parenthood. *Journal of Family Issues*, 6(4), 483-503.
- Goswami, D., & Conway, G. S. (2005). Premature ovarian failure. *Hum Reprod Update*, 11(4), 391-410.
- Graziottin, A. (2007). Effect of premature menopause on sexuality. *Women's Health*, 3(4), 455-474.
- Graziottin, A., & Basson, R. (2004). Sexual dysfunction in women with premature menopause. *Menopause*, 11(6, Part 2 of 2), 766-777.
- Greene, J. G. (1998). Constructing a standard climacteric scale. *Maturitas*, 29(1), 25-31.

- Greer, G. (1991). *The change: women, aging and the menopause*. London: Hamish Hamilton.
- Greil, A. L. (1997). Infertility and psychological distress: a critical review of the literature. *Social Science Medicine*, 45(11), 1679-1704.
- Groff, A. A., Covington, S. N., Halverson, L. R., Fitzgerald, O. R., Vanderhoof, V., Calis, K., et al. (2005). Assessing the emotional needs of women with spontaneous premature ovarian failure. *Fertility and Sterility*, 83(6), 1734-1741.
- Groves, R.M. (1990) Theories and Methods of Telephone Surveys: *Annual Review of Sociology*. Vol. 16, pp. 221-240
- Gudykunst, W. B. (1997). Cultural Variability in Communication. *Communication Research*, 24(4), 327-348.
- Halliday, L., & Boughton, M. (2009). Premature menopause: Exploring the experience through online communication. *Nursing & Health Sciences*, 11(1), 17-22.
- Hammer-Burns, L., Covington, S. (1999). Psychology of Infertility. . In L. Hammer-Burns, Covington, S. (Ed.), *Infertility Counseling: A comprehensive handbook for clinicians.*: Parthenon Publishing Group.
- Heidegger, M. (1962). *Being and Time*. New York: Harper. (Original work published 1927)
- Hendrick, S.S., & Hendrick, C.T. (2004). Close relationships research: A resource for couple and family therapists. *Journal of Marital and Family Therapy*. 30(1) 13-27

- Higgs, J. (2001). Charting standpoints in qualitative research. In H. Byrne-Armstrong, J. Higgs, & D. Horsfall (Eds.), *Critical moments in qualitative research* (pp. 44-67). Oxford, England: Butterworth-Heinemann.
- Hill, C. E., Thompson, B. J., Williams, E. N. (1997). A guide to conducting consensual qualitative research. . *The Counselling Psychologist*, 517–572.
- Hilton, B.A., Crawford, J.A., Tarko, M.A. (2000). Men’s Perspectives on Individual and Family Coping with their Wives’ Breast Cancer and Chemotherapy. *Western Journal of Nursing Research*. 22(4) 438-454.
- Houck, J. A. (2008). *Hot and bothered: Women, medicine and menopause in modern america*. New York: Harvard University Press.
- Hurlbert, D.F., Apt,C., Hurlbert, M.K.,Pierce, A. P. (2000). Sexual compatibility and the sexual desire-motivation relation in females with hypoactive sexual desire disorder. *Behavior Modification*, 24(3), 325-347.
- Hvas, L. (2001). Positive aspects of menopause: A qualitative study. *Maturitas*, 39(1), 11-17.
- Hvas, L. (2006). Menopausal women's positive experience of growing older. *Maturitas*, 54(3), 245-251.
- Hycner, R. H. (1985). Some guidelines for the phenomenological analysis of interview data *Human Studies*, 8, 279-303.
- Imeson, M., & McMurray, A (1996). Couple’s experiences of infertility: A phenomenological study. *Journal of Advanced Nursing*, 24, 1014-1022.

- Jean Hailes Foundation. www.jeanhailes.org.au. (Website accessed 10 May 2011).
- Johnson, J. (2003). On receiving the diagnosis of multiple sclerosis: managing the transition. *Multiple Sclerosis*, 9(1), 82-88.
- Johnson, M. H., Everitt, B. (2000). *Essential Reproduction* (5 ed.). Oxford, London: Blackwell Science.
- Kalantardiou.S.N., Nelson.,L.M. (2000). Prematuer ovarian failure is not premature menopause. *Annals of the New York Academy of Sciences*. 900. 393-402.
- Kalu, W. J. (1990). Bereavement and Stress in Career Women. *Women & Therapy*, 10(3), 75-87.
- Kaufman, W. (2000). *The Basic Writings of Nietzsche* New York: The Modern Library.
- Knobf, M. T. (2002). Carrying On: The Experience of Premature Menopause in Women With Early Stage Breast Cancer. *Nursing Research*, 51(1), 9-17.
- Koch, T., & Harrington, A. (1998). Reconceptualising rigour: The case for reflexivity. *Journal of Advanced Nursing*, 28(4), 882-890.
- Komesaroff, J. A., Rothfield, P., Daly, J. (1997). *Reinterpreting menopause: cultural and philosophical views*. New York: Routledge.
- Kopitzke, E. (2002). Stress and infertility. *Current Womens Health and Reproduction*, 2(3), 194-199.

- Kornstein, S. G., Young, E.A., Harvey, A.T., Wisniewski, S.R., Barkin, J.L. (2010). The influence of menopause status and postmenopausal use of hormone therapy on presentation of major depression in women. *Menopause, 17*(4), 828 - 839.
- Kraft, A., Palombo, J., Mitchell, D., Dean, C., Meyers, S., Schmidt, A. . (1980). The psychological dimensions of infertility. *American Journal of Orthopsychiatry, 50*, 618-627.
- Kubler-Ross, E. (1969). *On death and dying*. New York: Macmillan.
- Lalos, A. (1999). Breaking bad news concerning fertility. *Human Reproduction, 14*(3), 581-585.
- Leake. J. (1777). Medical instructions towards the prevention and cure of chronic or slow diseases peculiar to women. Vol 1. Printed for R. Baldwin: London.
- Lebovic, D. I., Gordon, J.D., Taylor, R.N. (2005). *Reproductive endocrinology and infertility : A handbook for clinicians*. Arlington, VA: Scrub Hill Press.
- Leiblum.S.R., Aviv.A., Hamer.R. (1998). Life after infertility treatment: a long term investigation of marital and sexual function. *Human Reproduction. 13*(12).3569-3574.
- Lennon, M. C. (1982). The Psychological Consequences of Menopause: The Importance of Timing of a Life Stage Event. *Journal of Health and Social Behavior, 23*(4), 353-366.
- Lesser, J. G., O'Neill, M. R., Burke, K. W., Scanlon, P., Hollis, K., & Miller, R. (2004). Women Supporting Women: A Mutual Aid Group Fosters New Connections Among Women in Midlife. *Social Work With Groups, 27*(1), 75 - 88.

- Liao, K. L. M., Wood, N., & Conway, G. S. (2000). Premature menopause and psychological well-being. *Journal of Psychosomatic Obstetrics & Gynecology*, 21(3), 167-174.
- Lichtman, R.R., Taylor, S.E. & Wood, J.V. (2008). Social support and marital adjustment after breast cancer. *Journal of psychosocial oncology*. 5 (3).
- Lindh-Åstrand, L., Hoffmann, M., Hammar, M., & Kjellgren, K. I. (2007). Women's conception of the menopausal transition – a qualitative study. *Journal of Clinical Nursing*, 16(3), 509-517.
- Link, P. W., Darling, C.A. (1986). Couples undergoing treatment for infertility: Dimensions of life satisfaction. *Journal of Sex and Marital Therapy*, 12, 46-59.
- Luborsky, J. L., Meyer, P., Sowers, M. F., Gold, E. B., & Santoro, N. (2003). Premature menopause in a multi ethnic population study of the menopause transition. *Human Reproduction.*, 18(1), 199-206.
- Lukse, M. P., Vacc, N.A (1999). Grief, depression and coping in women undergoing infertility treatment. *Obstetric Gynaecology*, 2, 245-251.
- Mahlstedt, P. (1985). The psychological component of infertility. *Fertility and Sterility*, 43, 335-346.
- Mansfield, P. K., Koch, P. B., & Gierach, G. (2003). Husbands' Support of Their Perimenopausal Wives. *Women & Health*, 38(3), 97-112.
- Matsubayashi, H., Hosaka, T., Izumi, S., Suzuki, T., Makino, T. (2001). Emotional distress in infertile women in Japan. *Human Reproduction*, 16(5), 966- 969.

- McCarthy, B. (2003) Marital sex as it ought to be. *Journal of Family Psychotherapy*, 14 (2)
- McCormick, T. M. (1980). Out of control: One aspect of infertility. *Journal of Obstetric, Gynaecological and Neonatal Nursing*, 9, 205-206.
- McEwan, K. L., Costello, C.G., Taylor, P. (1987). Adjustment to infertility. *Journal of Abnormal Psychology*, 96, 108-116.
- McKinlay S, J. M., Thompson B. (1972). An investigation of the age at menopause. *Journal of Biosocial Science*, 4, 161-173.
- Meirow, D., & Nugent, D. (2001). The effects of radiotherapy and chemotherapy on female reproduction. *Human Reproduction Update*, 7(6), 535-543.
- Menning, B. (1980). The emotional needs of infertile couples. *Fertility and Sterility*, 34, 313-319.
- Merari, D., Feldberg, D., Elizur, A (1992). Psychological and hormonal changes in the course of invitro fertilisation. *Journal of Assisted Reproduction and Genetics*, 9, 161-169.
- Merleau-Ponty, M. (2005) Trans: Colin Smith. *Phenomenology of Perception*. (London: Routledge, 2005 (Original work published, 1945)
- Metz, M.E & Epstein, N. (2002). Assessing the role of relationship conflict in sexual dysfunction. *Journal of Sex and Marital Therapy*. 28(2):139-64.
- Minichiello, V., Aroni, R., Timewell, E., & Alexander, L. (1995). *In-depth*

interviewing (2nd ed.). Melbourne, Australia: Longman.

Morokoff, P.J & Gilliland, R. (1993). Stress, sexual functioning, and marital satisfaction. *Journal of Sex Research*, 30(1), 43-53

Nelson, L. M. (2009). Primary Ovarian Insufficiency. *New England Journal of Medicine*, 360(6), 606-614.

Nelson, L. M., Covington, S. N., & Rebar, R. W. (2005). An update: spontaneous premature ovarian failure is not an early menopause. *Fertility & Sterility*, 83(5), 1327-1332.

Neugarten, B. L., Hagestad, G.O. (1976). Age and the Life Course. In R. Binstock, Shanas, E (Ed.), *Handbook of Aging and the Social Sciences* (pp. 35-55). New York: Van Nostrand-Reinhold.

Newman, N. E., Zouves, C.G. (1991). Emotional experiences of in vitro fertilisation participants. *Journal of In Vitro Fertilisation and Embryo Transfer*, 6, 322-328.

Newton, C. R., Hearn, M.T., Yuzpe, A.A. (1990). Psychological assessment and follow-up after in vitro fertilisation: Assessing the impact of failure. *Fertility and Sterility*, 54(5), 879.

Newton, C. R., Hearn, M.T., Yuzpe, A.A., Houle, M. (1992). Motives for parenthood and response to failed IVF: Implications for counselling. *Journal of Assisted Reproduction and Genetics*, 9(1), 24-31.

Nippita, T. A., & Baber, R. J. (2007). Premature ovarian failure: a review. *Climacteric*, 10(1), 11-22.

- Oddens, B., den Tonkelaar, I., Nieuwenhuyse, H. . (1999). Psychosocial experiences in women facing fertility problems: A comparative survey. *Human Reproduction, 14*(1), 255-261.
- O'Donoghue, T., Punch K. (2003). *Qualitative Educational Research in Action: Doing and Reflecting*. Routledge (2003).
- Orshan, S. A., Furniss, K. K., Forst, C., & Santoro, N. (2001). The Lived Experience of Premature Ovarian Failure. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 30*(2), 202-208.
- Overlie, I., Moen, M. H., Morkrid, L., Skjæraasen, J. S., & Holte, A. (1999). The endocrine transition around menopause - a five years prospective study with profiles of gonadotropines, estrogens, androgens and SHBG among healthy women. *Acta Obstetrica et Gynecologica Scandinavica, 78*(7), 642-647.
- Packham, J. C. (2004). Overview of the psychosocial concerns of young adults with juvenile arthritis. *Musculoskeletal Care, 2*(1), 6-16.
- Packham, J. C., & Hall, M. A. (2002). Long term follow up of 246 adults with juvenile idiopathic arthritis: functional outcome. *Rheumatology, 41*(12), 1428-1435.
- Panay, N., & Kalu, E. (2009). Management of premature ovarian failure. *Best practice & research. Clinical obstetrics & gynaecology, 23*(1), 129-140.
- Parry, D. (2005). Women's experiences with infertility: the fluidity of conceptualisations of 'family'. *Qualitative sociology, 28*(3), 275-291.
- Pasquali, E. A. (1999). The Impact of Premature Menopause on Women's Experience of Self. *Journal of Holistic Nursing, 17*(4), 346-364.

- Patton, M. Q. (1990). *Qualitative Evaluation and Research Methods*. (2 ed.). Newbury Park, CA: Sage Publications, Inc.
- Paulson, J. D., Haarman, B.S., Salerno, R.L., Asmar, P. (1988). An investigation of the relationship between emotional maladjustment and infertility. *Fertility and Sterility*, 49, 258-262.
- Paulson, J. F., & Bazemore, S. D. Prenatal and Postpartum Depression in Fathers and Its Association With Maternal Depression. *JAMA: The Journal of the American Medical Association*, 303(19), 1961-1969.
- Peterson, B.D., Pirritano, M., Block, J.M. & Schmidt, L. (2011). Marital benefit and coping strategies in men and women undergoing unsuccessful fertility treatments over a five year period. *Fertility and Sterility*. 95(5). 1759-1763.
- Petras, K. (1999). *The Premature Menopause Book: When The "change Of Life" Comes Too Early*. New York: Harper Collins.
- Popat, V., and Nelson, L.M. (2007). Spontaneous primary ovarian insufficiency and premature ovarian failure [Electronic Version]. *emedicine,medscape.com/article/255974*,
- Porter M, Penney G, Russell D, Russell E, & A., T. (1996). A population based survey of women's experience of the menopause. *Br J Obstet Gynaecol* 103, 1025-1028.
- Purewal, S., & van den Akker, O. B. A. (2009). Systematic review of oocyte donation: investigating attitudes, motivations and experiences. *Human Reproduction Update*, 15(5), 499-515.

- Ratka, A., Miller, V., Brown, K., Jenschke, M., & Simpkins, J. (2009). Association of Various Dimensions of Hot Flashes with Systemic Levels of Gonadal Steroids. *Exp. Biol. Med.*, 234(4), 395-402.
- Ravel, H., Slade, P., Buck, P & Lieberman, B. (1987). The impact of infertility on emotions and the marital and sexual relationship. *J. Reprod. Inf. Psychol.* 5. 221-234
- Rebar, R. W. (2009). Premature Ovarian Failure. *Obstetrics & Gynecology*, 113(6), 1355-1363
- Rebar, R., Connolly, H. (1990). Clinical features of young women with hypergonadotropic amenorrhoea. *Fertility & Sterility*, 53, 804-810.
- Salpeter, S. (2005). Hormone therapy for younger postmenopausal women: how can we make sense out of the evidence? *Climacteric*, 8(4), 307-310.
- Sandler, B. (1968). Emotional stress and infertility. *Journal of Psychosomatic Research*, 12, 51-59.
- Santen, R.J., Allred, D.C., Ardoin, S.P., Archer, D.F., Boyd, N., Braunstein, G.D., Burger, H.G., Colditz, G.A., Davis, S.R., Gambacciani, M., Gower, B.A., Henderson, V.W., Jarjour, W.N., Karas, R.H., Kleerekoper, M., Lobo, R.A., Manson, J.E., Marsden, J., Martin, K.A., Martin, L., Pinkerton, J.V., Rubinow, D.R., Teede, H., Thiboutot, D.M., Utian, W.H. (2010) Postmenopausal hormone therapy: an Endocrine Society scientific statement. *J Clin Endocrinol Metab.* 7(1).1-66.
- Santrock, J. W., Bartlett, J.C. (1986). *Developmental psychology: A life-cycle perspective*. Dubuque, Iowa: WC Brown.

- Schmidt, P. J., Cardoso, G. M. P., Ross, J. L., Haq, N., Rubinow, D. R., & Bondy, C. A. (2006). Shyness, Social Anxiety, and Impaired Self-esteem in Turner Syndrome and Premature Ovarian Failure. *JAMA*, 295(12), 1374-1376.
- Sheed and Ward (1989). *Truth and Method* 2nd ed., London
- Shelling, A. N. (2000). X chromosome defects and premature ovarian failure. *Australian and New Zealand Journal of Medicine*, 30(1), 5-7.
- Shelling, A. N. (2010). Premature ovarian failure *Reproduction*, 140 633-641.
- Sigelman.C.K., & Rider.E.A. (2008). *Lifespan human development*.
Wadsworth:Cengage Learning. Belmont.USA.
- Simpson, J. L. (2008). Genetic and Phenotypic Heterogeneity in Ovarian Failure. *Annals of the New York Academy of Sciences*, 1135(1), 146-154.
- Singer, D., & Hunter, M. (1999). The experience of premature menopause: a thematic discourse analysis. *Journal of Reproductive & Infant Psychology*, 17(1), 63.
- Sklar, C. (2005). Maintenance of Ovarian Function and Risk of Premature Menopause Related to Cancer Treatment. *JNCI Monographs*. (34). 25-27.
- Smith, J. A., Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Methods*. London: Sage.
- Smith, J. A. (2007). Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Well-Being*. 2, 3-11.

- Smith, J. A., Flowers, P., Larkin, M. (2009). *Interpretive Phenomenological Analysis: Theory, Method and Research*. London: Sage.
- Sommer, B., Avis, N., Meyer, P., Ory, M., Madden, T., Kagawa-Singer, M., et al. (1999). Attitudes Toward Menopause and Aging Across Ethnic/Racial Groups. *Psychosomatic Medicine*, 61(6), 868-875.
- Speroff, L., Glass, R.H., Kase, N.G. . (1994). *Clinical Gynecological Endocrinology and Infertility* (5 ed.). Baltimore, MD: Williams and Wilkins.
- Speroff, L., Fritz, M.A. (2005). *Clinical gynecologic endocrinology and infertility* (7 ed.). Philadelphia, PA: Lippincott, Williams and Wilkins.
- Stanton, A., Dunkel Schetter, C. (1991). *Infertility: Perspectives from stress and coping research*. New York: Plenum Press.
- Stedman's Medical Dictionary. (2000). *Stedman's Medical Dictionary*, 27 ed Philadelphia: Lippincott Williams and Wilkins.
- Stewart, D. E. (2005.). *Menopause: A mental health practitioner's guide*. Arlington, VA: American Psychiatric Publishing.
- Stubbs, M. L., Cohen, S. M., & Carr, F. (2008). Menopausal Women's Perceived Causes of Hot Flash. *Health Care for Women International*, 29 (7), 755 - 765.
- Teaff, N. L., M.D and Wiley, K M. (1999). *Perimenopause - Preparing for the change: A guide to the early stages of menopause and beyond* (Revised 2nd edition ed.). Roseville, California: Prima Publishing.

- Uchino, B. N., Cacioppo, J.T., Kiecolt-Glaser, J.K. (1996). The relationship between social support and physiological processes: A review with emphasis on underlying mechanisms and implications for health. *Psychological Bulletin*, 119, 488-531.
- Ulrich, M., Wetherall, A. . (2000). Motherhood and infertility: Viewing motherhood through the lens of infertility. *Feminism and Psychology*, 10 (3), 323-336.
- Ussher, J. M. (1989). *The psychology of the female body*. London and New York: Routledge.
- Utian, W. H. (1997). Menopause: a modern perspective from a controversial history. *Maturitas*, 26 (2), 73-82.
- Utian, W. H. (2005). Psychosocial and socioeconomic burden of vasomotor symptoms in menopause: a comprehensive review. *Health Quality and Life Outcomes*, 5 (3), 47.
- Valentine, D. P. (1986). Psychological impact of infertility: Identifying issues and needs. *Social Work in Health Care*, 11(4), 61-69.
- van der Stege, J. G., Groen, H., van Zadelhoff, S. J. N., Lambalk, C. B., Braat, D. D. M., van Kasteren, Y. M., et al. (2008). Decreased androgen concentrations and diminished general and sexual well-being in women with premature ovarian failure. *Menopause*, 15(1), 23-31
- van Karseren, Y., Schoemaker, J. (1990). Premature ovarian failure: a systematic review on the therapeutic interventions to restore ovarian function and achieve pregnancy. *Human Reproduction Update*, 5, 483-492.

- Van Manen, M. (1990). *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. Ontario: The Althouse Press.
- Ventura, J. L., Fitzgerald, O. R., Koziol, D. E., Covington, S. N., Vanderhoof, V. H., Calis, K. A., et al. (2007). Functional well-being is positively correlated with spiritual well-being in women who have spontaneous premature ovarian failure. *Fertility and Sterility*, 87(3), 584-590.
- Weaver, S. M., Clifford, E., Hay, D.M., Robinson, J (1997). Psychosocial adjustment to unsuccessful IVF and GIFT treatment. *Patient Education and Counselling*, 31, 7-18.
- Welt, C. K. (2008). Primary ovarian insufficiency: a more accurate term for premature ovarian failure, *Clinical Endocrinology* (Vol. 68, pp. 499-509): Wiley-Blackwell.
- White, L., Edwards, J. N. (1990). Emptying the Nest and Parental Well-Being: An Analysis of National Panel Data. *American Sociological Review*, 55(2), 235-242.
- Williams, L. S. (1988). It's Going to Work for Me." Responses to Failures of IVF. *Journal of Advanced Nursing*, 39(6), 563-570.
- Williams, R. E., Kalilani, L., Di Benedetti, D.B., Zhou, X., Granger, A.L., Fehnel, S.E., Levine, K.B., Jordan, J., Clark, R.V. (2008). Frequency and severity of vasomotor symptoms among peri- and postmenopausal women in the United States. *Climacteric*, 11(3), 32-43.
- Willig, C., Stanton-Rogers, W. (2008). *The sage handbook of qualitative research in psychology*. Sage, London.
- Wilmot, W. W. (1995). *Relational Communication*. New York: McGraw-Hill.

- Wilson, J., Kopitzke, E. (2002). Stress and infertility. *Current Women's Health and Reproduction*, 2(3), 194-199.
- Woad, K. J., Watkins, W. J., Prendergast, D., & Shelling, A. N. (2006). The genetic basis of premature ovarian failure. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 46(3), 242-244.
- Woolett, A. (1985). Childlessness: strategies for coping with infertility. *International journal of behavioural development*. 8(4). 473-482.
- Wright, J., Duchesne, C., Sabourin, S., Bissonette, F., Benoit, J., Girard, Y. (1991). Psychosocial distress and infertility: Men and women respond differently. *Fertility and Sterility*, 55(1), 100-108.