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**New Zealand Women's Preference for
Treatment Decision-Making when
Considering Hormone Replacement
Therapy.**

A thesis presented in partial fulfilment of the requirements
for the degree of Master of Arts in Psychology at Massey
University.

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ABSTRACT

The menopause phase has increasingly been defined as a deficiency disease amenable to treatment. The main medical treatment for menopause is Hormone Replacement Therapy (HRT). At present very little is known about how New Zealand women make their decisions regarding HRT. What is known is that the medical information concerning HRT is uncertain and doctors are an important factor in the decision-making process. Recent research has shown that there is much dissatisfaction with the service doctors are providing New Zealand women. Much of this dissatisfaction may result from the mismatch of decision-making styles between doctors and women. Accordingly it was necessary to investigate the style preferences of New Zealand women. The aim of the present study was to test the Charles, Gafni & Whelan (1999) theoretical framework for treatment decision-making on New Zealand women considering HRT. The present study seeks to identify three distinct styles of decision-making preference and investigate whether the style preferences are maintained throughout the entire process. One hundred and forty-eight mid-aged women were surveyed about their decisional style preferences. The measure used was designed specifically for the present study and was unique with regard to incorporating stages within the decision-making process. The Charles et al. (1999) framework was found to be an appropriate model for conceptualising the decision-making context of HRT. Support was also found for the dynamic nature of treatment decision-making proposed by Charles et al. (1999) as the three main styles were also found to be amenable to change. The Charles et al. (1999) framework could be a useful educational and assessment tool for doctors and women. Future research is needed to replicate the results of the present study.

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CHAPTER ONE: INTRODUCTION

1.1 Introduction

The menopausal stage of a woman's life can be dominated by the presence of distressing symptoms and a variety of conflicting philosophies about how best to negotiate this life stage. The conceptualisation of menopause as a medical condition in need of treatment results in many women facing the decision about whether or not to use hormone replacement therapy. It is estimated that in 1999 approximately 100,000 New Zealand women were prescribed HRT (Women's Health Action Trust, 2002). The decision these women and many more others faced is complicated by medical uncertainty and how best women and their doctors can interact to produce good decisions.

Recently in New Zealand there have been several studies investigating issues relevant to HRT. For instance, how women manage menopause, their experience of consultations with their doctors (Budge, Stephens & Carryer, 2000) and women's knowledge and reasons for HRT use (Breheny & Stephens, 2000).

At present very little is known about how New Zealand women make their decisions regarding HRT. There has been burgeoning research into how medical treatment decisions are made and how to improve outcomes in terms of patient satisfaction and health states. There is no standardised way of measuring treatment decision-making (Benbassat, Pilpel & Tidhar, 1998) and many of the measures used have not been well validated (Entwistle, Skea & O'Donnell, 2001). The type of condition or illness being considered appears to limit the usefulness of many measures beyond the treatment context in which the measures were developed. A review of the literature indicates that most of these measures are informed and developed through research into life threatening illnesses. As a result the decision-making process relevant to HRT consideration has gone largely un-investigated.

The present study seeks to investigate what New Zealand women prefer in terms of their roles and responsibilities within the doctor-patient relationship. The exploratory nature aims to highlight the needs of women in this decisional context and how best doctors could accommodate these needs.

The remainder of the introduction contains five sections. An introduction to menopause and medical treatment discusses the debate surrounding how menopause is conceptualised in modern society and describes the symptoms that have led to the development of medical treatments. Hormone Replacement Therapy (HRT) is identified in section two as the main medical treatment for menopause and as such the risks, benefits and decision-making contexts are summarised. The doctor is an important influence on HRT decision making. Section three of the introduction looks at the doctor's role in the decision-making process and their role in the level of dissatisfaction New Zealand women report with this service. The traditional medical decision-making models are described within section four, with an emphasis on their respective strengths and weaknesses. These models are then discussed within the theoretical framework that the present study aims to test as being applicable to the HRT decision-making context.

The introduction concludes with a summary of the research domain and the exploratory aims of the present study.

1.2 Menopause and Medical Treatment

Menopause is a normal biological process for women generally occurring between the ages of 40 and 60 years. The word menopause literally means last menstrual period and is due primarily to reduced oestrogen levels. Women become menopausal in a variety of ways but normally experience the process as a gradual transition rather than a sudden event (Johnson, 1997).

The word menopause, however, is also used in relation to the symptoms that may begin a few years before periods stop. The phase commonly called menopause transition or peri-menopause occurs an average four years before a woman's menstrual cycle ceases and is associated with changes in menstrual patterns and frequently the beginning of

vasomotor symptoms, for instance, hot flushes (Johnson, 1997). As menopause draws nearer ovulation stops and so does progesterone production. By the time menstruation has ceased most women are experiencing symptoms. The regularity and severity of the hot flushes, in particular, often increase and for this reason women consider Hormone Replacement Therapy (HRT).

While vasomotor symptoms always spontaneously resolve without treatment (Johnson, 1997) generally within 5 years, late postmenopausal symptoms are said to last for the remaining years of life (Johnson, 1997). Atrophic vaginitis is the major symptom that arises during these years and unopposed estrogens are effective in the reversal of these changes (Johnson, 1997; Kumar & Clark, 1994).

The two major symptoms of menopause highlighted so far are indicative of what the literature terms 'oestrogen-deficiency' problems and as such are amenable to treatment (Griffiths, 1999; Foster, 1995). The concept of treating menopause as a preventable and curable deficiency disease was first argued by American gynaecologist Dr Robert Wilson (Greer, 1992; Rothert, 1990). This development came as an enormous consolation to those previously regarded and treated as neurotic or mad. The ensuing medical model now largely adopted to manage the menopause comprises two key elements: That associated symptoms are of a treatable deficiency disease and that untreated menopause will create potential lethal physical problems (Greer, 1992).

Many other symptoms have been associated with menopause, for instance; sleep disturbances; mood swings and decreased libido (Breheny & Stephens, 2000; Jones, 1999; Johnson, 1997); muddled thinking; anxiety attacks and skin problems (Consumer Institute of New Zealand, 2001). Greer (1992) in particular, states that it is not known which symptoms are physical, psychosomatic or psychological. An additional consideration is that it can be difficult to distinguish menopausal symptoms from those caused by aging or life events independent to the menopausal change. (Foster, 1995; Greer, 1992). Despite the plethora of symptomology commonly associated with menopause, it appears that vasomotor symptoms and atrophic urogenital changes are the only two symptoms which experts agree are conclusively related to the menopause (Foster, 1995; Greer, 1992).

The long-term health effects of decreased oestrogen levels include an increased risk of osteoporosis and cardiovascular disease. Long-term oestrogen replacement therapy may reduce the risk of hip fractures by about 25% and reduce the risk of heart disease by about 50% (Mort, 1996), although these claims appear to be still under examination (Griffiths, 1999). In particular, many experts appear unconvinced that the strong correlation between taking oestrogen during menopause and a lower risk of cardiovascular disease proves a causal relationship (Foster, 1995).

In line with treating menopause as a deficiency disease HRT has become a significant social trend and an important component in the medicalisation of menopause. Gwyn & Elwyn (1992) suggest that medicine itself, and in this case HRT, might be perceived as a metaphor for 'getting well'. This medicalisation lends itself to the influence from other cultural models and values such as ageism. Marmoreo, Brown, Batty, Cummings & Powell (1998) conclude that ageism can become a powerful and even weighted factor influencing decision making in favour of HRT. Griffiths (1999) argues well that what is in effect, although not necessarily blatantly so, playing on women's fear of ageing and for their health as they age is a means to expand medical control over women.

The increasing lay emphasis, proposed by Williams & Calnan (1996), upon the 'unnatural' aspects of modern medical technology, may signify a symbolic fight back for control over the human body. A study of 45 year old women's future intentions cites the main reason for not intending to use HRT is a general proclivity not to take medication and the belief that treatment of menopause is unnatural. Budge et al. (2000) also produce evidence that women are developing critical thinking, and as a result, are challenging the medical discourse to secure power over the decision about taking therapy.

Similarly Hunter, O'dea & Britten, (1997) found that menopause is not a highly medicalised process in practice when looking at medical help-seeking behaviour, but temper that claim when acknowledging the relaxed and perhaps artificial context within which women discussed HRT. Ghali, Freund, Boss, Ryan & Moskowitz (1997), in contrast however, concluded that doctors tend to underestimate how prevalent the medical view of menopause is among many women and to what degree patients view menopause as a medical problem.

The use of consultation rates as a means to operationalise the concept of viewing menopause as a medical problem is suspect, however, as it is difficult to tell whether consultation equates to the conceptualisation of menopause as a medical problem or rather a process where medical reassurance is sought. It may well be that women seek medical advice to assess the normality of their experience or to rule out alternative explanations for their symptoms. This does not necessarily mean that their medical seeking behaviour constitutes them construing menopause as a medical problem.

Griffiths (1999) further states that the medicalisation of menopause is being limited by the activity of women who have been encouraged by the increase in information and the media. However, this activity is limited by the medical uncertainty and the complexity of the information regarding HRT and by their own vulnerability during the menopausal process. What is clear is that beliefs about medication are not fixed, and according to Hunter et al. (1997), can shift depending upon the presence or absence of problematic symptoms.

Sufficient medical information, which is sufficiently confusing, may result in further dependence on medical intervention and interpretation. While women may be perceived as being active, their activity largely appears to be concerned with negotiating medical complexities. It remains unclear whether women would resist the medicalisation of menopause if medical science and practice could satisfactorily provide clear direction.

Regardless of the swing in ideology between medicalisation and the naturalness of menopause, "a women's experience of menopause is inevitably positioned between her perception of bodily changes and discursive constructions of menopause which are influenced by social, political and cultural practices and traditions" (Hunter et al. 1997: p1541). Thus women face potentially conflicting images of menopause, which likely affect both their experience of menopause and their decisions about medical treatment.

1.2.1 Summary of menopause

Menopause is the term used to denote both the normal biological process experienced by women between 40-60 years and the range of symptoms which begin a few years

before periods stop. The menopause phase has increasingly been defined as a deficiency disease amenable to treatment, although it has been suggested that there remains enough support for the natural conceptualisation of menopause so as to offer resistance to such medical control.

1.3 Hormone Replacement Therapy

The main medical treatment for menopause is Hormone Replacement Therapy (HRT). New Zealand guidelines state that HRT is the best medical treatment available for menopause (New Zealand Guidelines Group, 2002). The number of New Zealand women taking HRT has doubled between 1991 and 1997 (North & Sharples, 2001). The use and promotion of HRT is the focus of much medical activity (Griffiths, 1999), and increasing sociological and psychological research. In particular, recent research has been concerned with investigating the experience and implications of HRT and women's attitudes and experiences of both the treatment and the medical service provided to them. There are a variety of New Zealand based studies exploring the New Zealand women's experience of menopause and HRT (Breheny & Stephens, 2000; Budge et al., 2000). Some of these studies point to a need to better understand how New Zealand women make decisions regarding HRT, which is supported by other studies world wide (Benbassat, Pilpel & Tidhar, 1998; Degner, Kristjanson, Bowman & Sloan, 1997; Mort, 1996). These studies point to a need to better understand treatment decision-making styles and preferences in general. What follows is a brief introduction to HRT and a summary of relevant research concerning its application, implications and complexities, all of which highlight a need for much better understanding of the decision-making process.

Hormone Replacement Therapy (HRT) is the name given to describe oestrogen and progestin regimens used to replace naturally depleting levels of these hormones following a woman's transition through peri-menopause and post-menopause phases of her life. HRT can be prescribed as a means to alleviate menopausal symptoms. Clinical evidence on the whole would appear to support the claim that HRT alleviates hot flushing and vaginal atrophy (Foster, 1995) as would the evidence of many menopausal

women themselves who claim their symptoms were relieved. Indeed Rosenberg (1993) states unreservedly that unopposed oestrogens can reverse atrophic urogenital changes.

Whilst the claim that HRT is an effective treatment for vaginal atrophy is widely supported (Johnson, 1997; Rosenberg, 1993; Rothert et al., 1990) there are some reasons for caution when considering the claim that HRT offers relief from hot flushes. Griffiths (1999) cautions that there is a lack of correlation between hormone levels and the experience of hot flushes. In fact, scientific knowledge concerning what happens to a woman's hormones during the menopause is as Foster (1995; p.67) states "most notable for its absence".

HRT is also offered as possible protection from long-term conditions thought to be related to hormonal deficiencies, for instance cardiovascular disease and the more prominently promoted osteoporosis. The North & Sharples (2001) research indicates that more New Zealand women are now taking HRT to prevent possible future illness rather than symptom management. Observational studies indicate unopposed estrogens protect against cardiovascular disease (Rosenberg, 1993), but some suggest this claim is still under debate (Griffiths, 1999; Hunter et al., 1997). In particular, many experts appear unconvinced that the strong correlation between taking oestrogen during menopause and a lower risk of cardiovascular disease proves a causal relationship (Foster, 1995).

Likewise Foster (1995) states it appears odd that HRT - being very similar to the combined pill which is known to increase the risk of cardiovascular disease in young women - should be prescribed to protect older women from the same disease. HRT's possible positive effect on cardiovascular disease should further be accepted with caution as only long-term use can be expected to lower the risks (Jones, 1999). The long-term use of unopposed estrogens, however, may increase the risk of breast cancer and endometrial cancer (Jones, 1999; Rosenberg, 1993). This risk is thought to persist long after cessation (Rosenberg, 1993).

Oestrogen is similarly considered as effective protection from osteoporosis (Jones, 1999; Mort, 1997; Rosenberg, 1993; Rothert et al., 1990) although as with the cardiovascular disease claim, critics maintain only long term use, perhaps as much as seven years, is needed to demonstrate a significant benefit (Foster, 1995).

To counter some of the risks associated with unopposed oestrogen use, progestin is added to the regimen and there is evidence that the addition of progestin to HRT reduces the risk of endometrial cancer caused by unopposed oestrogen (Jones, 1999; Rosenberg, 1993). This introduction may also offset some of the positive effects of oestrogen in the prevention of heart disease (Jones, 1999). Although the medical research to date is uninformative Rosenberg (1999) suggests that progestin could actually increase the risk of cardiovascular disease. The medical data is further complicated by the fact that at least five years use is usually recommended in order to derive long term health benefits. This may be construed as a double bind, however, as women on HRT for over five years are more at risk for developing breast cancer (Jones, 1999; Foster, 1995).

There is little empirical evidence to suggest that HRT can relieve psychological problems such as depression and anxiety (see Usher, 1989 cited in Foster, 1995), which may well be seen as support for, among others, Greer's (1992) claim that too many ailments are being assumed as attributable to menopause. Prescribing hormones for unrelated psychological problems is likely to be largely ineffective unless such medication acts as a powerful placebo (Foster, 1995). However depression and anxiety may, in many cases, be a product of the experience of symptoms such as hot flushes and, therefore, may be relieved as a consequence of HRT's effect on the menopausal symptom itself.

There have been rapid changes in attitudes about HRT use over the last 20 years (Newton et al., 1997), probably related to the inculcation of the medical model of menopause and the assertion of women's rights to achieve medical credibility and intervention when experiencing symptoms. Where once women were regarded as neurotic for experiencing symptoms for which no medical intervention was offered or deemed necessary, they have now become patients with disease through an attempt to achieve medical consideration.

HRT is an unusual medication because it is justifiably prescribed to women who as yet have no obvious health problems (Hunter et al., 1997). But this raises issues as to whether powerful drugs should be used to prevent possible illness among healthy people (Rosenberg, 1993). Especially since it is not always easy to identify high-risk

women. In the case of those at risk of osteoporosis, for instance, densitometry is not shown to be an effective screening measure for hip or vertebral fractures (Rosenberg, 1993). HRT is also unusual as the management of symptoms and the possibility of prophylaxis are offered within the one regimen (Budge et al, 2000).

In summary, there is continuing scientific uncertainty surrounding the risks and benefits of HRT use and how women can best use the existing information to make it personally relevant to their medical status, concerns and goals. The level of scientific uncertainty may well manifest through the high adherence problems associated with HRT use, which the literature shows has been an important impetus for further research.

1.3.1 HRT adherence

The majority of past HRT users stopped taking therapy on their own rather than on their doctor's advice (Newton et al., 1997). Two-thirds are reported by Hunter et al. (1997) to have stopped within nine months citing unacceptable side effects, in particular monthly bleeding. Newton et al. (1997) also found that concerns about bleeding are particularly strong deterrents to HRT use. However Sarrel (1999) suggests that this is a reason for discontinuation rather than refusal to initiate treatment. The development of HRT treatment regimens that eliminate bleeding appears essential to making HRT acceptable to many women (Newton et al., 1997).

Unrealistic expectations, such as that HRT will directly improve their well being, probably also contribute to the well known adherence problems of HRT use, as women who become disappointed with the results stop treatment (Liao, Hunter & White, 1994). Evidently the high consultation rates together with the extensive adherence problems suggest many women consult for support and information not necessarily treatment (Liao et al., 1994). This support and information service may well be neglected by doctors due to their misinterpretation of medical seeking behaviour as treatment seeking behaviour.

It has been proposed that the long-term continuance rate is highest for those who leave the doctors office understanding exactly why they are taking HRT (Sarrel, 1999). This

suggests that some women initiate therapy without fully understanding why they should do so and begs the question as to what role their doctor plays in colluding with this situation.

1.3.2 The decision to use HRT or not

Given the adherence problems associated with HRT and the suggestion some women initiate therapy without being privy to any decisional process, an examination of factors possibly influencing decision making appears warranted. The decision to use HRT or not is complex and the uncertainty about the risks and benefits makes the decision more difficult (Griffiths, 1999). Women's decisions appear to be influenced primarily by concurrent or relatively short-term issues as opposed to long-term prevention (Hunter et al., 1997). Hunter et al. (1997) concludes that hot flushes and disruption of daily life are larger considerations than morbidity and the mortality risk. This would indicate women adopt a symptom management attitude toward taking therapy.

This finding is, however, in contrast to Griffith's conclusion (1992) that fear of cancer is shown to be closely related to the attitude women develop concerning HRT. It may be that fear of cancer is not afforded the same aversive consideration when making an actual decision to take therapy or not. Alternatively it may be that short term issues are more salient among those inclined to favour HRT, but the mortality risk remains a larger influence for those women not so inclined.

Most women in the Budge et al. (2000) study were concerned not to become passive recipients of the decision made. The Jones (1999) study supports this finding and shows that nine out of thirteen users made their own decision to use HRT. The principle factor considered was the short-term negative body changes attributed to menopause, for instance the hot flushes, sleep disturbance, heavy periods, depression, atrophic vaginitis and decrease in libido. The mediating factor appears to be when initial symptoms are compounded by further symptoms. Within this group of decision-makers women appeared more likely to rely on their own feelings and subjective intuition, especially given the medical uncertainty surrounding HRT (Jones, 1999).

Some women realised the problem of deciding whether or not to take HRT was not so much of uncertainty but equivocality. Meaning a lack of information is not as problematic as dealing with multiple conflicting interpretations (Bond & Bywaters, 1998). This claim is supported by Bond & Bywaters later work (1999) and Budge et al. (2000), as they found that the strongest feature of the decision-making process is the need to interpret the risk/benefit ratios in a way that had personal relevance. The process of interpreting medical information generally involves or may be left entirely to a woman's doctor whose influence can effect both the interpretation and the resulting decision.

1.3.3 Summary of Hormone Replacement Therapy

Hormone Replacement Therapies have been designed to replace the depleting levels of hormones due to menopause. They offer relief from symptoms associated with the decrease in hormones as well as protection from long term conditions thought to result from hormone deficiencies. The risks however include an increased risk of breast cancer and endometrial cancer. The scientific uncertainty surrounding the risks and benefits and whether powerful drugs should be used on at present healthy women make Hormone Replacement Therapy an unusual and complicated medication in need of careful consideration. These factors may well be associated with the considerable adherence problems.

The media, family and friends are important sources of information about therapy but none are found to directly affect attitudes. Fear of cancer however is closely linked to attitudes and impacts on the degree of choice women feel they have. While short term considerations were found to primarily influence women who decide to take therapy the risk of cancer remains as the major influence not to take therapy for those who choose not too. Different styles of decision making have been identified although neither shared nor paternalistic styles were entirely satisfactory. It may well be that one style can not suffice all aspects of the process let alone all women concerned in the process. It appears interpretation of the risks and benefits is the strongest feature of the decision making process and because this process is fraught with medical uncertainty the doctor plays a vital role in providing sound support.

1.4 The Doctor

Historically doctor recommendations are important determinants of treatment decisions (Mort, 1996). Doctor influence is identified by Hunter et al. (1997) as one of the three main themes when women are asked about their own decisions about HRT use. It is predominantly because of the complexity of medical information that women need to trust doctors with interpretation (Griffiths, 1999), yet attitudes and preferences of doctors and women are known to differ, especially regarding health outcomes associated with HRT (Mort, 1996). While the literature suggests that patients are better suited than doctors to judge the value of health states (Mort, 1996) there is evidence that many women are subjected to their doctor's judgement and bias regarding preferred outcomes. (Hunter et al. 1997; Mort, 1996; Quill & Brody, 1996; Unic, Verhoef, Stalmeier & Van Daal, 2000.)

The concept of risk aversion is a possible cause of doctor bias. Unic et al. (2000) cite Elstein et al. (1986) concerning a lack of concordance between physician's decisions and decision analytic recommendations regarding the prescription of therapy to menopausal women. It is suggested that the main reason for the discrepancy is that doctors place considerable emphasis on the risk of endometrial cancer in their decisions. This would imply that they adopt a risk adverse attitude (Unic et al. 2000), which may be in contrast to the symptom management attitude of many women, particularly those inclined to favour HRT.

Doctors have been found to be less knowledgeable about hormone therapy rather than more knowledgeable (Ghali et al., 1997) and are often perceived as no better informed than the women (Budge et al., 2000). A surprising finding considering that it appears many doctors continue to give authoritative advice on this subject when they may actually know remarkably little about it other than, through the somewhat cautious endorsement offered by the FDA, for instance, there exists a safe and effective form of treatment (Foster, 1995).

Several studies have found that doctors are not the major providers of information about HRT (Budge et al., 2000; Jones, 1999; Griffiths, 1995), which may in part be due to

them underestimating patients desire for information (Ghali et al., 1997; Ong, de Haes, Hoos & Lammes, 1995; Waitzkin, 1984). Whilst the lack of doctor provided information is an often cited barrier to effective decision making and impinges on patient satisfaction (Kettunen, Poskiparta, Liimatainen, Sjogren & Karhila, 2001; Jung, Van Horne, Wensing, Hearnshaw & Grol, 1998), Kettunen et al. (2001) assert that it can not be assumed that all patients want to receive more information and more participation.

In addition, doctors also tend to overestimate patient's general concern about heart disease and breast cancer (Ghali, 1997). This may be among 'pro HRT' patients only as 'anti HRT' patients cite this as the most important factor influencing them not to take HRT (Budge et al., 2000; Jones, 1999; Sarrel, 1999). Budge et al. (2000) found that some doctors suggest to their patients that they should use HRT but did not satisfactorily explain why. While Mort (1996) states most physicians would agree that the decision to take HRT should be individualised, the evidence highlighted so far would suggest that this is not always practiced.

Bond and Bywaters (1998) suggest that it is in spite of, rather than assisted by, their doctors that women interviewed in their study came to an enhanced understanding about what was best for them. Likewise Budge et al. (2000) found that doctors were frequently described as 'not interested' and women felt they were treated like 'hypochondriacs' for presenting with vague complaints that are difficult to quantify. They claim some doctors were persuasive in their method of presenting information or advice about HRT, and in turn that women are quick to sense when their doctor believed HRT was the desirable option (Budge et al., 2000).

Similarly Guadagnoli & Ward (1998) report research showing one in four mothers of children with acute medical problems had not mentioned their greatest concern because they felt that they were not given the opportunity or not encouraged to do so. This would suggest that patients need encouragement or at least a facilitative atmosphere to express matters of concern to them and that often doctors are not providing this environment when needed. The problem may be more in identifying which patients require these considerations.

Many women fear that they only hear the good side of HRT because doctors and pharmaceutical companies are perceived as being affiliated (Budge et al., 2000). Mort (1996) suggests further that the doctor may be perceived as a 'double agent' and this perception compromises the covenantal relationship. While women are often critical of their doctors, especially in the safe environment provided through focus group research, some still accept their advice (Budge et al., 2000; Griffiths, 1999). This finding offers further support for the need to acknowledge the strength of the doctor's influence in the final decision and the need to either limit this or enhance it depending on the preferences of the patient.

Bearing in mind the responsibility and perhaps pressure doctors may feel is placed upon them in decision making, the authoritative rather than affective aspects of their manner may well be emphasised and indeed deemed necessary to convey competence. It is affective behaviour, however, that seems to be important in determining patient's satisfaction (Bensing, 1991). Doctors may not need to be concerned about being perceived as less competent by their patients when they encourage patients to take a significant role in the treatment decision making process (Hailey, Willoughby, Butler & Miller, 1998).

Related to this affective skill is the assumption that a better understanding of beliefs underlying women's decisions can assist in developing more effective strategies to ensure women make informed decisions about initiation and maintenance. Doctors need to increase their attention to patients' menopausal attitudes (Budge et al., 2000; Ghali, 1984; Hunter et al. 1997; Rothert et al., 1990), and they must become expert at learning about patients as unique human beings (Quill & Brody, 1996) if they are to put into practice the acknowledged right women should have to individualised decision-making.

Another barrier to achieving better understanding is that medical jargon can be used and understood differently by the doctor and the patient (Hadlow & Pitts, 1991). The widest gaps in interpretation include the term 'depression' (Hadlow & Pitts, 1991; Ong et al., 1995), which is significant because depression or rather depressive like symptoms is a common cause of concern for menopausal women and a common reason for initiating medical consultation.

Through communicative styles, patients can exert considerable control of the information that they receive, for instance, if they express concern, frequently ask questions and express worries and emotions, they can receive more information. These patient characteristics may be seen as indicators by doctors as to how much information they should deliver, but women have been found to often not know what to ask. Relying on a glimpse of patient communication style is surely not sufficient a means to judge their level of preferred involvement. Both Ong et al., (1995) and Street (1991) found that the more educated and younger patients received more diagnostic information. This may suggest that menopausal women of today may be disadvantaged through social constraints and the legacy of an arguably once more subjugated gender role.

While women often hold unorthodox views and challenge medical discourse in relaxed settings like focus groups it remains unclear whether they could express this in doctor-patient interactions.

1.4.1 Summary of the doctor

The doctor is an important influence on treatment decision making. Focus group research has highlighted considerable dissatisfaction with the service doctors are providing New Zealand menopausal women. While factors such as the doctor's perceived lack of information, knowledge and interest, along with their perceived personal bias, an affiliation with pharmaceutical companies, and their use of medical jargon are common complaints from women themselves, it is the doctors affective behaviour that appears to influence patient satisfaction.

A need for doctors to gain a better understanding of women and pay more attention to their attitudes is indicated by previous research. This may be best demonstrated when the doctor accommodates to the women's style or level of preferred participation, rather than impose their own personal preference to any interaction. Previous research also suggests that assuming such preferences without formally discussing it is just as unsatisfactory and possibly as inaccurate as expecting women to adopt the style of interaction best suited to the doctor (Benbassat, Pilpel & Tidhar, 1998). While there is evidence to suggest that doctors acknowledge the need to individualise care, there is

also evidence that this is not always practiced. Perhaps the failure to accommodate this need lies more in the lack of definition of individualised care rather than in any resistance to service it. Again it is suggested that individualised care can best be achieved through accommodation to the patients preferred style of decision-making.

1.5 Decision making models

Treatment decision-making styles may be largely defined by the roles and responsibilities each participant adopts within the decision-making process. In the case of medical decision-making the participants are primarily the doctor and the patient. Individual patients inevitably have different preferred styles of making decisions with their doctor (Benbassat et al., 1998). Likewise different doctors may be more inclined to favour differing decisional styles with their patients. Benbassat et al. (1998) state that styles exist on a continuum in reality and many everyday clinical decisions likely reflect a hybrid model (Charles, Whelan & Gafni, 1999). It appears, however, that a presentation of the three main styles is the best way to conceptualise the different ways of making treatment decisions. The three main medical treatment decision-making styles previously identified and often cited in the decision making literature are 'paternalistic', 'shared' and 'informed' (Benbassat et al., 1998; Charles, Gafni & Whelan, 1999; Gwyn & Elwyn, 1999; Marzuk, 1985; Quill & Brody, 1996).

Decision-making styles are an important aspect of doctor-patient interaction, especially in medical problems for which there is no best treatment and a complex decision making context. It is suggested that patient preferences for different styles are important and must be recognised, as they affect the doctor-patient relationship (Benbassat et al. 1998). Determining such preferences may well be regarded as a basic clinical skill (Benbassat et al. 1998).

The decision making process itself has been proposed by Charles et al., (1999) as being comprised of three distinct analytical stages; information exchange; deliberation; and the final decision making. The legitimacy of the claim that there are three distinct stages is important not only as a means to accurately identify each particular decision making

style but also as a means to account for why one style is not always entirely satisfactory throughout the entire process. An examination of the doctor-patient interactions within each stage will be used as a means to identify the different decision-making styles.

1.5.1 The paternalistic model

The paternalistic approach to treatment decision making operates with the doctor assuming the dominant role. The paternalistic style is identified through doctor dominance in all three stages of the process. The doctor initiates what information is discussed and typically limits this to medical information delivered from doctor to patient, in an amount seen as appropriate by the doctor. The patient participates only through the provision of their medical history and symptomology, which is generally delivered by means of answering doctor initiated questions. The paternalistic style is further characterised by the doctor assuming responsibility for considering any treatment choices that may exist and making the final decision on behalf of their patient. Professional authority is afforded based on the assumption that the doctor is in the best position, given their clinical knowledge and experience, to exercise professional concern for the welfare of their patient and act according to their best interests.

Quill & Brody (1996) state that 25 years ago most major treatment making decisions were made exclusively by the doctor. The Hippocratic Oath was, as cited by Nadelson (1991:p9), “unique in emphasising the cure of the patient as the single over-riding responsibility of the doctor”. Due largely to such a claim of beneficent intent the paternalistic model could be relied upon and more importantly justified. “Subsequently medical ethics has also been concerned with the dignity, honour and reputation of the profession” (Nadelson, 1991:p9). The dual responsibility casts doubt over such previously relied upon assurances and has lay the paternalistic approach open to scrutiny.

Among the many points of contention, Quill & Brody (1996) highlight inappropriate biases caused by gender, ethnicity and SES, which manifest as a result of the full authority assumed by doctors and affects the treatment decisions made. Without the

opportunity to be involved in treatment decisions the patient's best interests are often difficult to determine and as such, the decision and the treatment are potentially subjected to biases and the influence of incongruent doctor-patient values. Quill & Brody (1996) state that the paternalistic approach may be detrimental because patients may compromise their care by developing a negative response to the paternalistic posture in the form of being mistrustful and unwilling to accept advice. They may also overreact to statements about risks and side effects if such information is delivered within this style (Nadelson, 1991). Medical power in consultation may suppress the expression of unorthodox views (Hunter et al. 1997), a situation which may later be expressed through 'non-compliance'.

It is no wonder, therefore, that paternalistic decision-making has been largely criticised, especially surrounding issues concerning what Nadelson (1991) terms as, appropriate definition and scope or whether paternalistic justifications can be morally acceptable. The paternalistic approach to decision making, rather than relegated to extinction due to all of the perceived flaws, however, remains a current and well-practiced method of making decisions. There is research to suggest much of the benefit thought to be derived from non-paternalistic styles is suggestive and provides an unconvincing basis for the critique of the paternalistic style (Guadagnoli & Ward, 1998; Maruk, 1985; Taylor, 2000). The attitudes and values of some doctors also support the paternalistic approach. For instance, Elwyn, Edwards, Gwyn & Grol, (1999) found medical registrars often initiated the paternalistic style during their consultations, with the underlying assumption being that most patients do not want to be involved, and further, the doctors assumed that they were good 'intuitive' judges of the patient's preferences.

Guadagnoli & Ward (1998) implicate patient driven dependency when they suggest that some patients may adopt a passive role because that is what they have done in the past and they may be unaware that there are different options available. Historically paternalism has been so dominant according to Kettunen et al., (2001) that patients are accustomed to leaving matters to medical staff. Subsequently, Guadagnoli & Ward (1998) state that because the paternalistically inclined patient has not reached a level of readiness to assume more collaborative responsibility, it is the doctor's responsibility to encouraged such development.

The paternalistic approach to decision-making is an approach now very much out of favour with those who research and inform the medical profession in relation to treatment decision making. The fact that this approach continues to be employed has seen burgeoning research attempt to contextualise the when, why and how it has endured, as a means to identify which aspects of both patient and doctor may still be supporting its use. The goal often is to then provide direction in the form of ‘collaborative re-education’ for doctors and patients in an attempt to steer them toward the more politically correct shared approach.

Of course, the paternalistic style may in fact be favoured by some simply because it is in fact their preferred style. The approach may be particularly attractive in situations where the patient feels unable to cope with the responsibility of making decisions, perhaps due to current life events. Others may favour this approach when the medical information is confusing and, hence, they choose to defer to the doctor’s experience with similar situations and patients. Some patients may prefer to keep the doctor-patient interaction and relationship removed from personal issues, especially when such interaction concerns more intimate topics. The paternalistic approach therefore offers a reassuring personal distance, for which, some patients are happy to concede control.

In the mission for researchers and practitioners to push the shared model remarkably little attention has been paid to the notion that some patients, for whatever reasons, may prefer the paternalistic approach to decision making. In the rush to banish paternalism from the consultation room there are patients who may miss out on their preferred style because it has been generalised as less effective and less correct. Some patients, however, evidently achieve support from the medical profession’s continued implementation of what is fast becoming the politically incorrect paternalistic approach. Taylor (2000) supports this view and concludes that these people must not be forgotten.

1.5.2 The informed model

The informed model of treatment decision-making was developed largely in reaction to paternalism (Charles et al., 1999). Originating in the United States as a means to limit malpractice suits, the informed approach sees the locus of decision making shift toward the patient and their family (Nadelson, 1991). Whilst all treatment decisions can only be implemented having achieved informed consent, this legal requirement is not to be confused with the informed model of treatment decision making. The model itself is more patient autonomous and is characterised by complete patient deliberation and decisional responsibility. The purpose of the consultation is to provide the patient with all of the medical information they require to make their treatment decision.

The litigious climate, in the United States especially, and the fear of encroachment on patients rights may cause many doctors to become what Maruk (1985) terms noncommittal. They provide a mass of medical facts and information and leave the decision making to the patient. While this may mean that the patient is positioned well to make the best decision for themselves, much of the truly beneficent potential of medical paternalism is lost (Quill & Brody, 1996). Another consideration is the potential risks to patients including increased anxiety and the experience of regret if there is an adverse outcome when the decision is heavily patient influenced (Nadelson, 1991).

Some patients in response to less than satisfactory service from their doctor in the past may well adopt the informed style. The experience of not being listened to or being given adequate time and consideration may mean many choose to assume responsibilities previously afforded to their doctor. The spread of consumerist attitudes into the health sector and the availability of alternative sources of information and medical resources undoubtedly aid this scenario.

The informed style may be particularly attractive in situations where no one best treatment exists and the risks and benefits must be calculated according to personal and subjective values. Less than adequate previous experience, a growing consumerist awareness and a growing source of alternative information and resources may mean

some patients choose to adopt the responsibility of making their own treatment decisions.

1.5.3 The shared model

As with the informed model the shared model of treatment decision making was developed to negate some of the shortcomings of paternalism. The shared decision-making model operates under and according to the notion of collaboration. The doctor and patient exchange information; the patient leads in the areas where they are the experts, such as their symptoms, preferences and concerns, while the doctor leads in their domain of expertise, specifically the details of the disease and the treatment options (Quill & Brody, 1996). Information exchange is therefore reciprocal and flexible according to patient needs, while deliberation and decision-making are undertaken in partnership.

Quill & Brody (1996) conclude this approach is relationship centred rather than exclusively patient-centred. Shared decision making is described by Gwyn & Elwyn (1999: p439) as an “interesting blend of the humanistic medical philosophy of patient-centeredness and newly resurgent and ever growing consumerism”. Quill & Brody (1996) also suggest that the model should ideally be open with respect to not denying potential imbalances in power; open dialogue is assumed to admit biases and is a better protector than artificial neutrality.

Much of the recent research widely acknowledges that patients should play a more active part in treatment (Avis, 1994). Further that there exists a need to “develop methods of involving patients that seem neither insincere nor rhetorical” (Elwyn et al., 1999: p755). Avis (1994) cites research which concludes that involvement in treatment decisions gives patients more control, appears also to improve outcome, and may increase the effectiveness of treatment (Coulter et al. 1999), although Guadagnoli & Ward, (1998) state that the evidence for a positive outcome for patients who participate in decisions about their medical care is suggestive rather than conclusive. Likewise the Benbassat et al. (1998) review of the decision-making literature highlights much inconsistency over whether active participation is associated with higher patient

satisfaction. Shared decision making, nevertheless, is attracting substantial attention as a means by which patient's preferences can be integrated into clinical decisions (Coulter et al. 1999) to achieve such benefits.

Sharing decisions entails sharing the uncertainties and involves exposing the fact that data are often unavailable or not known. This can cause anxiety to both the patient and the doctor (Elwyn et al., 1999). High quality shared decision-making also requires convenient access to current information (Mort, 1996). The benefits associated with shared decision making include that therapy is concordant with the values and preferences of the patient (Elwyn et al. 1999; Guadagnoli & Ward, 1998). Guadagnoli & Ward (1998) state that satisfaction with the decision-making process is increased, as is compliance with treatment. Some times even though the decision may not change during the collaborative or negotiation processes, Quill & Brody (1996) point out that the meaning of the decision to both of the participants may be more fully appreciated. Of course other times Quill & Brody (1996) also suggest that the exploration may lead to a better decision. Sharing the treatment decision may also unburden the doctor when there is a lot of uncertainty about what is the best thing to do (Elwyn et al. 1999).

It is not easy, however, for those used to the paternalistic model to play a more active role (Bond & Bywaters, 1998; Budge et al., 2000). They may in fact become reluctant collaborators (Waterworth & Luker, 1990). Likewise while some patients may reasonably expect to be involved in decisions, engaging in the shared process is not always easy for health care professionals (Simmonds, 2000) who face constraints due to time, resources, communication difficulties and often lack of training with respect to collaboration and negotiation.

Sharing decisions is considered appropriate in situations of professional equipoise, when a choice exists between two or more viable options (Elwyn et al., 1999; Gwyn & Elwyn, 1999). Gwyn & Elwyn (1999) state that equipoise must first exist in order for shared decision making to take place and thereby justify the term and that equipoise is in fact the key factor in identifying the contextual framework that facilitates the 'sharing' of decisions. As such, when there is a choice of two or more viable treatment options there is a strong case for offering patients the choice to participate in making the treatment decision. (Coulter et al. 1999) The shared approach undoubtedly offers many

benefits to patients seeking collaborative input into their treatment decision making. It is not, however, without shortcomings.

1.5.3.1 Controversy with the shared model

There are practical limitations inherent to the shared model of treatment decision-making such as a lack of time necessary to commit to effective shared decision-making (Elwyn et al., 1999). Likewise patient instrumentalism limits participation in decision-making (Avis, 1994). Guadagnoli & Ward (1998) suggest that such instrumentalism manifests when patients are more concerned with doing what is right like pleasing the doctor than in participating in decision making.

Waitzkin (1984) highlight further barriers to adhering to the shared philosophy by saying that it is not enough to simply elicit information from the patient as a means to encourage sharing, as this can amount to an interrogation that is subtly dominating and can interfere with the preferred mutual exchange of information. The final result of such potential pressure, according to Waitzkin (1984), is that the patient input is inevitably stifled. There also exists a potential for the patient to cause covert damage to their medical care, as according to Gwyn & Elwyn (1999), they might be seen to be symbolically challenging the status quo of medical knowledge by questioning the authoritative voice of medicine through initiating topics.

Along with the practical limitations, the shared model may also be critiqued with regard to its validity or the model's utility to negotiate the complexities it is purported to be able to. For instance, Waterworth & Luker (1990) dispute the claim that patient rights-which this model is envisaged as custodian too - are synonymous with their collaboration and cite Levin et al. (1977) to suggest that perhaps some people prefer to remain passive and dependent. The Waterworth & Luker (1990) research concludes that promoting individualised care - as has been deemed appropriate for HRT consideration - does not mean initiating active patient involvement for all. Patients' desire for information and involvement in decision making is not universal (Mort, 1996; Ong et al., 1995). In fact the need for information and involvement in decision-making is not necessarily correlated (Mort, 1996). This is supported by the Benbassat et al. (1998)

review of patients' preferences for participation in clinical decision-making when they conclude that the preferred level of participation in information seeking and actual decision-making differ; the former resulting in higher participatory preferences.

Finally, the shared model can be discussed in terms of features and flaws, as a means to critique its potential for patients and as a means to contrast it against other models. However, some claim the very nature of whether such a model exists, except in theory in an idealised analysis of doctor-patient interaction, should first be investigated before espousing its merits. Any attempt to adopt equality in doctor-patient relationships would only be a simulation according to both Guadagnoli & Ward (1998) and Gwyn & Elwyn (1999), and leaves intact the essential nature of the power imbalance. Nadelson (1991) claims, for instance, that whether the individual relationship is paternalistic or not, the paternalistic nature of the profession may still influence the patient's decision and hence cast doubt over the notion and merits of collaboration.

Nadelson (1991) concludes that there is in fact an increase in paternalism in the United States health care system even though there has been a decrease in paternalism in relation to individual doctor-patient relationships. The paternalistic nature has shifted from doctors into bureaucracies (Nadelson, 1991). Support for this claim may come from the observation that although more women participate in the medical profession their relative absence from policy-making positions essentially preserve this traditional type of paternalistic perspective (Nadelson, 1991).

It has been proposed that the specific attitude regarding shared decision making seems to be exhibited through the more general consumerist attitudes (Kim et al., 1993). Avis (1994) describes the current conceptions of consumerism as a 'supermarket' version of involvement, however, where the patient/consumer chooses the time and place but has no part in the processes of production. "Consumerism reinforces the status quo by focusing on the patient as consumers of health care rather than producers of health" (Avis, 1994: p296).

Gwyn & Elwyn (1999) used discourse analysis on the transcript of a consultation involving a request for antibiotics for a child's sore throat. Although attempting to participate in a collaborative approach the authors claim that by introducing new terminology, initiating turn-taking sequences and controlling topic choice the doctor is

effectively sabotaging the chances of a genuinely negotiated shared decision.

Asymmetry is also interactionally achieved - Patients often exhibit “a central concern to avoid any response that could serve to imply that the participant’s versions and assessment of the conditions had an equivalent status” (Gwyn & Elwyn, 1999: p442).

This issue of asymmetry in the doctor-patient relationship is similar to the instrumentalism consideration highlighted earlier as a practical limitation. Avis (1994) supports the legitimacy of this barrier to the shared approach when he suggests that patients limit the intrusion of the medical profession into their personal lives by ‘receiving’ care instrumentally, in essence becoming a work objects. This receiving of care is done at the expense of participation and Avis (1994) appears to conclude that this is the major factor limiting the shared approach.

1.5.4 Summary of the decision making models

The paternalistic style is characterised by the doctor assuming the dominant role. Information exchange is largely one-way and medically orientated, with the doctor controlling the provision of medical information and eliciting only essential medical facts from the patient. Deliberation and decision-making remain the responsibility of the doctor and the patient maintains a largely passive role during the process.

The informed style sees the locus of decision-making shift toward the patient. Information exchange is likewise largely one-way and medically orientated, with the patient being provided with all of the relevant medical information to enable them to consider their choices and make their final decision. The doctor remains largely removed as the patient adopts the active role in the process.

The shared style is characterised by the doctor and patient collaborating during each aspect of the process. Information exchange is reciprocal and consists of personal as well as medical information. Each partner leads in the area of his or her own expertise. Deliberation and decision-making are achieved through negotiation as both partners seek to have their respective needs and concerns met.

These three decision making styles are distinct with regard to how information exchange, deliberation and the final decision are conducted. Distinct roles are adopted by both the patient and the doctor within each style and because these roles are reciprocal and interdependent it is often the patient who must adopt the role assigned to them through medical dominance, misevaluation or habit. Further to this the three styles are often cited as either/or propositions. Each style has been afforded a tenure of popularity only to be replaced as the 'style de jeux' by the next style, devised largely in reaction to its predecessors obvious flaws. The current climate of 'collaboration as ideal' is also not without flaws however and there remains a need to acknowledge and harness the positive aspects of each style.

1.6 The Charles, Gafni & Whelan Model of decision-making

Charles, Gafni & Whelan (1999) propose a framework of treatment decision making that incorporates a more dynamic perspective to the decision making process. The proposed framework includes all three models; paternalistic, shared and informed and acknowledges that each decision making model can be utilised with benefit depending on the preferences of the patients involved. Rather than continue along the path of advocating the shared model to the possible detriment of those not so inclined, this framework seeks to include all approaches so that the patient may be afforded a suitable match.

The three main models of treatment decision-making; paternalistic, informed and shared are described within three distinct analytical stages in the decision-making process; information exchange, deliberation and the final decision. The model clearly and effectively defines the characteristics of each style within each stage and provides necessary description of the general path each model follows including behavioural expectations of doctor and patient.

Information exchange, in accord with the paternalistic style of decision-making, is largely one-way from doctor to patient. It is concerned with medical information in an amount to satisfy the minimum legal requirement. The shared style of information exchange is listed within the framework as two-way between doctor and patient. It is

concerned with both medical and personal information in any amount seen as necessary by either party for decision-making. Finally, the informed style is defined as largely a one-way flow of information from doctor to patient. The information is medical and is also sought in any amount deemed necessary for decision-making.

The deliberation stage is likewise listed in terms of the defining characteristics of each style. Paternalistic is described as doctor alone or with other doctors. Shared is alternatively described as doctor and patient (plus potential others) and informed as patient (plus potential others). The paternalistic, shared and informed style of the final decision is simply characterised by doctor, doctor-patient and patient respectively.

The authors claim the framework has many advantages;

- it provides clear and necessary description of the various analytic stages in the decision making process
- it can be used by doctors to help explain the various approaches that can be used
- it makes explicit the possibility that each treatment decision-making process can combine elements from different models at different stages, and
- reinforces the importance of flexibility so the doctor can identify and respond to changes in patient preferences (Charles et al. 1999).

The Charles et al. (1999) framework to treatment decision making has been devised and informed through their research on the meaning of shared decision making to women with early stage breast cancer. Decision making approaches and patient preferences are known to differ when made during the presence of a life threatening disease but many of the considerations may well parallel the concerns of women who are considering HRT as a viable medication to aid them through the menopausal stages. Instances of these similar concerns include; symptom management versus long term risks, attitudes toward powerful medications, prophylaxis measures, societal attitudes toward femininity and youth, how best to make generalised medical data personally relevant and how best to utilise the personal resources offered by doctors. It is assumed therefore that the Charles et al. (1999) framework for treatment decision making will provide useful direction to those engaging in consideration of HRT with their doctor.

The discussion concerning the merits and shortcomings of each decision-making model highlights that there is no one best way to negotiate such a complex process. Each patient must be allowed to participate in the decision making process to the extent that they wish (Simmonds, 2000). It has been shown that women are in the best position to know what they value in terms of health outcomes but it has also been shown that they are often vulnerable due to their symptoms and fears for their continued health. It has also been shown that the medical information concerning HRT is uncertain and difficult to interpret in a way that has personal relevance. Further, rather than being helpful in the decision making process, doctors have been found to be of little help, perhaps due to the mismatch of preferred decision-making styles.

The Charles et al. (1999) framework can be utilised to address several concerns highlighted in previous treatment decision-making research and accords with many major conclusions. For instance, Avis (1994) concludes that doctors can not assume that all patients want to receive more information and more participation. Even if the patient is well informed they may not want to be involved in decision-making (Waterworth & Luker, 1990). Patient preferences for involvement in decision-making widely vary between different groups as distinguished by age, educational status, disease type and severity (Gwyn & Elwyn, 1999).

By conceptualising the decision-making process into three distinct analytical stages, the Charles et al. (1999) framework also accords with the Ong et al. (1995) research indicating that patients may have a strong desire for medical information but still place the responsibility of decision making on the doctor. Kettunen et al. (2001) similarly conclude that patients who leave the final decision to their doctor may well favour collaboration with regard to information exchange. The Benbassat et al. (1998) review of published surveys states that the preferred level of participation differs between information seeking and the final decision-making. These findings, however, may be indicative of decisions made during the presence of life threatening conditions or serious chronic diseases, rather than in situations of symptom management or where equipoise exists. Whether such conclusions can be generalised to the HRT decision-making context remains unclear.

1.6.1 Summary of the Charles, Gafni & Whelan model

The Charles, Gafni & Whelan (1999) treatment decision-making model was informed and devised through the authors research into the decision-making process faced by women with early stage breast cancer. The proposed framework includes all three main decision-making models previously identified and commonly known as paternalistic, informed and shared. Further, the proposed model includes a means by which to divide the treatment decision-making process into three distinct analytical stages; information exchange, deliberation and decision. The framework, therefore, incorporates a more dynamic perspective to the decision-making process.

Support for acknowledging the process as multi-faceted and providing a way to delineate this is found, and is especially relevant to the present study, in the research of those who find none of the traditional treatment decision-making models are entirely satisfactory both with regard to all people or throughout the entire process of HRT consideration. The Jones (1999) study states nine out of thirteen women made an informed decision to use HRT. Within this group of decision-makers women appeared more likely to rely on their own feelings and subjective intuition, especially given the medical uncertainty surrounding HRT (Jones, 1999). This may reflect a mistrust of medical authority as Jones (1999) suggests perhaps due to 'bad experiences' like not being listened too, taken seriously or not being given adequate information. The study also found the remaining four participants adopted the paternalistic style because they considered their doctor to be the expert, and therefore, better qualified to make the decision.

According to Griffiths (1999) the choices women make may need to change with circumstances so the decision is conditional and appropriate for re-examination. As contexts change so may the decision style. While the paternalistic style may be adopted due to a women's current life pressures she may in turn adopt a more informed style when these pressures subside. This may in fact affect the adherence problems, in so far as what is essentially a change of decision can be interpreted as non-compliance. The Donovan & Blake research (1992) poses the question about whether non-compliance is in fact an example of 'informed' and reasoned decision-making. They conclude that the real issue is investigating how medical staff can understand and participate in the

'informed' decision, rather than continue to erroneously assume such a decision is an instance of non-compliance.

Budge et al. (2000) identified the paternalistic and shared style as the two main styles of consultation and concluded that neither was entirely satisfactory in the context of menopause and HRT consideration. This finding suggests the process of decision-making is not homogenous and that stages exist for which different interaction styles may be preferred to offer overall satisfaction with the service provided by doctors.

The Charles, Gafni & Whelan (1999) framework creates room for each model to be used with benefit between people and between stages, depending on the preferences and needs of the women involved.

1.7 Conclusion

Despite many well founded claims for the natural conceptualisation of menopause, this stage in a woman's life is now firmly established as a medical condition, indeed a deficiency disease for which medical consideration and intervention is sought and deemed appropriate. The principle medical treatment of menopause is Hormone Replacement Therapy (HRT). HRT is a hormone regimen, which offers both symptom relief and possible protection from future conditions thought to result from depleting levels of hormones due to menopause. The scientific data concerning HRT is, however, uncertain and potential users must negotiate how best to make such information personally relevant. The treatment decision within this context is whether to take HRT or not. The process however involves considerations about whether symptom management should be favoured over possible long term side effects, about whether the risks outweigh the possible long-term benefits and whether such uncertain and confusing medical information should be used as an accurate basis on which to make these important decisions.

Considering the medical uncertainty and the subjective nature of evaluating the medical information, a woman's doctor is an important factor in the decision making process. Yet research has suggested that it is despite of their doctor rather than because of them

that women come to a final decision that suits them. Research has concluded that there is much dissatisfaction with the service doctors are providing New Zealand women considering HRT.

Many of the studies supporting this offer factors such as a lack of information, a lack of patient control and a need to provide individualised care as issues affecting patient satisfaction. Accordingly the 'shared' model of medical decision making, which purports to negotiate such issues through collaboration, may well be regarded as the best treatment decision making model for women and doctors to adopt. However, research has also found this model not to be entirely satisfactory within the context of menopause and HRT consideration. One reason for this could be the preference of some patients not to enter into a collaborative and more personal or equal relationship with their doctor. Another could be that patients' needs for individualised care is not synonymous with collaboration and, hence, the shared model of decision making. Much of the dissatisfaction may therefore be accounted for in the mismatch of decision-making styles between doctor and patient, rather than the superiority of one style over the other.

The notion of preferential styles is as important now, as it was as an argument against paternalism. Mainly because the shared model is increasingly being promoted as ideal and may well leave as many women disadvantaged due to incongruent preferences as the imposed paternalistic stance did to those not so inclined. The Charles, Gafni & Whelan (1999) model incorporates all three models of decision making, thus providing a dynamic and flexible approach which can be used as both an educational tool and a means by which to more accurately judge and monitor patient preferences.

The model does not seek to advocate one style over the others but seeks to offer patients the opportunity to express their preferences throughout what is thought to be a three stage process of decision making and guide doctors in how best to accommodate this. Although the model was devised and informed through research relating to early stage breast cancer many of the considerations and complexities may well parallel those of women considering HRT. The potential of the Charles, Gafni & Whelan (1999) framework to be utilised with benefit to New Zealand women considering HRT makes it necessary to first test the models theoretical tenets on this population.

1.8 Research goals

The aim of the present study is to test the Charles, Gafni & Whelan (1999) theoretical framework for treatment decision-making on New Zealand women who are considering HRT. The present study seeks to identify three distinct styles of decision-making preferences; paternalistic, informed and shared. Of particular interest will be the proportions of women who show preferences for particular styles of decision-making and whether any of the included demographic or medical variables are related to particular style preferences.

Further to this, the present study also seeks to assess whether the three proposed styles can be identified as preferences throughout the three distinct stages in the decision-making process. Of particular interest will be whether the style preferences are maintained throughout the entire process or whether different stages of the process lend themselves to different styles. Also of interest will be whether the preference for the shared approach to deliberation and making the final decision, in particular, are achieved within the women's interactions with their doctor. In line with this aim the present study would also like to look at whether paternalistic experiences of the decision-making process are congruent with women's preferences.

2. CHAPTER TWO: METHOD

Data was collected through a four section questionnaire designed to support two separate studies. Section two was the basis of the present study and consisted of a 20-item questionnaire. The items found in section two of the questionnaire were generated specifically for the present study. Section four of the questionnaire included seventeen demographic items used for the present study. One item from section three of the questionnaire was also used for the present study. A full copy of all sections and items used for this study can be found in Appendix B.

2.1 Sample

The sample consisted of one hundred and forty eight cases. The participants were mid-aged New Zealand women who were randomly selected from the New Zealand general and Maori electoral roles. The sampling procedure involved eliciting an initial sample of 1000 people with the criteria for entry being those aged 45 years. This initial sample was further reduced manually by excluding males. The title "Mr" was the main exclusion criteria and when titles were not available first and middle names were used to make the distinction. On occasion, when given names were uninformative or unfamiliar, occupation was also considered. Very few entries remained in doubt after this process, but those that did were included, so as not to omit potential female participants. The selection process reduced the initial sample of 1000 to a final 354 person sample.

The first posting resulted in the return of 76 completed questionnaires, 19 uncompleted returns and 42 questionnaires were returned marked 'gone no address'. Following the second posting 25 completed and 19 uncompleted questionnaires were returned. The third posting resulted in a further 48 completed and 2 uncompleted returns. There was one request for a Te Reo Maori version of the questionnaire, but this was not returned. From a total sample of 354, less 42 marked gone no address, 148 questionnaires were

returned giving a 47% response rate. There were few missing responses to items and accordingly it was decided not to replace these via mean substitution. Statistical analysis of the relationships among the data was undertaken through the SPSS 10.1.3 for windows statistical package.

2.2 Sample description

There were one hundred and forty eight cases in the sample. Age and ethnicity information for the sample is presented in Table 1. As can be seen the range of age within the sample was from thirty-eight to forty-eight years, with the average age being just over forty-five years. The majority of the sample population was N.Z. Pakeha/European, with N.Z. Maori representing 19%. This distribution is adequately reflective of the population at large, as according to the New Zealand Census, 14.3% of the national population identify as Maori (Statistics NZ, 2001). Twenty percent of the sample identify with an Iwi and Hapu. Similarly 19.3% identify with a Marae, with 52% of these participants having visited a marae at least once within the last year. Thirty-nine percent of the sample state they know at least some Maori language.

Table 1: Age and Ethnicity of Participants

	Frequency	% of total
<u>Age</u>		
38	1	.7
44	1	.7
45	82	55.8
46	61	41.5
47	1	.7
48	1	.7
Total	147	
<u>Ethnicity</u>		
NZ Pakeha/European	97	68.3
NZ Maori	27	19.0
Pacific Island Nation	4	2.8
Asian	7	4.9
Indian	1	.7
Other	6	4.2
Total	142	

Table 2 contains information about employment status and the level of education of participants. Forty-five percent (44.5%) of the sample were employed full time. Higher

education was recorded for 52.1% of the sample, with University, Polytechnic or teacher training accounting for 41.1% and other trade or vocational training accounting for the remaining 11%.

Table 2: Employment Status and level of Education of Participants

	Frequency	% of total
<u>Employment Status</u>		
Employed Full-time	65	44.5
Employed Part-time	42	28.8
Student	3	2.1
Self-employed	10	6.8
Homemaker	19	13
Not in paid employment	7	4.8
Total	146	
<u>Level of Education</u>		
Primary School	1	.7
Secondary School for 1-2yrs	10	6.8
Secondary School more 2yrs	59	40.4
University, Polytechnic or teacher training	60	41.1
Other trade or vocational training	16	11
Total	146	

The sample consisted of fourteen participants who had used HRT in the past, nine of these participants currently use HRT. The current percentage of HRT users within this sample is 6.1%. Fifty-three percent (52.4%) of the sample have taken the contraception pill for over five years at some time in their lives.

Table 3: Past and Present HRT and Contraception Pill Use

	Frequency	% of total
<u>Used HRT in past</u>		
Yes	14	9.5
No	134	90.5
Total	148	
<u>Currently using HRT</u>		
Yes	9	6.1
No	139	93.9
Total	148	
<u>Used contraceptive pill for over five years</u>		
Yes	77	52.4
No	70	47.6
Total	140	

The number of times a participant had seen a General practitioner in the past twelve months ranged from zero to twenty-four, with the mean number of times being 3.4 occasions. Forty-two percent (41.9%) of participants had seen a GP within the last three

months. The majority of the sample, 62.8%, rated their general health as being very good to excellent. Twenty-nine percent of participants rated their health as good, while 8.3% of the sample thought their general health was fair to poor.

2.3 Procedure /Research design

A 44-item pilot study was generated to gather preliminary data and gauge the usefulness of proposed items. From this pilot study a 20-item questionnaire was developed. Criteria for item selection included psychometric properties, response comments from pilot study participants and results from subsequent research conducted primarily in Britain regarding similar constructs and research questions.

A cover letter, written in both English and Te Reo Maori, containing the purpose of the study, including an invitation to participate, instructions and the participants rights was attached to the front of the questionnaire before distribution. These attachments can be found in Appendix A. Once the questionnaire had been compiled it was sent to the corresponding postal addresses supplied on the electoral role. A request option was included on the front page for the questionnaire to be supplied in a Te Reo Maori version. The respondent could tick this option and return the English version, upon which a Maori language version of the questionnaire would be sent out. The questionnaires were sent back to Massey University by mail in the return envelopes provided and were then forwarded to the researcher.

A page was attached at the back of the questionnaire for the respondents to complete if they wished to be sent a summary of the results. The summary of results request form was separated from the completed questionnaire upon return to the university. Once the results were compiled a summary was sent to those who had requested the results. The results were presented in aggregate form and did not identify any individual. The results were also kept confidential and could not be traced back to the individual respondents.

Two weeks following the first posting, a reminder postcard was sent to potential participants who had not yet returned either their completed or uncompleted questionnaires. A copy of the postcard can be found in Appendix C. One week after the

reminder postcard was sent out another questionnaire including a cover letter was posted to all respondents who had not yet returned their questionnaire. The cover letter in this posting acknowledged that often people had misplaced their questionnaire, but would still like to be involved in the study. A copy of this cover letter can be found in Appendix D.

2.4 Measures

The complete questionnaire is a eighteen-page document. The covering letter including instructions, the participants rights and assurances of confidentiality are detailed on the first two pages in both English and Maori. A form for the respondent to request a summary of the results is found on the last page. The complete questionnaire comprises of 4 separate sections. Sections two and four are the basis of the present study. A full copy of the applicable sections of the questionnaire is presented in Appendix B.

Section two begins on page six of the document and was directed at all respondents. The respondents were asked at the beginning of the section to circle the number that represented the answer that was best for them. Response options ranged from 1 to 5, with 1 corresponding to strongly disagree and 5 corresponding to strongly agree. The questionnaire included scales designed to measure the preference for 'paternalistic', 'informed' and 'shared' decision-making, both as an overall strategy and at the information exchange, deliberation and the final decision stages. The following is a description of each scale including example items.

2.4.1 Paternalistic style preference

The 'paternalistic' style is characterised by doctor dominance within the doctor-patient interaction, while the patient remains largely passive. Information exchange is limited to mainly medical information, delivered by the doctor to the patient, in an amount seen as appropriate by the doctor. The patient participates by way of answering doctor initiated questions, generally regarding medical history. Items 1 and 12 capture the type, amount and direction of information exchange that characterise the paternalistic style, and are as follows; "I feel my doctor knows best how much information I need to be told about

HRT” and “I would prefer not to disclose my personal non-medical information to my doctor”.

Deliberation within this style is conducted by the doctor. Item 3 “I would prefer to leave the doctor to consider the choices about treatment” was designed to measure this paternalistic preference. The final decision is also conducted by the doctor and items 5,8 and 16 complete the six items that measure the paternalistic preference. For example, “If the doctor and I disagree I will accept the doctor choice”, “The best decision is more likely to be made by the doctor” and finally “I prefer to leave the final decision about treatment to the doctor”.

The paternalistic approach to decision-making was represented by six items. Two items captured a preference for paternalistic information exchange, one item represented a paternalistic preference toward deliberation and three items measured whether the participant would prefer the final decision to be made within the paternalistic approach.

2.4.2 Informed style preference

The informed style of decision-making was represented by four items. This style of decision-making is characterised by patient responsibility. The patient seeks information from the doctor to enable them to deliberate and make their own decision regarding the best treatment option. Two items were used to measure a preference for informed information exchange. Item 6 states “The main purpose of a doctor’s appointment is to gather all the medical information I want from the doctor” and item 12 states “I would prefer not to disclose my personal non-medical information to my doctor”. A single item measured the preference for informed deliberation and states “I would prefer to consider my choices about treatment without my doctor’s input”. Items 4 and 13 were designed to measure the preference for making an informed decision and are as follows; “The best decision is more likely to be made by me” and “I prefer to make the final decision about treatment myself”.

2.4.3 Shared style preference

The shared decision-making style is collaborative with two way direction of both medical and personal information in an amount and type reflective of the particular patient. Items 2 “It is important for me to tell my doctor about my personal feelings and concerns regarding HRT” and 7 “I feel the need to discuss my personal non-medical information with my doctor” are used to look at shared information exchange.

Deliberation within this style is conducted together and often involves negotiation. Items 14 and 17 measure shared deliberation and are “I prefer to consider my choices about treatment with my doctors help” and “I would like to have an equal say in any discussions about my treatment options”. Items 10 “I would prefer to make a joint decision” and 19 “The best decision is more likely to be made if my say is equal to the doctors” are used to measure the collaborative nature of the shared final decision.

The shared style of decision-making was represented by six items. Two items measured the preference for shared style information exchange, two items measured shared deliberation and two items measured whether the participant would prefer the final decision to be made within the shared approach to decision-making.

Items 11 and 20 are included to measure ‘paternalistic’ examples of deliberation and final decision, which are initiated by the doctor. The items state “My doctor does not allow me an equal say in discussions about my treatment options” and “My doctor does not allow me an equal say in the final decision about treatment”. Items 15 and 18 are used to measure achieved shared decision-making. These items state “My doctor treats me as an equal partner in discussions about my treatment options” and “My doctor treats me as an equal partner when we make the decision about my treatment”.

2.4.4 Background information

Section four of the document covers demographic information. Within this section demographic information was collected including: age, ethnicity, occupation and level of qualifications participants possess. Information regarding the last time they saw their doctor and the frequency of visits in the last 12 months was also included along with

information asking whether participants had experienced a hysterectomy or not, whether they had or were currently using HRT and whether they had used the contraceptive pill for over five years at some time. Items pertaining to Iwi and Marae affiliation and Maori language knowledge were also included in this section. One item from section three of the complete questionnaire measuring general health was used as part of the present study. The items asked “In general, would you say your health is...” and available responses ranged from 1, “excellent” to 5 “poor”. The use of a single self-report general item to assess health is supported by Bird & Fremont (1991) who state that it may be more reliable than doctor ratings. The full items can be found in Appendix B.

3. CHAPTER THREE: RESULTS

The measure used for the present study was designed specifically for this research. Accordingly the first section of this results chapter will focus on scale construction. The next section of this chapter will report on the analysis used to test whether three decision-making styles were identified within the context of HRT consideration. The results section of the present study will also explore whether the styles of decision-making were maintained throughout the entire process or whether certain stages leaned themselves to particular styles. Finally demographic variables will be analysed to identify any relationships with style preferences.

Prior to any analysis the data was screened for accuracy of input. There were 148 cases available for analysis.

3.1 Scale construction

The sixteen items designed to measure the three styles of decision-making at each stage of the process were factor analysed. Principle components analysis with oblique rotation (SPSS/PC) was used for extraction. Components with eigenvalues greater than 1.00 were extracted and items with loadings greater than .45 were included. When decision-making styles were tested, direct oblimin converged in 16 iterations of a six-factor solution, which accounted for 67% of the total variance. The items related to 'paternalistic' decision-making loaded into one factor, while both the 'shared' and 'informed' items loaded into the remaining five factors with little correspondence to the expected pattern of relationships. The anomalies in the factor solution suggested that there were validity problems with some items, which accordingly, were considered for removal.

Item 7 asked the respondent to rate how much they agreed with the statement 'I feel the need to discuss my personal non-medical information with my doctor'. This item did not significantly correlate with item 2, the other 'shared' information exchange item. Item 7 was dropped as it was deemed to have less face validity than item 2. Item 12 was also an information exchange item, designed to measure 'type' of information exchange. This item was relevant to both the 'paternalistic' and 'informed' preference scales, as these styles share the common component of a proclivity to exclude non-medical information from the doctor-patient interaction. This item was dropped from further analysis because it was significantly related only to item 7 and inclusion distracted from the differentiation between 'paternalistic' and 'informed' information exchange.

Only Items 7 and 12 loaded together into factor five of the original solution. Further extraction of a four-factor solution showed that neither item achieved a loading of greater than .45. This finding provided additional support for the removal of these two items.

The 'shared' scale originally consisted of two deliberation and two decision stage items, both of which did not significantly related to each other. The coefficient alpha reliability estimates for the proposed deliberation scale was .13, while the coefficient alpha for the proposed decision scale was .23. This may be due to each item within the stage scale representing a perspective either side of the decision-making continuum. For instance, item 14 states 'I would prefer to consider my choices about treatment with my doctor's help', while item 17 states 'I would like to have an equal say in any discussions about my treatment options'. The latter represents a perspective from or toward the 'paternalistic' end of the continuum and the former capturing the 'shared' preference from the 'informed' end of the treatment decision-making continuum.

The decision items were likewise designed and it was decided to drop items 17 and 19 from further analysis. The initial analysis resulted in four items being dropped from any further analysis. The following table represents the remaining 12 items that were used to capture the nine theoretical constructs of treatment decision-making.

Table 4: Final Items used to Measure Decision-making Styles at each Stage.

Variable	Item
Paternalistic Information exchange	1 'I feel my doctor knows best how much information I need to be told about HRT'.
Paternalistic Deliberation	3 'I would prefer to leave the doctor to consider the choices about treatment'.
Paternalistic Decision	5 'If the doctor and I disagree, I will accept the doctor's choice'. 8 'The best decision is more likely to be made by the doctor.'. 16 'I prefer to leave the final decision about treatment to the doctor'.
Informed Information exchange	6 'The main purpose of the doctor's appointment is to gather all the medical information I want from the doctor'.
Informed Deliberation	9 'I would prefer to consider my choices about treatment without my doctor's input'.
Informed Decision	4 'The best decision is more likely to be made by me'. 13 'I prefer to make the final decision about treatment myself'.
Shared Information exchange	2 'It is important for me to tell my doctor about my personal feeling and concerns regarding HRT'.
Shared Deliberation	14 'I would prefer to consider my choices about treatment with my doctor's help'.
Shared Decision	10 'I would prefer to make a joint decision with my doctor'.

3.2 Identifying three styles of decision-making

With the removal of four problematic items from any further analysis the remaining 12 items were factor analysed to find three components of treatment decision-making. The method used for extraction was Principle components with oblique rotation, (SPSS/PC) which allows the items to be correlated. A three-factor solution was extracted with loadings greater than .45 included. When decision-making styles were tested, direct oblimin converged in 15 iterations of a three component solution, which accounted for 54% of the total variance. The KMO statistic of .667 was adequate to suggest that the factor model was appropriate for the data (Leong & Austin, 1996). The 'paternalistic' and 'shared' variables loaded together respectively corresponding to each expected domain of decision-making style. The 'informed' items loaded into the third component with one 'informed' item loading into the 'shared' domain of decision-making. The results of this analysis are shown in Table 5.

Each of the 'paternalistic' items loaded into factor one with a score above .65, which surpassed the inclusion criteria of a factor score above .45. The 'shared' information exchange item, however, loaded into factor two with a score of .446 and this was the lowest loading deemed sufficient for inclusion. Three of the 'informed' items loaded into factor three with a score above .59 and the fourth item measuring 'informed' deliberation loaded into factor two. None of the items scored more than .45 in more than one factor.

Table 5: Loadings on Three Components for Principal Components Extraction and Oblimin Rotation on 12 "Treatment Decision-making Style" Items (N = 148).

Items	Loadings		
	Paternalistic	Shared	Informed
I feel my doctor knows best how much information I need to be told about HRT.	.708	.157	-.014
It is important for me to tell my doctor about my personal feelings and concerns regarding HRT.	.094	.446	.428

Items	Loadings		
	Paternalistic	Shared	Informed
I would prefer to leave the doctor to consider the choices about treatment.	.759	.094	-.124
The best decision is more likely to be made by me.	-.239	-.160	.835
If the doctor and I disagree I will accept the doctor's choice.	.657	.072	-.100
The main purpose of the doctor's appointment is to gather all the medical information I want from the doctor	.059	.221	.683
The best decision is more likely to be made by the doctor.	.746	.235	-.057
I would prefer to consider my choices about treatment without my doctor's input.?	-.112	-.732	.166
I would prefer to make a joint decision with my doctor.	.162	.771	-.013
I prefer to make the final decision about treatment myself.	.439	-.215	.596
I would prefer to consider my choices about treatment with my doctor's help.	.147	.676	.262
I prefer to leave the final decision about treatment to the doctor.	.757	.148	-.184
Eigenvalue	3.17	1.87	1.47
Cumulative % variance accounted for	26.4	42.0	54.2

3.3 Descriptive statistics

Now that the data have been reduced to measure the three decision-making styles at each stage of the process the resulting variables distributions were examined. Table 6 reports the means, standard deviations, reliability and the scale range for each of the decision-making styles examined in the model. What follows is a brief description of each of these variables.

A paternalistic preference toward treatment decision-making is a five-item scale. A score of five represents the lowest possible paternalistic score and a score of twenty-five indicates the highest possible paternalistic preference. An informed preference for decision making is a four-item scale, four representing the lowest end of the scale, indicating the lowest possible informed preference. The shared approach to treatment decision making is a three item scale, with a score of three likewise indicating the lowest possible shared preference and a score of fifteen indicating a strong proclivity to the shared approach to treatment decision-making. The following scale scores reported in Table 6 have been reduced to a 5-point scale.

Table 6: Means, Standard Deviations, Reliability and Scale Ranges for the Variables of Overall Treatment Decision-Making Style Preferences.

Scales/Variables	N	Mean	S.D.	Reliability	Scale Range
Paternalistic	143	2.41	3.83	.78	1-5
Informed	144	3.56	2.53	.54	1-5
Shared	145	4.09	1.68	.50	1-5

The Paternalistic preference was assessed via a five-item scale. The mean response total was 12.05, which translates to a mean response for each item of 2.41. On a five-point scale this score represents a position between 'disagree' and neutral'. The mean response total on the informed preference scale was 14.24. This scale included four

items, which translates to a mean response for each item of 3.56. On the five-point scale this equates to a position in between the 'neutral' stance and 'agree'. The shared preference was assessed via a three-item scale and the mean response total was 12.27. The mean response for each item was therefore 4.01, which represents the 'agree' anchor in the five point scale.

The coefficient alpha reliability estimate for the paternalistic scale reached the "rule of thumb" desired level of 0.70 (Murphy & Davidshofer, 1998). The informed and shared coefficient alpha scores are lower than desired. The informed scale is only a four-item scale and the shared scale is only made up of three items. The small number of items in these scales may contribute to the low alpha levels.

Table 7 reports the means and standard deviations for each of the styles at each stage in the decision-making process. Table 7 demonstrates that the shared style of treatment decision making was preferred over the informed and paternalistic styles at the information exchange stage and the deliberation stage. The final decision stage however sees the informed style being favoured over the shared style. The paternalistic style rated consistently low at each stage of the process, particularly at the deliberation stage and less so at information exchange. While an informed final decision was favoured above any other style of final decision, informed deliberation was rated well below the other two stages. Reliability statistics apply to only the paternalistic decision scale and the informed decision scale as all other variables were measured with single items. The coefficient alpha reliability estimate for both of these scales was .71.

Table 7: Means and Standard Deviations for the Variables of Treatment Decision-Making Style Preferences Within Each Stage.

Scale/Variables		N	Mean	S.D.
Information Exchange	Paternalistic	147	2.73	1.26
	Informed	147	3.77	1.10
	Shared	147	4.23	.81
Deliberation	Paternalistic	147	2.16	.98
	Informed	147	2.39	.90
	Shared	145	4.03	.76
Decision	Paternalistic	136	2.38	2.23
	Informed	138	4.01	1.72
	Shared	146	4.00	.80

3.4 Testing the preferred styles across the three stages of the decision-making process.

The following section deals with testing whether the three styles of treatment decision-making are maintained throughout the entire process of making treatment decisions. The factor analysis suggested that there are changes across the stages, in particular, changes involving the informed and shared styles. Pearson's Product Moment Correlations (PPMC) were examined to explore relationships among the variables at the bivariate level.

Tables 8, 9 and 10 show the correlation coefficients between stages of the decision making process within each of the styles of decision making. As can be seen from Table 8, paternalistic information exchange, deliberation and decision are related to each other. The paternalistic associations were significant at the alpha level of 0.01. A preference for the paternalistic approach to information exchange is also significantly associated with a proclivity to sharing the deliberation process, while paternalistic deliberation shows a significant relationship with the shared final decision. All three stages within the paternalistic style show a significant negative relationship to the informed style of final decision, with the paternalistic decision stage also showing a negative relationship to informed deliberation.

Table 8: Correlations Between Stages Within the Paternalistic Style of Treatment Decision-Making.

Variables	Paternalistic Information exchange	Paternalistic Deliberation	Paternalistic Decision
Paternalistic Information exchange	1	.516**	.519**
Paternalistic Deliberation	.516**	1	.516**
Paternalistic Decision	.519**	.560**	1
Informed Information exchange	-.056	.053	-.044
Informed Deliberation	.023	-.078	-.238**
Informed Decision	-.277**	-.280**	-.359**
Shared Information exchange	.143	-.113	.081
Shared Deliberation	.228**	.003	.070
Shared Decision	.117	.210**	.125

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

The pattern of relationships differs within the informed approach to decision making. As can be seen from Table 9 both informed information exchange and deliberation are significantly related to informed decision but not to each other. Information exchange shows an association with the decision stage, which is significant at the alpha level of 0.01.

The association between deliberation and decision, however, was significant at the 0.05 level. Information exchange, while also significantly related to shared information exchange, is positively associated with shared deliberation rather than informed deliberation. A preference for the informed style at deliberation shows a significant negative relationship with the shared approach at all three stages of the process.

Table 9: Correlations Between Stages Within the Informed Style of Treatment Decision-Making.

Variables	Informed Information exchange	Informed Deliberation	Informed Decision
Paternalistic Information exchange	-.056	.023	-.277**
Paternalistic Deliberation	.053	-.078	-.280**
Paternalistic Decision	-.044	-.238**	-.359**
Informed Information exchange	1	-.025	.310**
Informed Deliberation	-.025	1	.207*
Informed Decision	.310**	.207*	1
Shared Information exchange	.206*	-.192*	.114
Shared Deliberation	.175*	-.215**	-.018
Shared Decision	.102	-.419**	-.126

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

A different pattern of relationships can again be seen within the shared approach to decision making. Table 10 shows that both shared information exchange and shared decision are significantly related to shared deliberation but not to each other. Both shared information exchange and deliberation are positively associated with informed information exchange and the shared decision is significantly related to paternalistic deliberation. All three stages within the shared approach show a negative relationship with informed deliberation, the shared decision stage association was significant at the alpha level of 0.01.

Table 10: Correlations Between Stages Within the Shared Style of Treatment Decision-Making.

Variables	Shared Information exchange	Shared Deliberation	Shared Decision
Paternalistic Information exchange	.143	.228**	.117
Paternalistic Deliberation	-.123	.003	.210*
Paternalistic Decision	.081	.070	.125
Informed Information exchange	.206*	.175*	.102
Informed Deliberation	-.192*	-.215*	-.419**
Informed Decision	.114	-.018	-.126
Shared Information exchange	1	.246**	.117
Shared Deliberation	.246**	1	4.01**
Shared Decision	.117	.401**	1

**** Correlation is significant at the 0.01 level (2-tailed).**

*** Correlation is significant at the 0.05 level (2-tailed).**

Figure 1 shows that the paternalistic style is rated more favourably at the information exchange stage than at either the deliberation or decision stages. The informed style of decision-making was rated the highest at the decision stage, while this style was notably less preferred at the time of deliberation. The shared style was rated favourably at all three stages of the process, particularly at information exchange. Figure 1 also shows that the main difference between the informed and shared styles can be seen at the deliberation stage of the process, with markedly less agreement toward the informed approach to deliberation.

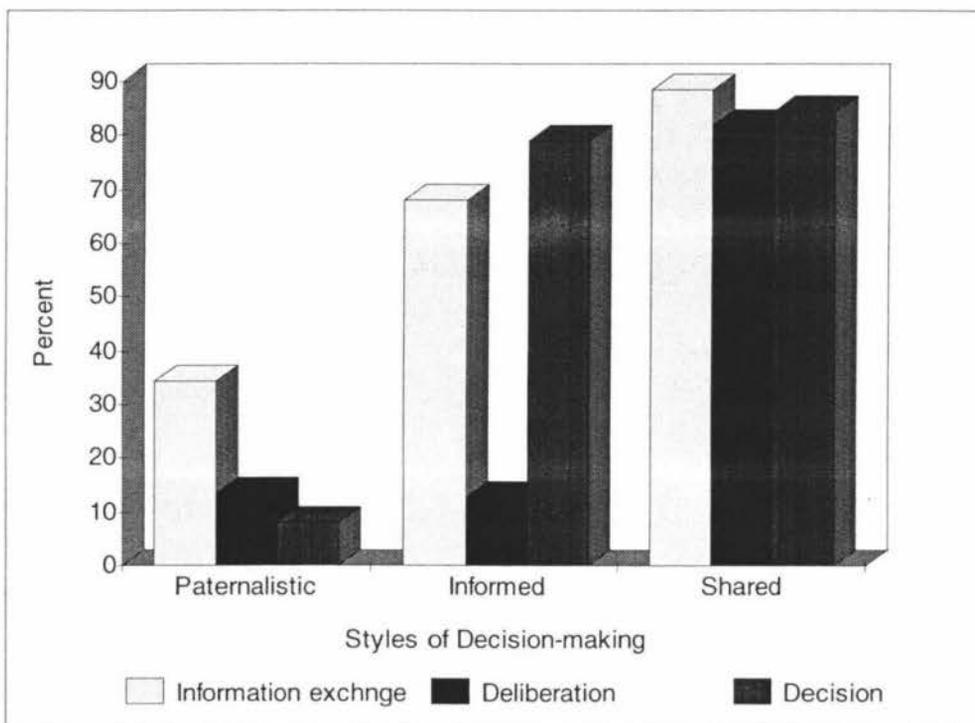


Figure 1: Percent of Women Who Agree with the Styles at Each Stage of the Process.

Figure 2 shows that 34.5% of participants rated that they agreed or strongly agreed with the paternalistic approach to information exchange. However, 75% of these participants also rated that they agreed or strongly agreed with both the shared and informed approach to information exchange. Only one respondent agreed or strongly agreed with the paternalistic approach to information exchange, while remaining neutral or disagreeing with both other styles at this stage of the process.

Figure 2 shows that 68.2% of participants rated that they agreed with the informed approach to information exchange. Of these participants, 62% agreed with the informed approach while remaining neutral or disagreeing with the paternalistic style and 7% while remaining neutral or disagreeing with the shared style. Six percent of those who agree with the informed approach to information exchange and 4% of all participants did so exclusively.

The shared approach to information exchange showed an 88.5% agreement rate. Of these participants who agreed or strongly agreed with the shared approach, 63% of them remained neutral or disagreed with the paternalistic approach and 28% of them remained neutral or disagreed with the informed approach to information exchange. Selecting cases that agreed or strongly agreed with the shared approach while remaining neutral or disagreeing with both the paternalistic and informed approaches shows that 19% of shared preference participants preferred the shared approach to information exchange exclusively and 16.9% of all participants favoured shared information exchange exclusively.

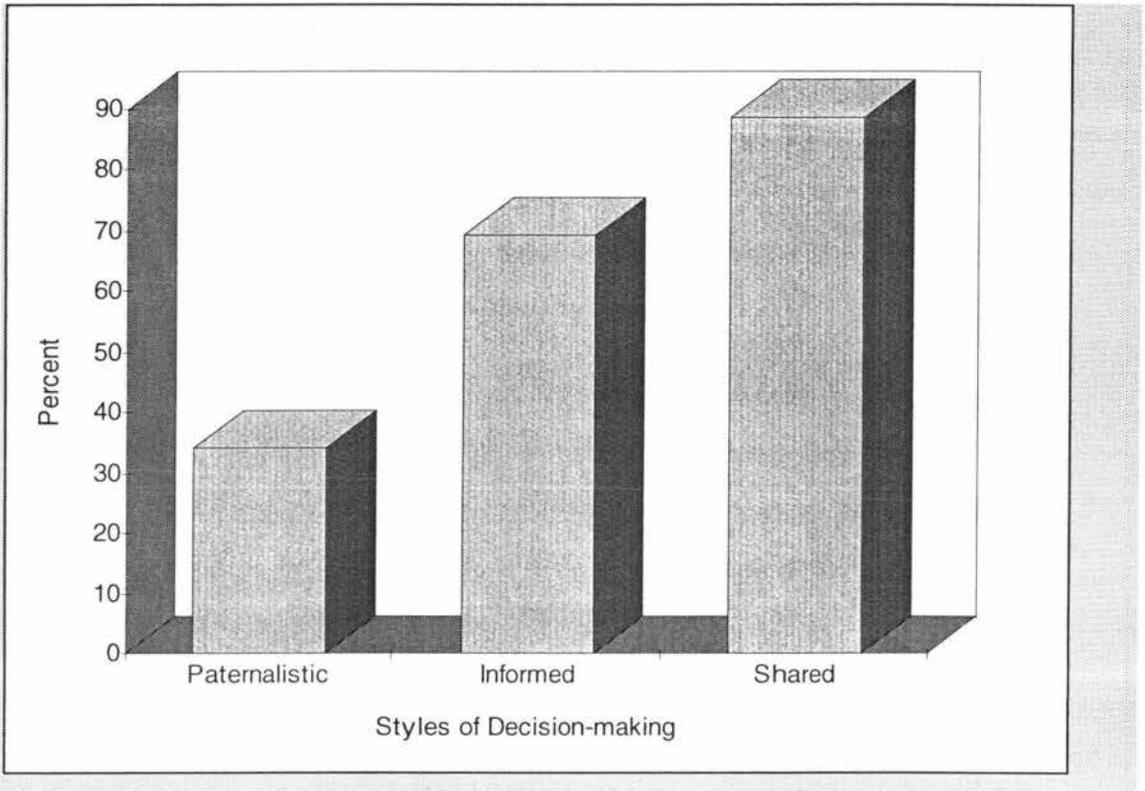


Figure 2: Percent of Women who Agree with Each Style of Decision-Making at the Information Exchange Stage.

Figure 3 shows that 13.5% of participants agreed or strongly agreed with the paternalistic approach to deliberation. Of these participants 85% agreed with the paternalistic approach while remaining neutral or disagreeing with the informed style of deliberation and 5% agreed with this approach exclusively or while remaining neutral or disagreeing with the shared approach to deliberation. Only one respondent preferred the paternalistic style of deliberation exclusively.

Of the 12.8% of participants who agreed or strongly agreed with the informed approach to deliberation, 84% of these did so while remaining neutral or disagreeing with the paternalistic approach and 26% exclusively or while remaining neutral or disagreeing with the shared approach to deliberation. Five participants or 3.4% of all participants preferred the informed style of deliberation exclusively.

Figure 3 also shows that 82.8% of participants agreed or strongly agreed with the shared approach to deliberation. Of those who agreed with the shared style, 85% do so while

remaining neutral or disagreeing with the paternalistic style and 89% do so while remaining neutral or disagreeing with the informed style of deliberation. The shared approach to deliberation was exclusively preferred by 77% of participants who agreed with this approach to deliberation and by 63% of all participants.

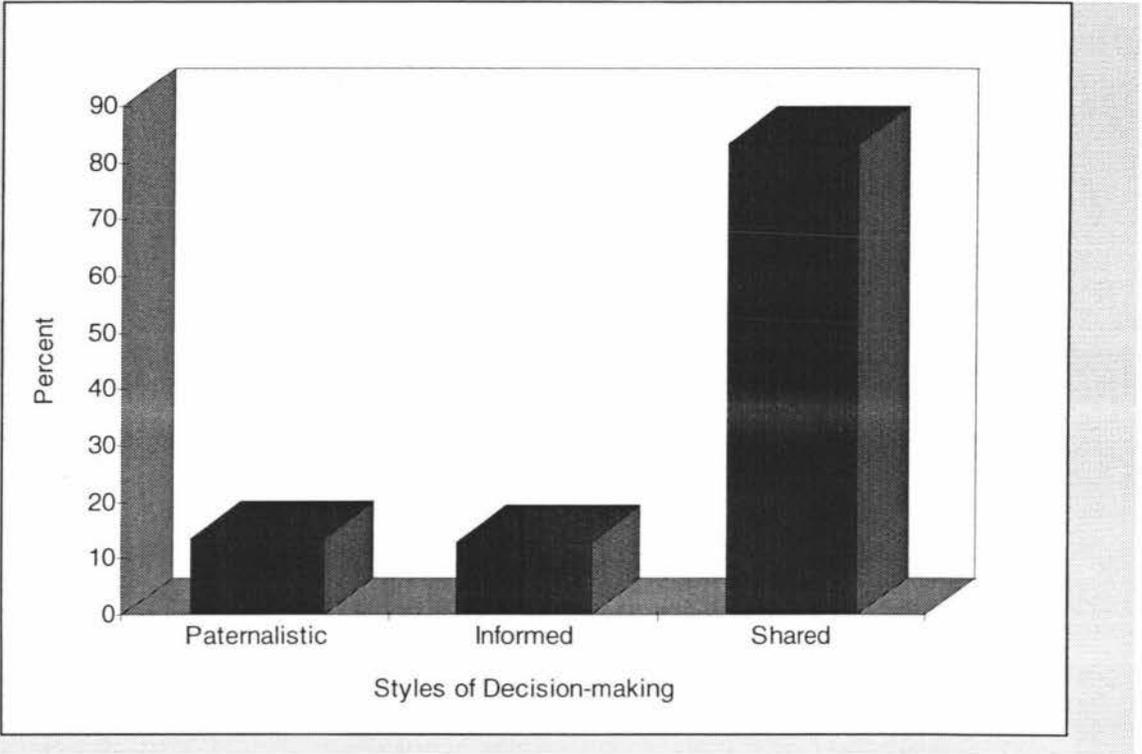


Figure 3: Percent of Women who Agree with Each Style of Decision-Making at the Deliberation Stage.

To make these comparisons within the decision stage of the process one decision item for each style was selected. Items 16, 13 and 10 were used to represent the paternalistic, informed and shared styles respectively. These items were selected because they each asked the respondent whether they prefer each style of final decision.

Figure 4 shows that 8.1% of participants agreed with the paternalistic approach to making the final decision. Of these participants, 33% agreed with the paternalistic approach while remaining neutral or disagreeing with the informed style and 8% while remaining neutral or disagreeing with the shared approach to the final decision. None of the participants preferred the paternalistic approach exclusively or while remaining neutral or disagreeing while both the shared and informed styles.

As can be seen in Figure 4, 79% of participants agreed with the informed style of decision. Ninety-four percent of these participants do so while remaining neutral or disagreeing with the paternalistic style of decision and 16% while remaining neutral or disagreeing with the shared style of making the final decision. Fifteen percent of participants who agree with the informed style and 12% of all participants exclusively preferred to make an informed final decision.

Eighty-five percent of participants agreed with the shared approach to making the final decision. Of these participants 90% did so while remaining neutral or disagreeing with the paternalistic approach and 21% while remaining neutral or disagreeing with the informed approach. Eighteen percent of participants who agreed with the shared style and 15% of all participants exclusively preferred to apply the shared style to the final decision.

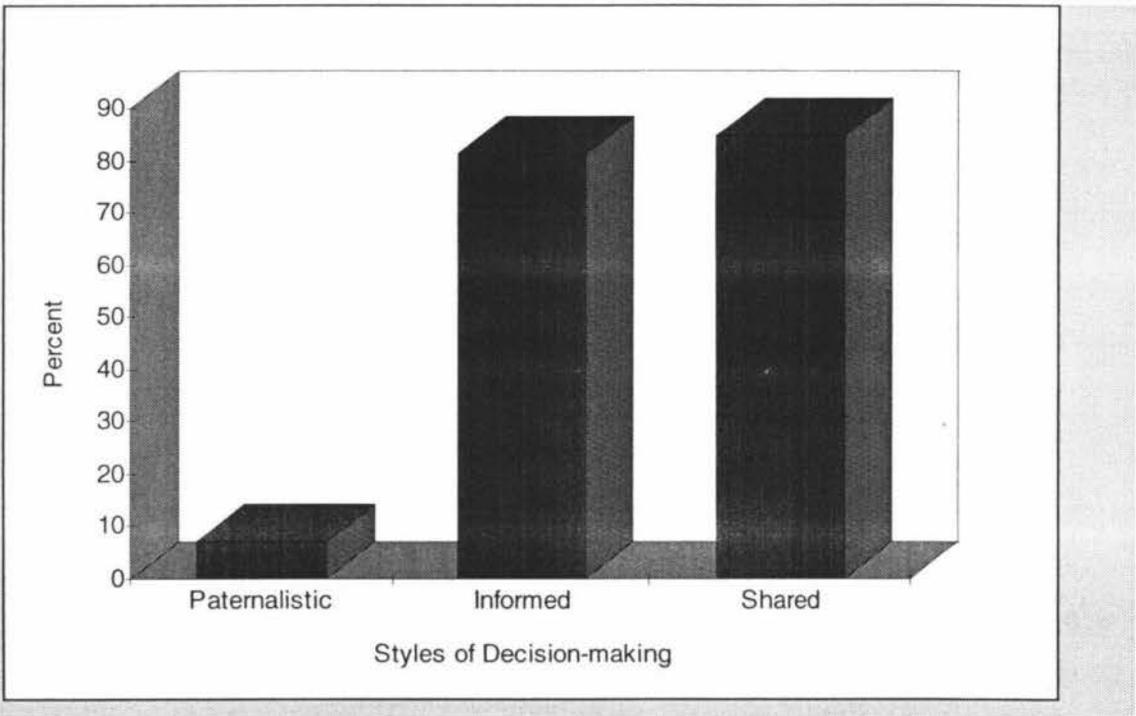


Figure 4: Percent of Women who Agree with Each Style of Decision-Making at the Decision Stage.

The results so far have mainly dealt with the preferences for each style at each stage as indicated by an agree or strongly agree response to items. The analysis suggests that many of the participants show a preference for more than one style at any one stage of

the process. The following figure looks at the percentage of women who exclusively prefer each style at each stage of the process.

Figure 5 shows that less than 1% of women preferred exclusively to adopt the paternalistic style to information exchange. Four percent stated that they preferred only the informed style of information exchange while 16.9% preferred only the shared style of information exchange. The deliberation stage shows a similar pattern with respect to the paternalistic and informed styles with less than 1% preferring only the paternalistic style and 3.4% exclusively preferring the informed style. The shared style only was preferred by 63% of the participants. None of the participants exclusively preferred the paternalistic style of making the final decision, while 12% and 15% preferred the informed and shared styles to the exclusion of all others respectively.

Figure 5 also shows that 67.1% of the participants preferred one style to all others within the deliberation stage of the decision-making process. The participants were less decisive with regard to decision and information exchange preferences, with 27% preferring one style to all others at the decision stage and 21.6% at the information exchange stage of the process.

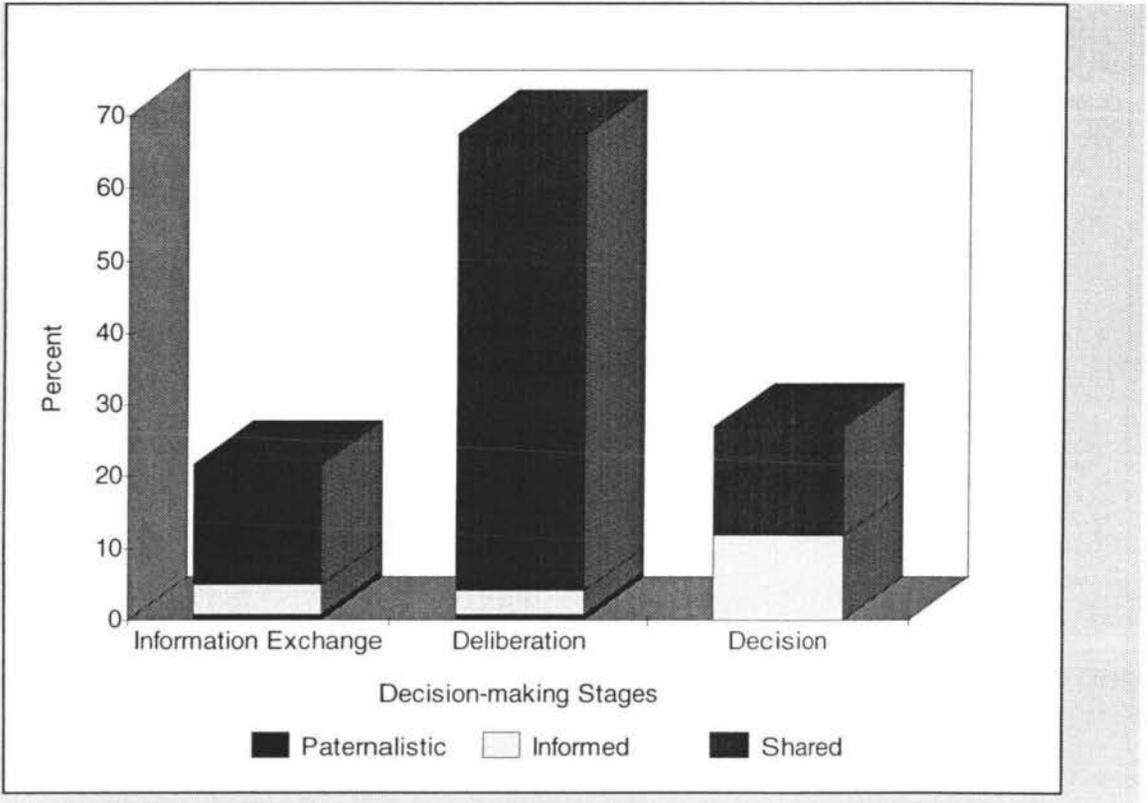


Figure 5: Percent of Women Who Exclusively Prefer Each Style at Each Stage of the Decision-making Process

3.5 Demographic variables and decision-making styles.

Several demographic variables were analysed to note any relationships or patterns with style preference for this population of women. As well as exploring relationships with overall style preferences, relationships were also analysed between demographic variables and style variables at each stage of the decision-making process.

The only significant relationship the ‘paternalistic’ style showed with any of the selected demographic variables was with ‘level of education’. The PPMC coefficient of -.084 was significant at the alpha level of 0.05, indicating a negative association between the preference to adopt the paternalistic approach to decision-making and the level of education of the participant. This finding is in line with several other studies, which report this well supported relationship.

The 'informed' style shows a significant relationship with the variable 'currently using HRT', again the coefficient of .184 was significant at the alpha level of 0.05. 'Currently using HRT' was a dichotomous variable where the score of 1 represented 'yes' and a score of 2 represented 'no'. In this instant, the coefficient statistic suggests that an increase in the 'informed' preference to decision-making is associated with not currently using HRT.

The 'informed' style was also associated with the variable concerning the 'last time the participant saw their doctor'. This demographic variable was rated on a six-point scale from 1 representing a consultation within the last two weeks to 6 representing a consultation more than one year ago. The coefficient of .216 was significant at the alpha level of 0.01, indicating that an 'informed' preference was associated with less recent contact with the doctor.

The 'shared' style of decision-making was also related to this demographic variable however the negative association shown by the coefficient -.183 indicates that a preference toward sharing decision-making is associated with the recency of the last consultation. This relationship was significant at the alpha level of 0.05. The results of this analysis are shown in Table 11.

Table 11: Correlations Between Selected Demographic Variables and Overall Style Preferences.

Demographic Variables	Paternalistic Style	Informed Style	Shared Style
General health	.088	.028	-.059
Used HRT in the past	-.077	.021	.051
Currently using HRT	-.011	.184*	.040
Used contraception pill \geq 5 years	-.098	.028	.025
Number of visits to GP	.027	-.061	.134
Last time saw doctor	-.106	.216**	-.183*
Level of education	-.084*	-.009	.149

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

The 'paternalistic' style of decision-making was only associated with 'level of education' when analysed as a single variable. When the 'paternalistic' style was isolated into stages the 'number of visits to their General practitioner' was also found to be related to paternalistic information exchange. As can be seen in Table 12 the PPMC coefficient found between these variables was .176 and this relationship was significant at the alpha level of 0.05. The association between the 'paternalistic' style and 'level of education' was found to be significant at the alpha level of 0.01 within the information exchange stage of the process and at the 0.05 level within the deliberation stage. No association was found between 'level of education' and a preference for making a 'paternalistic' final decision.

Table 12: Correlations Between Selected Demographic Variables and Paternalistic Style at Each Stage.

Demographic Variables	Paternalistic Information exchange	Paternalistic Deliberation	Paternalistic Decision
General health	.123	.062	.074
Used HRT in the past	-.144	-.066	-.026
Currently using HRT	-.010	.041	-.041
Used contraception pill \geq 5 years	-.101	-.126	-.093
Number of visits to GP	.176*	.027	.032
Last time saw doctor	-.110	-.030	-.134
Level of education	-.255**	-.198*	-.086

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

The correlation between the 'informed' style and both 'currently using HRT' and 'last time saw doctor' can be isolated to specifically apply to informed information exchange and informed deliberation respectively. The preference for informed deliberation was also found to be negatively associated with level of education, whereas no such relationship was found when considering this style as a whole. The results of this analysis are seen in Table 13.

Table 13: Correlations Between Selected Demographic Variables and Informed Style at Each Stage.

Demographic Variables	Informed Information exchange	Informed Deliberation	Informed Decision
General health	-.023	.145	.003
Used HRT in the past	.143	-.116	-.010
Currently using HRT	.179*	.018	.140
Used contraception pill \geq 5 years	.066	-.036	.056
Number of visits to GP	-.134	-.038	-.061
Last time saw doctor	.136	.172*	.166
Level of education	.026	-.197*	.114

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

As can be seen in Table 14 the preference for the shared approach to information exchange is not associated with any of the selected demographic variables. The significant negative association between the 'shared' style and 'last time saw doctor' was only found at the deliberation stage. Level of education was also found to be associated with shared decision.

Table 14: Correlations Between Selected Demographic Variables and Shared Style at Each Stage.

Demographic Variables	Shared Information exchange	Shared Deliberation	Shared Decision
General health	-.036	-.126	.037
Used HRT in the past	-.022	.015	.117
Currently using HRT	-.032	.012	.108
Used contraception pill \geq 5 years	-.005	.057	.000
Number of visits to GP	.125	.087	.062
Last time saw doctor	-.082	-.170*	-.126
Level of education	.008	.100	.205*

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

3.6 Testing for congruent styles

At the periphery of the scope of the present study was the aim to explore the level of doctor initiated paternalism with regard to treatment decision-making. Any in depth analysis was not supported by the design of the present study, however, an examination of items 11 and 20 provided some worthwhile information.

As can be seen from Table 15 the mean response to item 11 which asks whether the respondent agrees with the statement "My doctor does not allow me an equal say in the discussions about my treatment" was 1.93. On the five-point response scale this mean equates to an average position of 'disagree'. Similarly the mean response to item 20 "My doctor does not allow me an equal say in the final decision about my treatment"

was 1.90. Again equating to a position of 'disagree'. The level of the paternalistic approach to treatment decision-making attributed as 'doctor initiated' was lower than expected with only 4.8% indicating that their doctor initiates this approach at the deliberation stage and 2.8% at the decision stage.

Table 15: Means, Standard deviations and Scale range for the Variables Observing the Paternalistic Style as Initiated by the Doctor.

Variables	N	Mean	S.D.	Scale range
11 "My doctor does not allow me an equal say in the discussion about my treatment".	146	1.93	.899	1-5
20 "My doctor does not allow me an equal say in the final decision about my treatment".	143	1.90	.781	1-5

Fifty-seven percent of those participants who indicated that their doctor does not allow them an equal say at the deliberation stage also indicate that they prefer to leave the doctor to consider their treatment choices. Twenty-nine percent would prefer to be involved in a shared approach to deliberation and the remaining 14% were neutral about all of the style options.

Only one respondent who indicated that their doctor does not allow them an equal say in the final decision about their treatment also rated that they prefer to leave the doctor to make the final decision. Fifty percent of these participants rated that they disagreed with the doctor making the final decision, although 75% would accept the doctor's choice if they disagreed.

Items 15 and 18 looked at whether participants agree or disagree that their doctor treats them as equal partners in the deliberation and final decision-making stages. As can be seen from Table 16 the mean response for item 15 was 3.95. On the five-point scale this

response equates to a position of 'agree'. Similarly the mean response for item 18 was 3.87, which also corresponds to the 'agree' position on the five point scale. Seventy-seven percent of participants indicated that their doctor treats them as an equal partner when discussing their treatment options, although as shown in Figure 3, 83% agree with sharing the deliberation process. Many participants, however, agreed with more than one style of deliberation. Of those who exclusively preferred the shared style, 15% did not agree that their doctor treats them as an equal partner.

Table 16: Means, Standard deviations and Scale range for the Variables of Established Shared Deliberation and Decision-making.

Variables	N	Mean	S.D.	Scale range
15 "My doctor treats me as an equal partner in discussions about my treatment options".	144	3.95	.742	1-5
18 "My doctor treats me as an equal partner when we make the decision about my treatment".	143	3.87	.771	1-5

Seventy-three percent of participants indicated that their doctor treats them as an equal partner when they make the final decision about treatment. As was shown previously in Figure 4, 85% of participants agreed with making a joint decision. Again, many participants agreed with more than one style of final decision-making and of those who exclusively preferred the shared style, 14% did not agree that their doctor treats them as an equal partner.

4. CHAPTER FOUR: DISCUSSION

A discussion of the results along with an interpretation of the results as they relate to the research questions proposed in Chapter one follows. Subsequent to this the limitations of the present study are detailed and the implications of the findings are addressed. The discussion will then conclude with recommendations for future research.

4.1 Summary of findings

4.1.1 Three Styles of Treatment Decision-making

Within this study, the Charles et al. (1999) theoretical model of treatment decision-making was tested. The exploratory nature of the present study sought to seek support for the framework by finding three styles of decision-making within the HRT context.

There was support for the proposed framework as three distinct styles were extracted. The first component of treatment decision-making was identified as the 'paternalistic' style. All five items designed to measure this style loaded into factor one and each stage of the process was represented. The second component of treatment decision-making to be extracted was the 'shared' style. The three items designed to measure the 'shared' style at each stage of the process loaded into factor two. The 'informed' deliberation item also loaded into factor two along with the 'shared' items, however, this is indicative of change of style throughout the process and as such will be discussed later in the summary. The third component extracted was the 'informed' style of treatment decision-making. Three of the four items designed to measure this style loaded into factor three of the solution, representing 'informed' information exchange and 'informed' final decision.

4.1.2 The Consistent Use of Styles Throughout the Decision-making Process.

Having established that the three main styles of treatment decision-making were applicable to the HRT context, the present study also sought to explore whether the styles were maintained throughout the entire process.

The factor solution suggested that the 'paternalistic' style was consistently adhered to throughout the process by those women who preferred this style. The examination of correlation coefficients at the bivariate level supported this finding. Each stage of the decision-making process within the 'paternalistic' style was significantly related to the others in the positive direction expected. Along with this support for the homogeneity of the 'paternalistic' style, there was also limited support for the change of this style toward the 'shared' style. The association between 'paternalistic' information exchange and 'shared' deliberation indicated that some women may prefer to limit their involvement when it comes to providing personal information or actively eliciting information, but may wish to share the deliberation process with their doctor. Similarly some women who preferred to leave the doctor to deliberate about their treatment choices expected to still be involved in making a joint decision.

The examination of the correlation coefficients relating to the 'informed' style of decision-making offered support for the occurrence of change of style across the stages of the process. The women in the present study who preferred to actively seek medical information from their doctor were likely to want to make the final decision about HRT themselves. Those women who preferred to consider their choices about treatment themselves were also likely to prefer to make the final treatment choice themselves. However, preferring the 'informed' style of information exchange was not systematically associated with preferring the 'informed' style of deliberation, rather these women were more likely to want their doctor's help when considering their choices about HRT treatment. It appears, therefore, that a combination of the 'informed' and 'shared' styles were preferred by these women as a means to negotiate all of the stages within the decision-making process. The digression from the 'informed' style at deliberation time can also be seen from the factor solution, which showed 'informed' deliberation not loading with the other two stages in factor three.

The 'shared' style of decision-making was shown to be relatively stable across the stages of the process. Women who agreed with the 'shared' approach to information exchange were also likely to agree with this approach at deliberation. Women who preferred to share the deliberation process were likely to want to make a joint decision. The sharing of information, characterised in the present study as a two-way contribution of personal and medical information, was not systematically related to wanting to make a joint decision, nor however was it related to any other style of final decision-making. It is not likely, therefore, that any judgement could be made regarding how these women would prefer to make their final decision based solely on their proclivity to the 'shared' approach at information exchange.

The analysis of the 'shared' style also found that some women who agreed with the 'paternalistic' approach to deliberation, that is they endorse leaving the doctor to consider their choices, were still likely to want to be involved in making a joint final decision. Likewise the relationships between 'shared' deliberation and both 'informed' and 'paternalistic' information exchange likely reflects a change to the 'shared' style from some women who preferred the 'informed' and 'paternalistic' styles at information exchange. Regardless of the style favoured when providing and eliciting information the majority of women in the present study wanted their doctor's help with deliberating the choices to be made about HRT.

4.1.3 The Association Between Styles and Stages of the Process

In line with the previous aim, which investigated possible change within the decision-making process, the present study also sought to explore whether different stages of the process lent themselves to different styles.

The results of the descriptive analysis, looking at each style within each stage of the process, showed that for the women surveyed the 'shared' style was the most preferred style at each stage. The 'informed' style of preferring to make the final decision regarding HRT themselves rated a close second as the style of choice for making the final decision.

The descriptive analysis also looked at each stage within each style of decision-making. Women were more likely to prefer the "paternalistic" style when involved in information exchange than when deliberating or making their final HRT treatment decision. This may reflect a desire to avoid discussing personal issues with their doctor, especially some of the intimate topics concomitant with HRT discussions. In contrast, women were more likely to prefer the 'informed' style at the decision stage than at the deliberation stage of the process. This result indicates that women would rather make the final decision about whether to use HRT or not themselves, than be left to deliberate such a choice without their doctor's help. The "shared" style of treatment decision-making did not appear to lend itself to any particular stage of the process, as this style was rated consistently high at each of the three stages.

It was apparent from the data that many of the women surveyed agreed with more than one style at any one stage of the process. The results focusing on exclusivity found that the "paternalistic" style was exclusively preferred as a means to conduct information exchange and deliberation by only one woman and none of the women surveyed preferred only this style when it came to making their final decision. Marginally more women were found to exclusively prefer the 'informed' approach to information exchange and deliberation, however, perhaps as many as one in eight preferred only this style when making their final decision. For this group of women assuming responsibility for making the final decision was the only acceptable choice. In contrast to these results the women surveyed indicated that they were more likely to exclusively prefer the 'shared' style of treatment decision-making, especially when it came to deliberation. Two thirds of women stated that it was only acceptable for them to have their doctor's help when they considered their choice about whether to take HRT or not. For these women, assuming such responsibility entirely themselves or leaving this process up to their doctor were not acceptable options.

4.1.4 The Association Between Styles and Demographic Variables

The present study included demographic and medical variables for the purpose of investigating whether any of these variables were related to particular style preferences.

Bivariate analysis showed that only the participant's level of education was related to the 'paternalistic' style of treatment decision-making. The negative direction of the coefficient indicated that less formal education was associated with a higher 'paternalistic' decision-making score. Several studies have reported this relationship (Benbassat et al., 1998; Degner et al., 1997; Hack et al., 1994) The present study, however, concludes that in the context of HRT decision-making the association was found to relate only to the information exchange and deliberation stages of the process. No such relationship was found between women's level of education and their preference to leave the final decision about HRT to their doctor.

The number of visits women had to their GP in the last year also related to 'paternalistic' information exchange. The positive direction of the relationship indicated that as the number of consultations with their GP rose, so to did the women's endorsement of the 'paternalistic' approach to information exchange.

The significant correlation in the positive direction found between the 'informed' style and currently using HRT indicated that women not currently using HRT were also found to agree with the 'informed' style of decision-making. Neither the 'paternalistic' nor 'shared' styles of decision-making were found to be systematically related to the use of HRT. The recency of consultations also related to the 'informed' style. The positive direction of the coefficient indicated that women whose contact with their doctor was less recent were also found to agree with the 'informed' style of decision-making. Both of these relationships were isolated to apply to the 'informed' information exchange and deliberation stages only.

As with the 'informed' style, the 'shared' style of decision-making was also found to be related to the recency of consultations. The negative direction of this relationship, however, indicated that women with more recent contact with their doctor also agreed

with the 'shared' approach to decision-making. By isolating the 'shared' style into stages, it was found that this association applied to the deliberation stage of the process. Women who had more recent contact with their doctor were found to prefer their doctor's help when considering their choices about HRT treatment.

4.1.5 Achieving Congruent Styles

Also of interest within the present study was whether any of the "paternalistic" experiences of the decision-making process were congruent with women's preferences. For instance, whether any dominance assumed by doctors was in line with how women preferred to negotiate the decision-making process. In line with this aim the present study also sought to investigate whether the preference for the "shared" approach was achieved within the women's interactions with their doctor.

The results showed that over half of the women surveyed who indicated that their doctor initiated the 'paternalistic' approach to deliberation also indicated that they preferred this approach. A smaller group indicated that they would rather share the deliberation process, while the remainder of these women showed no style preference at this stage of the process. The results relating to whether the women felt their doctor did not allow them an equal say in the final decision showed, in contrast, that only one woman who agreed with this statement also indicated that she preferred to leave the final decision entirely to the doctor. Clearly the 'paternalistic' approach assumed by doctors was often acceptable during deliberation but not so when making the final decision. Half of these women, in fact, disagreed with the doctor making the final decision about whether they should take HRT or not.

Although more than three quarters of women surveyed indicated that they share the deliberation about their treatment options with their doctor, as many as one in seven women who exclusively preferred the 'shared' style of deliberation did not feel that their doctor treats them as an equal partner. Similar numbers of women who only agreed with making a joint decision did not feel that their doctor treats them as an equal partner.

4.1.6 Conclusion

The Charles et al. (1999) framework was found to be an appropriate model for conceptualising the decision-making context of HRT. The present study found support for the dynamic nature of treatment decision-making, as the three main styles found to be applicable to the HRT context were also found to be amenable to change. For instance, the results showed that women who may favour the 'paternalistic' approach at information exchange time may well favour the 'shared' approach to deliberation. Likewise although women may prefer the 'informed' approach to information exchange and indicate that they would prefer to make the final decision themselves, it does not necessarily mean that they wish to deliberate their choices without their doctor's input and advice. Finally, women who favour collaboration initially while exchanging information and deliberating their choices, may also prefer to make the final decision themselves.

These findings are important because a women's style of interaction at the information exchange stage, in particular, is thought to be indicative of their preferred style of decision-making. This finding supports the claim by Benbassat et al. (1998) that the need for information and the need to be involved in the final decision are not necessarily related. Auerbach & Pegg (2002) have also recently found that the desire for information was clearly unrelated to either the desire for behavioural or decisional control when tested on a student population.

It was unclear whether such claims could be generalised to the HRT decision-making context, however, as many of the Benbassat et al. (1998) reviewed studies appeared to involve patients with life threatening illnesses. Likewise the Auerbach & Pegg (2002) study involved a dissimilar population to that currently being considered. The results of the present study certainly indicate that the distinction between these two stages is often warranted and should be considered within the HRT context.

Interestingly, these results may be interpreted as evidence against the Hack et al. (1994) conclusion that patient preferences for information and decision-making are systematically related. It should be noted, however, that these authors found such a relationship when considering active versus passive patient preferences. The present study also found this relationship among 'paternalistic' and 'informed' women, but

not with those who preferred the shared approach. Given that this was the most preferred style, it seems unwise to ratify the Hack et al. (1994) proposed relationship without further investigation.

The results found that for the women surveyed the 'shared' style of decision-making was the most preferred style throughout the three stages of the process. The 'informed' style, however, was regarded favourably at the final decision stage. The 'paternalistic' style, while more likely to be preferred as a means to exchange information than at any other stage in the process, did not rival the other styles overall.

Although the present study found that many women prefer more than one style of decision-making at any one stage of the process, those women who preferred the 'shared' style were more likely to only prefer this style. This finding was especially relevant to the deliberation stage and indicated that for more than half of the women surveyed, regardless of initial style preference, only the 'shared' style was acceptable as a means to conduct deliberation.

While the majority of women who participated in the present study indicated that their interactions with their doctor were collaborative and equal, some also indicated that their preference for collaboration was not being supported by their doctor. This is particularly relevant to those who agree only with the 'shared' approach, as these women effectively disagree with the style of decision-making that they are involved in. The continued use of the 'paternalistic' style for this age group may be justified by the finding that half of the women who indicated that their doctor does not allow them an equal part in the deliberating process, agreed with leaving the doctor to consider their choices. A more effective way of identifying these women and their preferences, especially relating to the deliberation and decision stages is necessary. Especially to avoid subjecting the group of women that the present study identified as those who disagreed with the 'paternalistic' approach to an incongruent style.

Chapter one of the present study discussed that many New Zealand women were dissatisfied with the service their doctors were providing them regarding the management of their menopausal symptoms and HRT consideration. It was assumed that much of the dissatisfaction was the result of the mismatch of decision-making styles between doctor and patient. The present study has found that women's style

preferences can change throughout the process of HRT consideration and without initial and continual assessment there exists several ways in which dissatisfaction could be generated. For instance, those women who the doctor may judge as wanting to make an 'informed' decision, based on their proclivity to this approach at the information exchange stage and decision stage, being left to deliberate without their doctor's help. Dissatisfaction could also arise for those women who show a desire for the 'paternalistic' approach to information exchange having this style imposed throughout the rest of the process without continued assessment. Those women who would like to collaborate more after the initial stages, but who are not encouraged too based on their early style indications could also be left feeling dissatisfied with their experience and with the service their doctor provided them.

It is unlikely the many women would prefer the 'paternalistic' approach to decision-making over any of the other styles. The finding that some women nevertheless agree with this approach means that it is still worthwhile for doctors to be mindful of the support this style may provide at certain stages of the process. As was discussed in Chapter one, eliciting information can amount to an interrogative style that is subtly dominating. Women must be allowed to limit their participation at the information exchange stage if they desire to. The present study has shown that a proportion of these women will then adopt a more collaborative approach to deliberation and then perhaps even prefer to make a joint or 'informed' decision. Women who may well find support in the 'paternalistic' approach to both information exchange and deliberation may still, thereafter, prefer to be involved in making a joint final decision. In light of these changes it appears important for women to be aware that their preferences can differ between stages of the decision-making process and that they need not continue with a style simply because they have done so in the past.

The finding that almost as many women preferred to make an 'informed' final decision as a 'shared' final decision, despite not favouring this approach at the deliberation stage, indicates that for some women the proclivity to the 'informed' approach may result from the collaborative involvement during deliberation. Such a change should be assessed and encouraged within the consultation process rather than manifesting later through non-compliance. The results also indicate that for many women who wish to make their own decisions regarding HRT, they often also wish to

have their doctor's help while deliberating their choices. Such collaborative involvement may result in the women feeling obliged to share the final decision with their doctor. If this arrangement is not entirely satisfactory these women may express their control, and hence their 'informed' preference, later through 'non-compliance'.

Previous research has shown that Pakeha women were twice as likely as Maori women to be using HRT (North & Sharples, 2001). The discrepancy raises many questions including whether decisional styles differ between the two groups of women, and hence, affects the treatment decisions made. The present study found no significant differences between Pakeha women and Maori women with regard to their decision-making styles.

4.2 Limitations of the study

There are several limitations to this research design that need to be considered when interpreting the results.

The measure needs to be extended to include more items to cover all of the relevant distinguishing criteria. Within the construct of information exchange, in particular, the present items may not adequately capture all aspects indicative of those described in the theoretical model. For instance the type, amount and direction of information exchange within each style of decision-making. The limited items in the present study may therefore not discriminate between the three styles of information exchange well enough.

The use of single items to measure other variables within this study is also problematic. A variety of self-report measures used to capture decision-making preferences have not been well validated (Entwistle, 2001). As such there is little empirical evidence regarding the validity of single items or whether the present items have adequate external validity. No existing measures of treatment decision-making were found to have sufficient psychometric properties to offer any form of comparison with the measure used in the present study.

A larger measure, which better represented all of the distinguishing criteria relevant to the theoretical framework, would also provide a more sound basis for the process of

data reduction. The factor analysis integral to the present study would be more appropriately applied to a larger group of items.

The use of a single method to measure style preference may also be problematic. There is evidence, for instance, that narrative descriptions of decision-making style preferences may reveal discrepant information from that identified through self-report measures. The Entwistle et al (2001) study of women considering a hysterectomy found their narrative data was often at odds with the role descriptions selected from menu-based measures.

Also of concern within the present study is the presence of social desirability bias (Weiten, 1995). The expectation that women should be well-'informed' and responsible for their health outcomes is being increasingly publicised and portrayed as desirable. This may have led the women in the present study to over-rate their endorsement of the 'shared' and 'informed' styles and under-rate the 'paternalistic' style. Evidence of a similar response bias was found by Entwistle et al. (2001) when the role description "I left all the decisions regarding my treatment to my doctor" (Control Preference Scale by Degner & Sloan, 1992) was described in the narrative account as being equivalent to the respondent admitting they couldn't care less.

The results of the present study can not be generalised beyond the current sample. Further research is needed to replicate the factor structure with a different sample of women. The women sampled in the present study were 45 years old, and as such, represented women in the younger age range who may be considering HRT. Many of these women may not have experienced menopausal symptoms or be at present involved with the HRT decision-making context. The experience and severity of symptoms may impact on the decisional preferences that women adopt.

4.3 Implications

Given the limitations of the present study some provisional implications due to the findings can be considered and discussed.

The finding that three styles of decision-making exist within the HRT context indicates that doctors need to be aware that women may chose different styles of negotiating the HRT decision and that no one best style exists that will satisfy the needs of all women. The present study also found that HRT decision-making is not a single event but rather a process involving distinct stages. The finding that each of the decision-making styles are amenable to change throughout the process highlights the need for both doctors and women to be aware and open to the possibility of change and for doctors to be able to accommodate emerging needs.

The finding that most women may prefer the 'shared' style of decision-making highlights the need for doctors to be competent collaborators with sound negotiation skills. Their role in the partnership is to provide medical information and expertise. Doctors must, therefore, become better informed about HRT and must have access and knowledge of current research. One of the limitations of the 'shared' approach to decision-making is time constraint. If doctors are to enter into the 'shared' approach and adequately collaborate with women to make the HRT decision, they need to be able to negotiate these time constraints and find efficient means of providing partnership.

The present study found that most women exclusively preferred the 'shared' approach to HRT decision-making. This highlights the need for doctors to be well informed about the medical information concerning HRT, so they can fully participate in their role in the expected partnership. The finding that most women in the present study exclusively prefer the 'shared' style at deliberation, in particular, highlights that women clearly want their doctor's help when deliberating their choice to use HRT or not. Doctors must be able to provide this help without assuming dominance or compromising the collaborative nature of the interaction.

The conclusion that many women wish to make the final decision themselves emphasises the need for doctors to be able to communicate the legitimacy of this choice,

so that such a decision can be made respectfully within the consultation process and not manifest later through non-compliance.

The Charles, Gafni & Whelan framework (1999) could be presented as a treatment decision-making tool for women considering HRT. The framework could be used by doctors to help explain the various approaches that can be used and provides clear and necessary description of the various analytic stages in the decision making process. Incorporating the framework into the consultation experience of women considering HRT could help make explicit the opportunity that each treatment decision-making process can combine elements from different models at different stages. This proposed decision-making tool also reinforces the importance of flexibility, so the doctor can identify and respond to changes in patient preferences. Based on the present study it is concluded that the Charles, Gafni & Whelan treatment decision-making framework (1999) would be a useful educational and assessment tool for doctors and women making decisions regarding hormone replacement therapy.

4.4 Future research issues

Together the results and limitations of the present study have identified several issues that warrant further investigation. Future research is needed to replicate the results of the present study to provide support for the factor structure extracted and for the validity of the measure used. The theoretical framework tested in this study should be re-tested with samples of women who have reached the menopause phase in their lives and who are at present considering HRT. A variety of situational factors need to be considered. For instance, pre-existing attitudes toward HRT, the presence and severity of symptoms, the motivation for HRT consideration or more precisely whether HRT is being considered as a means to provide relief from symptoms or as a means to protect against future illness. Qualitative analysis may be used to assess the interpretation of the measure used in the present study. Perhaps a research design involving both quantitative and qualitative methods could be used to expand measurement knowledge and refine future development.

The key recommendation to be drawn from this research concerns measurement issues. Specifically, future research is required to develop measures to better assess women's HRT treatment decision-making styles. The present study has recognised the value of devising a measure that distinguishes between the stages of the decision-making process. This aim is supported by Entwistle et al. (2001) who emphasis the need to develop measures that better accommodate the complexity of interactions during decision-making than the single sentence role descriptions do. Further research is now needed to refine and improve the HRT decision-making measure.

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Women's Health Action Trust. www.womens-health.org.nz

APPENDIX A Letter to Sample

Massey University

COLLEGE OF HUMANITIES & SOCIAL SCIENCES

School of Psychology

Private Bag 11 222,

Palmerston North,

New Zealand

Telephone: 64 6 356 9099

Facsimile: 64 6 350 5673

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4 February 2002

Information: Decision Making and Hormone Replacement Therapy Study

Dear _____

My name is Christine Stephens and I am a lecturer in the school of Psychology at Massey University. With two masters' students, Tracey McLellan and Wendy Radford, I am carrying out research with mid-aged women.

We are writing to ask for your help with a survey on how women make decisions regarding Hormone Replacement Therapy (HRT). At present very little is known about how New Zealand women and their doctors make such treatment decisions. We seek to understand this decision making process so that women may be assisted if they are trying to decide whether to use HRT or not.

Your name was selected at random from those women, aged 45 years, on the electoral roll. Any information that you provide will be anonymous; it will not be linked to your name or address, and will be used only for the purpose of this study. No individual woman will be identified in any report from this survey.

We are very interested in replies from all women, including those who have not reached the menopause or have never taken hormone replacement therapy. However, your participation is voluntary (your choice). If you prefer a Maori language version of the questionnaire, please tick the box on the first page and return the questionnaire in the pre-paid envelope. We will send you a copy of the questionnaire in Te Reo Maori. If you do not wish to take part, please return the questionnaire in the pre-paid envelope and we will send no further reminders. Your questionnaire is coded, only so that we can remove your name completely from our address list as soon as we receive your questionnaire back (either completed or uncompleted).

If you are willing to take part, please answer the questions on the enclosed form and return them to us in the pre-paid envelope (no stamp required) within two weeks. Please note that completion of the questionnaire implies that you consent to participate in this survey. As a participant, you have the right to decline to answer any particular questions.

We will send you a summary of the results of the study if you complete the request form included with the questionnaire. This request form will be stored separately from the questionnaire as soon as we receive it and the record will be destroyed once we have sent you the information.

If you would like any further information or have any questions about the study please do not hesitate to contact Christine Stephens at the address above or phone us at 06 350 5799 ext. 2071.

Yours sincerely

Dr Christine Stephens

Tracey McLellan

Wendy Radford

4 February 2002

Te Whakatau Kowhiringa me te Haumanu Taiaki: He Kaupapa Rangahau

Tena koe _____

Ko Christine Stephens toku ingoa, he ptikenga ahau i roto i te Kura Hinengaro i Te Kunenga ki Ptirehuroa (Te Whare Wiinanga o Massey). Kei te mahi au i tetahi kaupapa rangahau i te taha o te hunga wahine pakeke. Tokorua ano aku kaiawhina; he akonga paerua, ko Tracey McLellan raua ko Wendy Radford.

He tono tenei kia awhina mai koe i tamatou kaupapa rangahau i ta te wahine whakatau i ana kowhiringa e pa ana ki te Haumanu Taiaki (HT). I tenei wa, kaore e nui nga mohiotanga e pa ana ki te hunga wahine o Aotearoa me te ahua o ta ratou whakatau i nga kowhiringa mo o ratou rongoa, i te taha o o ratou takuta. Ma te tenei rangahau e puta ai etahi maramatanga hei awhina i te wahine e whiriwhiri ana mena e tika ana te Haumanu Taiaki (HT) mona, kaore ranei.

He mea tipako matapokere to ingoa, mai i te hunga wahine he pakeke ake i te 45 tau i te rarangi poti. Ka noho matatapu to ingoa, e kore hoki e honoa o korero ki to ingoa, ki to wiihi noho ranei, a, ka whakamahia o korero mo tenei kaupapa rangahau anake. Kaore hoki e whiikina atu te hunga ka whai wahi mai i roto i nga purongo ka puta i tenei rangahau.

E tino hiahia ana matou ki nga whakaaro o nga wahine katoa, ahakoa kaore ano pea kia eke atu ki te wa o te koero, kua kore ranei e whakauia ki te haumanu taiaki (HT). Oti ano, kei a koe tonu te whiriwhiri ki te uru rai ki te kaupapa, kaore ranei. Ki te kore koe e hiahia ki te awhina mai, kei te pai noa iho -me whakahoki mai te rarangi patapatai i roto i te kopaki utu-kore, a, ka mutu i kona. Kua tohua to rarangi patapatai, e taea ai to ingoa te tango i ta matou rarangi wahi noho ina whakahokia mai te rarangi patapatai (ahakoa kua whakautua nga patai, kaore ranei).

Ina whakaae koe ki te awhina mai i te kaupapa nei, me whakautu nga patai, ka whakahoki mai ai i roto i te kopaki utu-kore i mua i te paunga o nga wiki e rua. Ina oti i a koe te rarangi patapatai koira e whakaatu mai ana i to whakaetanga ki te uru mai ki te kaupapa rangahau nei. Kei a koe ano te whiriwhiri ina kore koe e hiahia ki te whakautu i tetahi o nga patai.

Ina oti i a koe te puka tono i te mutunga o te rarangi patapatai, ka tukuna ki a koe tetahi tuhinga whakarapopoto o nga whakakitenga ka puta i te rangahau. Kia tae mai to rarangi patapatai, ka tangohia atu te puka tono nei, a, ka waiho ki wahi ke atu o nga rarangi patapatai. Ka oti i matou te tukutuku i nga tuhinga whakarapopoto, ka whakakorea enei puka tono. Ma konei, e ata tiaki ai to kiri matatapu.

Ki te hiahia koe ki etahi atu korero, mena he patai au, me whakapa mai ki ahau, ki a Christine Stephens. Kei runga nei te wahi tuku reta mai, ko taku nama waea: 06 350 5799 peka 2071.

Hei kona i roto i nga mihi.

Dr Christine Stephens

Tracey McLellan

Wendy Radford

Kua whakaaetia tenei kaupapa rangahau e Te Komiti Matatika Tangata o Te Whare Wananga o Massey (01/21)

APPENDIX B Decision Making Questionnaire

Cover page



Women's decision-making study.



Please read the instructions carefully and answer all questions.

Do not spend a lot of time on each question, usually your first answer is best.

Completing this questionnaire implies your consent to participate in this study.

Please send me a Māori language version of this questionnaire...

Section 2

Instructions: The next set of questions is about how you prefer to interact with your doctor. Please circle the number that shows how much you agree with each of the following statements if they were about you. We expect everybody's answers to be different - there are no right or wrong responses.

		Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
		1	2	3	4	5
1	I feel my doctor knows best how much information I need to be told about HRT.	1	2	3	4	5
2	It is important for me to tell my doctor about my personal feelings and concerns regarding HRT.	1	2	3	4	5
3	I would prefer to leave the doctor to consider the choices about treatment.	1	2	3	4	5
4	The best decision is more likely to be made by me.	1	2	3	4	5
5	If the doctor and I disagree I will accept the doctor's choice.	1	2	3	4	5
6	The main purpose of a doctor's appointment is to gather all the medical information I want from the doctor.	1	2	3	4	5
7	I feel the need to discuss my personal non-medical information with my doctor.	1	2	3	4	5
8	The best decision is more likely to be made by the doctor.	1	2	3	4	5
9	I would prefer to consider my choices about treatment without my doctor's input.	1	2	3	4	5
10	I would prefer to make a joint decision with my doctor.	1	2	3	4	5
11	My doctor does <u>not</u> allow me an equal say in discussions about my treatment.	1	2	3	4	5

Section 3

		Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
		1	2	3	4	5
12	I would prefer not to disclose my personal non-medical information to my doctor.	1	2	3	4	5
13	I prefer to make the final decision about treatment myself.	1	2	3	4	5
14	I would prefer to consider my choices about treatment with my doctor's help.	1	2	3	4	5
15	My doctor treats me as an equal partner in discussions about my treatment options.	1	2	3	4	5
16	I prefer to leave the final decision about treatment to the doctor.	1	2	3	4	5
17	I would like to have an equal say in any discussions about my treatment options.	1	2	3	4	5
18	My doctor treats me as an equal partner when we make the decision about my treatment.	1	2	3	4	5
19	The best decision is more likely to be made if my say is equal to the doctors.	1	2	3	4	5
20	My doctor does <u>not</u> allow me an equal say in the final decision about my treatment.	1	2	3	4	5

Section 4

Finally, we would like you to provide some background information about yourself so that we can compare the preferences of different groups of women. Tick the appropriate boxes or write your responses in the spaces provided below. Remember that the information that you give us is **confidential**.

1. **Have you used HRT in the past?**

1 Yes

2 No

2. **Are you currently using HRT?**

1 Yes

2 No

3. **Have you used the contraceptive pill for over 5 years at some time in your life?**

1 Yes

2 No

4. **Have you ever had any of the following operations?**

1 Hysterectomy (uterus removed)

2 Hysterectomy and both ovaries removed

3 Both ovaries removed

5. **How many times in the last 12 months have you seen any GP or been visited by one (e.g. family doctor, but not a specialist)?**

Number of times seen by any GP in the last 12 months:

6. **When was the last time you saw the doctor?**

1 In the last two weeks

2 More than two weeks ago but less than three months

3 More than three months ago but less than six months

-
- 4 More than six months ago but less than one year
- 5 One year ago
- 6 More than one year ago

7. **Please give your age in years.**

8. **Which ethnic group do you identify most with?**

- 1 N.Z. Pakeha/European
- 2 N.Z. Maori
- 3 Pacific Island Nation (please specify)
- 4 Asian (please specify)
- 5 Indian
- 6 Other (please specify)

9. **Do you identify with an Iwi and Hapu?**

- 1 Yes
- 2 No

10. **Do you identify with a Marae?**

- 1 Yes
- 2 No

If yes:

How often would you have visited this marae or any other marae in the last year?

- 1 none
- 2 1-5 times
- 3 more than six times

11. **Do you know any Maori language?**

- 1 Yes
- 2 No

If yes:

Do you speak a little or are you fluent or are you somewhere in between?

- 1 a little
- 2 somewhere in between

3 fluent

12. **How would you describe your main job?**

- 1 Employed Full-time (more than 30 hours)
 2 Employed Part-time (less than 30 hours)
 3 Student
 4 Self-employed
 5 Homemaker
 6 Not in paid employment (Unemployed/Retired/On a benefit)

13. **If you are in paid work, what is your main occupation?**

.....

OR

If you are retired, unemployed or permanently unable to work, what was your main occupation before you stopped working?

.....

14. **If you are married or living as married, what is or was your husband's/partner's main occupation?**

.....

OR

If separated, divorced or widowed, what was your husband's main occupation?

.....

15. **What is your highest level of education?**

- 1 Primary school
 2 Secondary school for 1 or 2 years
 3 Secondary school for more than 2 years
 4 University, polytechnic or teacher training
 5 Other trade or vocational training (please explain)

.....

Thank you very much for taking the time to complete the questionnaire.

Your contribution to this study is appreciated.

Please return this questionnaire in the pre-paid envelope provided (no stamp required).



If you complete this section it will be promptly removed from the questionnaire to protect your privacy.

Please send me a summary of the results at the conclusion of the study:

Name: _____

Address: _____

APPENDIX C Reminder Postcard to Sample

Massey University

School of Psychology

Massey University

Private Bag 11 222

Palmerston North

New Zealand

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WOMEN'S DECISION MAKING STUDY:

WHAKATAU

Two weeks ago you were sent a questionnaire about decision making for mid-aged women. If you have already returned the questionnaire please accept our thanks and appreciation.

If you have not responded yet we would very much like to hear from you. If you have any questions about the study or need a replacement questionnaire please phone 06 350 5799 ext 2071 or email to: C.V.Stephens@massey.ac.nz Thank you for your time.

Dr Christine Stephens

Tracey McLellan

Wendy Radford

TE RANGAHAU I TA TE WAHINE

KOWHIRINGA

Kua pau te rua wiki mai i te wa i tukuna tetahi rarangi patapatai ki a koe e pa ana ki ta te wahine pakeke whakatau kowhiringa. Mena kua whakahoki ke koe i te rarangi patapatai nei, ka nui ra nga mihi.

Mena kaore ano koe kia whalahoki korero mai, ka nuui to matou hiahia kia uru mai koe ki te awhini i te kaupapa nei. Ki te hiahia koe ki etahi atu korero, mena he patai au, me whakapa mai ki ahau, ki a Christine Stephens. Kei runga nei te wahi tuku reta mai, ko taku nama waea: 06 350 5799 peka 2071.

Dr Christine Stephens

Tracey McLellan

Wendy Radford

APPENDIX D Replacement Questionnaire

Massey University

COLLEGE OF HUMANITIES & SOCIAL SCIENCES

School of Psychology

Private Bag 11 222,

Palmerston North,

New Zealand

Telephone: 64 6 356 9099

Facsimile: 64 6 350 5673

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25 February 2002

Dear Mrs _____

My name is Christine Stephens and I am a lecturer in the school of Psychology at Massey University. With two masters' thesis students, Tracey McLellan and Wendy Radford, I am carrying out research with mid-aged women. Three weeks ago we sent you a letter about our study of decision making and hormone replacement therapy (HRT). Your name was selected at random from those women, aged 45 years, on the electoral roll. As you have not yet returned a questionnaire, either complete or uncompleted, we are contacting you again.

At present very little is known about how New Zealand women and their doctors make such treatment decisions. We seek to understand this decision making process so that women may be assisted if they are trying to decide whether to use HRT or not. We are very interested in replies from all women, including those who have not reached the menopause or have never taken hormone replacement therapy.

We would like to take this opportunity to sent you a replacement questionnaire for our study. We have found that often people would still like to be involved in the study that they were invited to participate in, but they have misplaced their questionnaire. If this is the case please feel welcome to respond to the enclosed questions and return them to us in the pre-paid envelope provided. If you prefer a Maori language version of the questionnaire, please tick the box on the first page and return the questionnaire in the pre-paid envelope. We will send you a copy of the questionnaire in Te Reo Maori. If you choose not to respond, we will not be contacting you again.

Your participation is voluntary (your choice) and you have the right to decline to answer any particular questions. Please note that return of the completed questionnaire implies that you consent to participate in this survey.

We will send you a summary of the results of the study if you complete the request form included with the questionnaire. This request form will be stored separately from the questionnaire as soon as we receive it and the record will be destroyed once we have sent you the information.

If you would like any further information or have any questions about the study please do not hesitate to contact Christine Stephens at the address above or phone us at 06 350 5799 ext. 2071.

Yours sincerely

Dr Christine Stephens

Tracey McLellan

Wendy Radford

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN protocol 01/21

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Tena koe MRS _____

Ko Christine Stephens toku ingoa, he pukenga ahau i roto i te Kura Hinengaro i Te Kunenga ki Purehuroa (Te Whare Wananga o Massey). Kei te mahi au i tetahi kaupapa rangahau i te taha o te hunga wahine pakeke. Tokorua ano aku kaiawhina, he akonga paerua, ko Tracey McLellan raua ko Wendy Radford. E toru wiki ki muri, i tukuna atu ki a koe tetahi reta e whakamarama ana i te ahua o tenei kaupapa e pa ana ki te whakatau kowhiringa me te Haumanu Taiaki (HT). He mea tlpako matapokere to ingoa mai i te hunga wahine he pakeke ake i te 45 tau i te rarangi poti. Na to kore whakahoki mai i te rarangi patapatai (ahakoa oti, kaore ranei), kei te whakapa atu ano matou ki a koe.

I tenei wa, kaore e nui nga mohiotanga e pa ana ki te hunga wahine o Aotearoa me te ahua o ta ratou whakatau i nga kowhiringa mo o ratou rongoa, i te taha o o ratou takuta. Ma te tenei rangahau e puta ai etahi maramatanga hei awahina i te wahine e whiriwhiri ana mena e tika ana te haumanu taiaki (HT) mona, kaore ranei. E tino hiahia ana matou ki nga whakaaro o nga wahine katoa, ahakoa kaore ano pea kia eke atu ki te wa o te koero, kua kore ranei e whakauia ki te haumanu taiaki (HT).

Kei te tukuna tetahi ano rarangi patapatai i te taha o tenei reta. Akene pea kua ngaro te mea tuatahi i tukuna i tera wa, a, e hiahia tonu ana koe ki te awahina mai i tenei kaupapa. Ki te pera, tena, me whakaoti tenei o nga rarangi patapatai, ka whakahoki mai ai i roto i te kopaki utu-kore. Mena e hiahia ana koe ki te rarangi patapatai reo Maori, tohua mai te pouaka i te wharangi tuatahi, ka whakahoki mai ai i roto i te kopaki utu-kore. Katahi ka tukuna e matou te rarangi patapatai reo Maori hei whakaoti mau. Ki te kore koe e whakahoki mai i te rarangi patapatai nei, kaore matou e whakapa atu ano ki a koe.

Kei a koe tonu te whiriwhiri mena ka uru mai ki te kaupapa nei, kaore riinei. Kei a koe hoki te whiriwhiri ki te kore koe e hiahia ki te whakautu i tetahi o nga patai. Ina oti i a koe te rarangi patapatai, koira e whakaatu mai ana i to whakaetanga kia uru mai ki te kaupapa rangahau nei.

Ina oti i a koe te puka tonu i te mutunga o te rarangi patapatai, ka tukuna ki a koe tetahi tuhinga whakarapopoto o nga whakakitenga ka puta i te rangahau. Kia tae mai to rarangi patapatai, ka tangohia atu te puka tonu nei, a, ka waiho ki wahi ke atu o nga rarangi patapatai. Ka oti i matou te tukutuku i nga tuhinga whakarapopoto, ka whakakorea enei puka tonu. Ma konei, e ata tiaki ai to kiri matatapu.

Ki te hiahia koe ki etahi atu korero, mena he patai au, me whakapa mai ki ahau, ki a Christine Stephens. Kei runga nei te wahi tuku reta mai, ko taku nama waea: 06 350 5799 peka 2071.

Rei kona i roto i nga mihi

Dr Christine Stephens

Tracey McLellan

Wendy Radford

Kua whakaaetia tenei kaupapa ran-ahau e Te Komiti Matatika Tan-ata o Te Whare Wananga o Massey (01/21)