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Hormone replacement therapy: perspectives from women, medicine and sociology

Frances Ellen Griffiths

Submitted for the degree of Doctor of Philosophy 1997

Abstract

Developed on the boundary between medicine and sociology, this thesis develops a critique of the perspectives of these disciplines through analysis of a study of women's perspectives on hormone replacement therapy. Women's perspectives are explored through a postal questionnaire survey and a study using individual interviews and focus groups. The survey results provide a measure of women's attitudes towards, and knowledge of, hormone replacement therapy. The individual interviews detail the way women move towards a decision about the therapy and identifies common themes, particularly women's fears and what influences their fears. The focus groups explore contrasting themes including women's control and choice in decisions about therapy, contrary themes in women's attitudes and the different ways of thinking used by the women. The results of the studies are assessed for their implications for clinical general practice. The thesis also takes a sociological perspective on women and HRT and on the research process, in particular exploring two themes. Firstly, the interaction between the social context, the research subject and the research process. This includes the social factors influencing the development of the research and choice of research methods, and the influence of the research methods on the results obtained. The second theme is the perspectives and levels of analysis used by the main disciplines contributing to the thesis; biomedicine, biostatistics, general practice and sociology. The thesis explores how the different perspectives and levels of analysis influence research and how they are used to manage the social context. These explorations are used to suggest future directions for research on hormone replacement therapy and for general practice.

**Hormone replacement therapy: perspectives from women,
medicine and sociology**

Frances Ellen Griffiths

Submitted for the degree of Doctor of Philosophy

University of Durham
Department of Sociology and Social Policy

1997

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12 MAY 1998

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Preface

This thesis crosses the boundary between the disciplines of medicine and sociology but is for examination within the discipline of sociology. The thesis responds to three research questions which are described in chapter one. The starting point for the thesis was an exploration of women's attitudes to hormone replacement therapy. For readers not familiar with the use of hormone replacement therapy the author offers a summary of its use in clinical medicine in appendix 0.

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Author's declaration

The research for this thesis was conducted by the author alone except for section **2.2 The use of HRT by women in one general practice** for which the research was conducted jointly with Ms. Bernadette Convery of Cleveland Medical Audit Advisory Group.

Statement of copyright

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Definitions

The following abbreviations are used throughout the thesis:

HRT hormone replacement therapy

GP general practitioner

CVD cardiovascular disease

Chapter One

The development of the research questions

1.1 Introduction

This thesis examines HRT from the perspectives of women, medicine and sociology. The field work for the thesis includes a questionnaire survey and an interview study asking women how they view HRT. The results of this field work contribute the women's perspectives to the thesis. As a GP the researcher has a particular medical perspective on HRT. From this perspective the thesis explores the medical evidence available on HRT and aims to inform general practice about women's perspectives on HRT. As a sociologist the researcher attempts to step back from both the research with women and from clinical general practice, to develop a sociological perspective on the use and promotion of HRT and on the research process of the thesis.

The research for this thesis took place over a period of five years and while the research was being carried out the social context for the research and the perspective of the researcher changed and developed. The research for the thesis is therefore presented in the order in which it was carried out, to provide a narrative of the research process.

The process of developing the research questions and carrying out the research forms an important part of the research data for this thesis. Commentary on this process forms a major part of the sociological perspective developed in the thesis.

The structure of the thesis also follows the accepted pattern of presentation of research results in the discipline of medicine; introduction, then research method clearly divided from research results, and finally a conclusion. In this thesis the research methods and the research results are presented in different chapters

following the medical pattern, however unlike medical research, each chapter also includes commentary. This pattern of presentation is influenced by the background of the researcher and by one of the aims of the researcher, to use the research results to inform general practice about women's perspectives on HRT. The pattern of presentation is a practical compromise for this thesis which has developed on the boundaries of academic disciplines, but the form of presentation also forms part of the research process for which a sociological analysis is developed.

This first chapter describes the start of the research process, setting the scene for the narrative by describing the background to the development of the first research question. This question was about women's perspectives on HRT, but in the process of attempting to answer it, further research questions were developed in response to the experience of the research process and to academic influences. This chapter briefly describes these experiences and influences and the development of a research question about research methods and about working across academic disciplines.

The description of how the research started provides background information for the thesis and introduces ideas that weave through the thesis. However the description also forms part of the research data of the thesis and is used as an example of how research questions and the research process are social products, not something unaffected by society, and how an understanding of the social context of research can be important for understanding research results.

As the development of the research is recounted from the researcher's perspective and includes description of her developing ideas, it seems appropriate to write this chapter in the first person (Webb 1992).

1.2 Setting the scene

1.2.1 Research as a social product

I shall tell the story of how the research questions for this thesis arose including my own personal story, that of the medical practice where I work and of my research environment. The research questions were influenced by their social context, by social structures, political and economic influences and individual people. However, the story behind a piece of research is not often described, particularly in biomedical journals, where the introduction to a paper may review other research that influenced the research question, but does not describe the constellation of factors that enabled the research to happen at a particular time and place, and why it developed in the way it did (Aldridge 1993). Some of this can sometimes be guessed from the list of authors, institutions and grant giving bodies, but the detail of this background is often left to other commentators to describe or researchers from other disciplines to analyse. For example Waldrop describes in journalistic style the detailed background and interaction of some of the academics involved in the development of the theory of complexity (1992) and Oudshoorn, an archaeologist, describes the social, physical and personal resources that influenced the development of research into sex hormones during the twentieth century (1994). A piece of research is more easily understood from a sociological perspective if information about the social context is available as this can help answer questions such as why the research was done at this point in time, in this way and in this institution or by this researcher.

I describe the research questions and activities as social products which may sound deterministic, as if the researcher had no influence, but this is not the intention. As a researcher I am a social actor and the decisions I make and my activities alter the social world. However, these decisions and activities are influenced to varying degrees by the social context. The values by which I live and work also influence the development of the research. This type

of influence is explored by Gorovitz and MacIntyre in discussing scientific research used in medical practice, describing how values can "guide, constrain and inform" research (Gorovitz and MacIntyre 1976:52). They also point to norms that may influence research, distinguishing internal and external norms: "Internal norms are concerned with such factors as verifiability, truth, and reason; external norms are concerned with such factors as curiosity, ambition, and social utility." (1976:52-53).

In this chapter I attempt to be explicit about my values and the external norms which influenced me in this research. The "internal norms" described by Gorovitz & MacIntyre are discussed in the chapters about methods and methodology.

The story of the development of my research questions is based on my memory, research notes and notes of my reading. It is prone to the bias of memory and to the rationalising of past events. It will also be affected by the aim of writing it (i.e. to demonstrate that the research questions are a social product). It therefore does not claim any absolute truth but it is intended to increase our understanding of research and its processes.

The social context, values and external norms influencing the development of the research questions will be described in three sections: why women and HRT; why HRT and prevention; why research?

1.2.2 Why women and HRT?

My initial research question developed following a conversation, in December 1989, about HRT and its use, with a fellow GP in the practice I had recently joined following completion of my vocational training for general practice. We discussed a report in the British Medical Journal about women who had had a hysterectomy and oophorectomy but did not receive HRT (Spector 1989). We considered whether we should search the medical records of the women patients in our practice for those who were

not receiving HRT and who were younger than the average age for the menopause, but had had a surgical menopause. (The age at which a woman will go through the menopause is not known in advance of it happening so the average age of the menopause for women was used here as a best guess of when a woman would have gone through the menopause naturally.) My colleague knew the author of the report we discussed and this personal link may have heightened our awareness of the paper. However it also struck a chord with one of the guiding principals of clinical medicine, that of doing no harm. Spector stated:

The observations that 70% of women who had had a bilateral oophorectomy had never received hormone replacement therapy is important. Women without ovaries are those most at risk of subsequent osteoporosis (Aitken, Hart and Lindsay 1973) and cardiovascular problems (Colditz, Willett, Stampfer, Rosner, Speizer and Hennekens 1987), and bilateral oophorectomy is regarded by most gynaecologists as an absolute indication for oestrogen treatment. (1989:1434-1435)

To use more direct and explicitly critical language, Spector seemed to be saying that doctors had removed these women's ovaries and were then failing to provide appropriate replacement therapy. This would seem to be contrary to the guidance from the General Medical Council on good medical practice which states: "You must not..... recommend or subject patients to investigations or treatment which you know is not in their best interest deliberately withhold appropriate investigation, treatment or referral" (General Medical Council 1995:6). Spector's paper had thus raised questions for me about the women in our own practice for whom we felt clinically responsible. However my interest in this area was also influenced by other experiences.

Before starting my vocational training for general practice, I had tutored an Open University, cross discipline course called 'Health and Disease'. Through this I had become more aware of research literature that looked critically at clinical medical practices

including hysterectomy. A debate about the number of hysterectomies performed had been initiated in the US many years earlier by Miller, who had found that when the uterus was examined after hysterectomy, no evidence of disease was found in 31% of the cases in his hospital (Miller 1946). A study of the rates of several different operations, including hysterectomy, in the US, Canada and England and Wales found that each country seemed to have different levels of surgery that was relatively independent of the type of operation (McPherson, Strong, Epstein and Jones 1981). Social and economic factors such as the number of surgeons, the method of payment for health care, and the national wealth have been proposed as factors influencing the number of operations (Coulter and McPherson 1986; U205 course team 1985: 59-72). This literature led me to question whether the women who had undergone a hysterectomy had really needed the operation.

Interest in this question about hysterectomy was fuelled by my understanding of the feminist criticisms of medical practice including the negative way the female body, particularly the uterus, is portrayed in medical texts (Martin 1987:27-53), the medicalisation of natural events such as reproduction (Oakley 1993:162) and the menopause (Foster 1995:71-73; Worcester and Whatley 1992), and the patriarchal values in the practice of medicine (Oakley 1993:20-25). My awareness of these criticisms came from my involvement, starting when I was a medical student, with an organisation called 'Women in Medicine', a national organisation of feminist doctors concerned with both women as doctors and women as patients. A sociological understanding of the power relations within society came from my year studying Social and Political Sciences as an undergraduate.

An experience as a medical student, of attending a pioneering clinic for the treatment of women with severe menopausal symptoms further prompted my interest in this area but in a slightly different way. As a student I had to do a lot of waiting around in order to observe what the doctors in the clinic were doing. During this waiting time I heard, from the women attending the clinic, how they

had had to battle their way to get referred there, and from the nurses about the pioneering nature of the clinic and the way it had dramatically improved so many women's lives. This image of women battling to get themselves referred to the clinic has remained with me and has influenced my approach to clinical medicine and then research, reinforcing for me the need to listen very carefully to people.

My interest in women and HRT was thus influenced by literature from the disciplines of clinical medicine and sociology, personal contacts, involvement in a political organisation and experiences in my training, teaching and clinical work. The values influencing my interest included the desire to do no harm as a doctor, and more than that, to be a "good" doctor and to promote the wellbeing of women within a patriarchal society with a male dominated medical profession. The external norms included the ambition to further these goals, and to be accepted in doing this, within my chosen profession of general practice.

1.2.3 Why HRT and prevention?

There are two main uses of HRT, the relief of menopausal symptoms and the prevention of osteoporosis and CVD. I chose to focus mainly on questions about its use in prevention. The role of the GP in the prevention of ill health was widely researched and discussed during my years of training. The Royal College of General Practitioners recommended that GPs should seek to identify all patients who smoked, had high blood pressure or were obese (Royal College of General Practitioners 1981:8-9) despite the negative results of a screening programme in South East London (South East London Screening Group 1977). GPs are regularly reminded to encourage patients to reduce smoking, high blood pressure and obesity (British Heart Foundation 1994) and in 1993 the government introduced a contractual requirement for GPs to collect this information from their patients (NHS Management Executive 1993). Hart was an enthusiastic and well known advocate of screening whose commitment arose from a

determination to avoid unnecessary death and suffering (Hart 1988). I worked with a GP with similar enthusiasm and commitment during my post-registration training for general practice, who would agree with the following summary of why GPs are willing to embrace prevention:

they experience a feeling of personal responsibility for the stroke patient whose hypertension has been unmeasured and uncontrolled and the woman with invasive cervical cancer who has never had a Pap smear (Mant 1994:1343).

The GP responsible for my training impressed me with his zeal and enthusiasm for prevention and I felt at ease with the active prevention policy in the practice I went on to join as a partner.

The practice I joined was a seven doctor practice with five full-time male doctors and two part-time female doctors in Stockton-on-Tees, a post-industrial town in the north-east of England. The practice has a list size of around 14,500 patients. There was a thirty year tradition of research and innovation in the practice which had included work on key areas of general practice development identified by the Royal College of General Practitioners in their report to the government on general practice in 1987 (Royal College of General Practitioners 1987:19). Improving the quality of the service had included summarising the medical records (Marsh and Thornham 1980) and computerisation, bringing a counsellor into the practice team (Marsh and Barr 1975) and examining the workload of general practice (Marsh and McNay 1974a,b). The multi-disciplinary team approach to primary care had been well developed and documented (Marsh 1976,1979; Marsh and Barr 1975; Marsh and Dawes 1995; Marsh and Kaim-Caudle 1976; Marsh and Meacher 1979) and prevention of ill health had been promoted through the development of well woman and well man clinics (Marsh and Chew 1984), a vascular clinic for monitoring people with high blood pressure and angina, a diabetic clinic for monitoring diabetic patients and an asthma clinic. The immunisation and cervical screening programmes achieved very

high coverage and the process of achieving this had been part of a research project (Marsh 1988).

As a GP I professed, and attempted to practice, preventive medicine but became aware of a number of dilemmas this raised both through my clinical work and from medical and sociological literature.

There was growing concern that some of the health checks such as those done in well person clinics were a waste of time (Mant 1994). This concern was supported by research looking at the effect of health checks in general practice on risk factors including smoking, alcohol intake, diet and exercise (Family Heart Study Group 1994; ICRF Oxcheck Study Group 1994), although the Oxcheck study had shown some improvement in diet and serum cholesterol among those screened. Scepticism about the evidence for prevention grew each time recommendations changed particularly about diet, as new evidence was produced (Frankel, Davison and Smith 1991). An interview study carried out in South Wales confirmed that this scepticism was also felt by the general public (Davison, Frankel and Smith 1992).

As a practising GP I am in a position of considerable influence in my relationships with patients and this, it can be argued, could be used positively for prevention. Morgan, Calnan and Manning describe the doctor-patient relationship as "characterised by a dominant and active doctor and a passive dependent patient" (1991:137), but they imagine a doctor - patient relationship that would be conducive to the aims of health education and prevention as of the

mutual participation type characterised by the doctor helping the patient to help himself or herself through advice - giving, and the patient becoming responsible for controlling his or her own health through the use of knowledge gained through the consultation with the doctor (Morgan, Calnan and Manning 1991:136-37).

Morgan, Calnan and Manning hope that the doctor-patient relationship "may change as a result of the practice of health education in the consultation" (1991:137). If the contractual requirements for GPs to collect data about the screening of their patients had continued in the form it was introduced in 1993 (NHS Management Executive), I would argue that the use of the doctor's power over the patient could have increased rather than decreased, as GPs may have almost coerced their patients into health checks, screening and prevention. However in 1996 the contractual requirement to collect health screening data was changed reducing the element of coercion and allowing each practice to decide their own approach to prevention (DoH and Welsh Office 1996). Despite this change, the pressure towards prevention continues in the form of "The Health of the Nation" (DoH 1991) targets which are used to judge the appropriateness of funding service developments in primary care.

The promotion of illness prevention and the use of targets such as "The Health of the Nation" (DoH 1991) reflects an acceptance of what has been termed surveillance medicine, distinguished from the pathological medicine which had dominated medicine until recently (Armstrong 1995). Surveillance medicine involves the observation of seemingly healthy populations whereas pathological medicine focuses on disease. In surveillance medicine the demarcation between illness and health is less clear than in pathological medicine and the measurement of risk factors is used to indicate future illness potential (ibid.). Armstrong argues that "this new medicine has important implications for the constitution of identity in the late twentieth century" (1995:393) and describes how people develop a risk identity, seeing themselves as a person with an apparently measurable risk of diseases such as heart disease.

I knew from my experience in clinical practice that sometimes individual patients expected or at least hoped that medical evidence could provide a prediction of their future health, or give them a measure of their individual risk. This seems to be encouraged by an image of scientific medicine as something precise and independent

of context and persons (Morgan, Calnan and Manning 1991:33) becoming incorporated into lay models of illness (Gordon 1988). The type of dilemma this produces for GPs is described by Willis:

It is a feature of the modern world that decisions tend to be taken by remote experts and to be based on the near-certainties of the statistical analysis of large numbers. But front-line workers such as GPs operate amongst the random events of the individual scale. For example, although I can say almost exactly what proportion of smokers will suffer heart attacks in a given period, that doesn't help me at all in telling the smoker sitting in front of me whether he will be one of the ones affected. (Willis 1995:24)

Research has shown that people accept that illness is distributed randomly, so although a population study may show statistical risks, within these statistical tendencies "there lies a more chaotic distribution of illness and death. Some fat smokers really do live till advanced old age, and some svelte joggers really do 'fall down dead'" (Davison, Frankel and Smith 1992:683). Added to this is the "popular belief and knowledge concerning the relationship of health to heredity, social conditions and the environment" (ibid.). This research indicates that individuals are aware that the chances of making much difference to future disease may be much smaller than the statistics might indicate, because they have no control over their heredity and often little over their social situation and environment. As a practising GP this raised a dilemma about how far I should promote prevention in my practice where I am dealing with individuals, even though they form part of a population to which the statistics apply.

Added to this dilemma was the experience from clinical practice, and from the literature, that the identification of risk factors can create anxiety for the patient (Stoate 1989) and patients may actively avoid screening due to fear of the test result (Bowling 1989). However, in the context of screening and intervention aimed at reducing the risk of CVD there is more recent evidence that anxiety or concern about health is not necessarily increased

(Marteau, Kinmonth, Thompson and Pyke 1996) but further research into the social and psychological costs of screening is planned (Stewart-Brown and Farmer 1997).

Medical evidence however convinces me that medical intervention for prevention does have a place, and the clinical experience of seeing fewer patients with major strokes over the time I have been in general practice, confirmed by local statistics (Guy 1993:49), has reinforced this. I have also seen very little of the infectious disease that used to cause so much morbidity and mortality and this increases my confidence in the medical intervention of immunisation even though I know that factors other than this medical intervention may have been important in the reduction of these diseases. For example, McKeown's work on infectious disease from the nineteenth century onwards demonstrates that factors other than immunisation must have been important in their decline, as the decline had started long before immunisation was used (McKeown 1984).

The social context for my research included a medical practice committed to prevention in a society where the prevention of illness had been discussed and developed for many years and supported by the government (DHSS 1976). However this context also included dilemmas about the use of prevention. At the time my research idea was developing these became focused for me on the development of a nurse run clinic in our practice giving advice about the menopause and providing follow up for those on HRT. The two doctors and the nurse involved in developing the clinic appeared to be very in favour of HRT, promoting it to women attending for advice, and making use of drug company information sheets. The follow up of women taking HRT involved a minimum of one visit to the clinic each year but the review did not appear to seek to re-examine whether the HRT was still needed. Although I was happy for women suffering from problematic symptoms of the menopause to receive appropriate advice and therapy, I felt there were many unanswered questions about the promotion of HRT including the degree of power or influence of the health professional over the

woman's decision to take HRT, the medicalisation of the menopause, the use of medication for preventing an event, such as a hip fracture, many years in the future, the real risks of therapy including any anxiety caused for the woman, and the usefulness of the follow up checks. These questions reflected my values which included questioning the power of health professionals and the medicalisation of people's lives. The clinic was developed by two male colleagues, one of whom was trained as a gynaecologist and working with us for just one year. This acted as a provocation to me as a female doctor dedicated to general rather than hospital practice and probably fuelled my ambition to look at my questions about HRT in more depth and to try to do this on behalf of women in general.

1.2.4 Why research?

The social context in which I worked, the values I worked by and the external norms influencing me led me to an interest in HRT and how women felt about it, particularly its use for prevention. This interest could have developed as participation in women's health groups or networks developing health services for women, through teaching or by writing for the medical press. However my interest developed as a curiosity to know whether women wanted health professionals to persuade them to take HRT, and this curiosity could only be answered by asking women. My curiosity was sustained and developed as a research question through having time to commit to research, being in a practice where research was an activity that was given approval and by developments in the region that encouraged GPs to do research, including the setting up of a network to provide advice and support for GPs engaged in research.

1.3 The development of the three research questions

1.3.1 Women, HRT and prevention

From my interest in women's attitudes to HRT and its use for prevention, I developed my original research question: do women

agree that most of them should be persuaded to take HRT for the prevention of osteoporosis and CVD? I chose my methodology, a postal questionnaire survey, the only methodology for measuring opinion with which I was familiar. I envisaged using the questionnaire as a voting system, asking the women to vote yes or no to the question of whether doctors should persuade women to take HRT. I recognised there were issues to take into account such as knowledge of the subject, relevance for the individual and women's perceptions of their doctor's attitudes, so in reality it would be more complex than a vote. However, following advice from experienced researchers and to increase the possibility of obtaining funding, I altered the emphasis of the research question to exploring women's attitudes to HRT and what influences them. This removed from the research two issues of importance to me. First was the possibly contentious issue that doctors persuade women to take HRT, perhaps using their position of power to persuade. Removing this left me feeling my research was missing something important and as my thesis developed I went back to this issue in my review of sociological literature and its relevance for HRT presented in chapter 2. The second issue was the idea that women should have a say in how much HRT was promoted by health professionals. Although lost from the title I managed to keep this issue alive in the research process and brought it into my conclusions, in a slightly altered form, when presenting my research to medical audiences through asking "Is the promotion of HRT for prevention important to women?" (Griffiths 1995b) and pointing out how much a woman's decision to take HRT was her own decision rather than due to professional influence (Griffiths 1995a).

My main aim in attempting to find out about women's attitudes to HRT was, and remains, the presentation of the results to my medical colleagues to prompt discussion of the issues about promoting HRT and to ensure the attitudes of women are taken into account. This aim was fuelled by two concerns, firstly that women may lose as well as gain from the promotion and use of long term HRT and secondly that social forces may be more important in the uptake of long term HRT than medical indications. These concerns

did not become central to the actual research carried out, but remained in the background and are discussed in chapter two.

The final form of my first research question was

What are women's attitudes to HRT and what influences them?

1.3.2 Methodology

Influenced by my background and experience I decided on a research method, a postal questionnaire survey, that I thought was adequate for the question I was interested in answering. However during the process of writing and piloting the questionnaire I began to question the adequacy of the method for the question, and noticed how the choice of method narrowed the research question from exploring many social, personal and medical influences on women's attitudes, to a limited number of questions that seemed possible to ask in a questionnaire. The process of understanding more about a research issue through subjective experience is called dynamic objectivity, described by Fox Keller as the "pursuit of knowledge that makes use of subjective experience in the interests of a more effective objectivity" (Fox Keller 1985:117). I have already described how my background and experience affected the development of my first research question, and in chapters three and five of this thesis I describe the methods used in trying to answer the question about women's attitudes to HRT. I also demonstrate how the type of answer I was able to give to the research question changed considerably from my original idea, influenced by the process of learning and the experience of the research methods. I also reflect on how the research process itself may have affected the results and on the limits to what it is possible to know. In this process I hope to have moved towards what Fox Keller describes as

a more realistic, more mature, and more humble relation to the world in which the boundaries between subject and object are acknowledged to be never quite rigid and in which knowledge of any sort is never quite total (1985:148-149).

During the process of doing the research I experienced the different processes of inductive and deductive research (Schillemans, Verrept and Maes 1993) both of which are included in research at some stage. For example, a hypothesis testing, randomised controlled trial is mainly deductive but had an inductive stage in the development of the research question. An interview study such as the one presented in chapters five and six aimed to be inductive, but as a researcher I brought my own ideas to the analysis and so it involved deduction. This distinction between induction and deduction has been helpful in clarifying the processes in research and in discussing these ideas with medical colleagues who are mainly familiar with deductive or hypothesis testing approaches to research.

My training in research methodology undertaken in the Department of Sociology and Social Policy at Durham University clarified for me the idea of adequacy at the level of cause; "causes really do exist, one event, state or variable produces another, a satisfactory explanation is relative to the question asked" (Marsh, C. 1982:69). The explanation is thus limited by the question asked and the methods used, a theme explored further in chapters three and five. Sociology often uses models to explain social phenomena that are an oversimplification for any individual, but that try to contain all the processes that are common to most people (Marsh 1982:77-78). Understanding more about the use of models prompted me to try using the results of the postal questionnaire to develop a model of what influences women to take HRT including a measure of these influences (chapter five). This uses the quantitative survey data to its limit.

Medical science uses models when describing physiological processes or biostatistical trends common to most people, although the concept of model, as explained by Marsh, is rarely discussed. The understanding of adequacy at the level of cause, the limits of what we know and the concept of models as a tool rather than an expression of truth that "help theoretical activity of a complex kind

(and) allow us to keep several ideas in the air at once" (Marsh 1982:73), prompted me to look at the biomedical, biostatistical and sociological evidence and models about HRT and to consider their value and limitations (chapter two). This interest was fuelled by my experience in clinical practice where explanation to patients about what is happening to them is often in the form of simplified models that are based on, but do not include, much of the complexity and limitations of medical evidence. Willis describes this as a controlled lie: "Generalists (GPs) must lie. Controlled lying, or slippage, is the only means we have of coping with the complexity and the uncertainty of life" (Willis 1995:57). Charlton emphasises the importance of these explanations in the therapeutic encounter as doctors explain to patients why they are sick and why the treatment should work, so making it more likely to work (Charlton 1993). The use of models in clinical practice is discussed further in chapter two.

A desire to understand more of the detail of what was happening when women developed attitudes to HRT lead to my interest in qualitative methods of research and the interview study described in chapter five and six. In describing a process of qualitative analysis of interviews, Crabtree and Miller state: "Immersion/crystallisation consists of the analyst's prolonged immersion into, and experience of, the text and then emerging after concerned reflection with an intuitive crystallisation of the text (Crabtree and Miller 1992:19). I came to realise that this crystallisation is a form of model of what is happening for individuals that draws out themes that are common to more than one woman. However, it is supported by more detail of the experience for the individuals than that from a questionnaire survey, and there is no quantification of what is happening.

This interest in using qualitative research methods of research led to an interest in the differences between qualitative and quantitative research. Qualitative research attempts to discover the detail and range of what is happening without the use of measurement whereas quantitative research tries to measure it. In order to measure something the researcher has to decide how to measure it

and how true a representation the measure gives. This is known as operationalization, and quantitative researchers have found many ways of refining this process. Qualitative research avoids this problem of operationalization. Instead it collects data, then from the data develops categories or models that represent the data (Armstrong 1996). Although the use of measurement is the key difference between qualitative and quantitative research, the methods are used in different ways. If a researcher has a method of measuring a phenomenon that can be applied, for example, to many different people, the measure can be used to investigate this phenomenon across a group of people. Qualitative research has to concentrate on smaller numbers of people for it to be possible to handle the quantity and detail of the data. Quantitative research tends to investigate individuals as members of a group, and may try to diminish the effects of their individual contexts, or at least control for them, so the results of the research may be generalisable to other groups of people in other contexts. The methods used for this include sampling theory and inductive statistics (ibid.). Qualitative research tends to see people as unique individuals, each in a specific context where the context is relevant to the research and is taken into account in the process of analysis.

My interest in the different approaches to research prompted the development of the second research question for this thesis:

What are the methodological questions raised by trying to answer the first research question and how can they be addressed?

1.3.3 Crossing the boundary of academic disciplines

As a GP I have been trained in biomedicine and biostatistics and then in the skills of general practice. During the course of the research for this thesis, I received training in sociology, and experienced using methods of research developed in the disciplines of sociology and psychology. There are three main academic disciplines contributing to the thesis: *biomedicine and biostatistics*, grouped together as they are taught together in medical training and

used by all Western trained medical doctors; *general practice* with its distinct set of skills taught to doctors after their general medical training (Royal College of General Practitioners 1996) which is the discipline in which I work; *sociology*, the primary discipline within which this thesis has been developed.

I have not included the discipline of psychology as a main discipline of the thesis, as I have no formal training in this discipline but, as attitudes were a focus of the research, ideas and methods from the discipline of psychology are included. However, the experience of attempting to use methods of research from this unfamiliar discipline taught me how different ways of looking at the world, or paradigms, as held by different disciplines and associated with different research methods (Crabtree, Yanoshik, Miller and O'Connor 1993), when taken out of their context can lose their associated assumptions, qualifications and limitations which would be familiar and implicit for a person trained in the discipline. This is discussed in regard to my questionnaire survey. The ways in which insights of an unfamiliar discipline can raise questions about the value of research findings, and add new interpretations, are discussed in the context of the interview study.

When attempting to present the results of my research on women's attitudes to HRT to a medical audience, I encountered a poor understanding of ideas such as the role of theory and models and the difference between inductive and deductive research. This was perhaps surprising as in clinical general practice we draw on many different disciplines, including sociology, and we use many different ways of knowing without thinking consciously about this practice (Tanenbaum 1993) In sociological literature I encountered a suspicion of doctors' motives such as in Marxist analyses (Morgan, Calnan and Manning 1991:35) and theories of "medicalisation" (Illich 1990:11). Sometimes such criticism seems to lack an understanding of context. For example, Ann Oakley describes an encounter in an antenatal clinic between a pregnant woman and a doctor as an example of how doctors are seen as the only experts on pregnancy:

The doctor says "Ah, I see you've got a boy and a girl", to which the patient replies, "No two girls." "Really are you sure? I thought it said (checks in case notes) Oh no, you're quite right, two girls." (Oakley 1993:21-22)

Having been in the doctor's position, I can imagine myself making that sort of ridiculous comment, despite my feminist leanings, through poor concentration caused by lack of sleep from being on call the previous night, and also not being alert enough to realise I should have apologised.

Apparent misunderstanding between disciplines could have a negative effect such as sociologists "doctor bashing" (Jordanova 1983) and lacking appreciation for the constraints within which doctors work. Doctors may have little appreciation of the social sciences (Turner 1987:224). Popper criticises very thoroughly the idea that "a rational and fruitful discussion is impossible unless the participants share a common framework of basic assumptions" (Popper 1994:34). He describes the difficulties of breaking through the barrier of a framework but also the enjoyment, the widening of horizons and potential breakthroughs in science. This idea seems both important and exciting to me and I enjoy the attitude he formulates as: "I may be wrong and you may be right, and by an effort, we may get nearer the truth" (ibid. p xii). Throughout the thesis, issues are considered from the perspective of the disciplines of general practice and sociology and the insights from working on this boundary are described.

Along with Popper, the exposition that was seminal in the development of my research question about the boundaries between disciplines, was that by Gorovitz and McIntyre, developing a theory of medical fallibility (1976). They describe the uncertainty of clinical medicine and how this uncertainty is basic to, and inevitable for, this applied science. They base this argument on the nature of science, "ignorance of what is not yet known is the permanent state of all science" (1976:53) and on the way we apply generalisations to

particular individuals. They describe how natural science looks for law-like relationships between properties and sees a particular object or person only as the bearer of properties. They go on to suggest that "many particulars - salt marshes, hurricanes and the higher primates, for example - cannot be understood solely as the sum total of the physical and chemical mechanisms that operate on them." (1976:57). An applied scientist, such as a doctor, has to understand what is distinctive about each individual, the latter being not fully knowable.

Since the effect of a given therapeutic intervention on a given patient is always to some extent uncertain no matter how much is known about the general characteristics of interventions of that type, every therapeutic intervention is an experiment in regard to the well-being of that individual patient (Gorovitz and MacIntyre 1976:64).

This theme is expanded by Willis (1995) and Charlton (1992) when considering the results from research on groups, such as evidence about the risk of smoking or the action of a drug, being applied to individuals in the medical consultation, and is discussed further in chapter two. This theme also links with the research question about research methods, in particular the difference between quantitative and qualitative research and the level of analysis used, for example, people being considered as part of a group or as unique individuals.

Gorovitz and MacIntyre developed their ideas from the reality of clinical medicine where "medical error not only occurs but seems unavoidable" (Gorovitz and MacIntyre 1976:51) but around the same time the science of "chaos" was developing with very similar ideas, but from the discipline of experimental mathematics using powerful computers. The science of complexity also emerged as a development from "chaos" theory and has been used in evolutionary biology and the study of social systems. Although the ideas from these theories of "chaos" and complexity are not central to this thesis, with its focus on women and HRT, during the process of the research I found them helpful in understanding the limitations

of research methods, making links between qualitative and quantitative research methods and understanding the relationship between different levels of analysis. As the concepts and terminology from the theories of "chaos" and complexity are not yet in common use in sociology or medicine, I introduce them in appendix 1.

My experiences of conducting research on the boundary of disciplines and learning from other academic disciplines encouraged me to develop my third research question:

What have the disciplines of sociology, clinical general practice and biomedicine with biostatistics to offer each other in terms of answering the first two research questions and developing relevant understanding of each other, and how can an interchange between disciplines further understanding?

1.4 Conclusion

This chapter has described the development of the research questions for this thesis. It has described the influences on the development of the first research question for the thesis, including my own background and training, political outlook and experience, the structure of my own general practice, the ideas and support of GP colleagues, opportunities for research created and developed by others, personal contacts, experience in clinical practice, the widespread promotion of HRT, government policy and the research and publications of the wider research community. The first research question has been demonstrated to be a social product, influenced by the social context at the particular time it was developed. The research question was however, developed by myself as a researcher as an independent social actor, so was not determined by the social context. As a researcher I had my own values and norms, which influenced the research question. The contrary nature of the idea that the research question is a social product influenced by the social context, yet is not an inevitable consequence of the social context, may have an analogy in the

theories of chaos and complexity. "Chaos" theory would suggest that if it was possible to measure all the influences on a system and to compute their interactions, the outcome, in this example the research question, could be shown to be inevitable, but the measurement and computation is not practically possible, and even in the future is unlikely to become possible. The outcome cannot therefore be shown to be inevitable. However the theory of complexity suggests more than that; there are emergent properties that cannot be explained by looking at the detail of their make up, even if this was practically possible. The emergent properties of individuals may include the ability to take decisions and perform social actions that alter the social world that are not an inevitable consequence of the context. However, the social context does influence social action, and the research question developed about women and HRT was prompted by what was happening at a specific time and place and involved particular people. Clarity about the social context for research can increase the sociological understanding of research, as sociology attempts to understand society, and the clarity may also reduce misunderstanding between disciplines. Developing the theme of the importance of the social context for research has been a central task for this chapter and contributes to both the second and third research question. The influence of the social context on the research process is considered further in the course of this thesis.

This chapter has also provided background for the remainder of the thesis and has introduced the other themes of the thesis. The starting point of the thesis is the exploration of women's perspectives on HRT with the aim of presenting the results of this research to general practice. However other issues about research have developed as important themes for the thesis, including questions about measurement, the use of models, and the levels of analysis used in research. The research carried out on women's perspectives on HRT is used, in the thesis, as a framework from which to explore and develop these other issues.

In the thesis each chapter tackles the three research questions, but focuses on certain aspects of them. The overall structure of the thesis follows the process of the research on women's perspectives on HRT. Chapter two examines the disciplines of biomedicine and biostatistics, general practice and sociology in the context of HRT. Chapter three describes and discusses the postal questionnaire survey method and chapter four its results. Chapter five describes the use of the survey results in developing models of what influences women to take HRT, and in cluster analysis. Chapter six describes and discusses the method for the interview study that followed on from the survey and chapter seven its results. The conclusions of the thesis are drawn together in chapter eight where ideas for potential future areas of research are also developed.

Chapter Two

HRT: medical and sociological perspectives

2.1 Introduction

This chapter aims to provide background to the research question about women's attitudes to HRT by discussing the provision of HRT in general practice and by examining medical and sociological literature relating to HRT.

In the next section, a study of the use of HRT in the researcher's own general practice provides background to a discussion on HRT provision for women in general practice, including the complexity of the decision to take HRT and the "compliance" of women taking HRT. Issues from doctor-patient consultations about HRT are then looked at more broadly in the remainder of the chapter.

Looking at medical and sociological perspectives on HRT provides background for the thesis, although of a different type to that discussed in chapter one where the focus was on the social context for the research, and tackles the research question about how the disciplines of biomedicine with biostatistics, clinical general practice and sociology understand each other. The disciplines of biomedicine and biostatistics are grouped together in the research question, but in this chapter they are distinguished and discussed separately as they have different assumptions and their evidence is used in different ways in clinical general practice. This chapter examines the nature of biomedicine and biostatistics and its evidence about HRT by looking at examples of a biomedical paper and a biostatistical paper rather than attempting to give an overview of the vast biomedical and biostatistical literature on HRT. The social contexts of the development of biomedical evidence and biostatistical evidence on HRT are considered, and a sociological analysis given of biomedicine and biostatistics in the context of HRT. The use of biomedicine and biostatistics in clinical general

practice is then considered. This chapter therefore looks at each side of the triangle connecting the three disciplines of sociology, clinical general practice and biomedicine, and the triangle connecting the three disciplines of sociology, clinical general practice and biostatistics. However, for each triangle, and on each side, the analysis is of the view facing only one direction. Discussing the social determinants of biomedicine and biostatistics and the sociological analyses of these disciplines involves looking from sociology towards biomedicine and biostatistics. Examining the way clinical general practice uses evidence from biomedicine and biostatistics involves looking from clinical general practice towards biomedicine and biostatistics. In the course of the chapter, a general practice response to the sociological analyses of medicine is offered, which involves looking from general practice towards sociology. The question of how biomedicine and biostatistics view sociology and general practice is not tackled in this thesis and a sociological analysis of the discipline of general practice is not explored in detail, although strands of this analysis are used.

2.2 The provision of HRT in general practice

Over the past ten years the provision of HRT has become one of the most commonly discussed issues in general practice. The clinical uses of HRT are described in appendix 0. It is reported that at the time of the menopause 85% of women experience hot flushes and 30% describe them as severe. Ten years after the menopause, hot flushes are still experienced by 57% of women and for 7% they are severe; vaginal dryness is experienced by 40-45% of women four to ten years after the menopause (Oldenhave and Netelenbos 1994). The rate of use of HRT, as assessed in general practice, varies from 10% of women aged 40-65 years (Spector 1989) to 20% of women aged 40-60 years (Coope and Marsh 1992). This contrasts with the experience, described in chapter one, of HRT being available only in pioneering specialist menopause clinics in the early 1980s. The reported rates of use of HRT do not distinguish its use for the relief of menopausal symptoms from its use to prevent osteoporosis and CVD. In the last five years, the use of HRT for prevention,

particularly to prevent osteoporosis, has been the subject of very intense promotion and discussion in general practice.

In 1993, with the assistance of the local Medical Audit Advisory Group, the researcher collected data on the prescribing of HRT in her own practice for comparison with the published data on the use of HRT, and to increase understanding of the provision of HRT in general practice, in particular whether women take the HRT prescribed (Griffiths and Convery 1995). The study method and results are presented in appendix 2. The proportion of women aged 40-59 years taking HRT was similar to that reported by Coope and Marsh (1992) and was also similar to that found in the questionnaire survey described later in the thesis. The proportion of women who had had a hysterectomy and bilateral oophorectomy when aged under 52 years who were taking HRT was 71%, much higher than the 30% reported by Spector in 1989. This higher rate may have been partly because of action taken in the practice prompted by Spector's report.

In medical literature compliance had been raised as a "problem" for HRT promotion as many women seem to stop taking HRT within a few years, so not gaining the possible preventive effects (Coope and Marsh 1992 Wren and Brown 1991 Ryan, Harrison, Blake and Fogelman 1992). Through the repeat prescribing system of the practice, it was possible to look at patients' compliance with HRT, as suggested by whether the women collected their prescriptions. There is evidence that many prescriptions are never taken to the pharmacy to obtain the drugs (Beardon, McGilchrist, McKendrick, McDevitt and MacDonald 1993), and drugs obtained may not be taken, so collection of prescriptions is not a true measure of compliance. Doctors have tended to study compliance as a problem residing with the patient, whereas Trostle has suggested that compliance is "better approached as an ideology supporting the authority of medical professionals" (Trostle 1988). It could be argued that HRT is something women can choose to take or not, balancing any immediate or potential benefit, their own feelings and

ideas about medication and any side effects or potential risks of the medication.

When publishing the results of this study in the *British Journal of General Practice* (see Box 2.1) we discussed compliance, emphasising the need for balancing the risks and benefits of therapy and for GPs to ensure women have the information they need to decide on the appropriate balance for them. This call for doctors to explain the risks and benefits of HRT to their patients is one that is repeatedly made in the medical literature (Grady, Rubin, Petitti, Fox, Black, Ettinger, Ernster and Cummings 1992; Sinclair, Bond and Taylor 1993; Medicines Resource Centre 1993). Whereas compliance implies acceptance of a doctor's instructions, providing women with the medical information and allowing them to make a decision about taking therapy for themselves is closer to the model of concordance suggested more recently:

The patient's task is to tell the doctor his or her health beliefs and the doctor's task is to enable this to happen. The doctor must also convey his or her (professionally informed) health beliefs to the patient. The intention is to form a therapeutic alliance - to help the patient make as informed a choice as possible about the diagnosis and treatment. Although this alliance is reciprocal, the most important determinations are made by the patient (author's own brackets) (Marinker 1997: 747-78).

The conclusion from the study report (Box 2.1) also recognises that "just as all prescribing is an experiment carried out by the doctor so all medicine taking is an experiment carried out by the patient" (Marinker 1997:748 discussing Horne 1997). The idea of prescribing as an experiment has been discussed in section 1.3.3 and this idea, from the perspective of the GP, is returned to later in this chapter. From the women's perspective, balancing of the risks and benefits of HRT is explored in later chapters. The call to provide women with information about risks and benefits of HRT may seem

When women are taking HRT for menopausal symptoms, compliance is not a worrying issue as the therapy is for the relief of symptoms. Each woman can decide for herself if the symptoms she is experiencing warrant taking therapy. However, when it is intended for prevention, poor compliance may reduce effectiveness. If the risks and benefits of therapy are understood by women, they can control for themselves the balance between effective prevention and any worries or problems about taking it. General practitioners need to ensure that the risks and benefits are explained clearly to women so that they can make informed decisions. However, for health policy and planning a measure of likely compliance with long-term therapy is important for estimating effectiveness. As well as knowing how many women start but do not continue with therapy, this study provides data on whether women seem to be taking the therapy continuously or not. The indication for long-term therapy is clearest for women with a premature menopause. In this study, among the women with a surgical premature menopause, the uptake rate was high and three quarters of women then took it continuously. There was only a small number of women taking therapy for osteoporosis prevention who had not had a hysterectomy so these estimates of compliance are limited. There may have been women for whom therapy was initially prescribed for menopausal symptoms but who continued it with osteoporosis prevention in mind. None of these were identified from the records. Only a fifth of women taking therapy for menopausal symptoms apparently used it intermittently so the continuity of therapy would be effective for prevention, although the duration may not.

For some women, menopausal symptoms can persist for many years (Oldenhave and Netelenbos 1994) so long-term use, apparently for menopausal symptoms, is to be expected. However, the two issues, symptom control and prevention, may not yet be clearly differentiated and recorded.

Available guidelines advise a consideration of risks and benefits for each individual (Grady, Rubin, Petitti, Fox, Black, Ettinger, Ernster and Cummings 1992; Medicines Resource Centre 1993). Therefore, clear discussion and recording of those are needed when HRT is started or continued for prevention. Women who have decided to take therapy appear to take it consistently and so effectively for prevention. Whether women want to take HRT at all will constrain its use in prevention.

Box 2.1 Discussion of women's use of HRT (from Griffiths and Convery 1995:357)

to imply that appropriate evidence on this is available to the medical profession and could be made available to women to inform their decisions. This implication is now explored by examining the nature of the evidence available, how it can be used and the problems faced in clinical general practice by the doctor and patient when considering HRT.

2.3 The paradigms of biomedicine and biostatistics

Scientific paradigms have been described as follows:

scientific paradigms are frame-works of formal knowledge that members of a given scientific community share, mainly due to having undergone similar education and professional initiations; to sharing a common professional language, rules of evidence, and conceptual schemes; and to relying on the same professional literature and communication of the same scientific community (Kuhn 1970:176 cited in Freund and McGuire 1991:204).

Clinical medicine uses evidence mainly from the biomedical and biostatistical paradigms although other disciplines also contribute. These two paradigms are often used together when examining a research question or managing a clinical problem. However, in this chapter biomedicine and biostatistics will be examined separately as they have different histories and different impacts on clinical general practice. Sociological analyses of the two paradigms overlap, although more recent analysis has separated biostatistics from biomedicine.

The medical profession has used biomedical ideas and research much longer than it has used biostatistics. The concepts and evidence of biomedicine are part of all Western clinical practice, including general practice. Biomedicine has been described as "reduc(ing) illness to a biological abnormality inside the body" and invests resources in the "careful examination of anatomical and physiological processes, both normal and abnormal, to identify the pathological basis of many diseases" (Armstrong 1994:1).

Biomedicine is a science of reductionism, where it is assumed that illness can be explained in terms of the detail of disordered bodily functions, and it assumes a mind-body dualism: "physical diseases are presumed to be located within the body..... (and) the body can be understood and treated in isolation from other aspects of the person inhabiting it" (Freund and McGuire 1991:226).

Biomedicine also assumes that each disease is caused by a specific, potentially identifiable agent or cause (Freund and McGuire 1991:227) so diseases come to have specific labels (Morgan, Calnan and Manning 1991:13). When a cause of illness is identified at the organisational level of cell biology or biochemistry and a remedy found, it is assumed that the remedy ought to be effective in all individuals with the illness (Tanenbaum 1994). The metaphor often used to describe the body in biomedicine is that of the body as a machine with specialised parts which can be repaired by attention to the particular part that is malfunctioning (Freund and McGuire 1991:227-28). It is argued that this metaphor is part of the reason why biomedicine emphasises the responsibility of the individual in exercising control, in order to maintain or restore health (Freund and McGuire 1991:228).

In contrast with reductionism, the science of complexity suggests that an individual is more than the sum of the biochemical structures and processes from which it is formed. One level of organisation of a complex system, in this example the individual, cannot be fully explained in terms of a lower level of organisation, such as biochemistry, as the complex system has emergent properties (Gorovitz and MacIntyre 1976).

The distinction, in terms of ways of thinking between the biomedical approach and the biostatistical approach is not clear cut, but whereas biomedicine looks at the detail of a process and assumes that this can be generalised to all individuals, biostatistics studies groups of patients and the results are in terms of statistical measures. Biostatistics includes epidemiology, randomised controlled trials, surveys, cohort studies and case control studies and the results give the probability of a treatment working or the

risk of developing a disease or dying for the group, which is then extrapolated to the population. Biostatistics does not establish outcome for an individual (Marinker 1994).

As mentioned above biomedicine and biostatistics, as ways of thinking, can not always be clearly distinguished. For example, both approaches may be used in one study, such as the observation of a group of people in a laboratory where biochemical measurements are made and statistically analysed. The laboratory sciences, which inform biomedicine, use mainly experiments in their contribution to biomedicine where a hypothesis is developed then tested in controlled conditions. The randomised controlled trial, a biostatistical method, is also a form of controlled experiment, originally developed for testing drug treatments.

Despite the overlap of methods and sharing of evidence between biomedicine and biostatistics, the type of question and the models used by the two types of medical research can be distinguished, as summarised below by Tanenbaum. The group she calls medical realists is analogous to those taking the biomedical approach and those she calls medical empiricists are analogous to those working with biostatistics.

Schools of Medical Thought (Tanenbaum 1994:30)

Realism	Empiricism
Ontological questions	Epistemological questions
Deterministic/mechanistic models	Probabilistic models
Laboratory or bench science	Effectiveness research, including outcome studies and clinical trials

Tanenbaum expands on this summary as follows:

Medical realists believe they can know, and conduct themselves so as to know, what actually occurs when someone gets sick or gets well. Empiricists concern themselves only with what they

can observe, measure and manipulate statistically; they aspire only to the demonstration of relationships, not to the understanding of cause and effect (ibid.).

Biostatistics has been referred to as "outcomes research" (Tanenbaum 1994), and are the forms of evidence favoured by the movement within the medical profession known as Evidence Based Medicine (EBM) (Sackett, Rosenberg, Muir Gray, Haynes and Richardson 1996). The idea behind EBM has been summarised as follows:

A NEW paradigm for medical practice is emerging. Evidence-based medicine de-emphasises intuition, unsystematic clinical experience, and pathophysiological rationale as sufficient grounds for clinical decision making and stresses the examination of evidence from clinical research (authors' capitals) (Evidence-Based Medicine Working Group 1992:2420).

The EBM movement uses a hierarchy of evidence with randomised controlled trials at the top, case control and cohort studies next then uncontrolled studies and consensus (Eccles, Clapp, Grimshaw, Adams, Higgins, Purves and Russell 1996). This hierarchy has been accepted by the Cochrane Collaboration in the UK whose mission is to "prepare, maintain and disseminate reviews of the effects of health care" (Cochrane Collaboration leaflet 1995). The acceptance of this hierarchy has prompted a great deal of controversy within the medical profession (James 1996; Smith 1996; Smith and Taylor 1996).

For a group of people it is possible to predict outcome in terms of statistical measures. For example the proportion of a group responding and not responding to an intervention can be expressed as a measure of probability for each group member. However this does not predict outcome for the individual group member. The science of "chaos" provides a model to explain why prediction for an individual is not possible. Computer models have shown how very small differences in initial conditions can become magnified to

produce very different outcomes. In reality it is not possible to measure these differences in initial conditions to infinite accuracy and so outcome is not predictable. Even if it was possible to measure small differences to infinite accuracy, the calculation of outcome may be too difficult (Cohen and Stewart 1994:189-190). So although biostatistics can give a probability of how many individuals in a certain group will respond to an intervention, for each individual it is not possible to predict outcome as initial conditions can vary in unmeasurable ways.

To sum up, clinical medicine uses both biomedicine and biostatistics, paradigms that can be distinguished although their methods and results are often used together. The two paradigms use different assumptions and provide different types of evidence for use in clinical medicine. The theory of "chaos" highlights the limitations of biostatistics and the theory of complexity challenges the assumptions of biomedicine. The paradigms of biomedicine and biostatistics are examined separately in the following sections of this chapter.

2.4 Types of evidence about HRT from biomedicine

To illustrate the type of evidence derived from biomedicine for the use of HRT, a paper written jointly by a gynaecologist and an endocrinologist will be described and analysed (Oldenhavé and Netelenbos 1994). The paper was chosen because it appears to give a thorough review of the type of biomedical evidence available.

Entitled "Pathogenesis of climacteric complaints: ready for change?" (*ibid.*), this paper assesses how the existing evidence about the menopause and HRT may give clues about potential directions for future research on the role of chemicals in the body, called interleukins, in the symptoms and bodily changes of the menopause. The authors use a reductionist way of thinking, assuming a specific aetiology for the symptoms and the separation of body and mind.

The type of evidence quoted in the paper is mainly reductionist. The paper assumes the reader knows and accepts the current biomedical understanding of anatomy, physiology and biochemistry as taught to medical students. It does not mention evidence from the study of anatomy, but this forms part of the background. It does discuss the study of the microscopic structure of the body, describing the role of osteoclasts (a type of cell found in bone). Evidence is also used from in vitro experiments where cells from human tissue are cultured in the laboratory and their responses to different chemicals, including those found in the human body, are measured. The paper also quotes evidence from research on animals such as mice and monkeys where changes such as heart rate and blood vessel size are measured after injections of hormones.

Evidence quoted in the paper about the normal functions of the human body includes studies of well women. This involved taking blood samples from many women and analysing the constituents. It also mentions the monitoring of well women in laboratory settings. Changes in blood flow, body temperature, the brain's electrical activity, as well as hormone level changes in the blood, were monitored to increase the biomedical understanding of hot flushes. This type of monitoring was also done with women who had a hysterectomy or who are on HRT, to assess the effects of these interventions.

The paper also refers to a number of surveys of women about menopausal symptoms, used to establish the frequency and severity of symptoms that women suffer. The surveys are extensions of clinical observation where the doctor observes patterns of symptoms and signs and describes these patterns as diseases. This process of describing disease predominated in the nineteenth century before the causes or pathology of the diseases were known and was an important precursor to the search for specific causes of disease. The surveys extend the observation beyond the population attending doctors to the whole community, and is part of what has been termed surveillance medicine (Armstrong 1995).

The paper by Oldenhave and Netelenbos (1994) illustrates the use of biomedical evidence in helping to increase understanding of the menopause and the role of HRT. The biomedical disciplines used in producing the evidence for this paper are anatomy, histology and biochemistry, endocrinology and physiology, involving methods such as invitro studies, animal studies, and laboratory studies of humans, and clinical observation. It also refers extensively to biostatistical studies, a form of evidence described and analysed in sections 2.8, 2.9 and 2.10.

2.5 Social influences on the development of a biomedical model of the menopause and the role of HRT

The sociology of medicine has included the study of the rise of biomedicine and the social factors that contributed to its development. These include the search for clinical signs through clinical examination aided by technological developments such as the stethoscope, the acceptance of post-mortems to identify precisely the disease that caused death and the development of clinics and hospitals where many patients could be observed and treated (Armstrong 1994; Charlton 1993). In this section, the social factors that affected the development of the medical understanding of the menopause and the use of HRT, through the development of a plentiful and reliable supply of female sex hormones in the twentieth century, will be discussed.

It has been suggested that the relatively low social status of women in a patriarchal society, linked with the idea of female frailty, has been a factor in making women and their complaints more amenable to clinical observation than men (Turner 1987:99 and 110). The existence of gynaecology clinics seems to have enabled the research and testing of female sex hormones to develop more rapidly than that of male sex hormones, as the equivalent of a gynaecology clinic for men did not exist (Oudshoorn 1994:110). It can be argued, from a clinical view, that gynaecology clinics existed because of real need including the disability caused by prolonged heavy menstruation and severe menopausal symptoms, as well as

life threatening problems such as ectopic pregnancy, post miscarriage haemorrhage and cancers of the reproductive system. Some of these problems affect young women and, until the advent of AIDS, there were no equivalents for young men except war and accidents.

Gynaecologists had studied the role of the ovaries in female disorders before the field of sex endocrinology developed in the first decade of the twentieth century, but this research had been limited by a taboo on the study of human sexuality (Oodshoon, 1994:20). Taboos and social morality affected the way research into sex hormones continued throughout the twentieth century.

Research into sex hormones was also guided by the previous training and experience of the researchers and by practical considerations. During the first three decades of the century, the supply of sex hormones limited research as the hormones were extracted from testes and ovaries which came from slaughter houses (Oodshoon, 1994:68). However when the hormones were found to be present in urine, the supply of "female" hormones increased as this was collected in antenatal clinics from pregnant women (Oodshoon, 1994:74). Collecting male urine was more problematic although it was attempted in military barracks, but was not very successful (Oodshoon, 1994:77). Laboratory scientists came to rely on pharmaceutical companies to gather the raw material for research and the discovery that the urine of pregnant mares was a rich source of "female" sex hormones was commercially very important as this was a relatively cheap source (Oodshoon, 1994:74). By the 1930s the hormones had been chemically isolated by biochemists and began to be synthesised, resulting in a reliable supply of a pure form of oestrogen that could be taken orally. This enabled clinicians to extend their use and testing of oestrogen (Bell 1987).

The measurement of sex hormones was by biological assays of which there were many, but standard measures were chosen by international conference. For "female" hormones the standard

assay was a vaginal smear test of rats or mice injected with the hormone (this area of research led to cervical smear screening for women). For "male" hormones the standard assay was the size of comb developed by a rooster injected with the hormone. The choice of test was another practical reason why research on "male" hormones did not develop as fast as that on "female" hormones: "the keeping of roosters is rather inconvenient" (Oudshoorn 1994:51) whereas rats and mice were more easily kept. A test using rats and mice did eventually take over as a standard test for the "male" hormone (Oudshoorn 1994:52).

The different groups involved in the research - laboratory scientists, pharmaceutical companies and clinicians - developed networks that were vital to continuing the work, and the importance of the different groups kept changing, pivoting around access to raw materials and research methods (Oudshoorn 1994:81). Clinicians were ambivalent about the incorporation into clinical practice of the results of the laboratory research on sex hormones. On the one hand they saw the research as enabling gynaecology to become more "scientific", yet they wanted to continue to see patients as individuals, using "science" along with clinical judgement, and were wary of becoming dependent on the laboratory for clinical diagnosis and treatment (Bell 1987).

Bell (1987) studied the writings of 37 physicians who were leading figures in the development of the clinical use of oestrogen, published between 1938 and 1941. The extracts quoted by Bell (1987) not only illustrate the ambivalence of gynaecologists about the use of "female" sex hormones as discussed above, but also an ambivalence about science in general. Bell suggests that the gynaecologists writing at the time "questioned whether science could adequately explain the problems of individual patients" (1987:536), a view consistent with the ideas of uncertainty and complexity from the science of "chaos" and complexity, and they questioned the "value of "mass statistics" in the practice of medicine" (1987:537), a view similar to the dilemma facing all

clinicians of how to apply the results of biostatistics to an individual (Gorovitz and MacIntyre 1976; Willis 1995:24).

Many social factors influenced the development of the use of sex hormones in medicine. As Oudshoorn concludes:

sex hormones may best be portrayed as a mixed blessing. The implication of my remarks is not a cultural or technological pessimism but rather that we need to understand science and technology with all its tensions and ambiguities. My argument throughout this book has been that bodies and technologies are not unequivocally determined by nature. Medical technologies do not necessarily have to be the way they actually are (1994:151).

Oudshoorn seems to imply that it is assumed that bodies and technologies are determined by nature. Maybe there are people who believe this, but it may also be that this impression is given because people use this type of language as a way of understanding the world. Willis argues that specialists may have a distorted view of the world due to their exclusive approach to a subject, shutting out the context and surroundings of their subject (Willis 1995:22). In general practice it seems very apparent that "medical technologies do not necessarily have to be the way they actually are". For example as technologies or drugs developed by specialists come to be used in general practice, the way they are used tends to be adapted.

In summary, the development of female hormones for use in clinical medicine was influenced by cultural, social and economic factors, the ideas and motivations of the laboratory and clinical researchers, and by practical problems such as the supply of raw materials and laboratory animals. Influences of a similar nature may continue to affect the use and promotion of HRT in clinical medicine.

2.6 Sociological analysis of the biomedical approach in the context of the menopause and HRT

The sociology of medicine of the last three to four decades has analysed clinical practice mainly based on biomedicine. Sociology includes many different theoretical approaches and its analysis of biomedicine reflects this (Gerhardt 1989:xxii). This section examines how different sociological analyses can illuminate the development of the use and promotion of HRT.

Sociologists have pointed to "a basic assumption of the scientific paradigm that medicine is objective and value-free" (Morgan, Calnan and Manning 1991:15). Having taken that assumption to be present, sociologists then question it. In this section four major theories will be described, based on the analysis presented by Morgan, Calnan and Manning (1991:23-37), and examined in the context of the menopause and HRT. The four theories are medicalisation, social constructionism, functionalism and Marxism. Although developed as distinct theses there is overlap between them so the medicalisation theory will be discussed in most detail then the others examined for their additional contributions.

2.6.1 Medicalisation

Medicalisation of the menopause has been commented on by several writers. For example:

While menopause is a normal biological process, in the last fifty years it has come to be seen as a medical problem in the United States and many other Western societies. The Western biomedical literature generally treats menopause as an estrogen deficiency disease (Freund and McGuire 1991:209).

Bell (1987) argues that the process of medicalisation of the menopause started back in the 1930s and 1940s, prompted by the development of oestrogen as an accessible drug for gynaecologists. Foster discusses the medicalisation of the menopause and its

characterisation as a deficiency disease and points out that there is no established correlation between hormone levels and one of the major symptoms of the menopause, hot flushes (Foster 1995:67). This lack of correlation was also noted as evidence for the need to look for new directions for research into the endocrinology of the menopause in the biomedical paper by Oldenhave and Netelenbos (1994).

Freund and McGuire summarise the process of medicalisation of the menopause as follows:

The definition of menopause as a deficiency disease resulted from the efforts of a small elite of specialists, together with the development of a disease aetiology that lent itself to medical management and the promotion of a pharmacological agent that could be used in the treatment of the newly created disease (1991:210).

Foster (1995) also gives an account of how doctors have been involved in the medicalisation of the menopause and, in a similar way to Freund and McGuire, she identifies two social forces contributing to the medicalisation of the menopause, doctors themselves and pharmaceutical companies. Although Foster quotes evidence for the effectiveness of HRT for the relief of severe menopausal symptoms (Foster 1995:73) she is concerned about more widespread use of HRT by women with only mild symptoms or none (Foster 1995:73-85), suggesting that women have become afraid of osteoporosis particularly through media coverage promoted by the drug companies. Foster points out that these companies have a financial interest in the increased consumption of HRT. Other proponents of the theory of medicalisation see the medical profession as actively extending its influence over areas of life not previously seen as its concern (Morgan, Calnan and Manning 1991:23). Bell's research (1987) supports the suggestion that a small elite of specialists influenced the process of medicalisation of the menopause. However both Foster (1995:66-85) and Freund and McGuire (1991:210) comment on the differing

approaches of specialists and GPs. By distinguishing a difference between specialists who may actively promote HRT (Foster 1995:71) and GPs who have been more reserved (Foster 1995:72) Foster shows how, although the sociological model of medicalisation of the menopause by the medical profession is persuasive, there is variation within the medical profession and so the reality is more complex than the model might imply.

Two themes within the theory of medicalisation will now be explored, firstly Illich's theme of iatrogenesis, then the theme of medicalisation to control disruptive behaviour

Clinical, social and cultural iatrogenesis

Illich, a proponent of the theory of medicalisation, describes the medical establishment as a major threat to health (Illich 1990:11) and describes three forms of iatrogenesis. Clinical iatrogenesis is where doctors cause sickness with their interventions and, although claiming to have interventions which improve health, actually provide little improvement to the health status of the community, most of which comes from the basic provision of food, clean water, socio-political equality and some low technology interventions such as hygiene (Illich 1990:21-44). Social iatrogenesis occurs through the impact of the medical organisation on society through, for example, the labelling of people as ill, making sickness the only escape from stressful or demeaning industrial work, and making suffering, mourning and healing outside the patient role a form of deviance (Illich 1990:49-56). Cultural iatrogenesis "sets in when the medical enterprise saps the will of people to suffer their reality ... to express their own values, and to accept inevitable and often irremediable pain and impairment, decline and death" (Illich 1990:133). By taking control of these areas of life medicine allows societies' traditional ways of coping to be forgotten (Illich 1990:138). Illich sees iatrogenesis as one aspect of the dominance of industry over society (1990:215).

From a clinician's perspective, these criticisms can provide a useful model for looking at the phenomenon of HRT. There are many

uncertainties about HRT and its effectiveness varies amongst individuals, as is the case for many medical treatments. HRT is probably not a safe and effective treatment for everyone so there is a danger of clinical iatrogenesis. However, HRT can make a big difference to some women's lives and may be important in preventing osteoporosis and CVD for some. Illich's analysis is of society, social forces and social organisations and so cannot easily take into account the desire to relieve an individual person's distress in specific circumstances, although his analysis may help to explain how or why the distress arises. Foster's sociological analysis of HRT seems to try to take into account the use of HRT to relieve individual distress (Foster 1995:67-84).

Illich's analysis points to a danger of HRT being seen as a treatment for everyone, and the menopause being seen as a medical problem. This form of social iatrogenesis has been advocated (Tooze-Hobson and Cardozo 1996), but also contested from within the medical profession (Bewley 1996; Marshall 1996).

Illich's cultural iatrogenesis may occur for a number of reasons. Responding to an individual's distress by giving HRT for menopausal symptoms, may contribute to cultural iatrogenesis as removing the suffering may remove a woman's will to seek social changes such as increased social acknowledgement of the menopause, or working conditions that allow more flexibility for coping with symptoms. This is a dilemma for those doctors who are aware of this process as, by attempting to help an individual patient as best as they can, they may contribute to social trends that are not good for the health of society in general. For illness prevention, the changing levels of hormones that occurs at the menopause is just one of many factors that contribute to the risk of osteoporosis and CVD. Other factors include exercise, smoking, diet and family history of these diseases. Community action and self care can make an impact on some of these, but the promotion of HRT could well distract individuals, institutions and the state from attending to diet, exercise and smoking. Public health doctors who are not involved with the care of individual patients may be in the

best position to help counter this problem through the promotion of individual lifestyle changes and lobbying for socio-economic changes including the upholding of human rights (Mann 1996). Medicalisation of the menopause has been criticised, particularly by feminists, who have proposed alternative treatments to HRT such as exercise and dietary regimes, seeking support from other women and understanding women's social pressures (Greer 1992; Phillips and Rakusen 1989). These approaches resonate with Illich's idea of allowing traditional ways of coping to flourish, but are often difficult for individuals because of lack of resources, which again raises questions about socio-economic equality. The ability of women to cope without HRT may become less if women become dependent on it, in the sense of a physical drug dependence. Whether this actually does occur is being debated within the medical profession (Bewley and Bewley 1992; Whitehead and Stevenson 1992; Compston 1992; Studd 1992; Griffiths 1995).

Controlling disruptive behaviour

Medicalisation has been regarded as "serving particular interests in society" (Morgan, Calnan and Manning 1991:24) including the idea that medicalisation is a way of controlling disruptive behaviour. There are a number of ways that the menopause and post-menopause can be seen as disruptive behaviour and this phenomenon can be modelled at different levels of analysis: the individual woman and her social networks, the state and state provision of health care and the power structures of the social system as a whole.

Morgan et al. describe medicalisation, using mental illness as an example, as follows:

the labelling of people as mentally ill occurs not because of the exercise of political power but because people are in fact unintelligible to their own friends and families as well as to the powerful unintelligibility is particularly threatening to the dominant twentieth century value of rationalisation (Morgan, Calnan and Manning 1991:26-27).

The feeling of being apparently unintelligible to friends and family is something the researcher, as a GP, has heard from women when talking about their experience of the menopause. At the level of analysis of family and social networks, HRT could be seen as a way of controlling the unintelligible behaviour of peri-menopausal women. Martin conducted a series of in depth interviews with women, and in her analysis proposes that hot flushes seem to be connected with embarrassment as the flushes reveal the menopause publicly (Martin 1987:166-78). Martin comments that young women tend to see the menopause as a time women go out of control where as older women tend to see it as a time of reduced anxiety about pregnancy, less hassle with menstruation and increased energy and potential. From experience in general practice and from the interview study described in chapter seven, this is sometimes reversed as some older women describe themselves as feeling out of control with their menopausal symptoms, and some young women look forward to the ceasing of menstruation and the need for contraception. However Martin's evidence adds to the idea that the menopause may be seen as something in need of control with HRT as a solution.

The definition of what is disruptive behaviour is controlled by "society's power holders" (Morgan, Calnan and Manning 1991:25-26) and in the context of HRT, an example of disruptive behaviour, as defined by those with economic and political influence over the health service, could be that of a woman who does not take measures, such as HRT, to prevent osteoporosis and has a fracture of the neck of femur in her 70s. The incidence of fracture of the neck of femur increases rapidly with age (Grimley Evans 1993) and almost without exception, someone with a fracture of the neck of femur will have it surgically pinned. This surgery is sometimes portrayed as a major problem for the health service as, it is argued, it uses up the budget of acute hospitals, it is very common and may become more common as the population ages. The slow recovery rate of patients means they may be in hospital several weeks. These factors have prompted a debate on the economics of preventing

osteoporosis and so hip fractures (Pitt and Brazier 1990). In this context, being elderly and having a fracture of the hip could be seen as disruptive behaviour and so, the promotion of the idea that HRT could prevent the hip fractures could lead to women who do not take HRT being seen as displaying disruptive behaviour, the more so if they then fracture their hip.

Feminist writers have suggested how older women can fight back "against ageism combined with sexism in society" (Foster 1995:81). Through support from other women they can examine and name the social and political pressures on them and see "personal problems as at least political issues" (ibid.). Turner explores this theme, examining why certain types of medical categories such as hysteria and melancholy were used to regulate and control women in a patriarchal social system (1987:97-98). He moves on to examine the current social system, describing it as "patrism", defined as follows:

a culture which is based upon prejudicial beliefs and practices of men towards women, but this system lacks a clear backing in law or religion. Men and women remain unequal in the market place but this is not fully sanctioned by an overarching system of patriarchal values (ibid.).

Turner goes on to explore how, under patrism "women are more likely to experience what I call "representational problems of the self" " (ibid.) giving anorexia nervosa and obesity as examples of this type of problem. Linked directly with these ideas is Turner's discussion of the change of definition of conditions such as melancholy and obesity from being a sin to a sickness, by describing the treatments advocated by Cheyne (1671-1743), who developed a diet and exercise treatment for melancholy, and contrasting this with modern diets:

Whereas the diets of writers like Cheyne attempted to control the inner body to promote a religious state of affairs, modern diets, cosmetics and other systems of body maintenance are aimed at

the outer body: looking good is equivalent to feeling good in a society based upon the dominance of the representational self (Turner 1987:24).

Applying Turner's analysis to HRT, the change in social structure from patriarchy to "patrism" has led to a change in what is seen as a medical problem. Under "patrism" the external visible self is seen as problematic and this could include hot flushes, external signs of ageing, and problems with sexual intercourse which, although not publicly visible, are still part of a woman's external presentation. These problems are portrayed as disruptive behaviour in the sense that they do not conform with society's image of what is desirable and the problems are therefore medicalised, with the provision of HRT as the medicine. Some advertisements for HRT directed at the medical profession have emphasised the preservation of a woman's "femininity" and "sexuality" beyond the menopause with the use of HRT (Bridgewater 1994), rather than the relief of symptoms causing debility. This appears to be a direct attempt to persuade the medical profession to see the menopause as a representational problem for women.

Summary

Conrad identifies four basic conditions for medicalisation to occur which can be used to summarise the medicalisation theory and its relevance for HRT. The four basic conditions are:

- (1) the traditional forms of control are inefficient or unacceptable;
- (2) there exists some medical form of control by, for example, drugs or surgery;
- (3) the problem must be associated, even if in a rather ambiguous sense, with some underlying organic cause; and
- (4) the medical profession must accept the deviant behaviour as being within its jurisdiction, while the greater the benefit of medicalisation to established institutions the more likely it is to occur (Conrad 1975 discussed in Morgan, Calnan and Manning 1991:27).

Conrad's first condition includes Illich's cultural iatrogenesis and the menopause being seen as disruptive behaviour, the second condition is met by the development of HRT, the third is the link between the menopause and hormones, and the fourth condition is met, to varying degrees, through the medical profession accepting the menopause as a medical problem. The benefit of medicalisation of the menopause to established institutions is exemplified by the benefits it gives the pharmaceutical industry and to certain specialists within the medical profession, particularly where income depends on fee for service such as in the US where the provision of HRT is linked with regular medical check ups.

2.6.2 Social Constructionism

Social constructionism is a critique of medicine that: "serves to challenge the claim that modern medicine is technical, asocial and value-free" (Morgan, Calnan and Manning 1991:33). The description of the social determinants of the development of HRT in the discipline of biomedicine in section 2.5 and the discussion of medicalisation in section 2.6.1, have challenged this claim. In general practice it seems very apparent that medicine is not technical, asocial and value-free, and the social pressures that impinge on general medical practice are often discussed, at least informally. Sedgwick gives an example of a medical category as a social construct that has particular relevance to osteoporosis, HRT and general practice: "The fracture of a septuagenarian's femur has, within the world of nature, no more significance than the snapping of an autumn leaf from its twig" (Sedgwick 1982:30 discussed in Morgan, Calnan and Manning 1991:29). Before surgical fixation of hip fractures was widely available, hip fractures used to be known as "the old lady's friend" as an elderly woman who fractured her hip would become bedridden for about six weeks during which time she was prone to bronchopneumonia and possibly death. However, a hip fracture is now actively managed, almost regardless of the general state of health of the patient. Many septuagenarians who snap their femurs can benefit from surgical fixation. However, it is when dealing with the people not included in the "many" that the

social construction of the disease becomes apparent in general practice. For example if a patient with severe senile dementia (itself a terminal illness but one that can go on for years), living in a nursing home, has signs that they have fractured their femur, the GP feels almost obliged to send them to hospital for an X-ray to check for a fracture, knowing that once in the hospital, if a fracture is found, they will have it surgically fixed. Occasionally an experienced doctor can, with the support of the nursing staff and relatives, arrange for the patient to be cared for in bed until they either succumb to bronchopneumonia or the fracture heals. However social expectations are such that this rarely happens and the GP bows to pressure for the patient to be sent to hospital.

From a general practice perspective this construction of a hip fracture as a medical problem requiring intervention seems, as discussed above, inappropriate for some individuals. However checking the nursing perspective reveals quite different issues. A septuagenarian with a fractured hip requires intensive nursing and can suffer considerable discomfort when moved for nursing care. The patient is prone, not only to bronchopneumonia, but to distressing pressure sores. The nursing care can be made more difficult if the patient is suffering from senile dementia. Operating to fix the hip fracture avoids some of the distress for the patient and many of the nursing difficulties. Thus examining the practical detail of the situation for nurses reveals that operating to fix the hip fracture may be an appropriate response.

In conclusion, as suggested by social constructionism, the use of the technology of modern medicine involves judgements about its appropriate use, and different groups and individuals may use different values in making these judgements. These judgements are also influenced by social pressures and the social consequences of using medical technology. Modern medicine involves technology, but it is not asocial and value free.

2.6.3 Functionalism

The "functional importance of health for society was recognised by Parsons who defined health as a person's optimum capacity for effective functioning in their roles and tasks in society" (Morgan, Calnan and Manning 1991:33). Parsons' description of the "sick-role" was developed as a model "towards which behaviour tends to conform" (Morgan, Calnan and Manning 1991:51), using the medical process as an illustration of his general theory of social systems. Parsons was implicitly critical of the biological idea of illness and his "sick role" provided an alternative to the biomedical model (Turner 1987:39). The idea of a "sick role" was that people took on this role, usually legitimised by a doctor, and with it came certain responsibilities for the individual that were intended to get the person back to health as soon as possible, as well as the right for the sick person to withdraw from normal social functioning while sick. The "sick role" was part of society's system for minimising the amount of illness and its disruptive effects on society by making return to health and work personally and socially desirable (Morgan, Calnan and Manning 1991:34; Turner 1987:57). The context of Parsons' analysis was a society where individualism, activism and achievement were valued (Morgan, Calnan and Manning 1991:34; Turner 1987:55). In the UK, in the 1990s, the pressures to return to "health and work" are different from those of the US in the 1950s, as being unemployable by being certified sick is economically better for many individuals, and politically better for the Government, than being unemployed and looking for work. The function of the "sick role" is therefore not always the same as in Parsons' analysis. However it still tends towards Parsons' model in some parts of the world of work. For example, where women are working in jobs that have previously been held mainly by men and the symptoms of the menopause such as hot flushes seem unacceptable, women may accept medicalisation of the problem and take HRT, legitimised by a doctor, as a way of maintaining themselves in the job. This could be interpreted as accepting a "sick role" in the sense that the symptoms become seen as sickness and so the women, in taking this "sick role", become responsible for

doing something about the symptoms, so they take HRT with the agreement of their doctors. Women doctors take more HRT than the rest of the population (Isaacs, Britton and McPherson 1995), perhaps partly because of their greater access to information about it. However the nature of their job may also make coping with hot flushes very difficult, so prompting them to take more HRT than the general population (Griffiths 1996). If women doctors accept the medicalisation of the menopause and so see menopausal symptoms as a medical problem, taking HRT would be a way of moving out of the "sick role".

2.6.4 Marxism

Marxism sees the capitalist economic system as shaping definitions of health and so has much in common with Illich's analysis. Morgan, Calnan and Manning, describing Navarro's analysis, suggest that the biomedical model with its emphasis on individual intervention was encouraged by the industrial bourgeoisie as it distracted attention away from social causes of ill health (1991:34-35). This analysis is similar to the suggestion that HRT could distract from the tackling of the issues of diet, smoking and exercise at a social level (see section 2.6.1). Navarro sees a further function of the medical system as encouraging the demand for consumption and so sustaining the capitalist economic system, and proposes that consumption is a response to the lack of control experienced by workers in the workplace. This lack of control leads to a need to look for self-realisation in the sphere of consumption (Morgan, Calnan and Manning 1991:36). Certainly the promotion of HRT has economic advantage for the pharmaceutical companies which, in turn, helps sustain the capitalist economic system. Women may consume HRT to feel more in control of their bodies, in particular to maintain themselves within a work situation where they have limited control, for example where they have to respond to the demands of the public or where they can not keep stopping to remove layers of clothing and open windows when they have a hot flush. This seems to fit with Navarro's analysis, that consumption is a response to the lack of control experienced by workers in the

work place. At the level of analysis of society, by maintaining themselves in their present work situation by taking HRT, it can be argued that women contribute to the maintenance of work situations where there is little worker control. However at an individual level, taking HRT can be seen as a person maintaining some control over their life by having some disposable income from their paid employment.

2.6.5 Conclusion

The sociological models, when applied to HRT, hold a great deal of explanatory power at their specific level of analysis, and increase our understanding of HRT as a social phenomenon. The sociological models, described in this section, have focused on biomedicine, although many of the criticisms also apply to aspects of medicine based on biostatistics. The discussion, in the context of experience in clinical general practice, has revealed some issues that do not fit the models well, particularly when analysis at the level of a social system is then applied to individuals. The models also fit less well where social phenomena are in the process of evolving. For example, Illich's idea of social iatrogenesis with HRT being seen as a treatment for everyone, is the subject of debate and is not, at present, generally accepted. Examining the models of social systems from the perspective of individuals and their particular context, such as is found in general practice, can contribute a reality to the sociological models which helps to clarify their limitations. The sociological models can provide general practice with a useful tool for analysis of its work that can otherwise be difficult to achieve because of its focus on individuals.

2.7 The use of the biomedical model in general practice in the context of the menopause and HRT

In the previous section sociological analysis has challenged the claim that modern medicine is "technical, asocial and value-free" (Morgan, Calnan and Manning 1991:33) and it has been argued that general practice also does not make this claim for medicine.

However the biomedical model is used in general practice, and some of the ways it is used may lead an observer to conclude that general practice does see medicine as "technical asocial and value free". GPs themselves will also vary in the assumptions they make and the amount of thought they give to such issues. This section explores ways in which the biomedical model is used in general practice consultations, rather than how the results of biomedical research are used.

The biomedical model has become incorporated into lay models of health and illness (Gordon 1988; Nettleton 1995:47) and a woman attending a GP may use biomedical ideas in presenting her reason for attending. In my clinical experience I have heard women use an expression such as "I wonder if it is my hormones?" when describing why they have come to see me. I would usually listen further, not so much for why they think it may be their hormones, but for the problem that is troubling them. Using "hormones" as an entry to the consultation may help women feel that it is alright to see the doctor as there is a "biomedical" question to ask. However, it does not necessarily mean that the women believe their problems are due to their hormones.

GPs may use biomedical ideas, such as the effect of hormone levels, to provide an explanation for a patient as to why they feel how they do, or why they should take, or at least try, the prescribed medication. This involves telling the patient a story to help their understanding of their problem. Using the biomedical model in this way does not mean that GPs believe it entirely and without question, but the story may help maximise the placebo effect (Charlton 1993). This is the non-specific effect of medical treatment and is affected by many aspects of the treatment including the colour and taste of tablets and the "bedside manner" of doctors. The effect is real and has been measured in various ways. Charlton suggests that:

In most situations, in the general run of human illness - the placebo effect seems to be the *single most important factor in*

therapy enough is known of the nature of placebo factors for doctors *deliberately* to maximise them. This is as valid a part of *effective* medicine as the application of group results (author's own highlights) (1993:13).

When consulted by a woman about menopausal symptoms, it may be appropriate to use the idea of a reduced level of oestrogen as the cause of hot flushes, even though it is not strictly true. Research has not revealed an association between hot flushes and oestrogen levels (Foster 1995; Oldenhave and Netelenbos 1994:67). Using the idea about hormones may help reduce the woman's own anguish and negative feelings about herself, or help separate out different components of the mountain of problems she may be carrying, so enable her to sort through them rather than be overwhelmed by them. The biomedical model may also be used because the woman herself uses it and seems to find it useful.

Although no association has been found between oestrogen levels and hot flushes, it is not completely untrue that oestrogen has something to do with hot flushes. The connection seems to be via adjustments, during the menopause, of the hypothalamus (a centre in the brain that affects hormone levels) (Oldenhave and Netelenbos 1994). The complexity of the biomedical model used in a consultation will depend on why it is used. When a simple model is used that is not precisely true, the GP is not lying in order to dupe the patient, but using "controlled lying" or "slippage" as Willis calls it (1995:57), in a way that hopefully will help the patient.

Clinical experience would suggest that HRT really does help some women with distressing menopausal symptoms, and this is supported by published clinical evidence. However a sociological assessment of this evidence has suggested some caution in assessing HRT as beneficial; some of the effect may be placebo, other non-medical interventions may help mild symptoms, and only a minority of menopausal women experience severe menopausal symptoms (Foster 1995:73). It is not possible to predict for an individual patient whether HRT will be of benefit. This is a

problem for all biomedical interventions as discussed in section 2.3. However some biomedical interventions are so successful that their effectiveness for individuals is not doubted (Charlton 1993), for example replacing vitamin B12 for pernicious anaemia or thyroxine for myxoedema. HRT is not generally so successful and Foster's caution may be justified. As the effect of HRT for an individual woman cannot be predicted, a GP may suggest a trial of therapy to a particular patient. A trial of therapy for a patient is based on the biomedical model of the intervention and evidence of its effectiveness from biostatistics, but does not assume that it is effective for all individuals. It is an approach to therapy used for several conditions including asthma and epilepsy. A trial of therapy for a patient is not a randomised controlled trial but involves suggesting to a patient that they try a treatment to see if it works for them. The offering of the therapy in this way uses the biomedical and biostatistical evidence for the therapy but assumes doubt about the universality of its effectiveness and acknowledges the complexity and individuality of patients (Gorovitz and MacIntyre 1976; Marinker 1997).

In conclusion, the biomedical model can be used to reduce a patient's distress about making a decision in the way that other models, including religious ones, have been, and still are, used to help individuals make life decisions. The biomedical model is used in varied ways and can be a useful tool in clinical practice, including enhancing the placebo effect. Biomedical evidence, along with biostatistics, is not necessarily applied irrespective of the patients' context and individuality.

2.8 The biostatistical paradigm and its evidence on hormone replacement therapy

An example of biostatistical evidence on HRT will be presented and the reliability of this form of evidence discussed. The example is a review article published in 1992 that draws on the English language literature since 1970 (Grady, Rubin, Petitti, Fox, Black, Ettinger, Ernster and Cummings 1992). This paper was commissioned by a

body called the Clinical Efficacy Assessment Sub Committee which reports to the Health and Public Policy Committee, part of the American College of Physicians. The aim of the paper is to "critically review the risks and benefits of HRT for asymptomatic postmenopausal women who are considering long-term hormone therapy to prevent disease or prolong life." (Grady, Rubin, Petitti, Fox, Black, Ettinger, Ernster and Cummings 1992:1016). The paper is about treating women who are "well", not already ill or distressed. It is firmly within the biostatistical paradigm, commissioned by a sub-committee interested in Clinical Efficacy and looking at women's risk of disease and death and how HRT may affect this. The paper reviews the extensive literature on HRT, uses meta-analysis techniques and makes estimates of the effect of taking HRT on the probability of diseases and on life expectancy. It uses evidence from biomedicine, such as histology and animal studies, for questions where the authors found biostatistical evidence does not exist. Grady et al. (1992) had to make many assumptions during their analysis as they did not have all the necessary evidence and this is a major drawback for their results. There was less evidence available on the effects of combined HRT preparations than on the effects of oestrogen alone. In the UK combined HRT is used more extensively than in the US, so this lack of evidence is more of a problem for UK readers than for those in the US.

In this paper, the authors focus on the risks and benefits of HRT for perimenopausal, or recently postmenopausal, women aged 50 years and particularly consider the effects of HRT on endometrial cancer, breast cancer, coronary heart disease, osteoporosis and stroke. The results are summarised in tables 2.1, 2.2, 2.3 and 2.4. It is particularly helpful to use the median ages for dying from the diseases for reference, when considering the changes in overall life expectancy. Of course half of the women who die, for example, from a osteoporotic hip fracture, are younger than the median age of 79 years old, and half are older, and an individual does not know where they will fall in the overall range. The spread around the median is also important but is not given in this paper. It is also

important to keep in mind the increase in incidence of many other diseases with age, including most types of cancer, dementia and arthritis. After considering the evidence for each disease separately, the authors calculate estimates of the increase in life expectancy for particular scenarios (table 2.5). The authors estimate that, primarily because of the protective effect from CVD, oestrogen therapy increases the life expectancy of a 50 year old white woman by 0.9 years and where the woman has had a hysterectomy, by 1.1 years. This depends on the woman taking long term HRT for around ten years and maybe longer. The increase in life expectancy is higher for women who have risk factors for, or a history of, CVD. For women taking combined HRT the authors do not have enough evidence to be sure about its effect, but for a 50 year old white woman with no risk factors, they calculate the increase in life expectancy as one year if progesterone does not alter the effects of oestrogen except to remove the risk of endometrial cancer. However, if the combined HRT does not provide the full CVD benefit and causes an increased risk of breast cancer then the estimated increase in life expectancy is only 0.1 years.

The median age of death from CVD and osteoporotic hip fracture, the diseases HRT may help to prevent, is relatively high and the increase in life expectancy is relatively small. How important these possible gains seem to a woman may depend on many other factors including other aspects of her health and social wellbeing, as well as whether she has risk factors.

Disease	Lifetime probability of developing disease	Probability of dying from disease (%)	Median age of death from disease (years)	Reduction in risk for having disease (%)	Relative risk of death for women
Endometrial cancer	2.6	0.3	68#	-	3.0
Breast cancer	10	3	69	-	1.25
Coronary heart disease	46	31	74	35*	0.65
Osteoporotic hip fracture	15	1.5	79@	25	0.75
Stroke	20	8	83	None known	0.96

Endometrial cancer is usually curable so median age is that of development of the disease not death

- Figure not given in Grady's paper

* may be greater for women who already have coronary heart disease

@ age of first hip fracture

Table 2.1 Summary of evidence on hormone therapy to prevent disease and prolong life in postmenopausal woman based on statistics for a 50 year old white woman using unopposed oestrogen (Grady et al. 1992)

Disease	Type and strength of evidence for unopposed oestrogen
Endometrial cancer	Extensive strong and consistent
Breast cancer	A lot, but results not consistent
Coronary heart disease	Extensive, consistent observational evidence
Osteoporotic hip fracture	Limited but consistent observational evidence
Stroke	No convincing evidence that oestrogen affects risk

Table 2.2 Summary of type and strength of evidence on hormone therapy to prevent disease and prolong life in postmenopausal woman using unopposed oestrogen (Grady et al. 1992)

Disease	Lifetime probability of developing disease	Probability of dying from disease (%)	Median age of death from disease (years)	Reduction in risk for having disease (%)	Relative risk of death for women \$
Endometrial cancer	2.6	0.3	68#	-	1.0
Breast cancer	10	3	69	-	Inadequate data
Coronary heart disease	46	31	74	Insufficient data	Inadequate data
Osteoporotic hip fracture	15	1.5	79@	25	0.75
Stroke	20	8	83	No evidence	0.96

\$ for combined HRT these figures are based on limited evidence

Endometrial cancer is usually curable so median age is that of development of the disease not death

- Figure not given in Grady's paper

@ age of first hip fracture

Table 2.3 Summary of evidence on hormone therapy to prevent disease and prolong life in postmenopausal woman, based on statistics for a 50 year old white woman using combined oestrogen and progesterone therapy (Grady et al. 1992)

Disease	Type and strength of evidence for combined therapy
Endometrial cancer	Histological, clinical and limited epidemiology
Breast cancer	Limited and inconsistent
Coronary heart disease	Inadequate data
Osteoporotic hip fracture	Based on assumption that combined HRT as effective as unopposed oestrogen as evidence very limited
Stroke	No evidence

Table 2.4 Summary of type and strength of evidence on hormone therapy to prevent disease and prolong life in postmenopausal woman using combined oestrogen and progesterone therapy (Grady et al. 1992)

	Life expectancy (years)	Net change in life expectancy with oestrogen alone	Net change in life expectancy with combined HRT with full benefit as with oestrogen alone	Net change in life expectancy with combined HRT with benefit reduced by progesterone
For a 50 year old white woman with:				
no risk factors	82.8	+0.9	+1.0	+0.1
hysterectomy	82.8	+1.1		
history of CVD	76.0	+1.5	+1.6	+0.6
risk factors for CVD	79.6	+1.5	+1.6	+0.6
risk factors for breast cancer	82.3	+0.7	+0.8	-0.5
risk factors for hip fracture	82.4	+1.0	+1.1	+0.2

Table 2.5 Net change in life expectancy for a 50 year old white woman treated with long term HRT (Grady et al. 1992)

In tables 2.1 and 2.3 the reduction in risk for having a specific disease is expressed as a percentage, for example unopposed oestrogen reduces the risk of CVD by 35%. This reduction of over a third sounds very important, however it actually results in a relatively modest increase in life expectancy. The expression of risk reduction in relative terms rather than absolute terms may lead to an impression that the gains are greater than they actually are in some fields of prevention, particularly when considering drug therapy for large populations to prevent heart disease (Davey-Smith and Egger 1994).

Grady et al. (1992) were limited by the evidence available and in their accompanying guidelines conclude "randomised trials are required to prove these effects and to define their magnitude, but such trials would need to be very large and to continue for many years" (American College of Physicians 1992:1038). A randomised controlled trial on HRT has now been set up in the UK (Medicines Resource Centre 1997). Already published is a randomised comparison of oestrogen versus combined HRT in women with hysterectomy (Medical Research Council's General Practice Research Framework 1996). All the women had therapy so there was no control group. The outcome measures for this trial were symptoms, blood pressure, weight and tests measuring blood clotting and blood lipids. These measures all have standardised systems of measurement developed in biomedicine except for symptoms, where women's reports of the presence or absence of symptoms was used with no graduations. Randomised controlled trials need standardised outcome measures and an attempt has been made to develop a more sensitive system of measuring quality of life for menopausal women for use in trials (Daly, Gray, Barlow, McPherson, Roche and Vessey 1993). The need for standardised measures of outcome limits the application of the randomised controlled trial to where these can be developed, and the usefulness of the results of these trials partly depends on how applicable the outcome measures are to clinical medicine. Randomised controlled trials also use standardised recruitment criteria for individuals participating in the trial. Care has to be taken to ensure the results

of a trial are applied to individuals similar to those in the trial and not to individuals who are perhaps more ill or less ill than those in the trial. The randomised controlled trial is the accepted, methodologically well developed, standard biostatistical method and theoretically is an ideal method for measuring outcome of medical interventions. However a well conducted randomised controlled trial may be so divorced from reality that its results are of little value to clinical medicine. The application of the results of randomised controlled trials is more problematic in general practice than specialised medicine as general practice deals with undifferentiated illness; people presenting to a GP have a very wide spectrum of illness and different aspects of illness such as the social, psychological and physical aspects are closely interwoven. Specialists see patients when the problem has been defined and the severity clarified to some extent.

For an intervention such as HRT which is mainly prescribed in general practice, it is appropriate for a randomised controlled trial to take place in general practice. The randomised comparison described above drew on general practice data. However it has been argued that carrying out a randomised controlled trial in general practice:

may either disrupt the culture of primary care to such an extent that the findings do not reflect real practice, or the methodological problems encountered may reduce the scientific reliability of the results (Pringle and Churchill 1995:1382)

Pringle and Churchill (1995) suggest that the less rigorous methods such as cohort studies and case-control studies are acceptable alternative methods when a randomised controlled trial is not practical.

Grady et al. based much of their meta-analysis on biostatistical methods other than randomised controlled trials including a number of cohort studies. These are studies that follow up a group of people and record what happens to their health, for example

whether they develop CVD. These cohort studies have been re-examined and evidence found of "unintended selection of relatively healthy women for oestrogen therapy", which indicates that at least some of the apparent cardioprotective effect of HRT may be due to selection bias; healthier women are less likely to develop CVD and are more likely to take HRT (Posthuma, Westendorp and Vandenbroucke 1994). This type of bias is well known and documented in epidemiology and can lead to over estimation of risks or benefits (Sackett, Haynes, Guyatt and Tugwell 1991:287-89).

Case control studies were the other main source of data for the meta-analysis by Grady et al. (1992). These studies identify "cases", for example women with CVD or osteoporosis, then identify "controls" which are women matched with the "cases" according to particular characteristics chosen by the researchers such as age, smoking habit and social class. Case control studies are liable to many biases and the method "deserves even greater caution in interpretation" than cohort studies (Sackett, Haynes, Guyatt and Tugwell 1991:289-90), but despite this there are a great number of this type of study. Sackett et al. give two reasons for this, firstly they are easy to carry out and with computerisation of medical records they are becoming even easier, secondly, they are the only feasible method for studying rare, late adverse effects of treatments (Sackett, Haynes, Guyatt and Tugwell 1991:290). An example of bias that can occur in cohort studies and case control studies is the over diagnosis of outcomes or cases. In a study of postmenopausal oestrogen therapy and vaginal bleeding, as bleeding was caused by oestrogen therapy there was a higher rate of performance of the diagnostic tests for endometrial cancer among women taking oestrogen therapy compared to those who were not. This higher rate of performance of the diagnostic tests resulted in the disorder, endometrial cancer, being detected in its early stages in women taking oestrogen. This resulted in an over estimate of the odds of oestrogen causing endometrial cancer because evidence for endometrial cancer was searched for much harder in the group of woman taking oestrogen than among those not taking oestrogen.

Further studies were needed to correct for this bias (Sackett, Haynes, Guyatt and Tugwell 1991:292).

In conclusion, the evidence on the use of HRT for prevention is limited but, based on the evidence available, the magnitude of benefit, even for those at highest risk, is relatively small and the diseases HRT hopes to prevent occur, on average, in relatively elderly women. Biostatistical methods have their methodological problems, but the method that is most rigorous, the randomised controlled trial, is difficult to perform in the reality of clinical general practice. Where a randomised controlled trial is carried out, great care has to be taken to ensure the entry criteria allow for the inclusion of the people for whom the trial has most relevance, and that the outcome measurements are measuring what is important for the clinical situation. All biostatistical evidence is about groups of people and can not give an individual woman a prediction of benefit from HRT.

2.9 Social influences on the development of biostatistics and its evidence on HRT

Surveying groups or populations, measuring details of the individuals and aggregating the results, developed in the nineteenth century. Foucault argues that this development was a response to the pressure of population in the industrial cities of the nineteenth century and the need to regulate the population (discussed in Turner 1987:16 and Nettleton 1995:112-13). Foucault argues that both the social sciences and medicine responded to this crisis of population with the development of sociology and social medicine, both concerned with the social causes of disease (Turner 1987:16-17). However, it is argued that sociologists use a different paradigm from social medicine or epidemiology:

Whilst sociologists are fundamentally concerned with social interactions and social processes, epidemiology is more concerned with the characteristics of *individuals* which, in

aggregate, predispose them to certain diseases (author's own highlight) (Stacey 1987 as discussed in Nettleton 1995:163).

The collection of population data allowed the development of the idea of what was "normal". Surveillance identified those who deviated from this norm, and were labelled as in need of intervention. Nettleton has traced this development for dentistry from the nineteenth century through to the present day (1992 discussed in Nettleton 1995:114), and Armstrong describes the intensive surveillance of the body of children that developed in the early twentieth century (1995).

During World War II a sociomedical survey was used to assess the perceived health status of the population. This is identified by Armstrong as a key event in the rise of what he terms surveillance medicine, when healthy and ill are all included in the surveillance: "The survey revealed the ubiquity of illness, that health was simply a precarious state" (1995:397). The need for a nation at war to know the state of health of the population thus contributed to the development of biostatistics in medicine, and the counting of illness that had not yet been brought to the attention of a doctor, or may never have been reported to a doctor. This led to the development of the idea of a largely submerged "iceberg" of illness or health needs (Nettleton 1992:39). Awareness of unreported illness is still seen as important for public health (Guy 1993:13). Medical sociology, from the 1950s to the 1970s investigated aspects of medicine that included the "iceberg" of illness and, Nettleton argues, was predominantly influenced by the concerns of the medical profession (1992:39).

The epidemiological study on smoking and lung cancer by Doll and Peto (1976) had a major impact on clinical medicine and it has been suggested that the fact that this study was on doctors may have helped this acceptance (Williams and Boulton 1988).

The twentieth century has seen an explosion in the number of pharmaceutical agents. This started with the replacement of

hormone and vitamin deficiencies using concentrated extracts and was followed by antibiotics. Some of these drugs were clearly effective, such as penicillin for pneumonia. However, therapies for illnesses which vary between individuals and are less predictable than pneumonia, needed studies of groups of patients to show overall benefit (Charlton 1993). By 1960 randomised controlled trials were being done on pharmaceutical products and now have become standard for drug therapies. Their use has also spread to the assessment of surgical therapies and diagnostic tests (Evidence-Based Medicine Working Group 1992).

The movement known as 'outcomes research' developed within biostatistics as a response to the findings of apparently unexplained variation in medical practice (Tanenbaum 1993). An example of this is the variation in hysterectomy rate discussed in section 1.2.2. Awareness of variation in medical practice along with concern over the cost of health care led the US government to fund outcomes research, as variation was seen as wasteful for health resources (Tanenbaum 1993). The outcomes research movement developed rapidly in the US from the late 1980s and was seen as an attempt to bring order and predictability to the American health care system (Ellwood 1988).

In 1989, the UK government introduced a requirement for medical audit into the NHS. This was defined as the systematic, critical analysis of the quality of medical care, including the procedures used for diagnosis and treatment, the use of resources and the resulting outcome for the patient (Secretaries of State for Health 1989). The extent of medical audit has however been limited by the lack of evidence of effectiveness for many medical treatments (Royal College of General Practitioners 1995). Opinions of experts have been used in the development of "gold standards" of clinical care which have then been used to measure clinical performance. This use of expert opinion and not evidence has been criticised by those advocating Evidence-Based Medicine (Evidence-Based Medicine Working Group 1992; Sackett, Haynes, Guyatt and Tugwell 1991). Although they accept the need for developing

clinical experience and accept the importance of understanding disease processes using the biomedical approach, they argue this is not sufficient and can be incorrect or misleading (Evidence-Based Medicine Working Group 1992). The Evidence Based Medicine movement emphasises the need for understanding the rules of evidence and for consulting and interpreting the literature, but emphasise the use of biostatistics which provides probabilities which, as Tanenbaum puts it, is a "demand for certainty about what is probable" (Tanenbaum 1993:1270).

In summary, the rise of biostatistics has been affected by political needs including the control and monitoring of populations and the assessment of the health of the population in times of war, by the interests and needs of groups in society including the medical profession and pharmaceutical companies, by economic factors such as concerns over the cost of health care, and by the efforts of individuals such as David Sackett and his team who have become leading figures in the Evidence Based Medicine movement.

2.10 Sociological analysis of the biostatistical approach in the context of the menopause and HRT

The sociological analysis of biomedicine in the context of the menopause and HRT was considered in section 2.6. The major sociological theses about medicine, developed in the past three to four decades, were examined. During this period biostatistics began to be widely applied in clinical medicine, so the sociological analyses of biomedicine included biostatistics to the extent that it had become part of clinical medicine.

The development of surveillance medicine along with biostatistics was discussed in the previous section. Over the last 20 - 30 years the surveillance of the population with the aim of preventing ill health has been introduced to general practice, as discussed in section 1.2.3. This use of biostatistics has been criticised by sociologists with arguments already familiar from the sociological analysis of biomedicine in section 2.6. These include concern about

the increased medicalisation of life, that the introduction of prevention is an attempt by general practice to enhance its professional status, and that by channelling prevention activities through general practice the wider social influences on health are overlooked (Williams and Boulton 1988). Those in general practice itself have pointed out the potential harm of screening (Herman 1996; Stoate 1989) and the need for effective public health policy on issues such as tobacco, food and transport (Mant 1994) as discussed in section 1.2.3. As the biostatistical evidence about HRT accumulates, general practice is reconsidering its approach to prescribing HRT, with some initial enthusiasm for its use in prevention now less certain (Gray, Evans, Sweeney and Steele 1996).

The biostatistical approach in medicine has also led to a change in the way people think about themselves, in terms of health. The concept of the "risky self" (Ogden 1995) has developed, where risks to health have become located within the self. This contrasts with earlier models of what was healthy and unhealthy spaces. For example the quarantine model drew lines between healthy and unhealthy spaces such as houses, towns or ships. In the sanitation model risks were located in the exchanges between the body and the external world. Now risks are seen to exist everywhere (Armstrong 1993). Ogden argues that the present evaluation of risk through surveillance has given rise to the location of risk within the individual. This risk identity has a temporal dimension. For example, a risk factor can develop into a pre-clinical form of disease, such as the abnormal cells that can be identified by a cervical smear, then in to an overt clinical manifestation. Surveillance medicine, in the form of screening, surveys and public health campaigns, search for the risk factors or early stages of disease, offer anticipatory care and attempt to transform the future by changing the health attitudes and behaviours of the present (Armstrong 1995). This idea of a risk identity that changes over time fits with the promotion of HRT for the prevention of future illness where there is an attempt to assess the risk of future harm

from osteoporosis or CVD for an individual, and to balance that against the potential risks of taking HRT.

In conclusion, the use of biostatistical methods of research has contributed to a change in the way individuals view their health, in as far as they assess their health in term of future risk. It has also widened the realm of influence of medicine beyond those who are currently ill.

2.11 The use of biostatistics in general practice in the context of the menopause and HRT

Women distressed by menopausal symptoms can try HRT and assess its immediate benefits and side effects for themselves. The GP can warn about possible long term side effects and while new evidence continues to be produced about HRT, this advice may include the suggestion that there is little evidence of harm for five or so years of use and, in five years time there should be more evidence available. A feminist critique of HRT concludes that:

under the circumstances it would seem that offering women a more sophisticated and up-to-date digest of the medical research, which is complicated, often contradictory and rapidly changing, may be as important a part of empowerment as offering information about alternatives (Lewis 1993:53) ("alternatives" referring to alternative therapies for menopausal symptoms).

Patient choice about a medical intervention such as HRT becomes very important where the probability of a poor outcome (disability or death) is very low, and patient choice may itself affect the therapeutic outcome (McPherson 1994a). Drug trials which have included placebo medication have shown better outcome for those taking their medication, whether it be the active ingredient or placebo, than those not taking it. (McPherson 1994a; Sackett, Haynes, Guyatt and Tugwell 1991:194), but there is no clear evidence about whether health care is more effective in an informed patient (Kee 1996).

If HRT is to be used for prevention and is not needed for symptoms, the GP has to assess the woman's risk identity (Armstrong 1995). In the UK, the use of HRT for prevention of CVD is currently advocated mainly for secondary prevention, that is for women who already have CVD (for example those who have had a heart attack or suffer from angina) in order to prevent further development of the disease. There are of course other risk factors, such as smoking, that would have a greater effect on a woman's risk than the introduction of HRT. Where HRT is being considered for the prevention of osteoporosis, the GP may assess risk factors such as family history of osteoporosis, and may suggest a bone density test. Bone densitometry gives a measure of risk but itself depends on a judgement about what is considered normal or not. In a paper assessing whether population screening for osteoporosis should be provided in the UK, the problem of defining this risk was highlighted:

There is no accepted cut-off point for bone density below which a woman is identified as being at high risk of fracture. With the cut-off point being taken as the lowest 20% of all bone density measurements, then only 28% of those so identified as 'high risk' would have gone on to suffer a fracture in later life in the absence of therapy. More importantly, 63% of all fractures will occur in women with bone densities above this arbitrary cut-off and so will not be identified (authors own highlights) (University of Leeds, University of York, Royal College of Physicians and Department of Health 1992:4).

This paper was much criticised after its publication as it only considered population screening rather than screening for those already considered at high risk. However the basic argument remains about where the cut-off point should be placed, even though people may disagree about the proportions involved.

Bone densitometry can be used to diagnose the presence of osteoporosis, but when used to assess future risk of osteoporosis, it

is being used as a screening procedure. Sackett et al. argue that early diagnosis in the form of screening must be based on evidence from randomised controlled trials as screening involves healthy people. Screening and any subsequent intervention can sometimes cause harm by getting the diagnosis wrong, the treatment can cause harm, and labelling the patient as someone with a health problem can have a detrimental effect. Telling a symptomless man he has hypertension can double his absenteeism from work, independent of any side-effects from drug treatment (Sackett, Haynes, Guyatt and Tugwell 1991:163-66). The labelling of a woman as at risk from osteoporosis, whether by identification of risk factors or by a measured risk from bone densitometry, may have an effect on her health. It could be argued that if identification of a higher than average risk encourages a healthy lifestyle with plenty of exercise and a calcium rich diet, this may improve her health, but it may also reduce her sense of well being.

The ethics of screening and using medical interventions such as HRT for prevention are not clear cut. It has been argued that preventive interventions provide the "greatest good for the greatest number" (Herman 1996:547), but evidence from its practice suggest this may not be the case (Herman 1996). For example, HRT may result in a relatively small gain in length of life when elderly, in return for the long term consumption of HRT, potential harm from screening and side effects of the therapy, and medicalisation of the menopause. Herman argues that reactive care has a firm ethical basis as it is extended to those requesting help because of disease, discomfort, disability, fear and anxiety (1996). GPs advise women who have sought their help about HRT and osteoporosis after becoming aware of this through the media or from friends and colleagues. Based on Herman's argument (1996), advising these women on screening and prevention is ethical whereas seeking out women for screening or advise is more questionable. As most women use the media as their main sources of information about HRT (Kadri 1991; Sinclair, Bond and Taylor 1993) this ethical argument seems to have, at least partly, moved beyond the medical profession into the media and commercial world.

Given the uncertainties about the medical evidence about HRT, the questions about the use of screening and prevention, ethical considerations, and possible cultural and health organisation effects, it is not surprising that the prescribing of HRT varies widely (Jolleys 1993). The point at which GPs decide to take action has been termed the threshold. Examples of thresholds include the decision to prescribe HRT; the action of arranging bone densitometry; deciding to seek out women on their practice lists who may benefit from HRT. The position of the threshold appears to be a major factor affecting variation in observed rates of medical intervention (McPherson 1994a). McPherson suggests that these differences in intervention threshold are seldom assessed in an unbiased way "partly because the uncertainties are not sufficiently stark and partly because consumer choice is (often illegitimately) cited as the driving force behind the decision" (1994:11). McPherson (1994) focuses his discussion on medical intervention for people with symptoms and signs of illness, but his argument can apply to intervention in the form of risk assessment or prevention. He discusses the problem of acknowledging, and studying, medical uncertainty:

the nature of the existence of medical uncertainty is complicated because on the whole it is disparaged. Medical teachers do not like it, for obvious reasons, and certainly patients don't like it at all. In both cases, the essential distinction between ignorance and uncertainty is blurred, but for entirely different reasons. Patients are hard put to acknowledge, much less recognise, the true extent of uncertainty when they have been led to believe that medicine is an exact powerful science; which of course it mostly is. The medical profession is hard put to admit to legitimate uncertainty when patients, on the whole, desperately hope for certainties. However, medical advance is ill served in the long run by concealing uncertainties (McPherson 1994a:9).

Many sociologists may disagree with the idea that medical science is mostly exact and powerful. However McPherson clearly sees the

uncertainties and the problems it can cause doctors and patients. The uncertainty caused by insufficient or unreliable evidence can be distinguished from the uncertainty for an individual when trying to make a decision based on evidence from biostatistics which gives probability for a group. McPherson, a researcher with long experience in biostatistical research makes this distinction as follows:

The tools of medical research have produced staggeringly impressive results but there remains staggeringly impressive uncertainties..... The relationship between the pursuit of clinical science and the pursuit of clinical practice is complicated. The objectives of the former are to establish the best clinical response to particular circumstances while those of the latter are to respond to a particular patient, which might often override the obligation to search for the truth (McPherson 1994b:62).

To avoid digression let us assume McPherson's uses the word 'truth' in the sense of the best evidence that biostatistics can provide rather than a claim to an absolute truth. One of the skills taught in the training of GPs is that of dealing with uncertainty (e.g. Neighbour 1996:225-232). There are many aspects of this, some of which have already been mentioned. In an encounter with a patient, the GP collects as much information from the patient as seems appropriate, but cannot be certain of having all the important information. Patients often only reveal intimate or painful information after many encounters with the GP. The GP cannot predict what will happen over time, but often uses observation over time to clarify the problem presented and test possible interventions. There may be borderline results from tests, raising questions about what is "normal". Even if the problem does seem to be clear, the evidence for an intervention may be incomplete or unreliable. Even where there is clear evidence about an intervention, the individual patient may not fit the criteria used in the research. Then, for biomedical research, the GP has to assume that the research, for example on a biochemical process, applies to the individual patient. Biostatistical research only provides a

probability for a group so the outcome for an individual is uncertain. The management of uncertainty and the skills of helping patients cope with uncertainty have to be central to the role of general practice.

It may be the ability of physicians to advise in the face of uncertainty, to help patients make good and helpful decisions on the basis of inadequate data, as much as their ability to act on the basis of evidence, that will retain their value to society (Taylor 1996:270).

Through the processes of training GPs and developing their skills, this issue of uncertainty for general practice and how to cope with it, has been explored, discussed, and ways of teaching the necessary skills researched. This has tended to be in the face of the certainties claimed by biomedical and biostatistical research. The more recent development of the theory of "chaos" may provide general practice with theory that backs up these skills. The theory points to the unpredictable nature of outcomes for a "chaotic" system and asserts that only observation over time can indicate how it will develop. The probabilities measured by biostatistics apply to groups of individuals. In terms of "chaos" theory, each individual is a "chaotic" system that has potential to change in response to an intervention. If the outcome of an intervention is observed for many individuals then the probability of an outcome can be calculated for the group. However, for each individual the outcome can only be observed not predicted.

In conclusion, some of the uncertainties with which general practice works have changed with the rise of biostatistical research. There is uncertainty about the effect of HRT long term because of insufficient biostatistical evidence. When further evidence is available there will still be uncertainty in the application of the evidence to individuals, although the evidence may provide a measure of risk and benefit for the population. GPs will still need to be observers, with patients, of how HRT affects each individual. Analogy with the theory of "chaos" helps clarify the limits to

medical certainty and provide a theory supporting the skills of coping with uncertainty in general practice

2.12 Conclusion

The chapter started by discussing a study of the provision of HRT in one general practice and some of the issues in a doctor-patient consultation about HRT. The provision of HRT in general practice is one aspect of the social context in which a woman considers the use of HRT. This chapter has examined other aspects of this social context including the medical evidence available about HRT. The research methods and evidence from biomedicine and biostatistics were distinguished, although overlap in their use was acknowledged. Biomedicine looks at the detail of physiological and pathological processes in the body and assumes that this detail applies to all individuals. The type of evidence about the menopause and HRT available from the biomedical paradigm assumes, even if it cannot yet demonstrate, a single identifiable cause for symptoms such as hot flushes. Biostatistics measures the probability of an outcome for a group but cannot predict outcome for an individual. The evidence about HRT and women's future health from the biostatistical paradigm reveals relatively modest average increases in life expectancy at a relatively old age, in return for taking HRT over ten years or more. Biostatistical evidence can be biased and to avoid this, the use of randomised controlled trials is advocated. However this type of trial can be difficult to do, may inappropriately squeeze an outcome into a measurable form, and the results may be difficult to apply to particular situations.

Although more distant from an individual woman than the provision of HRT and the medical evidence of its effects, the social influences on the development of the research that provides the medical evidence also forms part of the social context. The development of both biomedicine and biostatistics has been influenced by cultural, social and economic factors, by the ideas and motivation of individual people, by practical problems such as the availability of resources and by technological developments.

The sociological analysis of biomedicine and biostatistics contributes further understanding about the social context for an individual woman considering HRT. The sociological critiques suggest that the menopause has been, and is being, medicalised and the provision and use of HRT is a major part of the driving force of this medicalisation. The socio-economic system enables this process of medicalisation, and those benefiting socio-economically have an interest in maintaining the assumption that medicine is asocial, value free and an appropriate response to ill health or distress. Sociological analysis of biostatistics suggests there has been a change in the way medicine and ill health is viewed, proposing that individuals and their doctors now see health in terms of a risk identity.

Returning to a social context more immediate to the individual woman considering HRT, this chapter has considered the use of the evidence, from biomedicine and from biostatistics, by general practice. In individual consultations the biomedical model may be used as a form of explanation to reduce distress and to enhance the placebo effect, but its use is tailored to the individual. The use of the model does not mean its assumptions are accepted. Biostatistics claims to provide strong evidence for the use of medical interventions but many interventions have not been studied using biostatistics. Even where an intervention has been studied biostatistical evidence can only give a probability of outcome.

In the course of the chapter the theories of "chaos" and complexity have been used to challenge the assumptions of biomedicine and biostatistics. All the theories and ideas explored in the chapter, including those from the theories of "chaos" and complexity, form part of the social context for individual women as there is a passage of concepts from scientific discourse to lay discourse which alters the way individuals think and which are actively used by individuals (Billig, Condor, Edwards, Gane, Middleton and Radley 1988:26-27).

The theories of "chaos" and complexity have also contributed to clarifying the different levels of analysis used by different disciplines and how these interact. Much of biomedicine focuses on the level of analysis of cell biology and biochemistry and has developed research methods appropriate for research at this level of analysis. Biostatistics measures the characteristics of individuals, but aggregates them into groups so although the level of analysis is the individual, the results apply to individuals in groups, and how they apply to an individual alone is not predictable. General practice responds to particular individuals. Sociological analysis looks at social structure and social trends. Each of the levels of analysis interacts with its neighbouring level. For example general practice responds to individuals but uses biomedicine, biostatistics and sociology to inform what it does, and the action of an individual can contribute to a social trend such as the medicalisation of the menopause. A model developed at one level of analysis, for example the theory of the social construction of medicine or a biochemical explanation for symptoms, can lose some of its power of explanation when applied at a different level of analysis but the theories can also inform other levels of analysis.

This chapter has provided background for the remainder of the thesis by describing the social context for women's perspectives on HRT and has offered an analysis of aspects of this context. The importance of considering how social context influences both women's perspectives on HRT and the research for this thesis is a theme that continues through the thesis. Clarity about the level of analysis of the research, and of theory, is also a theme that is considered through the thesis. The thesis continues in the next chapter with an account of a postal questionnaire survey on women's attitudes to HRT and an analysis of the method used, including how the social context influenced the research process and the levels of analysis used in the development of the questionnaire.

Chapter Three

The questionnaire survey method

3.1 Introduction

This chapter describes the method used in developing a questionnaire and conducting a postal survey. The survey aimed to increase the understanding of women's attitudes to HRT and what influences them, and in particular to inform general practice of women's attitudes. The research process is used to illustrate questions about research methodology and the research perspectives taken by different academic disciplines.

In this introduction a brief outline of the questionnaire survey is given, as its process forms the backbone of the chapter. Different stages of this research process are used in the chapter to illustrate specific methodological questions and the perspectives of different disciplines. These are outlined later in this introduction.

The initial stages of the questionnaire survey were a literature search and a pre-pilot interview study, both of which aimed to inform the content of the questionnaire. A draft questionnaire was then developed and tested on a small number of women. Feedback from these women was used to refine the questionnaire. A pilot survey was conducted with 100 women from the researcher's own general practice list using a numerically coded pilot questionnaire. The women responding to the pilot survey were sent a second copy of the questionnaire to complete six weeks later, to provide data for testing the reliability of the questionnaire. The results of the pilot survey and reliability test were used to refine the questionnaire further. The pilot survey results and data from other published surveys were used in calculating the sample size for the survey. The sample frame consisted of the 28,900 women aged 20-69 years on the practice lists of eight general practices in Stockton-on-Tees, a post industrial town in the north east of England (the researcher's own practice was not included). The final version of the

questionnaire was sent to 1,649 women randomly selected from the sample frame stratified into five year age bands. Each questionnaire was marked with a code number for identifying responders. After two reminders 1,225 usable questionnaires were returned (74.3%). The questionnaire data was entered into the statistical computer software (Epi Info and subsequently SPSS) and analysed by cross tabulations. The pilot study results were not incorporated with the main study results.

This chapter focuses on the research method used up to when the questionnaires for the main study were sent out to women. The response rate, response bias and generalisability of the questionnaire are discussed in chapter four along with the results. Further statistical analysis of the survey results is discussed in chapter five.

The questionnaire survey took place in a particular social context and was conducted by the researcher with particular aims and interests. These social factors influenced the research, and are described before the chapter examines the research process itself.

The aim of the questionnaire was to increase understanding of women's attitudes to HRT, so the background to how the measurement of attitude was attempted is described. The researcher approached the measurement of women's attitudes to HRT with relatively little knowledge of the debate, particularly in the field of psychology, as to how attitude can be measured. The way in which attitude was measured by the questionnaire was assessed in retrospect, using a conceptual framework for understanding attitude and behaviour, the theory of planned behaviour (Ajzen 1988:132-133), developed in the discipline of psychology from quantitative research.

Following the consideration of the social context of the survey and the measurement of attitude used in the questionnaire, the pre-pilot and pilot stages of developing the questionnaire will be described, and the methodological questions they raise will be discussed.



These stages of the research process are chosen for discussion of methodological questions as they provide a variety of useful examples. This section forms the major part of the chapter.

Towards the end of the chapter, the final version of the questionnaire is used as an example for considering a sociological analysis of the method. This includes the idea of science as producing "facts", the problem of using methods across disciplines and the rhetoric of science and the use of codified language.

Finally the chapter describes how the sample was taken and the response rate enhanced and discusses ethical issues, including the use of power relations in this process.

3.2 Social factors influencing the research

3.2.1 The aims and interests of the researcher

The background to the researcher's interest in women's attitudes to HRT and particularly its use in prevention has been described in chapter one. The aims and interests of the researcher became focused on specific issues early in the research process as shown by the plan used for interviews with women in the pre-pilot stage of questionnaire development (box 3.1). The researcher was interested in women's personal views of HRT but also in their views on many other issues related to its long term use to prevent disease. She was also interested in the effect of the media coverage of HRT and in women's experiences with their GP. These themes were all represented in the questionnaire that was developed and recur during the interview study. It could be argued that the research was prone to bias with it only revealing what the researcher wanted to know. Its very focused nature contrasts with more exploratory research that may be conducted in the field of sociology, where a researcher may aim to find out about a particular subculture or social organisation, but may know little about it before commencing the research. However, researchers often have an interest or stake in their area of research and this does not invalidate the research,

Box 3.1 Researcher's plan for subjects to be covered during the pre-pilot interviews

- Introduction of researcher
- Description of the aims of the study (interview and questionnaire survey), the specific aims of interview to inform the questionnaire design, the confidentiality of what is said and that if quotes are used in a report they would be anonymous
- Discussion of HRT, distinguishing short term HRT used for hot flushes or other menopausal symptoms for 1-2 years and long term HRT used for prevention.
- Women's personal views on HRT
- Women's views on the health of the community and themselves, including priorities for health care, mass therapy, the use of persuasion, natural menopause versus hormone therapy, old age, death-its causes and timing.
- Exploration of what the women hear about HRT from the media and how they feel about it.
- Women's experiences of GP's behaviour around HRT and how women feel about that.
- Other relevant information about the women e.g. use of HRT.
- Future feedback of results and looking at draft questionnaire.

particularly where this stake is acknowledged. However the image of medicine as "asocial and value free" (Morgan, Calnan and Manning 1991:33), as discussed in chapter two, can lead to medical research ignoring the stake that the researchers have in the research and any bias this may cause. Commenting on medical research, and in particular biostatistics, Marinker states "when facts are determined by stakeholders the research bias may be as much in the questions posed as in the answers obtained" (Marinker 1994). Biomedical journals have attempted to address this problem of bias in part, by insisting on a signed statement of conflicts of interest and sources of funding for published research. The definition of conflicts of interest is not straight forward. A political aim such as

to increase awareness of women's views, as in this research, is more a motivation rather than a conflict of interest, so does not have to be declared even though the motivation shaped the research. Personal experience of considering and debating primary care research in research meetings has revealed that discovering the motivation of the researcher often clarifies the aims of the research and enables the methods to be refined. Motivations can vary; wanting to improve treatment for patients with a certain disease; proving the need for resources to be invested in a specific area of health care by government; providing evidence in a debate about the role of primary care; improving the training of doctors; describing a medical fashion, for example the use of a certain drug, to encourage debate about it. The field research for this thesis was motivated by the interest of the researcher in the attitudes of women to HRT with the aim of conveying, to those working in clinical general practice, women's perspectives on HRT. The reason for wanting to convey the women's perspective was to encourage general practitioners to take account of women's views about HRT when planning for and providing HRT, particularly if planning to promote the use of HRT. The researcher also wanted to ensure that general practitioners were aware that women had views about HRT, and could often make decisions for themselves about the use of HRT. The aims and interests of the researcher influenced the research process and results.

3.2.2 The prevailing culture and the original academic discipline of the researcher

Models used by science and ideas about what are "facts" are a product of a particular time, place and cultural context. In contemporary Western thinking there is an emphasis on numbers, with phenomena only regarded as "real" when they can be quantified (Helman 1996). This emphasis on measurement is very strong within medical sciences and the current interest in biostatistics has been discussed in chapter two. Most peer reviewed medical journals, until the last one or two years, rarely, if ever, included papers reporting qualitative research and publication of

qualitative research in medical journals is still difficult (Jones 1996). As the aim of this research was to disseminate the research results to GPs, the research needed to be in a form publishable in a medical journal. For the researcher these influences were sufficiently strong for the choice of research method, at the very start of the research process, to be almost inevitable. Other possible methods, such as an interview study, were not considered at the time of starting the research, however the researcher was aware of some of the shortcomings of the survey method so included a pre-pilot interview stage in the study design. This was seen as a way of ensuring an appropriate and relevant questionnaire rather than as an alternative research method. The possibility of an interview study following the questionnaire survey was suggested by a sociologist just prior to printing the questionnaires for the main survey.

3.3 The measurement of attitudes to HRT

The original intention for the research was to ask women whether doctors should persuade them to take HRT. As described in section 1.3.1, the emphasis of the research question was changed to exploring women's attitudes to HRT. For the original research question, a methodology that allowed women to explore the issues such as a focus group may have been appropriate, as women may have found the question surprising or difficult to answer without an opportunity for discussion. An indirect method of assessing women's views on the issue could also have been used, such as analysing women's health literature, both popular and academic. The change in emphasis of the research question became much clearer in retrospect than it was at the time, and involved a change in the level of organisation being explored. Asking women about the promotion and use of HRT, and in particular whether this should be promoted by doctors, is asking their views on a social phenomenon or trend - an increase in the use of HRT, and asking their views on the operation of a social structure - the medical profession. However, asking women about their personal attitudes to HRT is asking them to consider the therapy as an individual. This may include taking account of social trends and social

organisation, but the focus is on the individual considering the therapy.

Other research on women's attitudes to HRT influenced the design of the questionnaire survey. How women approach the decision to take, or not to take, HRT, had been explored in the US (Schmitt, Gogate, Rothert, Rovner, Holmes, Talarczyk, Given and Kroll 1991). In this study women were given a series of scenarios and asked to decide whether they would take HRT in the situation described. The authors' analysis grouped the women, according to how they approached their decisions about HRT (see box 3.2). This paper prompted the idea of grouping women according to their attitudes to HRT.

Box 3.2 Women grouped according to their approach to HRT (from Schmitt, Gogate, Rothert, Rovner, Holmes, Talarczyk, Given and Kroll 1991)

Women who consider acute need to be of pressing importance and so if menopausal symptoms are present they favour taking HRT.

Women who consider acute need to be of pressing importance but where there are other social/health problems so HRT is not favoured.

Women who weigh up costs and benefits and who feel benefits outweigh the costs so favour HRT.

Women who weigh up costs and benefits and who feel costs outweigh benefits and so do not favour HRT, including those who want a natural menopause and so do not favour HRT.

At the time the research for this thesis was started, a survey was underway in Scotland (Sinclair, Bond and Taylor 1993) using a questionnaire about HRT, based on one used in the US (Ferguson, Hoegh and Johnson 1989), which included a section about what would persuade women to take, or not to take, HRT. A series of statements were given (see box 3.3 for examples) and the women were invited to mark on a scale 1-5 whether each statement would persuade them to take HRT (score 1) or not to take it (score 5). This format was attractive for a questionnaire survey and would provide numerical results which, from the advice of a statistician, the researcher hoped could be used to develop a scoring system for attitude to HRT. Such a system would aim to assign each woman an attitude score. The scores would be spread across a score range so would conform to the criteria for using statistical processes such as multiple regression. Statistical analysis could then identify what factors may influence the attitude score, according to statistical criteria, assuming the factors that may influence it could also be measured in a way appropriate for the statistical method and that there was a causal relationship.

For the questionnaire survey the researcher decided to develop a question about women's attitudes based on the format and statements used by Ferguson et al. (1989) and Sinclair et al. (1993) (see box 3.3 for examples), and to use the pre-pilot interviews to develop new statements. At the time this was a practical decision as

Box 3.3 Examples of statements used to ask women what would persuade them to take HRT (Sinclair et al. 1993)

- To be effective, HRT would have to be taken for the rest of my life
- HRT might cause periodic bleeding like a menstrual period
- A test could be done to determine my risk of osteoporosis
- HRT would not cause cancer

the format had already been tested, there were published results with which to make comparisons and it offered numerical results for statistical analysis. These factors appeared to be very important to the researcher at the start of the research process. However, during the process of analysing the results, the researcher began to reflect on what the results really meant and how they related to the original aims of the research. In the discipline of psychology there is debate about the assessment of attitudes that is not explored in this thesis, although aspects of it are used. Here, the theory of planned behaviour, developed by Ajzen (1988), is used to try to gain understanding, in retrospect, of how women's perspectives on HRT were considered and explored in the initial stages of the research. This includes the aspects described above, and the issues discussed in the pre-pilot interviews, as outlined in box 3.1. In chapter six, a different aspect of the debate in psychology about expressed attitudes is used to increase understanding of the group processes in focus groups.

The theory of planned behaviour is a development of the theory of reasoned action which is a model of what precedes a behaviour (Ajzen 1988:132-135). The behaviour being considered in this analysis is the behaviour of taking HRT. Applying the theory assumes that, at some time, women will make a decision whether or not to carry out the behaviour of taking HRT. In the current social context in the UK, this is a reasonable assumption for most, but not all women. The theory of planned behaviour sees intention to perform a behaviour as a central factor determining whether the behaviour is carried out. Intention to perform a behaviour is in turn influenced by two factors:

one personal in nature and the other reflecting social influence. The personal factor is the individuals' attitude towards the behaviour Unlike general attitudes towards institutions, people or objects that have traditionally been studied by social psychologists, this attitude is the individual's positive or negative evaluation of performing the particular behaviour of interest. The second determinant of intention is the person's perception of

social pressure to perform or not to perform the behaviour under consideration (and) is termed subjective norm. Generally speaking, people intend to perform a behaviour when they evaluate it positively and when they believe that important others think they should perform it (Ajzen 1988:117).

These two factors, attitude toward the behaviour and subjective norm, interact with each other. Ajzen adds a further factor that influences intention to perform a behaviour that he calls perceived behavioural control.

This factor refers to the perceived ease or difficulty of performing the behaviour and it is assumed to reflect past experience as well as anticipated impediments and obstacles. As a general rule, the more favourable the attitude and subjective norm with respect to a behaviour, and the greater the perceived behavioural control, the stronger should be the individual's intention to perform the behaviour (Ajzen 1988:132- 133).

Perceived behavioural control interacts with attitude towards the behaviour and with subjective norm as well as having a direct effect on intention. Ajzen goes on to explain that perceived behavioural control:

is likely to take into account some of the realistic constraints that may exist (so) perceived behavioural control can influence behaviour indirectly, via intentions, and it can also be used to predict behaviour directly, because it may be considered a partial substitute for a measure of actual control (1988:133-134).

The theory of planned behaviour is summarised in figure 3.1. Each of the factors influencing behaviour will be considered and examples discussed, drawn from the development of the research question and questionnaire.

The study by Schmitt et al. (1991) measured the intention of women to take or not to take HRT in particular scenarios and so is

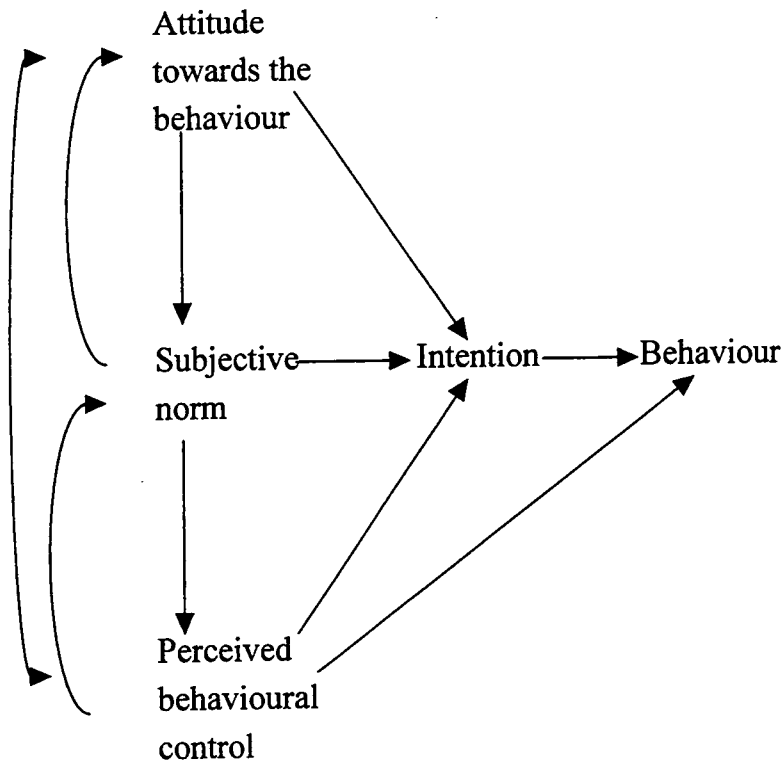


Figure 3.1 Theory of planned behaviour (Ajzen 1988:133)

measuring the factor just prior to behaviour in the theory of planned behaviour.

The form of question used by Ferguson et al. (1989) and Sinclair et al. (1993) (see box 3.3 for examples), with the woman's response being a score of how far each statement would persuade her to take HRT, seems to measure steps prior to intention. A woman who is persuaded to take HRT by a statement may go on to develop an intention to take HRT. According to the theory of planned behaviour, attitude towards the behaviour influences intention to take HRT. The definition of attitude used in the theory - "the individual's positive or negative evaluation of performing the particular behaviour" (Ajzen, 1988:117) - suggests a balancing of advantages and disadvantages for the individual in carrying out the behaviour. The form of question used by Ferguson et al. (1989) and Sinclair et al. (1993) seems to measure this. The question asks each woman to evaluate how far each statement would persuade them to

take HRT. Using the terms used in the theory this seems to be how far she would see the statement as being an advantage or disadvantage for her when considering HRT, with advantages persuading her and disadvantages not. However, as discussed below, there is interaction with other factors.

In the theory, subjective norm influences intention, and this may include whether a woman feels it is normal or acceptable behaviour to take HRT or to suffer hot flushes, and whether it is socially acceptable to reduce risk of future ill health as much as possible or to take it as it comes. The women in Schmitt et al.'s study (1991) who weighed up costs and benefits may accept a subjective norm about individuals taking care of their own health and striving to prevent future problems. Messages from the media, as explored in the pre-pilot interviews (see box 3.1) may be a source of subjective norms as well as other people known personally. Subjective norms may have been partly assessed by some of the statements used in the questionnaire (box 3.3). For example, a woman's response to the idea of taking HRT for the rest of her life may be partly measuring a subjective norm about the medicalisation of life. A woman's response to the statement about a test to measure risk of osteoporosis would depend on how far she accepts the authority of medicine and medical tests, however the response may also depend on how much a test increases the woman's sense of control in her life. Here there seems to be interaction between subjective norm and perceived behavioural control.

In the theory of planned behaviour, perceived behavioural control is the third factor influencing intention. In the study by Schmitt et al. (1991), the women who considered acute need of pressing importance may have low perceived behavioural control and the women who weigh up the risks and benefits may have high perceived behavioural control. The experience of women with their GP in the context of HRT, as discussed in the pre-pilot interviews (box 3.1), assesses one aspect of perceived behavioural control that may have its effect by influencing intention. However the GP also

has a direct effect on the behaviour of taking HRT as a doctor has to prescribe it.

The statement about HRT causing periodic bleeding (box 3.3) may be measuring all three influences on intention and how they interact. Women may have attitudes towards menstruation and in particular continuing to have bleeds after the menopause that influence intention to take HRT. They may have learnt a social norm about women after the menopause being past thinking about anything connected with sex. Some women may feel taking HRT would increase or decrease the control they felt over their bodies.

The theory of planned behaviour does not include "general attitudes towards institutions, people, or objects" (Ajzen, 1988:117), however the original research question, asking women whether doctors should persuade them to take HRT, included exploring this type of general attitude.

In conclusion, the aspects of women's perceptions of HRT that were considered at the start of planning the questionnaire survey included all the elements of the theory of planned behaviour. The actual method used to measure women's attitudes in the questionnaire seems to measure attitude towards the behaviour, as defined by the theory. However other factors that interact with attitude are also included.

3.4 Pre pilot stage of the questionnaire survey

This stage of the research will be described in a manner that highlights methodological questions. The literature search, the interviews and designing the pilot questionnaire will be discussed separately.

3.4.1 The literature search

At this stage of the research the aim of the questionnaire survey was very focused and so were the literature searches. HRT was seen as

the key to relevant literature rather than considering more general issues such as measurement of attitude or women's health. Medical indexes were the main source of literature as, at the time, there was little literature found in a search of social science literature through the "Bath Information and Data Services" and through a search of "Sociological Abstracts". This was probably because of the narrow focus of the search and because the widespread use of HRT was relatively new. The literature search had four main aims: to find out what was already known in order to build on questions of interest; to find out what was useful to measure in addition to specific questions about HRT; to find pre-tested questions that may be reliable and that would provide data that could be directly compared with other studies to increase the generalisability of the survey; to inform the choice of sample population for the survey. Examples for each of these aims are given.

To build on questions of interest

Reading the literature raised questions that the planned survey could help answer. Examples are given below.

No relation between a positive family history of fracture, indicative of osteoporosis risk, and receiving HRT was found in one study (Kadri 1991), a finding of some surprise and interest. It was therefore planned to include a question about family history of osteoporosis and about the woman's use of HRT.

Hunt reported that women had to put pressure on their GP to obtain HRT (Hunt 1988). Ferguson looked at factors that favoured HRT use and, of the factors suggested, "having a doctor recommend it" was rated most favourably by women currently taking HRT followed closely by the statements that "HRT would stop hot flushes" and "HRT would not cause cancer if taken properly" (Ferguson, Hoegh and Johnson 1989). Coope, a GP enthusiast for HRT, ran an osteoporosis clinic where, of the women started on HRT, only 38% were still taking it after one year (Coope and Roberts 1990). In another survey women were counselled in a hospital setting about HRT, after they had sustained a wrist fracture,

but only 36% of women took up the offer of HRT for prevention of osteoporosis (54% in the 50-55 year age band) (Wallace, Price, Elliott, MacPherson and Scott 1990). In Kadri's study (1991), some women commented that doctors appeared to be divided about the dangers of HRT and that this was unhelpful for them. This background raised two questions. How do women perceive doctors, particularly their own GP's, attitudes to HRT and how helpful do they find doctors in the process of making a decision about HRT. Questions on these areas were incorporated into the questionnaire.

Several studies had shown the media to be the main source of information on HRT for women (Hunt 1988; Kadri 1991; Ferguson, Hoegh and Johnson 1989). However, no studies had asked women what they had actually gathered about HRT from the media and how they felt about the media coverage. Questions on these areas were therefore planned.

What to measure in addition to questions directly related to HRT?

In a survey, the measurement of factors such as age, social class and education have two main functions. The first is to characterise the survey respondents to check for response bias by these measures. A major bias for postal questionnaire surveys can be that the survey may be more interesting or accessible to certain sections of the population than others. The theory of sampling and inductive statistics is based on the assumption that a sample is selected to represent a population (Armstrong 1996), so any response bias reduces the strength of this assumption. For a measure that is known for all those sent questionnaires, response bias can be assessed directly. For other measures, comparison has to be with other data. For example, a proxy measure of social class was included for comparison with census statistics.

The second reason for collecting demographic data is to assess its possible influence on the issues forming the focus of the survey. Whether or not to measure social class, or to use education as a proxy measure, was influenced by the literature. Coope found that

those attending her osteoporosis clinic were of higher social class than non-attenders (Coope and Roberts 1990), however, Draper found only very small differences in attitudes to HRT between social classes (Draper and Roland 1990). Kadri found past or present use of HRT was not related to social class (Kadri 1991) and other studies did not measure social class. Given this background and the complexity of measuring social class accurately it was decided not to attempt to measure social class in this study.

A paper from the US showed education seemed to influence attitude to the menopause (Lieblum and Swartzman 1986) and Schmitt et al. also identified education as a factor affecting a woman's type of decision making process about HRT (1991). The survey at the time underway in Scotland, measured education (Sinclair, Bond and Taylor 1993). As social class was not going to be measured in the survey, education was used as a proxy measure for this and could be compared with the study being undertaken by Sinclair et al (1993).

Menopausal status was included in the questionnaire because of its direct relevance to HRT and for comparison with published studies. Sinclair et al. (1993) had discovered an error in their questions about menopausal status during analysis, which had limited their analysis. The error concerned collecting details about hysterectomy. It became clear that because hysterectomy may be performed for many different indications, both pre-menopause and post-menopause, and may or may not involve removal of the ovaries, the clearest categories of menopausal status would be achieved by separating out all women who had had a hysterectomy and then dividing the remainder into premenopausal and postmenopausal groups.

To find pre-tested questions that may be reliable and that would provide data that could be directly compared with other studies to increase the generalisability of the survey

The form of a question can affect the response obtained in many ways, and examples of this are given in box 3.4. These problems are likely to have been solved to some extent for questions already

Box 3.4 Pitfalls for questionnaires (Lydeard 1991)

- poor phrasing or ambiguous vocabulary (words such as often, double barrelled questions, double negatives)
- leading questions
- loaded questions that suggest approval or disapproval
- prestige bias/social desirability i.e. the tendency to give socially acceptable answers
- tendency to give positive responses
- end-aversion or central tendency on numbered scales
- positive skew, when responses are not evenly distributed over the range of alternatives
- framing where response is affected by how the situation is presented
- halo effect where overall impression influences answers to specific questions

used in surveys and reported in the literature. Where questions are the same, results from studies can be directly compared, allowing assessment of the generalisability of the results. Where the area of interest is developing rapidly, as with HRT, the differences in time of when the surveys were done make these direct comparisons more difficult.

The literature search revealed a number of subject areas where appropriate questions had been used, however the usefulness of these questions varied.

A question used by Sinclair et al. (1993) on whether women had taken the oral contraceptive pill, provided a question so results could be compared.

Several studies had measured women's knowledge about HRT and had developed questions about this (Kadri 1991; Draper and Roland 1990; Roberts 1991; Ferguson, Hoegh and Johnson 1989). These

were utilised in the present study as the pre-pilot interviews indicated the importance of including questions to assess the knowledge base of the women.

Strong correlations had been found between attitudes to the menopause and attitudes to HRT (Ferguson, Hoegh and Johnson 1989). The questions about attitude to the menopause had been used in previous studies (Neugarten, Wood, Kraines and Loomis 1963; Lieblum and Swartzman 1986) and invited women to mark their responses to a list of statements (see box 3.5 for examples).

The thing that causes all women their trouble at the menopause is something they can't control - changes inside their bodies.

Male partners of menopausal women regard them as less sexually desirable following the menopause.

Because the menopause is brought on by diminished hormone levels, it should be viewed as a medical condition and treated as such.

Women who are having trouble in the menopause are those who are expecting it.

A woman feels like less of a woman following the menopause.

Psychological problems that women experience around the menopause are more greatly affected by life changes at that time (i.e. children leaving home, death of parents) than by hormonal changes.

Box 3.5 Six of the ten statements about the menopause used by Lieblum and Swartzman (1986), Ferguson et al (1989) and Sinclair et al (1993) in assessing attitudes to the menopause. (The six statements were used in the pilot survey.)

The questions about attitudes to the menopause seemed complex and, at the time the questionnaire was being developed, it seemed appropriate to use them in the current survey to avoid problems with developing new ones and so the results could be compared with other studies. However later, closer examination of the development and use of these questions raised queries about their reliability. The paper by Neugarten et al. (1963) reports a large interview study and the development of a questionnaire that included questions about the menopause. This was developed with women aged 40-50 years, then used in a survey of a wider age range of women. The women studied were relatively highly educated. From this study, Lieblum and Swartzman (1986) took three questions and added seven others, developed by the authors themselves. There was apparently no piloting of this ten item questionnaire and it was used with relatively educated women. This ten item questionnaire was used again by Ferguson et al. (1989) and then in a form adapted for the UK by Sinclair et al. (1993). Until these questions were used in the UK they had been used on relatively highly educated women so may not have been accessible to women with a wider range of educational attainment. The original age range on which some questions were tested was restricted and the ten item questionnaire was apparently not piloted so may have included questions not accessible to the general population. It is therefore difficult to be sure how reliable the questions are for assessing attitude to the menopause.

To inform the choice of sample population for the survey

Some previous surveys had involved a relatively high proportion of women from social classes 1-3N (Kadri 1991) or mostly more educated women (Ferguson, Hoegh and Johnson 1989), and some had restricted their survey to perimenopausal women or HRT users from the researcher's practice (Kadri 1991; Roberts 1991). The current study aimed to seek the views of a much wider range of women, by age, education and menopausal status, as did the study by Sinclair et al. (1993). So direct comparisons could be made, the

age range used by Sinclair et al. (1993) (20-69 years) was used. To avoid problems of the doctor - patient relationship affecting responses, women from the researcher's own practice were not included in the main survey.

Summary

The literature search was used to aid the development of the postal questionnaire, in particular tackling biostatistical questions such as generalisability, reliability and sampling.

3.4.2 Pre-pilot interview study

The aim of the pre-pilot interview study was to improve the quality of the questionnaire, particularly the questions that were to be designed for this study, as inappropriate questions in surveys can give meaningless results. A doctor designing questions on medical issues for non-medical people can face particular problems, as lay health beliefs may be very different from those of doctors who are part of a profession with its own distinctive world view and language (Helman 1991). Questions may therefore assume inappropriately, a particular world view and be expressed in language unfamiliar to, or with different implications for, lay people.

The pre-pilot interview study was designed to include women from a wide range of backgrounds and experience to provide insight into their ways of thinking, attitudes and use of language, particularly in relation to HRT and associated issues. Five women were interviewed individually, one from each of the following categories;

On long-term HRT

With a chronic disability or illness

Over 70 years and mentally lucid

Caring for an elderly dependant

From an ethnic minority group with good English.

These categories were chosen to guide the choice of women so women with a wide range of experience were included. The categories were not necessarily mutually exclusive. Women from the researcher's practice already had a relationship as a patient with the researcher or a colleague. As this may have affected what the women said in the interview, women from a neighbouring practice were included. Two women were from the researcher's practice and three from a neighbouring practice and the age range was 42 - 73 years.

Three group interviews, involving a total of 16 women, were held with groups with which the researcher had some indirect personal or professional connection. One was a women's health group on a deprived housing estate local to the researcher's practice and two were neighbourhood groups, one from a well appointed private estate and one from a council housing estate. The age range of the women attending the groups was 26-72 years.

During the interviews the women were encouraged to explain in their own words their feelings and attitudes to HRT and associated issues. However the researcher had a plan of the subjects to be covered (see box 3.1). All the interviews were tape recorded and transcribed. For analysis, the researcher read and colour coded the transcripts by subject areas, however more important to the aim of the interviews was the way women talked about the issues.

The level of understanding of women about HRT was fairly limited and the women's understanding of words such as osteoporosis was often confused, for example with osteoarthritis. The women were more comfortable using expressions such as thinning of the bones or brittle bones, so these expressions were used in the questionnaire to explain the word osteoporosis. The limited understanding of the women about HRT and its use for prevention was a prompt to include questions that assessed women's knowledge of these issues.

The women interviewed were interested and enthusiastic about discussing the subject of the interviews. They had mostly heard or

seen something about the subject in the media and were able to comment on what they thought about the media coverage. This encouraged inclusion of questions, in the questionnaire, about what women had learnt from the media and what they thought about it. The women were also able to talk about their fears for their health and what they thought were priorities for health care in Britain which encouraged inclusion of questions on these areas. The women were prepared to debate the use of medication in prevention, the role of diet and exercise, their expectations for their future health and the quality of life and death, and the discussion informed development of statements about what would persuade women to take HRT.

Within the focused aim of the questionnaire survey, the pre-pilot interviews were helpful in improving the wording of the questionnaire and reassuring the researcher that women were interested in the subject. The interviews were driven by the researcher's own interests which, along with the interviewer being a doctor, may have biased or inhibited the discussion to some degree. The interviews also acted as useful training for the later interview study, although this had not been planned at that time.

3.4.3 Designing the pilot questionnaire

The questionnaire was based on the researcher's interests and modified by the experience of previous studies and the initial qualitative study as described in sections 3.4.1 and 3.4.2. The overall design for the questionnaire was to initially ask about general health issues before focusing down onto HRT and the menopause. This was because it seemed likely that women's attitudes to health in general formed an important context for the way women approached issues related to HRT and the menopause.

A questionnaire was produced that included all the questions of interest to the researcher, who then asked a few practice staff members to fill it in. The overwhelming opinion was that it was far too long. A questionnaire that is very long may inhibit women

responding to all or part of it. However the range of issues for inclusion was very large. Several shorter questionnaires, focused on particular areas of interest, may have been more appropriate rather than attempting to combine all the interests into one, but these may have cost more to administer as printing and postage costs increase. Focused questionnaires could have been sent to specific age groups. For example, questions of general interest could have been sent to the whole age range and questions specific to the perimenopausal years could have gone to a narrower age range. This may have reduced the size of the sample needed. Using one questionnaire for all women meant that the sample had to be large enough to ensure sub-groups, such as postmenopausal women, were large enough for statistical analysis. Using shorter questionnaires for specific groups was not considered at the time, as the aim was to collect data from across the age range on all subjects, so data for groups within this could be compared, and comparison would be possible with the study by Sinclair et al (1993). The importance of this was enhanced by the emphasis on generalisability from biostatistics and criticisms of general practice research that, by the standards of biostatistics, studies were often too small and context specific. The original questionnaire was shortened before the pilot study by removing the questions that seemed least important, and again after the pilot study, guided by the assessment of the questions described later in this chapter. Following the advice of Lydeard (1991), six women were chosen at random, from the researcher's practice list, and asked to fill in the questionnaire with the researcher present. Five women agreed and the researcher was able to observe any difficulties with the questionnaire, discuss understanding of the questions and whether appropriate answers were available. The feedback was of limited use. This may have been because the researcher was a doctor from the woman's own practice so they felt inhibited about making criticisms because of wanting to appear loyal to their doctors, or because of concerns about how it may affect the health care they receive (Jones, Murphy and Crossland 1995).

The women's health groups involved in the initial qualitative study filled in the questionnaire and discussed it with the researcher, and a copy was sent to each of the members of the other two groups, inviting them to fill in the questionnaire and write comments on it. These groups may have felt more involved in the research and more independent, and they provided helpful comments on the difficulty of some of the questions, the length of the questionnaire and problems with wording, layout and instructions. Additional explanation was added to some questions, to allow for women having little or no knowledge of the topic, and instructions were clarified. The presentation in terms of format, type face and print size was made clearer.

The title had originally included the word menopause and the accompanying letter mentioned HRT. This focused respondents on these ideas from the start so may have restricted the answers to the questions about women's views on health in general. Also younger women felt the questionnaire was not relevant to them. For the pilot, the title was therefore changed to "Health Survey" and the covering letter emphasised the researcher's interest in women's views on health issues, and in particular, priorities in health care. This involved slight deceit as the focus of the questionnaire was HRT and the menopause and this became obvious to women as they read to the end. A few women in the pilot study commented on this and it may have affected women's responses. At the time, gaining information about women's views on health in general seemed vital to the aim of trying to understand women's perspectives on HRT when taken in the context of their life and health. The deceit therefore seemed to be necessary in the context of conducting the questionnaire survey. In retrospect, as discussed above, the questionnaire could have been split into smaller sections and sent to different groups of women. A section about general health issues could have been only about this, and a section about the menopause and HRT, for perimenopausal women, could have been clearly introduced as about these specific issues. This strategy could have avoided the use of deceit.

In a question about worries for personal health in the future, a tick list of possible concerns had been given. This was a leading question and almost all women expressed concern about all of them, so this was changed to an open question to try and find out women's main concerns.

A question about screening used a number of statements to which women were asked to respond on a numerical score from 1, strongly agree, to 5, strongly disagree. The scores revealed almost total agreement. Lydeard suggests that if an answer to a question is predictable, there is little to be learnt from using it (1991). In reality, it may be interesting and important to find that almost everyone supports the idea of screening. However, the aim of the questionnaire determined what questions seemed important and when developing the pilot questionnaire the aim was to measure views that were spread across a range. This aim was partly based on the biostatistical idea of a normal distribution of a characteristic across the population. Confirmatory statistics often assume a normal distribution curve for numerical interval data, for example in the z test and t test (Erickson and Nosanchuk 1992:141-143). If the ordinal responses to a question (such as a scale 1-5) are to be used in this form of statistical test, for the test to be reliable, the data has to have a fairly smooth distribution (Erickson and Nosanchuk 1992:159-160), so a range of responses is needed and the questions either adjusted to achieve this or discarded. The question about screening was shortened for the pilot questionnaire and discarded before the main questionnaire.

The design of the pilot questionnaire demonstrates the influence of biostatistical research methods on the research process and the researcher's attempts to make the questionnaire acceptable and accessible to women, yet within the constraints of the demands of biostatistical research methods.

3.5 The pilot study

The aim of the pilot study was to improve the quality of the questionnaire. The pilot study will be described followed by the use of the pilot results in adjusting the form of the questionnaire, however the focus of discussion will be methodological questions. A copy of the pilot questionnaire and covering letter are in appendix 3.1.

3.5.1 Pilot study process

Sample stratification

A random sample of 100 women aged 20-69 years, stratified into five year age bands, was taken from the researcher's practice, with the permission of the other doctors in the practice. At the time of doing the pilot study it was intended to stratify the sample by electoral ward as well as age. The stratification by electoral ward was intended to ensure the questionnaire reached a wide spectrum of women and allow comparison of response rates according to electoral ward. Cleveland Research and Intelligence, a department of the now disbanded Cleveland County Council, provided data on social factors by electoral ward including unemployment, housing tenure and car ownership. The pilot questionnaire sample was taken allowing for this stratification. However, stratification by electoral ward was not pursued beyond this stage as the data on social factors for the electoral wards showed that there was a great deal of overlap of social characteristics between electoral wards. Using smaller units such as enumerator districts may have given a more specific measure of the social characteristics but the process would have been time consuming and much of the available data was relatively old as the full 1991 census data was not available.

Response to pilot questionnaire

The pilot questionnaire and covering letter signed by the researcher, was sent out on 14 May 1993 to the 100 women with a stamped addressed envelope for reply. By 18th June 43 replies had been received. A reminder letter was sent to non responders. The final

total of responses was 58. This was a disappointing response rate, at the time attributed to an overlong questionnaire and too few reminders.

Reliability testing using test-retest method

On 1st July 1993 a second copy of the questionnaire was sent to the first 43 responders, identified by the code on the questionnaire, to test for reliability of the questionnaire by the test-retest method (Lydeard 1991). Only 15 retest questionnaires were returned and many questions had been left blank reducing further the number of responses that could be compared. The test-retest method for checking the reliability of the questionnaire assumes that if a question is reliable it will elicit the same response when asked at different times of the same person. This may be a reasonable assumption for questions about relatively stable characteristics, however variables such as knowledge and attitudes may change over time. It could be argued that, over a one month period, a woman is unlikely to make major changes in her knowledge about or attitudes to the menopause and HRT, however there are several other problems with the test-retest method for this questionnaire.

The questionnaire gives ideas and information about the menopause, HRT and prevention and so may raise a woman's awareness of the issues, which may then lead her to notice information about it in the media or discuss it with friends and family, a process that may change the woman's knowledge and attitudes. Receiving the questionnaire from a doctor at her own general practice may exacerbate this as she may think this indicates her doctor thinks the issues are very important.

Some of the questions, particularly responses to the open questions, may have been easily remembered. For example in the 15 comparable questionnaires there were no changes in the responses to the open question "What health problem are you most worried will affect you as you get older?" and only one change for the question "What single health or welfare problem do you feel deserves the highest priority at the moment?" where a woman had

named osteoporosis on the retest. The woman's awareness of osteoporosis may have been raised by the first questionnaire, and she may have felt the researcher saw osteoporosis as very important as many questions referred to it.

Responses given on a numbered scale may be less easy to remember. For the six statements about the menopause (box 3.5) women were asked to mark their degree of agreement on a scale 1 = strongly agree, 3 = neutral, 5 = strongly disagree. It was possible to compare the scores on test and retest for just seven women, however most of the responses differed. It may be that women's views had changed or it may be that it is too stringent a criterion to expect the test and retest results to match exactly; a difference in score of one may not mean the question is not reliable, nor indicate a major change in the woman's views. The problem is to decide what criterion to use and so two were tried. Firstly, changes in score from 1 or 2 to 3 or more or changes in score from 4 or 5 to 3 or less were counted. Out of the total of 35 responses for all six statements 22 were different using this criterion, indicating little reliability as the changes were, for example, from neutral to agree or strongly agree. The second criterion used was a numerical score change of more than two so did not count as a change, for example, a change from score 1, strongly agree, to score 3, neutral. Three women changed between test and retest for the first statement and one woman changed in each of the other statements except the one about the menopause being a medical condition when none changed. Using this criterion the questions appear more reliable but the criterion allows for considerable change.

In summary there are a number of problems with using the test-retest method for checking the reliability of this questionnaire. Knowledge about and attitudes to the issues in the questionnaire may change over time and this may be enhanced by receiving the first questionnaire. Some of the questions may be easily remembered and, although numerical scores may be less easily remembered, the researcher has to decide on criteria for the changes

in numerical scores which are considered to indicate real changes in the women's responses.

The low response rate to the retest questionnaire may reflect women's unwillingness to fill in a long questionnaire for a second time. The covering letter attempted to explain that the second questionnaire was to help an assessment of the value of the questions in the questionnaire. In retrospect, asking the women to do this seems quite an imposition.

3.5.2 Assessment of individual questions in the pilot questionnaire

The methodological issues raised by the assessment of the individual questions in the questionnaire will be discussed giving at least one example for each issue. A methodological issue may apply to other questions, including those given as examples for other issues.

Asking for only one response

The first question of the questionnaire asked "What single health or welfare problem do you feel deserves the highest priority at the moment?" followed by the instruction *Please write the one problem here* and leaving a space for the response. By asking for a single problem to be named it was hoped to identify what women really felt to be the highest priority and it made it easier to handle the responses. Some women named more than one problem, in which case the first one was used in analysis, however for that woman the different problems may have had equal priority. Although the design of the question attempted to focus women's priorities it may also have squeezed them so they no longer truly represented reality.

Coding of open questions

Categories for coding were developed as the pilot questionnaire was analysed. For the question "What single health or welfare problem do you feel deserves the highest priority at the moment?", different aspects of a particular health problem were grouped together for example, cancer research and cancer were grouped together and

breast screening was grouped with health checks and well woman clinics. The category "cancer" contained all types of cancer; "breast cancer", "childhood leukaemia", "all kinds of cancer". Cancer formed the biggest group for this question and in retrospect it may have been better to have started with a larger number of codes, particularly for cancer, and particularly as breast cancer has special relevance for women and HRT. Codes could have subsequently been combined where it seemed appropriate.

Social acceptability

The second pilot question gave women a list of health and welfare services and asked them to mark on a score of 1-5 the priority they would give to each service. The responses to this question are presented in table 3.1. A skew towards 1-3 on the scale was expected as few people would want to give something low priority as this may not feel socially acceptable. The questions involving children were given high priority by a majority of respondents making the response very predictable. Although it could be argued these questions were therefore not worth including, they were kept in as, if people have something to mark as high priority it may allow them to mark other services as lower priority, so priorities can begin to be distinguished. Screening for osteoporosis was given high priority by most women. There are several possible reasons; a television advertising campaign about osteoporosis, run by the Osteoporosis Society, had occurred just prior to the pilot study; women may have realised the researcher was interested in osteoporosis; screening for osteoporosis may have been a priority for them.

Ranking of priorities

The question about priorities for health and welfare services did not ask women to rank the services. Ranking was purposely avoided because of problems measuring this (Pfeffer and Pollock 1993), although more recently procedures for ranking priorities have been developed further (Bowie, Richardson and Sykes 1995; Hopton and Dlugolecka 1995). Women may have been doing some ranking in the way they answered the question, but this was not explicit.

Health or welfare service	High priority		Neutral		Low priority		Total
	1	2	3	4	5		
Provision of premature baby units	37	9	9	0	0	55	
Transport system for the elderly and disabled	18	22	10	5	0	55	
Higher taxes on cigarettes	26	6	7	5	10	54	
Cycle Lanes	10	8	19	7	9	53	
Promotion of long term HRT (hormone replacement therapy)	19	14	17	1	2	53	
Safe play areas for children	31	12	5	4	0	52	
Advice and advertising about safe sex	17	16	16	1	1	51	
Research into cure for dementia	30	13	10	2	0	55	
Screening for osteoporosis (brittle bones)	36	14	7	0	0	57	
Research into the cause of childhood leukaemia	41	10	3	1	0	55	
Sports facilities in all housing areas	6	10	22	11	5	54	
A national food policy so healthy foods are relatively cheap	21	12	16	3	3	55	

(total number of respondents = 58)

Table 3.1 Frequency of responses to the pilot question "The following is a list of health and welfare services. For each one *please circle the number* which best shows how high a priority you would give the service (*1 is highest, 5 is lowest*)"

Consistency of responses

Consistency was checked by assessing whether respondents answered similar questions in a similar manner (Lydeard 1991). For example, responses to the question "What health problem are you most worried will affect you as you get older?" were compared with responses to the question about priorities for health and welfare services (table 3.1). Dementia was named the most, consistent with it being given a priority score of one by a majority of respondents. The provision of facilities for exercise was given low priority, fairly consistent with women's knowledge about the role of exercise in prevention; 21 out of 58 women knew that inactivity increased risk of osteoporosis; 38 out of 58 women knew that inactivity increased the risk of stroke and heart attack.

Improving the questions by comparing the pilot results with other studies

The questions on knowledge about osteoporosis, CVD and HRT were based on questions used by Sinclair et al. (1993). Their analysis was not complete at the time of the pilot study but results from the US using a similar questionnaire were available for comparison (Ferguson, Hoegh and Johnson 1989). In this study most women knew that decreased dietary calcium intake was a risk factor for osteoporosis and in the pilot 54 of 58 women knew this. Most women knew being overweight was not a risk factor for osteoporosis where as in the pilot 50 women said it would make osteoporosis more likely. The wording of the question was altered from "overweight" to "being overweight" as the pilot response may have been due to ambiguity in the question. The pilot results on smoking, inactivity and family history of osteoporosis as factors affecting the risk of osteoporosis were similar to Ferguson et al.'s study (1989). Comparing the pilot results with other studies revealed an ambiguous question and was reassuring that the other questions were collecting comparable data. However comparison with other studies could be misleading, giving inappropriate reassurance about the quality of the questions. For example, the populations in different surveys may have different knowledge levels yet the questions may not be sensitive enough to reveal this.

Exploratory versus confirmatory statistics

Although the pilot questionnaire included a question asking the age of the women, this was omitted from the final version to save space. It was assumed it would be sufficient to know the five year age band for each woman from the sample stratification. The statistical knowledge of the researcher at this stage of the research, was that learnt for critically reading biostatistical papers published in medical journals and so was of confirmatory statistics for deductive research using a null hypothesis. It was planned to use confirmatory statistical methods to check hypotheses about the effect of age on knowledge and attitudes. Only knowing the five year age band restricted analysis to statistical methods for categorical data rather than continuous data, but as the rest of the data from the questionnaire was categorical this was probably not a major disadvantage. However, using the five year age bands assumed this was an appropriate division of the women by age. If the age of each woman had been collected, exploratory statistics could have been used to find the most useful divisions for the women by age for the purposes of the questionnaire, which may have been associated with socio-biological factors. When analysing the results a compromise was made by using the following socio-biological groupings: 20-25 years, young adult; 25-34 years, childbearing; 35-44 years, premenopausal/child rearing; 45-54 years, peri menopausal; 55-64 years, postmenopausal; 65-69 years, young elderly.

The range of experience included within the same response to a question

The questions on education, use of well woman clinics and use of the oral contraceptive pill illustrate different aspects of this methodological problem.

The pilot question on education was based on the one used by Sinclair et al. (1993) but combined two of their categories, university education and higher degree, into one category of university education. Analysis of the results showed that some

women marked more than one answer so the highest level of education marked was used. Table 3.2 shows the pilot results with the two categories of higher educational attainment combined. The uneven spread of responses prompted changes to the question intended to firstly, divide the group "left school on reaching 16 years or younger" to reflect the social class division between skilled and non-skilled manual workers, secondly, to identify those who completed formal education to A-level stage and thirdly to group together all those with higher education. The new categories were

- I left school with no formal qualifications
- I left school at 16 with qualifications
- I left school after taking A-level or equivalent exams
- I am doing or have done further training or education since leaving school

The questions on education used in the main survey were thus developed from the pilot study but not piloted themselves. In the main survey a larger proportion of women marked more than one category. So few women marked the category "I left school after taking A-level or equivalent exams" (37 women) that these were included with those with further training. These results may reflect

Left school on reaching 16 years or younger	35
Left school age 16-18 years	9
Vocational training beyond secondary school	7
Higher education, not university e.g. HNC, HND and University education	4

Table 3.2 Educational attainment pilot results: frequency of responses (total number of respondents = 58)

the lack of definition of the new categories, particularly the fourth category which, unlike the others, contained no reference to the type of further training or education nor the age of leaving school.

When developing the question the researcher had in mind degrees or professional training such as nursing or management training, however the category could include any type of training including youth training schemes and apprenticeships. Within our society, educational attainment is measured and has certificates awarded, although there may be debate about the accuracy and usefulness of this. For the survey, the aim was to measure educational attainment based on the measures used in society. However the measures used are very complex, especially for training beyond the age of 16 years, and have evolved, so current systems were not used when many of the women surveyed had most of their education. The question used about educational attainment only gives a very approximate idea of women's formal education and may have been interpreted quite differently by different women, despite the existence in society of formal measures of educational attainment.

With the aim of finding out about women's use of screening services, the question "Have you ever attended a "Well Woman Clinic"?" was included, requesting a yes/no answer but giving no definition of what was meant by "Well Woman Clinic". Clinics known as "Well Woman Clinics" have been set up by GPs, health authorities and private medical services with various aims including increasing the number of women having cervical smears, providing support and counselling services and screening for medical problems such as diabetes or risk factors such as high blood pressure. There is no accepted definition of "Well Woman Clinic" so the question is open to the woman's own interpretation based on her experience of what this might mean and the services available to her. The responses cannot be assumed to simply reflect a woman's use of screening services.

The apparently straight forward question "Have you ever taken birth control pills" provided two possible answers; "No, I have never taken them" or "Yes I am taking them now or have taken them at

some time in the past". The answer, "Yes", to this question may include a wide range of experience from continuous use for many years to taking it for a month or less or using emergency oral contraception. Women may also interpret the question differently, for example, does taking the birth control pill for a few months then abandoning it forever fit with the answer "Yes" or "No"? In terms of the measurement of any intake of the pill the answer is "Yes" however, the woman herself may feel she has never taken the pill in a way significant to her and also may have forgotten she tried it. Thus women with similar opportunities to use the birth control pill but with different experiences and attitudes to it may answer the question in the same way. The women's possible responses would also be affected by the historical development of the use of birth control pills. Women in their sixties would have been in their thirties when the pill was becoming widely available so may have already completed their families and have had a permanent form of contraception making the pill irrelevant. When the pill was first coming into use availability varied so women did not have an equal chance of using it.

To conclude, within the same response to a question there may be a wide range of experience. Where accepted measures of experience exist, such as for formal education, they may be too complex to be easily measured in a brief question. There may be no agreed definition of the object of the question such as "Well Woman Clinic". The interpretation of the question may vary as in the example for the birth control pill. Access by women to education, clinics and medical interventions such as the birth control pill varies and has evolved over time so a woman's response may reflect access or lack of access, rather than interest, ability or intention to use a service or intervention.

Women's perceptions and medical definitions

A question asked "Have any of your parents, brothers or sisters had osteoporosis (thinning of the bones or brittle bones) as they became older?" and offered the responses "No", "Yes" and "Don't know". The phrasing of the question takes into account the medical

definition of a positive family history of osteoporosis - that a first degree relative has suffered from osteoporosis - and also provides an interpretation of the medical term osteoporosis. The question appears to be collecting data about the frequency of a medical category "family history of osteoporosis". However, to be sure about the frequency of this medical category, further checks on the evidence women use to answer the question may be needed such as, how definite was the diagnosis of osteoporosis in the relative and can the woman be sure that she would have known of the diagnosis in a relative as not all families share medical information. The question, as asked, provides data on women's perception of whether they have a family history of osteoporosis. As the focus of the questionnaire is on women's perceptions and views this may be appropriate. When designing the question, the researcher used the medical definition of family history, which is a fairly restricted definition because this seemed important from her medical perspective. However, women may perceive that osteoporosis runs in their family even when only more distant relatives are affected, and this perception may influence their attitudes to HRT. The design of the question would have prevented these women from providing information about this perception. A question such as "Do you think osteoporosis runs in your family?" may have been more appropriate.

The first question of the series of questions used to define a woman's menopausal status asked about the woman's perception of her menopausal status: "Do you consider you are going through, or have gone through the menopause (change of life)?" The second question asked "have your menstrual periods stopped?" (In the pilot this was prefixed with "If yes," but this was removed for the main survey to simplify the layout). The medical definition of a natural menopause is when menstruation stops permanently. However, women can stop having menstrual periods for reasons other than the menopause or hysterectomy. Women who were not having periods but did not consider themselves to be going through or have gone through the menopause, were included with the premenopausal women. Women who considered themselves to be going through or

have gone through the menopause, and whose periods had stopped, were defined as postmenopausal. Women who were still having periods were defined as premenopausal even if they considered themselves to be going through the menopause. For this latter group, the medical definition of the menopause was given precedence over the women saying they considered themselves to be going through the menopause. For the aim of the survey, the women's perception of whether they were menopausal may have been more appropriate than giving priority to the medical definition, as this perception may influence the woman's attitudes more than a medical definition.

In conclusion, medical definitions of family history and the menopause were used, partly influenced by the background of the researcher and by a desire for the results to reach a medical audience. However it may have been more appropriate to try and measure women's perceptions, rather than only using medical definitions, so the influence of these perceptions on the intention to take HRT could be assessed.

Leading questions

The pilot questionnaire asked women about what they had heard about HRT in the media and provided a tick list of possibilities. As this seemed to be a leading question it was changed to an open question with no restriction on the number of answers except that indicated by the amount of space provided. Questions with tick lists are easier to analyse than open questions but may be more likely to influence the response. The difficulties of using open questions come mainly with analysis. The responses have to be coded with the difficulties of classification and how detailed the coding should be, as discussed above.

Influence of questions on the responses to subsequent questions

A question asked women with whom had they had discussed HRT, and provided a tick list of options. The subsequent question asked which of the people listed was the most important in helping with the decision to use, or not to use, HRT. In the pilot study the tick

list had not included "no-one". This was added to make it a definite option rather than assuming that no answer meant "no-one" and to encourage women to consider "no-one" as an option for the subsequent question as the tick list was likely to influence the answer they gave.

3.5.3 Summary

During the pilot study care was taken with checking the questionnaire. Leading questions were avoided. The influence of one question on another and the problem of social acceptability was considered. The consistency of results was checked and the pilot results were compared with other studies. The reliability of the questionnaire was tested using the test-retest method, but there was a poor response to the retest, and there were problems applying this form of reliability assessment to the questionnaire. The nature of the method meant that a range of experience for women was often squeezed into a limited number of responses or categories. The medical background of the researcher influenced the questionnaire design, particularly in the use of medical definitions and the use of confirmatory statistics.

3.6 The questionnaire: a sociological analysis of the method

A copy of the questionnaire and covering letter used for the main survey is in appendix 3.2. This section examines the sociological analysis of science as producing "fact", the use of methods out of the context of their discipline of origin and the rhetoric of science including the use of codified language. The questionnaire used in the survey, and the methodological questions raised in section 3.5 will be used as examples.

3.6.1 Science as producing "fact"

The discussion of methodological problems in the preceding section provides examples of, what Bartley (1990) calls, the informal account of scientific method, the imprecision and uncertainty that

was present before the method and results were formalised into accepted rhetoric, and before "facts" lost the qualifications that surround them. For example, the differences in experience that could be included in the same answer to the question about taking the birth control pill was not commented on in a biostatistical report of the results of the questionnaire survey (Griffiths and Jones 1995). Ranking of priorities for health care services was avoided but the results of this question was presented as a list of services ranked according to their total score (Griffiths 1995c), so giving an impression of explicit ranking. When the fears women have for their future health are discussed it is easy to forget they may have many fears as important, or almost as important, as the one they wrote down. Coding of open questions by a researcher was commented on in the method section but the difficulties and imprecision of the process was not explored (Griffiths 1995b). The imprecision of the questions in the questionnaire contrasts with the precision of counting and statistical analysis. Comparisons with other biostatistical literature may be misleading as any imprecision and uncertainty in the study reported in the literature tends to be lost, so it is not clear where compromises were made.

A questionnaire survey such as the one presented here, done with care and with a large sample size, is likely to reflect, in general, what is happening within the community, despite the imprecision and uncertainties. Treated as what they are, general indications, measured in a particular culture and context, for the specific aims of the research, the results can be useful for understanding what is happening in the community. However, research can be viewed by some as producing "fact". Bartley (1990) identifies social groups that may become involved in the production of scientific "facts", including funders, the government, pressure groups and professional groups who have particular interests in the establishment of certain scientific "facts" and who form alliances that promote this process. The motivation is often social, political or economic gain. I have discussed my social and political motivation for this research in section 1.3.1, including the intention that the research ensures that attitudes of women are taken into

account. However, the results of the research could be used to give social, political or economic advantage to a social group not intended by the researcher. For example, the results may be used by pharmaceutical companies to inform their promotional campaigns, or sections of the medical profession may use them to advocate a specific role for themselves. I suspect the pharmaceutical companies have done much of the field work in this thesis already, although the research department of one company showed interest in learning more detail about the survey. An article advocating widespread use of HRT (Tooze-Hobson and Cardozo 1996) refers to my published survey results about women's fear of cancer (Griffiths 1995b) as a starting point for arguing that much of the fear of cancer, associated with HRT, is unfounded. It could be argued that this citation indicates the research has made doctors aware of women's views. However, the article advocated a major role for the medical profession in providing advice, therapy and medical surveillance.

3.6.2 The use of methods out of context of their discipline of origin

The questionnaire was developed following mainly the guidelines written by Lydeard (1991) for a general practice audience and with some advice from a medical statistician. Although Lydeard's guidance was an accurate account of how to develop a questionnaire using techniques from psychology and sociology, it did not include the background to the methods described nor the assumptions and qualifications that surround them. The importance of this was not recognised at the time and so techniques inappropriate to the aims of the questionnaire were sometimes applied. For example, the use of the test-retest method for checking the reliability of the questionnaire was probably inappropriate for many of the questions, although it is a well tried and tested method for certain types of questionnaire. The assumption that for a question with a range of scores, the responses had to be spread across that range was not always appropriate, however the assumption of a normal distribution underlies much confirmatory statistics which can be a very powerful research tool. Working with

researchers across disciplines and researchers being clear about the context and qualifications of their own discipline, and allowing for this in other disciplines, can help prevent misunderstandings about the use of research techniques.

3.6.3 The rhetoric of science and the use of codified language

A research report, including the method section, may be written to try and persuade people of the truth of its results. The study of this scientific rhetoric has been undertaken by researchers such as Soyland (Soyland 1994:1). As the aim of the researcher was to convey to GPs what women were thinking about HRT, the reports of the research submitted for publication used the conventions of presenting medical research, as the researcher aimed to persuade the editors of the medical journals, the referees and the journal readers of the truth and value of the research. The method section of the submitted reports did not discuss the imprecision, uncertainty and qualifications discussed in this chapter. For example, the pilot study described in this chapter was summarised as "the questionnaire was piloted on 100 women in one general practice" (Griffiths 1995a,b; Griffiths and Jones 1995). Although this seems to fit with the idea of scientific rhetoric, summarising an imprecise process in a form that persuades of its value, the brevity of the account of the pilot is also because some methods have become well established and so the description of their process codified. The idea of piloting a questionnaire has become well established in primary care research, although the process of piloting may not be as well known as the use of the codified version of its description may imply, as questionnaire techniques are borrowed from sociology and psychology where the processes were established (Moser and Kalton 1985). It is possible that a GP researcher reading the method sections of the published papers and wanting to repeat the study, may have gone through more or less the same process to pilot the questionnaire as their understanding of the code may be similar (Armstrong 1996). However, a different researcher may also approach the piloting process quite differently. Even if

the overall technique was similar, the detail of what was done is likely to vary.

3.6.4 Conclusion

The account of the method of the questionnaire survey given in this chapter has its own rhetoric including this conclusion (Soyland 1994:30-31). However being aware of the limitations of research methods and accounts of them, including how they are socially and culturally conditioned (Helman 1996), does not necessarily remove all their value. Analysis of methodology could lead to a nihilistic position where all methods appear too flawed to be of use and all research accounts too full of rhetoric to be trusted. An alternative position finds the analysis highly informative for understanding research and developing methods for future research.

3.7 Taking the sample, improving the response rate and ethical considerations

The sample frame was prepared, and the sample taken, during the final stages of preparing the final questionnaire. The questionnaire was sent out in September 1993 and was followed by two reminders to non-responders. The details of the process are described below and ethical considerations discussed.

3.7.1 The sample frame

Ten general practices in Stockton-on-Tees, each including a doctor known to the researcher, were asked if they were prepared to allow their patients to be approached for the study, using their practice lists for the sample frame. As a GP it was relatively easy for the researcher to gain this permission from colleagues and was one reason for choosing this sample frame. Eight practices agreed, with a combined list size of 86,944 patients. This included one practice who agreed providing the names and addresses of the patients were not disclosed to the researcher.

With the computerisation of GP patient lists, it has become relatively easy for these lists to be used as sample frames for studies such as this postal questionnaire survey. However the data patients provide to their GP is for clinical care not research, so disclosing patient lists could be construed as breaking medical confidentiality (Jones, Murphy and Crossland 1995). The practice not prepared to disclose the patient details was probably ethically more correct than the researcher and the other practices. The issue of medical confidentiality was perhaps blurred by the researcher being a medical colleague. However, the study was not part of clinical work, although it aimed to inform it.

The sample frame was formed from the women aged 20-69 years on the practice lists of the eight practices in June/July 1993. The practices were spread through the whole borough of Stockton-on-Tees and so their patients were likely to be fairly representative of the town's population. The practices varied in size from a single handed practice to a group practice of 10 doctors, but all were computerised and tended to be involved in medical audit, so the doctors were not necessarily representative of all the doctors in the town. This may have introduced some bias in the survey, particularly for questions about the women's experiences of their GPs. Stratification of the sample frame by age group was relatively easy as it was done by each practice computer.

3.7.2 Calculating the sample size

The questionnaire included a broad range of questions which may have been more appropriately split up into smaller questionnaires as discussed in section 3.4.3. For analysis it was intended to divide women according to menopausal status and use of HRT. To calculate the sample size, data on menopausal status and HRT from Sinclair et al. (1993) was used to estimate the smallest expected size of a sub group: 3% of women were postmenopausal ex-HRT users. Any further analysis that would be done on this sub group was not taken into account. The population size and this smallest expected

frequency was entered into the programme for calculating sample size in Epi-Info which uses the equation

$$\text{sample size} = n / (1 - (n / \text{population}))$$

(Dean, Dean, Burton and Dicker 1990:258).

where n is the smallest expected frequency. For a 95% confidence level the estimate of the number of responses needed in the analysis was 1009 and if the response rate was the same as for the pilot (58%) a sample of approximately 1700 was required, a 1 in 17 sample of the sample frame (1649 questionnaires were actually sent out). This involved a very large number of women filling in a questionnaire in order to be sure of enough women in the smaller sub groups. It was probably inappropriate to ask so many women to be involved yet, at the time, this appeared to be following standard biostatistical guidelines. It could also be argued that it is unethical to ask more people to take part in research than is absolutely necessary for the aims of the research. The research is an intrusion for people and may raise questions and anxieties for them. Women may have felt that being included in the survey indicated that their doctor believed them to be at risk in some way (Jones, Murphy and Crosland 1995), particularly as their future health was one of the main themes of the questionnaire.

3.7.3 Enhancing the response rate.

Following advice from Lydeard, a response rate of over 70% was the aim, as with this response rate biases due to poor response "seem to disappear" (1991:87). The presentation and the layout of the questionnaire was developed to try and increase the response rate, a "freepost" return envelope was included with the questionnaire, and the address for return and the use of "freepost" was written on the questionnaire to reduce non-response if the envelope was lost. The questionnaire was accompanied by a letter (see appendix 3.2) on letterhead of the patient's own practice and signed by one of the GPs, as this has been shown to increase the

response rate (Lydeard 1991). Information about funding of the survey was included in the covering letter for ethical reasons and to help increase response rate, as Government sponsorship may increase response rate (Lydeard 1991).

The sending of questionnaires was delayed until September 1 to avoid the holiday season. On 16 September a reminder letter was sent to non-responders. On 15 October a second reminder letter, a further copy of the questionnaire and a further Freepost envelope was sent to those still not responding. This number of reminders could be interpreted as harassment or at least putting undue pressure on the women. The women were receiving a request from their own GP, a person in a position of power, and may have felt reluctant to refuse perhaps because of personal loyalty to their GP or because they feared being discriminated against in their future care (Jones, Murphy and Crosland 1995).

3.7.4 Conclusion

As the research involved National Health Service patients, the approval of the local ethical committee for the questionnaire survey had been obtained before commencing the survey. However the survey raises ethical considerations that at the time of doing the survey had not been widely discussed in general practice research, including using patient lists to access participants, the potential for increasing participant's anxiety, and exerting pressure on patients to participate in the research. These issues are perhaps now more carefully considered with the increasing amount of research that is done in general practice, either by GPs or by other researchers using general practice for access to patients and data.

3.8 Conclusion

The questionnaire survey was carried out early in the process of research for this thesis. This chapter has described the process of developing the questionnaire and conducting the survey, which aimed to increase understanding of women's attitudes to HRT.

However the chapter has also analysed this research process in the light of the other two research questions of the thesis.

The questionnaire was developed with attention to the detail of the method, as seemed appropriate at the time. The social context, including the background of the researcher influenced the research process. This can be identified in the way the research question was developed and the method chosen, but also in details of the research process such as the use of medical definitions in the questionnaire.

Although care was taken in preparing the questionnaire, it contains imprecision and uncertainty. For example, a wide range of experience on a number of issues was squeezed into a small number of categories. A qualitative approach would allow for the expression of the range of experience, however it would not enable the experiences to be counted so easily. The questionnaire survey provides numerical results that can give an indication of what is happening in the community, but needs to be interpreted in the context of the research method used, with its advantages and limitations. The use of scientific rhetoric and codified language can make this interpretation of the research more difficult.

The chapter provides an example of how theory from a different discipline can help illuminate the research process. A number of different aspects of women's perspectives on HRT were considered when planning the questionnaire survey, and at the time the choice of method for measuring women's attitudes was based mainly on practical considerations. The theory of planned behaviour, from the discipline of psychology, helps to clarify what aspects of women's perspectives were considered and measured. The question used in the survey, asking women how far each of a series of statements, about HRT and related issues, would persuade them to take HRT, seems to ask women their attitude to taking HRT, as defined by the theory.

The chapter also provides an example of the tension of working across disciplines. In the pre-pilot stage, the literature search

focused on biostatistical issues for the questionnaire survey. However, the pre-pilot interview study shows an awareness of the importance of checking how women themselves understand and view the issues, an approach familiar in the social sciences.

The initial research question about women and HRT aimed to find out about women's attitudes to HRT, as a social phenomenon, and the social system promoting HRT. However this was abandoned early in the research process. Throughout the remainder of the research process described in this chapter, the focus of the research has been the individual, although the survey aims to aggregate the data from individuals. The analysis of the research process itself sees the research and the researcher as part of a social system. Thus different aspects of the research process are using different levels of analysis.

This chapter has considered the research process of the questionnaire survey up to when the questionnaires were sent out to the women and reminders sent. The next chapter describes the results of the survey and explores their significance.

Chapter Four

Questionnaire survey results

4.1 Introduction

The questionnaire survey method has been described and discussed in chapter three, up to sending questionnaires to 1649 women aged 20-69 years in the town of Stockton-on-Tees. Presentation of the results begins with describing the response rate, followed by an assessment of response bias and a discussion of the generalisability of the data. The frequency of the variables measured by the questionnaire is then presented, with appropriate cross tabulations to refine the analysis, and with discussion of what the results appear to be demonstrating. Methodological problems illuminated by the analysis are discussed.

The aim of the questionnaire survey was to inform general practice of women's perspectives of HRT, so the implications for general practice of the survey results are considered, in section 4.3, in terms of the intellectual and practical challenges they raise. In the final section of this chapter, the researcher attempts to take a step back from the survey results and from general practice to consider the sociological perspective. Themes raised by the survey results and their implications for general practice are discussed from a sociological perspective informed by the sociological theory discussed in chapter two. In this way the women's perspectives on HRT, as measured by the questionnaire survey, and a general practice perspective on these results, are examined from the third perspective used in this thesis, that of sociology. The perspectives of the different disciplines contributes further to understanding the importance of considering the social context for research, and the different levels of analysis used by different disciplines in research.

Statistical notes

Where the survey data was explored using cross tabulations, Chi square was used to test for trends. Where statistically significant

trends were found ($p < 0.05$), Cramer's V was calculated to assess the power of the trend, or for 2 x 2 tables, the equivalent calculation phi. The value of Cramer's V and phi ranges between zero and one with a high value indicating a powerful trend. A trend with a Cramer's V or phi of >0.3 is moderately powerful (Erickson and Nosanchuk 1992:256) and of interest for the social trend it indicates.

As discussed in section 3.5.2, the women were divided into the following age groups: 20-25 years, young adult; 25-34 years, childbearing; 35-44 years, premenopausal/child rearing; 45-54 years, peri menopausal; 55-64 years, postmenopausal; 65-69 years, young elderly. As the sample of women sent questionnaires was selected evenly across five year age bands, the size of the youngest and oldest age groups used for analysis was smaller than the other groups.

4.2 Questionnaire survey results

4.2.1 Response rate and characteristics of respondents.

The number of usable questionnaires returned was 1225 (74.3%). The response rate by age group is presented in table 4.1. The trend of response by age group is fairly weak, as shown by the Cramer's V. The response rate for the practices varied between 66.8% and 82.9%. There was no relationship between response rate and the number of doctors in the practice or between the response rate and the doctor patient ratio in the practice.

The number of women in each educational attainment group was as follows: "I left school with no formal qualifications" 443 (36.2%); "I left school at 16 with qualifications" 249 (20.3%); "I left school after taking A-level or equivalent exams" or "I am doing or have done further training or education since leaving school" 517 (42.2%). Education was unknown for 16 women (1.3%). There

Age group	Number of women sent a questionnaire	Number (percentage) of women returning a questionnaire
20-25 years	178	101 (56.7)
25-34 years	416	291 (70.0)
35-44 years	374	278 (74.3)
45-54 years	315	257 (81.6)
55-64 years	249	208 (83.5)
65-69 years	117	90 (76.9)

Chi square = 53.1, 5 degrees of freedom, $P < 0.001$, Cramer's $V = 0.18$

Table 4.1 Response rate to questionnaire survey by age group

was a very strong relationship between age group and education group with older women tending to have lower educational attainment. (chi-square = 231.3, $p < 0.001$, Cramer's $V = 0.62$).

The menopausal status of respondents was as follows: premenopausal 730 (59.6%); postmenopausal 301 (24.6%); had a hysterectomy 191 (15.6%); unknown 3 (0.3%). When asked if they had experienced significant menopausal symptoms related to periods stopping or the change of life, of the postmenopausal women, 181 (60.1%) said "yes", of those who had a hysterectomy 112 (58.6%) said "yes" and for premenopausal women 119 (16.3%) said "yes". As discussed in chapter three, the women who were still having periods but said they had experienced menopausal symptoms were categorised as premenopausal, although the women may have felt they were going through the menopause.

The number of women who said they had experienced menopausal symptoms, but were still having periods, seemed relatively high considering the wide age range included. This, and the researcher's clinical experience of women attributing symptoms to the menopause, prompted analysis of these responses by education.

The question about experience of menopausal symptoms was marked "yes" among the premenopausal women, by 43 of the 147 women who had left school at 16 with no formal qualifications (29.3%), 29 of the 175 who had left school at 16 with qualifications (16.6%) and by 45 of the 322 who had taken A levels or further training (14.0%) (Chi square = 16.25, 2 degrees of freedom, $p < 0.001$, Cramer's $V = 0.16$), a weak relationship (education unknown for two women). There was no statistical relationship between level of education and response to this question for postmenopausal women and those who had had a hysterectomy.

The women who had experienced menopausal symptoms were asked to tick which, of a list of symptoms, they had experienced. Of the 465 women in the age groups 45-54 and 55-64 years combined, the age range most likely to have experience of menopausal symptoms, 338 women had not had a hysterectomy, and for these women, the number (percentage) of women who had experienced symptoms was as follows: hot flushes 210 (62.1%); depression 131 (38.8%); dry vagina 117 (34.6%); difficulty sleeping 153 (45.3%); just didn't feel well 140 (41.4%). For the 191 women of any age who had had a hysterectomy the results were: hot flushes 111 (58.1%); depression 84 (44.0%); dry vagina 78 (40.8%); difficulty sleeping 100 (52.4%); just didn't feel well 76 (39.8%).

A question asked women if they had suffered from any of the following: osteoporosis, stroke, angina, heart attack. Of the questionnaire respondents 23 had themselves suffered osteoporosis (1.9%), and 42 had suffered CVD (stroke, angina or heart attack) (3.4%). The following questions about family medical history gave a choice of answering "yes", "no" or "don't know". When asked if they had a first degree relative with osteoporosis, 78 women said "yes" (6.4%), 166 women responded "don't know" (13.6%), 931 said "no" (76.0%), and 50 women gave no response (4.1%). When asked if a first degree relative aged less than 60 years had suffered a heart attack, angina or stroke, 400 said "yes" (32.7%), 25 responded

"don't know" (2.0%), 778 women said "no" (63.5%), and 22 women gave no response (1.8%).

Of questionnaire respondents 801 women said they were taking or had taken the birth control pill at some time (65.4%), 393 said they had never taken it (32.1%), and 31 women did not respond to this question (2.5%).

Response bias

The response rate was sufficient to reduce worry about responder bias according to Lydeard's criterion of needing a response rate of over 70% (Lydeard 1991). However, not all women responded to each question, so within the overall response rate there are some lower response rates where responder bias may be having an effect. The variation in response rate from practices cannot be accounted for by the limited data available about the practices. The variation in response rate by age may have been because the questionnaire focused on HRT, which would hold more interest for the peri- and postmenopausal age groups. Although the overall response rate appears satisfactory the respondents may not be representative of women in the youngest age group, and some practices were under represented.

The sample was drawn from women on the lists of eight general practices, assuming that the practice populations were likely to be representative of the town, as the eight practices had a combined list size of 86,944 patients, just over half the total population of the Borough of Stockton-on-Tees (total population 173,400, based on Cleveland Research and Intelligence Projections 1992), and the practices were spread through the whole of the Borough.

To assess whether the respondents were representative of the town their educational attainment was compared with the social class structure of the town, based on occupation of the head of household. The socio-economic group (social class) of head of household based on the 1981 census was:

Managers and Professionals	18.5%
Other non-manual	18.6%
Skilled	37.1%
Semi-skilled	18.4%
Unskilled	7.5%

If "managers and professionals" plus "other non-manual" groups are equivalent to the group in the survey with the higher educational attainment, and the three manual categories are equivalent to the two groups with lower educational attainment, then the survey respondents could be said to be representative of the population of the town as far as educational attainment can be used as a proxy for social class. Two major problems with this comparison are that the social class data is very old and the data is based on head of household so probably rarely based on the occupation of a woman in the household.

Generalisability

The age range in the study sample was chosen to allow comparison with previous studies (Sinclair, Bond and Taylor 1993; Ferguson, Hoegh and Johnson 1989). In the UK study, Sinclair et al. (1993) divided their women by ten year age bands but their response rate by age followed a similar pattern to that obtained in this study, lowest for the youngest age group (20-29 years), peaking in the age group 50-59 years and dropping slightly for the oldest age group (60-69 years).

In reporting their study Sinclair et al. (1993) divided their respondents by educational attainment into two groups, those educated beyond secondary school level (30.2%) and those not educated beyond secondary school (69.5%). If their category of "educated beyond secondary school" is equivalent to having taken A levels or further training, and their category "not educated beyond secondary school" is equivalent to the two lower groupings by educational attainment, then Sinclair et al. (1993) appear to have fewer women with higher educational attainment. However this comparison may be misleading

due to differences in the wording of the question, as discussed in section 3.5.2.

The study from the USA by Ferguson et al. included "Seventy three percent of women (who) had an educational background beyond high school" (1989:134) so they surveyed women of higher educational attainment than in this study, but in a society where a higher proportion of young people go on to education beyond school.

The responders to the survey by Sinclair et al. (1993) included 56.1% of women who were premenopausal, a similar proportion to that found in this survey. Their grouping "postmenopausal" included 43.9% of women, but the authors add a note that this category included those who were "menopausal" but do not define this and they do not report a separate figure for women with hysterectomy. The categories premenopausal and postmenopausal covered all their respondents because there was an error in their questionnaire, as discussed in chapter three. Direct comparison with the proportion of postmenopausal women and those who have had a hysterectomy is therefore not possible. The wording of the question about experience of menopausal symptoms was similar to that used by Sinclair et al. (1993), although their question had only invited women who were no longer having periods to answer it, and asked about symptoms experienced for more than six months after the last menstrual period. The question used in the current study invited women to answer who considered they had experienced menopausal symptoms, and gave no time span. However the results for the two studies were very similar. The proportion of women reporting hot flushes was lower than the 85% reported by Oldenhave et al. (1993). This difference may be accounted for by the wording of the question which, in the current study, asked about significant symptoms, not any symptoms.

The comparisons made in this section are reassuring, in that the women surveyed in Stockton-on-Tees do not appear to be a particularly unusual group, based on these characteristics, compared with other studies and so the survey results are probably generalisable

to Britain. However the comparisons are not straightforward due to differences in the questions asked and the form of analysis.

4.2.2 Health or welfare priorities

Over 40% of women named cancer as the health problem deserving highest priority in Britain today, both AIDS and "maintaining the national health service" were named by 7% of women and heart disease was named by 5.6 % (see table 4.2). Osteoporosis was only named by four women and stroke by two women and are included in the category "individual named medical problems" in table 4.2. The number of respondents naming each of the top five priorities, or not, was cross tabulated with age. There was no statistically significant trend by age for naming cancer, maintaining the NHS or heart disease as priority. AIDS tended to be named as priority more by the youngest age group with 20 of the 101 women in the <25 years age group naming it (19.8%) (Chi square 36.41, 5 degrees of freedom, $p < 0.001$, Cramer's $V = 0.17$). "Care of the elderly" was named as priority more by older women with 43 of the 512 women aged over 45 years naming it (8.4%) compared to 16 of the 654 women aged 20-44 years (2.4%) (Chi square = 21.18, $p < 0.0001$, $\phi = 0.14$). These are both weak trends that are not surprising for these issues as they are fairly age specific. There was no significant trend between reporting a family or personal history of CVD and giving priority to heart disease, which seems a more surprising finding, however the question about family history of CVD used a limited medical definition so many women with experience of CVD in their family would have answered "no" to the question.

When the women were given a list of health related issues to score for priority, three of the four given highest priority involved children, "health checks to prevent heart disease" came second, "screening for osteoporosis" came fifth, and facilities to enable people to take exercise came bottom (see table 4.3). The priority given to medical interventions may have been high partly because the questionnaire

Health or welfare problem	Number of women (percentage)	
Cancer	498	(40.7)
AIDS	87	(7.1)
Maintaining the NHS	86	(7.0)
Heart disease	68	(5.6)
Care of the elderly	59	(4.8)
Children's health and welfare	45	(3.6)
Health screening tests	36	(2.9)
Poverty	26	(2.1)
Health Education	24	(2.0)
Mental health	21	(1.7)
Housing/homelessness	18	(1.5)
Unemployment	13	(1.1)
Dementia	12	(1.0)
Drug problems	11	(0.9)
Arthritis	10	(0.8)
Other socio/medical problems	47	(3.8)
Individual named medical problems	29	(2.4)
Other social/environmental problems	12	(1.0)
Other	22	(1.8)
Don't know/too many to choose/ unfair to prioritise	31	(2.5)
No answer given	70	(5.7)
Total	1225	(100)

**Table 4.2 What single health or welfare problem do you feel
deserves highest priority in Britain today?**

	Sum of scores	Standard deviation
Research into the cause of children's leukaemia	1446	0.53
Health checks to prevent heart disease	1518	0.56
Safe play areas for children	1704	0.77
Provision of premature baby units	1752	0.76
Screening for osteoporosis	1805	0.73
Research into cure for dementia	1835	0.79
Advice and advertising about safe sex	2011	0.97
Transport for elderly and disabled	2164	0.86
Making healthy foods cheap to buy	2220	1.60
Higher taxes on cigarettes	2702	1.45
Promotion of long term HRT	2784	1.00
Cycle lanes	3068	1.31
Sports centres on all housing estates	3681	1.29

Statements are presented with the 'most important' at the top.
 Score 1 = very important; Score 3 = undecided; Score 5 = not at all important

Table 4.3 The importance given to things that could improve the health of people in Britain

was accompanied by a letter from their GP, so the women may have marked medical interventions as priority if they felt their GP would support these ideas.

The priority given to services for children is in keeping with the findings from an interview study of 2,005 people by Bowling (1996) where "treatments for children with life threatening illness" was given highest priority. Bowling found preventative screening services and immunisations given rank 3 in the ordering of priorities in keeping with the priority given to "health checks to prevent heart disease" in this study. This comparison supports the suggestion that the survey respondents were not an unusual group compared to other women in Britain.

4.2.3 Women's fears for their future health

The major issues which the women worried would affect them personally as they aged were cancer, dementia, arthritis and heart disease (see table 4.4). The position of cancer in first position and heart disease in fourth position in the rank order is similar to the rank order for the priority for health problems (table 4.2). This finding is not surprising as a woman's fears are likely to influence where she feels priority should be given for health services. The distribution of causes of death for North Tees Health Authority, which is the Borough of Stockton-on-Tees plus a few outlying rural areas, in 1992, was cancer 28.59%, coronary heart disease 27.65%, cerebrovascular disease (stroke) 10.48%, with other causes making up the remainder (Guy 1993:23), however nearly four times as many women named cancer as their main fear in the survey compared to heart disease. The median age of death from cancer, particularly breast cancer, is lower than for heart disease (see table 2.3) and the mode of death may be different with cancer being associated with pain and emaciation and heart disease with sudden death. The age and mode of death may be influencing women's fears more than the risk of dying from the disease. Pain and disability prior to death and mode of death may also be the reasons

Health problem	Number of women (percentage)
Cancer	377 (30.8)
Dementia	230 (18.8)
Arthritis	142 (11.6)
Heart disease	108 (8.8)
Immobility/disability/loss of independence	55 (4.5)
Stroke	51 (4.2)
Osteoporosis	49 (4.0)
No worries	33 (2.7)
Menopausal problems	17 (1.4)
Worsening current medical problem	16 (1.3)
Loss of vision	15 (1.2)
Not sure	13 (1.1)
Other individual named medical problem	43 (3.5)
Other socio/medical problem	13 (1.1)
Ageing in general	5 (0.4)
No answer given	58 (4.7)
Total	1225 (100)

Table 4.4 What health problem are you most worried will affect you as you get older?

women fear arthritis and dementia. Both these were named by relatively few women as a priority health problem for the community.

Women's fears for their future health were cross tabulated with age. Naming cancer decreased with increasing age (chi-square = 120.36, $p < 0.001$, Cramer's $V = 0.31$). When stratified for age, there was no trend between naming cancer, or not, and education. This trend with age may be because women are aware that cancer can affect younger age groups, but with increasing age other medical problems are as likely to occur such as dementia and arthritis. These fears increased with age (for dementia Chi square = 47.57, $p < 0.001$, 5 degrees of freedom, Cramer's $V = 0.20$ and for arthritis Chi square = 18.48, $p < 0.01$, 5 degrees of freedom, Cramer's $V = 0.12$). There was no trend with age or education for naming heart disease and there was no trend between menopausal status and naming osteoporosis. Unlike the question about priorities for health services (section 4.2.2), in this question women who said they had a family history of CVD were more likely to name heart disease but the relationship was weak (Chi square = 40.16, 2 degrees of freedom, $p < 0.001$, Cramer's $V = 0.18$). There was no relationship between naming stroke and having a family history of CVD.

4.2.4 Knowledge about CVD, osteoporosis and HRT

The level of knowledge about "smoking", "high blood pressure" and "being overweight" as risk factors for CVD was very high, a large majority also knew that "lack of exercise" and a family history of CVD increase the risk of CVD, but few women knew about the role of oestrogen in CVD. If the role of oestrogen had been expressed as taking HRT to prevent CVD, the responses may have been different. Knowledge about low calcium in the diet being a risk factor for osteoporosis was high and a large majority knew about the role of oestrogen, but far fewer knew of the link between "lack of exercise" and osteoporosis and "smoking" and osteoporosis (see table 4.5).

Risk factor	Osteoporosis	CVD
Smoking	128 (10.5)	1133 (92.5)
Low levels of calcium in what you eat	1078 (88.0)	49 (4.0)
Lack of exercise	355 (29.0)	1036 (84.6)
Having a parent who has (or had) osteoporosis	839 (68.5)	53 (4.3)
Being overweight	146 (11.9)	1132 (92.4)
Lack of female hormones (oestrogen)	918 (74.9)	81 (6.6)
Having a parent who has had a stroke, angina or heart attack	22 (1.8)	1042 (85.1)
Having high blood pressure	28 (2.3)	1140 (93.1)

Table 4.5 Number of women (percentage) marking each risk factor as likely to increase the risk of osteoporosis / CVD (n=1225)

When given a list of potential warning signs of osteoporosis, 683 marked "arthritis-like pain" (55.8%) and 505 marked "there are no warning signs" (41.2%). The other symptoms listed in the question ("depression/irritability", "hot flushes" and "dry vagina (front passage)") were marked by less than 9% of women. Women may be confusing osteoporosis with arthritis, the commonest form of which is osteoarthritis. Osteoarthritis can cause pain and swelling of joints, particularly of the hips, knees and spine. It occurs more commonly as people get older and joints become worn, and is a major cause of disability and distress in older people. Osteoporosis is a thinning of the bones that causes no symptoms until a bone fractures, which can happen with minimal trauma or none.

4.2.5 Women's sources of information about HRT and their perception of the media coverage of HRT

When asked about sources of information about HRT, 111 women (9.1%) indicated that they had never heard of it and 44 women (3.6%) did not respond to the question. For women who had heard of HRT, magazines and newspapers and friends and relatives were the most commonly reported sources of information, both for those who had never thought about taking it and for those who had thought about taking it but had not taken it. For those women who had taken HRT, a doctor was the most commonly reported source of information, however even for these women, magazines and newspapers and friends and relatives remained important sources of information. For women who had not taken therapy, the doctor was reported relatively rarely as a source of information (see table 4.6).

An open question asked women to describe the most striking things that they had heard or read about in the media concerning HRT (table 4.7). A total of 858 women (70.0% of all questionnaire respondents) answered this question of whom 128 indicated they

Information source**	<u>Number (percentage) of women who had</u>		
	<u>never thought of taking HRT</u> (n = 806)	<u>thought of taking HRT but had not</u> (n = 168)***	<u>taken HRT</u> (n=173)***
Magazines/ newspapers	410 (50.9)	117 (69.6)	109 (63.0)
Friends/relations	410 (50.9)	111 (66.1)	70 (40.5)
TV/radio	234 (29.0)	75 (44.6)	55 (31.8)
Doctor	41 (5.1)	33 (19.6)	128 (74.0)
Nurse	20 (2.5)	17 (10.1)	21 (12.1)

n = number of women in group.

*71 women did not respond to the question asking whether they had thought of taking HRT

** Women could choose more than one item.

***No data on usage for seven women who had thought about HRT

Table 4.6 Main sources of information about HRT among women who had and who had not considered using it and among those who had taken it

number of women naming each item

Helps menopausal symptoms/hot flushes	171
Prevents osteoporosis	129
Keep young/prevent ageing	108
Feel well/health/active/good	93
May have long term side effects such as cancer	83
Magic/wonderful/miracle cure/new woman	80
Makes life easier/improves well being	74
Side effects-immediate e.g. breast tenderness, weight gain	49
Works for some women and not for others	44
Relieves tiredness/depression/mood swings	44
Prevents heart attacks/strokes	31
Continued bleeding after menopause	22
Good and bad reports	16
Not enough advice for women at menopause/ not taken seriously	14
Famous people e.g. Joan Collins take HRT	13
Improves sex life/dry vagina	13
Other positive views	38
Other negative views	22
Other information	37
Other misinformation	13
Not heard anything	128

Number of women giving an answer to this question = 858

Women were able to name as many items as they chose

Table 4.7 What are the most striking things you have heard or read about hormone replacement therapy in the media, (TV, radio, magazines, newspapers)?

had not heard anything about HRT. The response rate increased with education in all age groups except those under 25 years where no trend was found. The relationship between education and response rate increased in strength from the 25-34 year age group (chi square = 10.1, $p < 0.01$, Cramer's V = 0.19) to the 65-69 year age group (chi square = 10.3, $p < 0.01$, Cramer's V = 0.35). The responses to the question cannot be seen as generalisable to the population sampled for the survey as the response rate is relatively low and the respondents tend to be of higher education, especially in the older age groups, than those not responding. Women of lower educational attainment may be less confident about what they have heard or read in the media and about expressing this in writing. However the responses are still of interest for what strikes the respondents about the media coverage of HRT.

The use of HRT to help menopausal symptoms or hot flushes was the most common response, followed by its role in preventing osteoporosis. Positive images of the effect of HRT on health, well being and youthfulness were divided according to slightly different strengths and aspects when coded for analysis. The mildest positive statements indicated an improvement in well being; more forceful statements were those about becoming more active or more healthy; the strongest statements were those which included words such as "magic" or "wonderful". Statements about youthfulness were coded as a separate aspect. When combined, these positive images were mentioned more than any other topic. Negative reports about HRT were coded as long term side effects, immediate side effects and other negative views. Continued bleeding after the menopause was coded separately and may be seen as a negative effect. When taken together these negative reports were mentioned less than the positive reports.

In answer to the question "Have you found the information from the media helpful?" 582 women indicated "yes" (47.5%) and 367 indicated "no" (30.0%); 276 did not respond (22.5%). There was no significant trend with age or education. In answer to the question "Do you feel the information about HRT in the media is correct?"

574 women indicated "yes" (46.9%) and 213 indicated "no" (17.4%); 438 did not respond (35.8%). There was no significant trend with age or education. Although women's images of HRT from the media seem mostly positive there are indications that women may have some resistance to the messages from the media. Women who did not find the media information helpful may not yet have needed that information, but the lack of trend by age indicates that peri and postmenopausal women were included in this response group. The relatively large number of women not responding to the questions may include some who were uncertain about the helpfulness and usefulness of the media.

4.2.6 People influencing women's decisions about HRT

The questionnaire asked women if they had ever thought about taking HRT before now, and 348 women said they had. The proportion of these women in each age group is presented in table 4.8. The next question asked the women to indicate, with whom they had discussed HRT, and gave the following list to choose from: your family doctor (GP), hospital doctor, nurse at doctor's (GP) surgery, husband/partner, relative/friend, no one. Women could mark more than one of the list. Forty four of the women had who had previously thought about taking HRT indicated they had discussed HRT with no one and 304 women indicated they had discussed it with someone. The combined category of husband/partner/relative/friend had been consulted by 150 of the 304 women (49.3%). Of these 150 women, 59 women reported having discussed it with this group only. Their GP or practice nurse had been consulted by 206 of the 304 women (67.8%).

Age group	Number of questionnaire respondents	Number (percentage) of women reporting they had previously thought of taking HRT
20-25 years	101	15 (14.9)
25-34 years	291	34 (11.7)
35-44 years	278	97 (34.9)
45-54 years	257	129 (50.2)
55-64 years	208	62 (29.8)
65-69 years	90	11 (12.2)

Table 4.8 Number of women (percentage) who had previously thought about taking HRT

The next question was linked and asked who was most important in helping them decide whether or not to use HRT. Table 4.9 summarises some of the results for the 304 women who had thought about taking HRT and discussed HRT with someone. The left hand column lists the main categories of people with whom women had discussed HRT, as used for analysis (all possible combinations were not used) Of the 150 women who discussed HRT with husband/partner/relative/friend, 91 women indicated they had also discussed HRT with a health professional and are included in these groups in table 4.9. Of the 304 women who had discussed HRT with someone, 20 women named themselves as most important in deciding about HRT, and 125 women left the question blank or wrote "no one". The GP or practice nurse were named most commonly as being the person who was most important in helping women to make a decision about HRT, however, non-health professionals were named by a substantial minority of women.

Although GPs and practice nurses were named most commonly as being the most important person in helping women to make a decision about HRT, hospital doctors were important for the relatively small number of women who saw them. However a

Number of women reporting

Person most important in HRT decision

Discussion with	GP/ practice nurse	Hospital doctor	Relative *	Self	Other **	No response ***	Total
GP or practice nurse (not hospital doctor)	82	0	18	16	2	50	168
Hospital doctor (not with GP or practice nurse)	0	8	1	0	0	8	17
Hospital doctor and GP/practice nurse	11	14	2	0	1	10	38
Relative* (no medical person)	0	0	14	3	0	42	59
No-response	5	1	0	1	0	15	22
Total	98	23	35	20	3	125	304

* Husband/partner/relative/friend

**For example, well woman clinic or family planning clinic

***Respondents left question blank or wrote "no one"

Table 4.9 Discussion of HRT and most important source of help in deciding about HRT among 304 women who had thought about taking HRT and discussed it with someone

substantial number of women were not able to say who was most helpful in their decision about whether or not to take therapy. This may be because several people were equally helpful, because no one was particularly helpful, because the woman relied on her own judgement and did not feeling influenced by anyone, or because the woman had not yet reached a decision. The phrasing of the question may have guided women to name someone other than themselves, or no one, as most helpful in making their decision. Phrased differently, the number of women naming themselves as most important may have been higher.

4.2.7 GP attitudes

In the questionnaire women were asked about their perceptions of their GP's attitudes to taking HRT for menopausal symptoms, osteoporosis and CVD. In an earlier question women were asked if they had discussed HRT with their GP (see section 4.2.6). The question invited those who had thought about taking HRT to indicate who they had discussed this with, but some who did not indicate they had thought about taking it also answered. There were 226 women who indicated they had discussed HRT with their GP, of whom 146 (64.6%) felt that their practitioner was in favour of prescribing therapy to relieve menopausal symptoms, nine felt that their practitioner was not in favour (4.0%), and 68 were unsure of their GP's attitude (30.1%); three women did not respond. Of the 226 women, 133 women felt that their practitioner was in favour of its use to prevent osteoporosis (58.8%), one felt that her practitioner was not in favour (0.4%) and 87 were unsure (38.5%); five did not respond. There were 77 women who felt that their practitioner was in favour of its use for the prevention CVD (34.1%), three felt that their practitioner was not in favour, (1.3%) and 140 were unsure (61.9%); six did not respond.

There were 999 women not included in the group who had thought about taking HRT and had discussed it with their GP or nurse at their GP surgery. Of these 84 felt that their practitioner was in favour of its use for relieving menopausal symptoms (8.4%), 11 did not (1.1%) and 863 indicated that they did not know (86.4%); 41 did not respond. A

total of 117 women felt that their practitioner was in favour of its use for the prevention of osteoporosis (11.7%), four did not (0.4%) and 814 did not know (81.5%); 64 did not respond. Ninety six women felt their practitioner was in favour of its use for preventing CVD (9.6%), eight did not (0.8%) and 831 did not know (83.2%); 64 women did not respond.

These results suggest some methodological problems about the questions. Although the response rate to the questions was high, many women chose to mark the "do not know" option. This option was included as women may have no idea about their GP's attitude. This was probably the case among women who had not discussed HRT with their GP. The relatively high use of this option among women who had discussed HRT with their GP may indicate that some women avoided expressing their true opinion about their GP's attitude, despite having been reassured about the confidentiality of their responses. All but one of the practices involved in the survey included more than one doctor, so another problem may have been confusion about who the question was asking about, the doctor the women were registered with or another doctor whom they saw at the surgery. Other possibilities are that the GP's tried not to convey their own opinion, that they did not communicate well with their patients, or that women did not think about what the GP said as their opinion.

4.2.8 Women's experience of the primary health care team

Women were asked again, this time at the start of a question about their experiences of the primary health care team with regard to HRT, whether they had discussed HRT with their GP or nurse at the GP surgery, to which 233 responded positively. This is a slightly higher than the 206 women who indicated they had thought about HRT and discussed it with a GP or nurse at their GP surgery in an earlier question. As discussed in section 4.2.6 this earlier question asked if women had previously thought about taking HRT then said "if yes who did you discuss it with?" The analysis in 4.2.6 reflects the structure of the question. In section 4.2.7, 20 women were included in the analysis who had discussed HRT with their GP but did not indicate having

thought about HRT. Here there were 27 women who did not indicate they had thought about taking HRT, but who indicated that they had discussed HRT with their doctor or nurse at their GP surgery. These women may not have judged themselves as having thought about taking HRT, may have been discussing HRT for another person or may have been discussing the subject in general terms.

Reported experience of the primary health care team with regard to HRT, among the 233 women who reported having discussed therapy with their GP or nurse at their GP surgery, is shown in table 4.10. Over 70% of women did not feel they would have had to persuade the team to initiate therapy. Approximately two thirds felt they were given enough time and information. There was some variation in these results between practices. The proportion of women who felt they had received sufficient information varied between 43% and 74%, the proportion reporting having been given enough time varied between 46 % and 71%, the proportion reporting feeling muddled varied between 3% and 27%, and the proportion who felt the need to use persuasion varied between 5% and 25%. However, the different negative views came from patients of different practices.

Women's responses about their experience of the primary health care team in relation to HRT may have been more positive than the reality as the questionnaire was sent with a covering letter from their GP. The proportion of women expressing satisfaction with the amount of time and information received was almost identical to that in a previous study using the same questions (Kadri 1991) however, this study had also used a questionnaire sent out by the GPs.

4.2.9 Use of HRT

Of the 348 women who were identified as having previously thought about taking HRT, 164 (47.1%) were premenopausal, 84 (24.1%) postmenopausal and 98 (28.2%) had had a hysterectomy

	<u>Yes</u>	<u>No</u>	<u>Don't know</u>
Was given enough information n=214	138 (64.5)	62 (29.0)	14 (6.5)
The doctor or nurse seemed unsure if it would work for me n=199	45 (22.6)	107 (53.8)	47 (23.6)
There was enough time to discuss HRT n=210	141 (67.1)	52 (24.8)	17 (8.1)
Felt muddled as different nurses and doctors said different things n=193	27 (14.0)	152 (78.8)	14 (7.3)
Doctor or nurse uncertain about HRT use for more than a few years n=197	24 (12.2)	86 (43.7)	87 (44.2)
Would have had to persuade doctors/nurses to initiate HRT n=200	29 (14.5)	144 (72.0)	27 (13.5)

(n = number of respondents; percentages given in brackets)

Table 4.10 Reported experience of the primary health care team with regard to HRT among 233 women who had discussed HRT with their general practitioner or practice nurse

(for two women menopausal status was not known). The age groups were presented in table 4.8. There was no association between having thought of taking HRT and education except for those aged 65-69 years where the more educated were more likely to have thought of taking it (chi square = 7.68, $p < 0.05$, Cramer's $V = 0.33$). A substantial minority of women appear to be thinking about taking HRT well before it is relevant for them and as these women reach menopausal age they may be accustomed to the idea of taking HRT.

Of the women aged 45-64 years, 90 (20.0%) were currently using HRT. Use by menopausal status is presented in table 4.11. There was no association between use and education for women of all ages except those aged 35-44, where lower education was associated with more use (chi square = 22.68, $p < 0.0005$, Cramer's $V = 0.41$). As discussed in section 4.2.1, there was a weak association between lower education and more reporting of significant menopausal symptoms in premenopausal women. These associations contrast with the lack of association between having thought about taking HRT and education.

The rate of use of HRT reported in published studies varies, with a survey in 1989 from Hampshire reporting a current rate of use among women aged 44-64 years of 11.9% (Kadri 1991), a survey in 1991 of women in Grampian reporting 9.3% of postmenopausal women currently using HRT (Sinclair, Bond and Taylor 1993) and Coope's osteoporosis prevention clinic achieving an uptake of 20% among women aged 40-60 years in 1991 (Coope and Marsh 1992). A higher rate of use was found among women doctors in 1993, with 28.4% of women doctors aged 40-65 years currently taking HRT (Isaacs, Britton and McPherson 1995). As reported in appendix 2, 19.9% of women aged 40-59 years were taking HRT in the researcher's practice in the same town and around the same time as the questionnaire survey. The variation in rates may be due to differences in the populations studied, but with the use and promotion of HRT evolving, the differences in when the surveys were carried out may be a major

	<u>Never taken</u>	<u>Currently taking</u>	<u>Taken in past but now stopped</u>	<u>Total</u>
<i>Menopausal status</i>				
Premenopausal	651 (92.0)	44 (6.2)	13 (1.8)	708
Postmenopausal	221 (78.4)	20 (7.1)	41 (14.5)	282
Had a hysterectomy	96 (52.2)	66 (35.9)	22 (12.0)	184
<i>Personal medical history</i>				
Had osteoporosis	14	5	3	22
Had cardiovascular disease	28	8	4	40
<i>Family medical history</i>				
Postmenopausal or had a hysterectomy and family history	13	14	9	36
Postmenopausal or had a hysterectomy and family history	105 (66.9)	30 (19.1)	22 (14.0)	157
cardiovascular disease				

(Percentages in brackets; omitted where total < 100)

Table 4.11 The use of HRT by women, grouped by menopausal status, personal medical history and family medical history

cause of variation, apart from the study by Coope and Marsh (1992) where use of HRT was actively promoted.

For postmenopausal women there was an association between the use of HRT (currently taking or taken in past but now stopped) and past use of the contraceptive pill (chi square = 21.16, $p < 0.00005$, Cramer's $V = 0.28$). A similar association was found by Sinclair et al. (1993).

The reported use of HRT was, not surprisingly, associated with experience of menopausal symptoms (chi square = 227.12, $p < 0.0001$, Cramer's $V = 0.47$). The association was strongest for women of highest educational attainment (chi square = 128.12, $p < 0.00001$, Cramer's $V = 0.53$).

The use of HRT by all women with a personal medical history of osteoporosis or CVD is presented in table 4.11. The numbers of women with these health problems is small. HRT is advocated as a medical intervention for treating osteoporosis yet less than half of the women reporting osteoporosis have taken HRT at some time. HRT is being advocated for secondary prevention of CVD, but the numbers using it are small. A family history of osteoporosis is a medical indication for women to consider taking HRT from the time of the menopause (natural or surgical) to prevent osteoporosis. There were 36 women who fit this category and more than half had taken HRT at some time (see table 4.11). In the UK, HRT is not advocated for the primary prevention of CVD. The rate of use of HRT by women who are postmenopausal or who have had a hysterectomy is similar whether or not they have a family history of CVD (see table 4.11).

4.2.10 Attitude to the menopause

The mean score and standard deviation of the scores given to the four statements about the menopause are presented in table 4.12. For the statement "Natural things such as eating healthy food and taking exercise are better for problems of

	Mean score	Standard deviation
Natural things such as eating healthy food and taking exercise are better for problems of the menopause than HRT	3.19	1.64
A woman feels like less of a woman following the menopause	4.81	1.89
A woman who experiences distressing menopausal symptoms such as severe hot flushes should be on HRT	2.83	1.60
Psychological problems that women have around the menopause are more because of life changes at that time (i.e. children leaving home, death of parents) than changes in their hormones	4.07	1.93

Score 1 = Strongly agree

Score 4 = Neither agree or disagree

Score 7 = Strongly disagree

Table 4.12 Score given by women to statements about the menopause

the menopause than HRT" 434 of the 1198 women giving a response marked score 4, neither agree or disagree (36.2%) the largest group of responders, 264 of the women responding marked score 1 (strongly agree) (22.0%), 340 women marked score 2 or 3 (28.4%) and 160 marked score 5,6 or 7 (disagree) (13.4%). This pattern was very similar to that found by Sinclair et al. (1993) for this statement. When the women were divided by menopausal status, postmenopausal women were found to be most likely to agree with this statement and premenopausal women most likely to disagree (Chi square 78.51, 12 degrees of freedom, $p < 0.001$, Cramer's $V = 0.36$), a moderately strong trend.

For the statement "A woman feels like less of a woman following the menopause" 573 of the 1204 women responding disagreed with the statement (score 5,6 or 7) (47.6%), 372 women marked the neutral score 4 (30.9%) and 259 agreed with the statement (score 1,2 or 3) (21.5%). The mean score for this statement was similar to that found by Sinclair et al. (1993) but in their survey over 70% disagreed with the statement and they do not report the number of women using the other scores. When the women were divided by menopausal status, postmenopausal women were found to be most likely to disagree with this statement and premenopausal women least likely to disagree (Chi square 83.38, 12 degrees of freedom, $p < 0.001$, Cramer's $V = 0.37$). Postmenopausal women responding to this question do so with experience of life after the menopause and so this trend is not unexpected.

For the statement "A woman who experiences distressing menopausal symptoms such as severe hot flushes should be on HRT" 351 of the 1205 women responding marked score 1 (strongly agree) (29.1%), 361 marked score 2 or 3 (30.0%), 379 marked score 4, neither agree or disagree (31.5%) and 114 marked scores 5,6 and 7 (9.5%). This was a similar trend to that found by Sinclair et al. (1993). When the women were divided by menopausal status, women who had had a hysterectomy were found to be most likely to agree with this statement and postmenopausal women least likely to agree (Chi square 57.49, 12 degrees of freedom, $p < 0.001$, Cramer's $V = 0.31$),

but almost half of the postmenopausal women agreed with the statement. Women who have had a hysterectomy may experience severe symptoms of the menopause if it is surgically induced and have already accepted medical intervention in having a hysterectomy. The finding that postmenopausal women were least likely to agree with this statement may reflect a difference in attitudes by generation.

For the statement "Psychological problems that women have around the menopause are more because of life changes at that time (i.e. children leaving home, death of parents) than changes in their hormones" 445 of the 1196 women responding agreed by marking score 1,2 or 3 (37.2%) and were spread fairly evenly between these three scores, 337 women marked score 4, neither agree or disagree (28.2%), 84 women marked score 5 (7.0%), 120 women marked score 6 (10.0%) and 210 women marked score 7, strongly disagree (17.6%). Sinclair et al. (1993) found similar proportions of women agreeing and disagreeing. When the women were divided by menopausal status, postmenopausal women were found to be most likely to agree with this statement and premenopausal women most likely to disagree with the statement (Chi square 46.89, 12 degrees of freedom, $p < 0.001$, Cramer's $V = 0.28$). Postmenopausal women are answering this question in the light of their experience whereas premenopausal women can only judge by the experience of others and images and information they glean. It would be interesting to know if their attitudes are changed by experience or whether this is a generation effect which persists.

4.2.11 What would persuade women to take HRT

The question which aimed to measure women's attitudes to HRT gave a series of statements about HRT, and asked the women to mark on a scale 1-5, how much each statement would affect their decision to take HRT. The scale was labelled "would persuade me to take HRT" for score one, "would make no difference to my decision" for score three, and "would persuade me not to take HRT" for score five.

As discussed in section 3.3, when designing the questionnaire the researcher hoped this question would provide an overall attitude score, with each part of the question contributing to the score. The researcher therefore undertook to check how far the statements were tending to measure the same thing, known as the internal consistency of the question. This was assessed using the item-total correlation. Lydeard suggests that if item-total correlation is above 0.2 the item can be kept in the question (1991). The item-total correlations were all above the suggested cut off point (see table 4.13).

The mean scores and their standard deviation for how far each statement would persuade women to take or not to take, HRT are presented in table 4.14. The lowest response rate to any of these statements was 1093 (89%) of the total number of questionnaires returned. The results are presented in rank order of mean score with the statement that would most persuade women to take HRT at the top.

The responses to the first three statements in the ranked list (table 4.14) were mostly score 1 (would persuade me to take HRT), with over 60% of women marking this score for the three statements and less than 7% using score 4 or 5 (would persuade me not to take HRT). Women appear to be persuaded by the possibility of preventing future illness, especially where a medical test or medical evidence can give some measurement of risk or reassure about lack of risk. The responses may be biased by the questionnaire being sent with a supporting letter from their GP. As far as women see their GP as advocating prevention and tests, women may have felt it more acceptable to be more persuaded by these statements, however this is unlikely to account for the whole of this trend. Understanding the weight given by women to the results of a test and to medical evidence, in their decisions about HRT, is important in clinical care and health policy, particularly with the increasing emphasis on patient participation. Women may be giving a test result more weight than the test's ability to predict future illness really merits as all medical

Statement	correlation coefficient
Taking HRT for five to ten years may stop me having a fracture of the hip when I am in my seventies	0.62
I would be less likely to have a heart attack or stroke if I took HRT for five to ten years	0.58
HRT would not cause cancer if taken properly	0.54
If I take HRT I might live longer	0.53
Taking HRT would make dying suddenly in old age less likely	0.53
I would feel younger on HRT	0.50
For it to work properly I would have to take HRT for the rest of my life	0.47
A test showed I was prone to thinning of the bones or brittle bones (osteoporosis)	0.42
HRT might cause monthly bleeds like menstrual periods	0.33
Exercise and a good diet could stop me getting thin or brittle bones (osteoporosis) as much as taking HRT	0.26
$p = <0.0001$ for all values	

Table 4.13 Item - total correlations for question that asked women how far the statements would persuade them to take HRT or not to take HRT

Statement	Mean	Standard deviation
A test showed I was prone to thinning of the bones or brittle bones (osteoporosis)	1.61	1.03
I would be less likely to have a heart attack or stroke if I took HRT for five to ten years	1.68	1.00
Taking HRT for five to ten years may stop me having a fracture of the hip when I am in my 70's	1.68	1.00
HRT would not cause cancer if taken properly	1.91	1.13
I would feel younger on HRT	2.16	1.10
If I take HRT I might live longer	2.21	1.05
Taking HRT would make dying suddenly in old age less likely	2.41	1.13
For it to work properly, I would have to take HRT for the rest of my life	3.15	1.23
Exercise and a good diet could stop me getting thin or brittle bones (osteoporosis) as much as taking HRT	3.24	1.37
HRT might cause monthly bleeds like menstrual periods	3.66	1.08

Score 1 = would persuade me to take HRT

Score 3 = would make no difference to my decision

Score 5 = would persuade me not to take HRT

Table 4.14 Scores given by women to statements about what would persuade them to take HRT or not to take HRT

tests are based on an understanding of a range of normal values and a statistical cut off beyond which the value is designated abnormal, a process which cannot produce absolute certainty for an individual

The statement "HRT would not cause cancer if taken properly" was given score 1 (would persuade me to take HRT) by 574 of the 1121 women responding to this statement (51.2%), score 2 by 212 women (18.9%), score 3 by 243 women (21.7%) with only 92 women marking score 4 or 5 (8.2). The statement implies there is a "proper" way of taking HRT that avoids an increased risk of cancer. In medical terms this would be avoiding HRT in women with a very strong family history of breast cancer and checking there is no pre-existing gynaecological or breast cancer when starting HRT which may be exacerbated by the HRT. Reassurance that HRT will not cause cancer seems to be important an influence on women's decisions about HRT but giving advice on this is not straight forward. This is discussed further in section 4.3.1. The results are in keeping with women's fear of cancer, discussed in section 4.2.3.

Although the next three statements "I would feel younger on HRT" "if I take HRT I might live longer" and "taking HRT would make dying suddenly in old age less likely" have a mean score between 2 and 2.5, the scores 1 and 3 were the most used with over 74% of women for each statement using these scores, divided relatively evenly between them. Women therefore seem to divide according to whether these statements would strongly persuade them to take HRT or whether they would make no difference to their decision.

For the statement "for it to work properly, I would have to take HRT for the rest of my life" 497 of the 1093 women responding marked score 3 (45.5%) and the next largest group, 219 women, marked score 5 (20.0%). This indicates that women divide mainly in to those for whom taking medication is not an issue and those who do not want to take long term medication.

Scores 3 and 5 was used by over 50% of the women responding to the statement "exercise and a good diet could stop me getting thin or

brittle bones (osteoporosis) as much as taking HRT" but responses were spread across the rest of the range, as reflected in the standard deviation. The statement compares the effect of taking HRT with exercise and a good diet, and asks if this would persuade the women to take HRT. However the statement does not convey certainty about which is better. Women may have been uncertain about how far the statement was true and so unsure how to respond.

For the statement "HRT might cause monthly bleeds like menstrual periods" 515 of the 1123 women responding indicated this statement would persuade them not to take HRT (score 4 and 5) (45.9%), 513 women indicated it would make no difference to their decision (score 3) (45.7%) and only 95 women used score 1 and 2 (8.5%). This response was expected based on clinical experience and seeing pharmaceutical companies launch a number of products which do not give a regular monthly bleed. However the number of women for whom it would make no difference to their decision was surprisingly high.

The pattern of responses of the women to the statements about HRT indicate that the women tend to cluster on certain scores in each statement rather using an even spread of scores. The use of the score 3 may be partly accounted for by women tending to avoid using the extreme categories of a scale (Lydeard 1991) however the substantial use made of the extremes would indicate this was not a major problem. Further analysis, described in chapter five, uses this pattern of response to categorise women by cluster analysis for stratifying the sample for the interview study that followed on from the questionnaire survey.

4.2.12 Knowledge of bone densitometry

A set of questions about bone densitometry was added to the questionnaire at the request of the local Director of Public Health who, at the time of the survey, was evaluating the bone densitometry service at the local district hospital. An explanation

about bone densitometry was given at the start of the set of questions.

The question "Have you heard of bone densitometry?" was answered by 1214 of respondents (99.1%). Of these 884 had not heard of bone densitometry (72.8%) and 330 had heard of it (27.2%). For comparison with the evaluation of the bone density service (Madhok, Kirby, Fordham, Stamp, Green and Cooper 1996), the responses of women aged 45-64 years (n=465) were analysed. Of these 149 women (32.0%) had heard of bone densitometry and 316 (68.0%) had not. Madhok et al. sent a questionnaire to women (mean age 57 years) four weeks after they had a bone density test and asked if they had been aware of this type of test before they were referred for it. Of those responding 73% said they had heard of it, a much higher proportion than in the survey.

In the study by Madhok et al. some women may have had poor recall of what they really knew before their bone densitometry test was carried out. It is possible they had heard of bone densitometry but did not know what it actually was until they had the test. In the current survey, women who had heard of bone densitometry but were unsure about what it was, may well have answered that they had not heard of the test because of the uncertainty of their knowledge. Women who have bone densitometry carried out may be more likely to have taken steps to find out about bone densitometry before seeing their GP about the test or a related issue. The process of deciding about a referral in general practice can take place over a number of weeks or months so the women may have been involved in discussions about the test with medical professionals before the referral was made. The results of the two surveys seem to demonstrate numerically a process of information gathering, storing and retrieval by women, however an understanding of the process and thus an explanation of the contrasting numbers can probably only be found through qualitative methods.

The remaining questions in this section revealed a total of 22 women had undergone bone densitometry. Of these, 10 women said their GP had suggested it, four said it was suggested by a hospital doctor, four said they themselves suggested it and two said a nurse at the GP's surgery suggested it. To the question "Have you heard of the bone densitometry service at South Cleveland Hospital?" only 343 women answered the question (28.0%). Of these, 105 had heard of the service.

4.2.13 Summary

The characteristics of the women who responded to the questionnaire survey suggest that there is no reason to suppose they are a particularly unusual group and thus one where the generalisation of findings to a larger population would be suspect. When asked about health and welfare, many women expressed concern about cancer for themselves and for the community. There was poor knowledge about the effect of exercise and smoking on the likelihood of developing osteoporosis and relatively high knowledge about medical interventions for preventing osteoporosis and CVD. Osteoporosis was sometimes confused with arthritis which was the main fear for future health for some women. The media was women's main source of information about HRT and the messages perceived by the women tended to be positive although some women were uncertain about the accuracy and usefulness of the media information. Doctors were often important in helping women to decide whether to take HRT or not, but relatives and friends were also important and a substantial minority of women did not feel anyone was particularly important in their decision. HRT was used relatively little compared to the rate of reporting of significant menopausal symptoms and the use by women with risk factors for osteoporosis and cardiovascular disease was low. Women's attitudes to the menopause appear to vary with generation, which may reflect women's experience or changing social attitudes. Women gave importance to future risk of osteoporosis and CVD, and to medical tests, when considering taking HRT.

4.3 Implications of the survey results for general practice

The implications of the survey for general practice will be discussed, by considering two aspects, firstly the intellectual challenges and secondly the practical challenges.

4.3.1 Intellectual challenges for general practice

There are at least three themes from the questionnaire survey results that challenge general practice intellectually. The first is the fear, particularly of cancer, expressed by the women, the second is the importance women give to medical tests and risk assessment, and the third is the importance of non-medical people and the woman herself in a decision to take or not to take HRT.

Fear of cancer

Fear of cancer was clearly expressed by women when asked the open question about priorities for health care and what health problems they feared as they get older. GPs are very aware of the fear of cancer from their clinical work and that it is such a fear that frequently prompts a patient to consult about symptoms. Fear of breast cancer is not surprising given that women in Britain have the highest rate of breast cancer in the world, with each woman having about a 1 in 12 chance of developing it at some time in their life (Gray, Evans, Sweeney and Steele 1996). Against this background, and the fear women have of cancer in general, both taking and prescribing HRT with even a small chance of increasing the possibility of breast cancer may seem unacceptably risky. It has been calculated that a GP may be faced with a woman patient, prescribed HRT, developing breast cancer about once each year (ibid.). This is not something GPs would want to face as they feel responsibility for the health of their patients as discussed in section 1.2.3. However balanced against this is the potential benefit from preventing CVD, a major cause of death for women, but one that tends to occur at an older age than breast cancer. Heart disease was named by a substantial number of women as the health problem they were most worried would affect them as they got older. As

discussed in chapter two, statistics on the effectiveness of HRT in preventing CVD (Grady, Rubin, Petitti, Fox, Black, Ettinger, Ernster and Cummings 1992; Velde and Leusden 1994) do not answer all the questions about whether promoting HRT for prevention will provide women with an overall gain in health. Even if there was more biostatistical evidence, the GP would still not be sure whether any benefits shown by the evidence would be felt by an individual woman. There is a further dilemma about prevention of illness such as CVD that is highlighted by the survey results on the health problems women most fear will affect them as they get older. HRT taken for prevention may make it less likely that women will die from CVD but this may leave women more likely to live to develop dementia, a problem that increases in frequency with age and the major health worry named by nearly one in five of the women. Arthritis also increases with age causing pain and disability, and was named by more than one in ten women as the main fear for their health in the future.

Importance given to medical tests and risk assessment

The women's responses to the statements about HRT in table 4.14 indicates the importance given by women to medical tests and risk assessment. The women scored the three statements about risk assessment as the statements that would most persuade them to take HRT and, of the three, the statement that included a test was the most persuasive. This evidence is also supported by the results of the questions asking women their knowledge of risk factors for CVD and osteoporosis where risk factors associated with medical intervention were widely known. In a context of uncertainty about the biostatistical evidence on HRT and its inability to predict outcome for any individual a GP provides advice about HRT to women who may give medical tests and risk assessment great value. This value may include some hope or expectation of certainty from medical evidence and medical tests, as discussed in section 2.11. The intellectual challenge for a GP in this context is how to come to a shared understanding with patients when there is so much uncertainty in the medical evidence and its application, yet a hope or expectation of certainty from the patient. The way women

consider and use medical evidence and medical tests, in the context of HRT, is considered further in the interview study described in chapters five and six, and indicates that for women considering HRT, the expectation of certainty and the value given to medical evidence may not be as strong as the survey seems to indicate, and that it varies depending on the context. The evidence of the value women give to medical tests and risk assessment may appear strong partly because of the way the evidence was collected, a survey focusing on medical issues and carried out by a doctor with the support of the women's own GPs. The intellectual challenge for GPs may therefore be to understand why a patient may place a high value on a medical test or risk assessment, that is to understand the patient's context, in order to reach a shared understanding.

Importance of non-medical people and the woman herself in a woman's decision to take or not to take HRT

As HRT is currently only available on prescription in the UK, it is not surprising that many women found a health professional the most helpful in coming to a decision about whether to take or not to take HRT, as the health professional controls access to HRT and so is in a powerful position to persuade a woman in her decision about HRT. However other non- health professionals and the woman herself also played a role in the decision making. In the UK the Committee on the Safety of Medicines decides whether a medicine is to be available on prescription only or available without prescription, based mainly on biomedical and biostatistical evidence about the medicine. For a GP, the decisions of the Committee form part of the context for clinical practice as it determines the boundaries for prescribing medicines. However a GP still has scope for deciding how much influence to use in a woman's decision to take, or not to take, HRT, if and when a woman decides to ask her GP about this, or if a woman decides to seek to use HRT. Given the uncertainties about HRT, particularly when taken for prevention, a GP may feel it important to influence a woman on this decision, in an attempt to maintain responsibility for the decision. On the other hand, given the uncertainties, a GP may feel it important for the woman herself to make the decision. The latter

approach prompts questions about how much information a woman needs in order to make such a decision, and how far it is the responsibility of the prescribing GP to ensure the woman has appropriate information. Medico-legally the GP takes responsibility for the provision of HRT by signing a prescription, so however much the GP leaves the decision to the woman herself, the GP can still be held responsible for the prescription.

For women considering the use of HRT for the control of menopausal symptoms, the factors influencing a woman's decision about whether to take or not to take HRT may differ from a woman considering taking HRT mainly for prevention. In the former situation the woman is likely to consider the severity of the symptoms and the distress they cause when considering HRT. When used mainly for prevention, the decision to take or not to take HRT has similarities with other forms of medical intervention for prevention, including screening procedures. The question about the provision of information about a medical intervention, is considered in the current debate, in the UK, about the use of screening for prostate cancer in men over 50 years old. Recent reviews of the use of a blood test for screening for prostate cancer, discourage its use. This advice comes from those considering the population perspective, and is based on the lack of evidence of benefit from screening and the harm that screening can do, particularly through increased medical intervention (Woolf 1997). In his discussion of the reviews of screening for prostate cancer, Woolf (1997), a family physician from the USA, suggests that on a population basis the decision not to promote screening seems appropriate, however individual patients should be provided with information about screening for prostate cancer so they can decide for themselves whether or not to be screened. He also suggests that providing this information is a doctor's responsibility. The debate on this issue will probably continue. However, applying the argument to the provision of HRT for prevention would suggest that doctors have a responsibility to provide individual patients with information about HRT, as the individual has a right to decide on their options whatever the evidence for the intervention based on populations and

whatever the local health policy. As a GP it is quite difficult to see past the practical implications of this suggestion, such as the time needed to discuss these issues with individuals. However, the intellectual argument seems to tackle the problem of how to apply population evidence to individual patients, as discussed in section 2.11, firstly by separating policy for populations from individual decisions and suggesting the two need not be linked, and secondly placing responsibility for the provision of information on doctors, but the responsibility for the final decision with the individual patient. The first suggestion, that policy for populations and for individuals need not be linked, seems to be an intellectual side step around the challenge of how to apply evidence from populations to individuals. Individuals form part of groups or populations and are intricately linked, and policy for populations will not be carried out if not applied to individuals. The second suggestion, that patients should make the final decision about a medical intervention, is in keeping with medical ethics and the idea of the autonomy of the patient. However placing the responsibility for the provision of information on doctors raises intellectual as well as practical questions: how much information; who should be given it and when; how much persuasion should be linked with the information; what may the effects of the information be, such as increasing fear; how should the provision of the information be linked with service provision; should information be disseminated when the service may not be available for everyone. Surrounding these questions of detail is the overall question as to whether doctors should be responsible for the provision of information about medical interventions for prevention. For HRT some of these questions have at least been partially answered, or avoided, for doctors by the media taking a major role in providing women with information, as confirmed by this survey. This may raise further questions about who controls the type of information provided through the media, particularly as the information from the media, as perceived by the women in the survey, seems to give a positive image of HRT. However, the widespread discussion of HRT in the media means that general practice can take a mainly reactive role, responding to women seeking further information or advice, rather than taking

responsibility for the provision of information about HRT generally. Thus for HRT doctors may not need to consider the question about taking responsibility for the provision of information to the population generally. However this is only possible because of the widespread media interest in HRT which may be fuelled by the commercial advantages of informing women about HRT. Medical interventions without commercial value may need a quite different approach from the medical profession.

Summary

The results of the questionnaire survey support the suggestion that the provision of HRT is "intellectually and emotionally difficult" for both doctor and patient (Gray, Evans, Sweeney and Steele 1996). This section has explored three of the intellectual challenges for general practice, prompted by the survey results. In the next section practical challenges to general practice are discussed.

4.3.2 Practical challenges for general practice

The practical challenges for general practice prompted by the questionnaire survey results include the resource implications of an increase in use of HRT, targeting the promotion of HRT for prevention appropriately, and providing time for an informed discussion about HRT.

Resource implications of an increase in use of HRT

There are a number of indications in the survey results that the use of HRT by women has the potential to increase in the future. The number of women reporting significant symptoms associated with the menopause is far higher than the number of women taking HRT (see sections 4.2.1 and 4.2.9), so the number of women taking HRT may increase if a larger proportion of women experiencing menopausal symptoms choose to take HRT, and their doctors agree to prescribe it. The association between taking HRT and being a past user of the contraceptive pill (section 4.2.9), may indicate that as the generations accustomed to taking the contraceptive pill reach menopausal age, a larger proportion of women will take HRT. The

analysis of the trend by educational attainment for reporting menopausal symptoms by premenopausal women was prompted by a clinical impression that HRT may sometimes be used when there seems to be little else to offer women who are distressed. The finding of the association between HRT use and educational attainment in this group would need further investigation but may point to HRT being used as a "cure-all".

The resource implications for general practice of a potential increase in use of HRT have to be considered in the social context. An increase in use of HRT will increase the money spent by the health service on HRT, unless the cost of HRT is reduced proportionately, as negotiated between the National Health Service and the pharmaceutical companies. Attendance at GP surgeries by women may change with any increase in use of HRT. There may be an increase in attendance to discuss HRT, to obtain a supply of HRT or to be monitored when on HRT. Attendance for monitoring will depend partly on the amount of monitoring that doctors decide to do. Annual medical checks have been suggested for women on HRT (Greendale and Judd 1993), however the idea of annual checks developed in the fee for service health system of the USA, where many women use unopposed oestrogen and have an annual endometrial sample taken to check for endometrial cancer. In the UK, where combined HRT is used, annual endometrial sampling is not medically indicated and the structure of the health service, including the payment systems, does not encourage frequent medical checks. Although an increase in the use of HRT may result in more women attending GP surgeries for the provision of HRT, overall attendance may not increase, or may decrease, if HRT is providing relief of distressing symptoms. However the potential for HRT to be used as a "cure-all" may result in an increase in attendance if women perceive their needs in terms of medical intervention. The possibility of women becoming dependent on HRT, as discussed in section 2.6.1, may increase women's needs for medical help in dealing with the dependence. It is difficult to predict the overall effect on the health service and in particular general practice if an increasing proportion of menopausal women

decide to take HRT for symptom relief. The promotion of HRT for prevention of osteoporosis and CVD may also increase use of health services by women in connection with taking the HRT, but would have the aim of decreasing the need for medical intervention in the future by preventing osteoporosis and CVD. However, women may still require medical intervention or nursing care for other diseases of old age.

Targeting the promotion of HRT for prevention

The survey revealed a relatively low level of use of HRT among women with a personal or family history of osteoporosis or CVD, yet these are the women that may have most to gain from taking HRT for prevention. The identification of women who had an early surgical menopause and were not on HRT, in the researcher's own practice, has been discussed in section 1.2.2. Identifying these women and, where judged appropriate, offering them HRT, is a way of targeting the promotion of HRT towards those most likely to benefit. Given the relatively low rate of use of HRT by women with a personal or family history of osteoporosis and CVD, it could be argued that GPs should search for these women on their practice lists, and offer HRT. This is a practical challenge for general practice for many reasons. From the researcher's experience described in appendix 2, family history of osteoporosis is not frequently recorded in patients notes, although a family history of CVD is more frequently recorded in the medical records as this was encouraged by the strategies for prevention discussed in section 1.2.3. If it was decided to contact women considered to be potentially able to benefit from taking HRT, this may raise anxiety for the women and it would be difficult to provide clear reassurance for a woman, in a context where the issues are so complex and evidence still uncertain. If HRT is offered and accepted, women may find the side effects of the HRT distressing and may require several changes of preparation before finding one that is acceptable or may find none acceptable. If the evidence in favour of the use of HRT for prevention increases, the pressure on GPs to seek out women at risk will increase. In this situation the task may become easier as more evidence may help reduce the uncertainty about the

risks and benefits about HRT, although it cannot completely remove the uncertainty for individual women.

Time for an informed discussion about HRT

The discussion in section 4.3.1, about the role of the woman and the doctor in a woman's decision whether to take or not to take HRT, has raised questions about the responsibility of doctors for providing information about HRT. The survey results have also highlighted some specific issues for GPs to be aware of when discussing HRT with women.

Many women seem to confuse arthritis and osteoporosis, and awareness of this can help GPs to understand why women may be enquiring about HRT, as some may hope to prevent arthritis but may not specifically mention this. The media is women's major source of information about HRT, and the image of HRT perceived from the media tends to be positive. Awareness of this can again help GPs understand the motivation for women asking about HRT and what their expectations may be. The positive image of HRT in the media may make discussion with a patient about the complexity of the decision about HRT, more difficult, as her expectations may be raised. Some women may tend to view HRT more positively than others, and this is explored further in the discussion of cluster analysis of the survey data later in this chapter.

Providing information about HRT and discussing the issues associated with a decision to take, or not to take, HRT, takes time in a consultation. However the provision of time for this type of discussion is not a problem only for HRT, but applies to most medical interventions where doctors and patients discuss an intervention in a way that allows the patient to make as informed a choice as possible (Marinker 1997). The survey results indicate that a majority of women felt they had received enough time and information about HRT when consulting the doctor or nurse at their surgery, but a substantial minority were not satisfied.

Summary

It is difficult to know how any increase in the use of HRT will affect the type and amount of work in general practice, but it may increase costs and demands on time. Targeting the use of HRT for prevention may become appropriate, but the uncertainties in the evidence for its use make this difficult at present. The survey has revealed specific issues about information on HRT for GPs to be aware of, but the practical dilemmas about providing appropriate information about HRT so women can make an informed choice, apply to many medical interventions.

4.3.3 Conclusion

The survey results raise practical challenges for general practice, particularly about time and resources for providing services linked with HRT. These practical challenges have been discussed separately from the intellectual challenges to help clarify the issues, however they are very closely linked. As a service that responds to patients' requests for help or advice, GPs may be asked to respond to an issue raised by a patient before having time to examine the intellectual debate on the issue. With the media being an important source of information about medical issues for patients, this may occur more frequently. Some of the uncertainties that GPs work with in providing advice to women about HRT have been discussed in chapter two. This section has discussed further uncertainties linked with the provision of HRT in general practice including the intellectual uncertainty a GP may feel about an issue when asked for a response by a patient.

4.4 A sociological analysis of the questionnaire survey results

4.4.1 Introduction

In chapter two, sociological theories of biomedicine and biostatistics were discussed in the context of HRT. This section examines the results of the questionnaire survey in the light of those sociological theories. The choice of themes that are examined in

this section was guided by the researcher seeing some correspondence between what the survey results appeared to be showing and the sociological theories examined in chapter two. The themes also overlap with those discussed in the preceding section on the implications of the survey results for general practice, including the importance given to medical evidence and risk assessment, the possible use of HRT as a "cure-all", a potential increase in the use of HRT and the media coverage of HRT. This overlap contributes to the final conclusion of the sociological analysis.

4.4.2 Medical evidence, risk assessment and social context

The survey results indicate that women give importance to medical evidence and risk assessment when considering whether to take, or not to take, HRT. Importance was also given to medical interventions when the women were asked to consider the importance of different health and welfare services. Much less importance was given to non-medical services, such as the provision of exercise facilities, that can contribute to preventing health problems such as CVD and osteoporosis. Far more women knew about the role of oestrogen in preventing osteoporosis than about the role of exercise in its prevention. These findings suggest that women accept, and give importance to, medical interventions such as screening and risk assessment for the prevention of future health problems. These findings support the theory of medicalisation as discussed in section 2.6.1 and the idea that people now see themselves as having a risk identity as discussed in section 2.10. However these conclusions seem less certain when the social context of the questionnaire survey is taken into account.

The questionnaire itself was developed and sent out by a doctor and used medical definitions. Some of the questions may have given the impression that there was medical certainty about aspects of prevention such as the use of health checks to prevent heart disease and screening for osteoporosis. Risk assessment and prevention of future health problems were underlying assumptions of the

questionnaire. In this context women may be more likely to give importance to medical evidence about prevention and to the idea of risk assessment.

The survey was carried out at a time when the National Health Service may have been perceived as under threat, with the changes occurring under the Conservative government at the time. This concern was specifically mentioned by some women in the open question about priorities for health and welfare services. The perceived threat may have prompted women to give more importance to medical interventions than if the NHS had not been perceived as under threat.

In section 3.2.2, the influence of the Western cultural emphasis on numbers, on the development of the research was discussed. This cultural emphasis may also influence what women know about and see as important. As mentioned earlier, more women knew about the medical intervention of measuring blood pressure than the effect of exercise in the prevention of CVD, and far more women knew about the role of oestrogen in preventing osteoporosis, than the role of exercise in prevention. It is much easier to measure a person's blood pressure or a dose of oestrogen, than it is to measure the amount of exercise people take. So in a culture that emphasises measurement these interventions may be researched more, talked about more and seem more real to people.

The biomedical emphasis on the responsibility of the individual in exercising control in order to maintain or restore health was discussed in section 2.3. When it is suggested to women that HRT may prevent CVD or osteoporosis, as in the questionnaire, the biomedical emphasis on individual responsibility may make women more persuadable to take HRT for prevention. When women accept this emphasis on individual responsibility they may also be inclined in this context, to give relatively little importance to the provision of exercise facilities such as cycle lanes and sports centres as the provision of these facilities is not an individual responsibility. Although the activity of taking exercise is an individual

responsibility, the link between the provision of exercise facilities and individuals taking exercise may not be as clear for people as the link between services such as premature baby units and the individuals needing the service as, in theory, it is possible for individuals to take exercise anywhere, without special facilities. The promotion of long term HRT was also given relatively little importance when women were asked to score the importance of health and welfare services. This again may be because the statement referred to the promotion of taking long term HRT, rather than individuals actually taking HRT. HRT is available through the NHS, and is therefore, in theory, available to everyone. Individuals are also registered with a GP who may be perceived as the person to advise individuals on health matters. Therefore women may not perceive any need for HRT to be promoted.

Although the survey results seem to strongly indicate that women give importance to medical evidence and risk assessment, the social context of the survey results reduce the strength of this conclusion, as the social context would influence women towards these responses. However taking account of the social context does not necessarily invalidate the conclusion as all responses occur in a context. It does suggest that it may be important to find out more about how women develop their attitudes to HRT and related issues, and how much the questionnaire responses reflect the women's responses to the social context of the research and how different the attitudes expressed may be in a different social context. This is tackled, to some extent, in the interview study described in chapters five and six.

4.4.3 The sick role and HRT

In section 4.2.1 it is reported that, in the premenopausal group, significant menopausal symptoms were reported more frequently by women of lower education than by other women. This trend by education was not found in the postmenopausal group or among women who had had a hysterectomy. In the survey for this thesis, educational attainment was used as a proxy measure for social class.

A survey in Belfast, of women aged 48-52 years, found women of lower social class more likely to report suffering menopausal symptoms than women of higher social class (McKnight and Steele 1997). This effect was independent of other influences measured, including menopausal status. There are many possible explanations for these findings drawing on social theory. Some women, particularly premenopausal women that indicate they have suffered menopausal symptoms, may be looking for a biomedical explanation for their symptoms, interpreting how they felt as something to do with their bodies and which they are unable to control. This interpretation draws on the theory of medicalisation explored in section 2.6.1, in particular the idea of social iatrogenesis where sickness becomes the only escape from stressful or demeaning industrial work and suffering is defined in terms of sickness (Illich 1990:49-46). However, this interpretation assumes that menopausal symptoms are seen as a form of sickness by the women. In section 4.2.9 it is reported that no trend was found between educational attainment and women having thought about taking HRT prior to completing the questionnaire, yet, for women aged 35-44 years, there was a strong trend between lower educational attainment and more use of HRT. This raises a question about who is interpreting women's symptoms as menopausal symptoms, defining this as a sickness, and responding to this with HRT. If women of lower educational attainment are no more likely to have thought about taking HRT than other women, it may be that they present symptoms to their GP, which the GP interprets as possibly menopausal in nature, and prescribes HRT. The woman may initiate the visit to the GP and sees herself as, in some way, needing medical help, so is taking on a sick role. However this needs confirmation, by the GP, as a sickness through the interpretation of the symptoms as something that will respond to therapy. It may also be that women of lower social class or lower educational attainment suffer more menopausal symptoms, including before their periods stop, and are more in need of HRT. This raises the question why would they suffer more menopausal symptoms. The therapy considered in the survey was the provision of HRT, however epidemiological evidence has shown that women

of lower education are also more likely to have a hysterectomy than those of higher education (Kuh and Stirling 1995). GPs responding to a woman with distressing menopausal or menstrual symptoms, where socio-economic factors may be increasing the woman's distress and decreasing her ability to cope with the symptoms, may be well aware of the influence of socio-economic factors. However GPs have only limited power in society to help change an individual's socio-economic situation, mostly limited to defining people as sick or disabled or not. However GPs can provide medical interventions to help a woman's distress, such as HRT and hysterectomy, in the hope that these interventions may help to some extent. By responding to the individual in this way the GP may be being as sensitive and helpful to the patient as possible yet be promoting the medicalisation of the individual's symptoms, for which in a different context, an economic, social or emotional solution may have been found. These individual acts of medicalisation contribute to the social trend of medicalisation discussed in section 2.6.1. This type of tension between being sensitive to the individual and trying to reconcile this with the wider picture of trends within the provision of medical services, is faced throughout the health service (Marinker 1996).

4.4.4 HRT use and medicalisation

In section 4.2.9 it was reported that, for postmenopausal women, there was a higher use of HRT among past users of the birth control pill. This trend may indicate that these women have accepted the use of extrinsic hormones to help control their fertility and, later in life, any menopausal symptoms. However, the survey also reveals that HRT is used by a relatively small number of women experiencing significant menopausal symptoms, that postmenopausal women were most likely to agree with the idea of using diet and exercise rather than HRT to help problems of the menopause, and postmenopausal were most likely to disagree with the idea of taking HRT for distressing menopausal symptoms. These findings may indicate that many postmenopausal women are not wanting to use HRT, yet there may be a group of women who, having used hormonal contraceptives,

may want to make use of HRT during the menopause. It could be argued that this group of women have accepted the medicalisation of their fertility and menopause as the hormonal preparations used were developed through medical research and are provided through the medical service. However women may use hormonal contraceptives and HRT for many reasons including convenience, peer pressure, expectations for their work or recreation, effectiveness or cost. Hormonal contraceptives and HRT are currently only available on prescription so women have to obtain them from the medical service. Thus in the current context, women using hormonal contraceptives or HRT have to accept them as a medical intervention, as they cannot obtain the preparations elsewhere, and so in this context appear to accept medicalisation of their fertility and menopause. The survey results cannot reveal how far women see fertility and the menopause as requiring medical intervention, or how far they see themselves in control but using the resources that are currently available. The issue of control is explored in the interview study reported in chapters five and six. The survey results have to be interpreted with attention to the wider social context for the women where their choices are limited by the current social system.

4.4.5 HRT in the media

In section 4.2.5 it is reported that the media, including magazines, newspapers, TV and radio, are commonly used sources of information about HRT for women. Women's perceptions of what they read or hear about HRT from the media tends to be positive. A sociological study of the popular media coverage of HRT could be undertaken to explore how much media coverage of HRT actually occurs and whether it tends to be positive about HRT. Widespread coverage of HRT by the media would be in keeping with the theory of medicalisation of the menopause, discussed in section 2.6.1, with the media taking a role in promoting the widespread use of HRT by women (Foster 1995:73-85). It would also be in keeping with the Marxist analysis discussed in section 2.6.4, where promoting the consumption of medical treatment may be seen as sustaining the capitalist economic system (Morgan, Calnan and Manning 1991:36).

However, as the proportion of women actually using HRT is relatively small compared to the number who have experienced menopausal symptoms, the media coverage of HRT may give an impression of society accepting the widespread use of HRT by women around the menopause when the actual use of HRT is not so widespread. The media coverage of HRT is a different social phenomenon from the actual use of HRT. It may be affected by quite different social factors and its study would probably involve different aims, research theory and research methods from those used in this thesis. However there may be links between the media coverage of HRT and the actual use of HRT, and the interview study, described in chapters five and six, explores the way in which individual women perceive and then use the information about HRT from the media. This provides some detail of the links between the social phenomenon of the media coverage of HRT and the social trend of women actually taking HRT.

4.4.6 Conclusion

There are a number of themes in the sociological analysis of the issues raised by the questionnaire survey and discussed in the preceding sections, which are also themes that recur throughout the thesis. The first is the importance of social context for research. For example, the design of the questionnaire used in the survey is an important part of the context for interpreting the results of the survey; the resources of the medical services and the form of doctor-patient interactions that occur, and the tensions within this, are important for interpreting the data about the use of HRT; the structure of health care provision, including regulations about the availability of hormonal contraceptives and HRT by prescription only, affect the conclusions, particularly how far the data supports the theory of medicalisation of the menopause.

The second theme that recurs in the preceding analysis and throughout the thesis is awareness of the level of analysis used. Research may appear to be about similar themes such as the media and HRT or about the use of HRT and the medicalisation of the

menopause. However the research may have different aims, theory and methods, with results and conclusions sometimes seeming contradictory. This has been discussed by Nettleton in the context of differing perspectives taken by different sociologists in developing a sociology of the body, particularly the difference between viewing the body as a social construction or viewing it as lived or animated (Nettleton 1995:110). Nettleton goes on to discuss the suggestion by Turner of "epistemological and/or methodological pragmatism" (Turner 1992:17), accepting that the perspective adopted by a sociologist depends on the level of analysis used in the research and that the methods used will depend on the type of research that the sociologist wants to undertake (Nettleton 1995:110-111). This pragmatic approach allows for debate, but debate that accepts that it is possible to have different perspectives on an issue, and these different perspectives may even appear to result in contradictory conclusions. Using different perspectives can add to our knowledge and understanding. Taking this pragmatic approach requires a respect for the language of others (Marinker 1996) and a respect for the assumptions of others, as a fruitful discussion should not require a common framework of basic assumptions (Popper 1994:34).

In section 4.3, the intellectual and practical implications for general practice, of the questionnaire survey results, were discussed. The sociological analysis, in this section, has attempted to take a different perspective. The author of both sections is the same, and this may limit the degree to which the perspectives differ. However, taking these different perspective reveals how specific the intellectual and practical implications, discussed in section 4.3, are to the context of general practice, as it has developed and functions in a particular time and place. This social context includes the medical culture, the general culture, the economic system, government policy and legal issues. The following are three examples. The intellectual challenge to general practice of the importance women may give to medical evidence and risk assessment, is specific to a medical culture that puts emphasis on biostatistical evidence and to a research study conducted by a GP and which included medical assumptions. The intellectual challenge about the decision to take HRT, and linked with this, the

role of the GP in providing medical information, arise in a context of the type of medico legal responsibilities placed on doctors in the provision of HRT and associated advice and information, the promotion of HRT in the media, and the commercial interest of the pharmaceutical companies in women using HRT. The practical challenge for general practice of coping with the provision of services, if there is an increase in the use of HRT, arises from a context of HRT being only available on prescription, and being seen as a medical intervention requiring some medical advice and follow up. Understanding the context is very important for understanding the reasons these intellectual and practical challenges arise. However this does not make the challenges less real for general practice, as general practice has to respond to what is happening in the social world. Sociological analysis can help to maintain awareness of how the challenges are tied to a specific context, helping general practice to see them as part of wider social trends. It also provides a different way of looking at the situation, using a different language. As Marinker suggests, the assumptions of general practice cannot be adequately criticised in its own language (1996) but requires what Rorty describes as "irony":

the willingness to respect the language of others, and (more difficult) to accept that it is impossible to mount an adequate critique of the ideas expressed in a contingent language by using the same language (authors own brackets) (Rorty 1989 discussed in Marinker 1996:16)

(A contingent language refers to one that is based on principles, values and assumptions specific to one particular time and place).

Drawing together the conclusion on the theme of social context for research, it is clear that the questionnaire survey, developed by a GP with the aim of informing general practice about women's attitudes to HRT, is specific to a particular time and place and the method, results and conclusions are influenced by the specific social context. The influence of social context may be more removed from the research process in certain forms of research, particularly experimental

research, than in this survey where social context may influence every stage of the research process. However all research is carried out at a specific time and place and is influenced in some way by the social context. Awareness of the social context of research can increase understanding of the research.

The social context for the questionnaire survey is closely bound with the level of analysis used in the survey. The survey aimed to inform general practice of women's attitudes to HRT. Individual women were asked questions about themselves as individuals and issues about HRT, and how they as individuals related to social phenomena such as the media coverage of HRT, and about any medical encounters about HRT. The level of analysis is focused on the individual women but includes their relationships with health professionals and with the wider social world. The questionnaire survey results have been used in this thesis in two ways. Firstly to continue the aim of challenging general practice, but secondly to inform a sociological perspective on HRT. Although this data forms part of the social phenomenon of the use of HRT, a fuller sociological perspective would consider more than the actions or attitudes of individual women. It would consider the social systems and social groups involved in the provision of HRT, and other social trends. Taking a sociological perspective on the use of HRT involves a different level of analysis from taking a general practice view, and requires a different language and uses different assumptions. The questionnaire survey provides one form of data that can be used to contribute to developing a sociological perspective. In the next chapter of this thesis the questionnaire survey results are analysed further, pushing the data to its limits for informing the sociological perspective on HRT.

4.5 Summary

This chapter has presented three perspectives on HRT using the questionnaire survey results as its focus. Firstly the questionnaire survey results have provided a description of women's perspectives on HRT, as measured by the survey. Secondly the results of the

questionnaire have been considered from the perspective of clinical general practice by considering the intellectual and practical challenges raised by the survey results for general practice. Thirdly the questionnaire survey results and the implications for general practice have been discussed from a sociological perspective. This analysis has contributed to two themes that recur throughout this thesis, the importance for research of considering its social context and the different levels of analysis used in research. The next chapter explores ways in which the questionnaire results can further contribute to the sociological understanding of women's attitudes to and use of HRT.

Chapter Five

Further analysis of the questionnaire survey results

5.1 Introduction

The questionnaire survey provides a large body of data about individual women and their perspective on HRT and related issues. The data on individuals can be combined to provide an overview of women's perspectives on HRT and used to test a sociological perspective or model about HRT. As a sociological model is concerned with processes that are common to groups of people or most people, it tends to be an oversimplification for any individual (Marsh 1982:77-78). In chapter four a descriptive account of the survey data was presented, with analysis limited to cross tabulations that refined the data to make the descriptions clearer, such as identifying differences between age groups or educational groups. In this chapter the data will be analysed further to explore what more the data can contribute to a sociological perspective on HRT and to explore the limits to analysing the data.

In section 1.3.2, the idea of using models to understand causes for social phenomena was introduced. In this chapter the survey results are used to try to develop a model of what causes women in general to take HRT. The theory behind the development of causal models is introduced, then the choice of outcome and data used is described and discussed followed by a description and discussion of the process of identifying causal variables. Two numerical processes of developing the causal models are then described and their limitations discussed. Finally the limitations of the data and the methods, for the development of a causal model, are discussed.

In section 4.2.10, it was noted that when women were asked how far statements about HRT would persuade them to take it, rather than being evenly spread across the score range available, women tended to divide into groups. The idea that women can be categorised into groups using the questionnaire data is explored in

this chapter using cluster analysis. This is exploratory analysis that aims to find how items of analysis, in this case the women who responded to the survey, can be categorised, according to chosen variables. It is used here to see if there are categories into which woman can be divided that are meaningful for a sociological perspective, and that can be used for stratifying the sample for the interview study that followed on from the survey.

The data from the questionnaire was collected with the intention of performing the basic analysis of finding frequencies and using cross tabulations. The data was not collected with the idea of developing causal models, or with the idea of cluster analysis, in mind. The data is being used to its limit by attempting these analyses and the nature of the data restricts the extent of analysis possible.

5.2 Development of models about what influences women to take HRT

5.2.1 Introduction

Models have been described as a tool for helping theoretical activity of a complex kind by allowing us to keep several ideas in the air at once (Marsh 1982:73). A causal model attempts to identify the causes of a social phenomenon and give a measure of the strength of the effect of the causes on the outcome. Models are developed from data collected from groups of people. The process uses equations, but representing the equations as flow graphs is conceptually easier for people (ibid.). A causal model can make it easier to see how different factors seem to influence an outcome but using such a model assumes that one event, state or variable produces another, that causes really do exist (Marsh 1982:69). However causation is not the same as complete determination and causes can change over time and be affected by people (Marsh 1982:70). The idea of a cause as necessary and sufficient to produce an outcome, as developed by Galileo and used in sciences that contribute to biomedicine, is too deterministic for social

phenomena which are measured by probability (Hage and Meeker 1988:4). Hage and Meeker give several reasons for this. Firstly, there are countervailing forces such as individual variation and peoples' own actions, secondly, social phenomena have complex sets of causes and thirdly, chance can play a part (1988:6). The idea of cause for social phenomena is similar to that used by biostatistics and the statistical methods are often the same. To start developing a model of causation it is necessary to identify possible causes and their time sequence, and consider the possible mechanisms of the causal effect that may not be directly observable (Hage and Meeker 1988:9-10). So developing a model begins from ideas about what might make sense in terms of causes and effects. A cause can be defined as "one of a set of conditions, an Insufficient but Necessary part of an Unnecessary but Sufficient group of conditions or events which may include chance" (authors' own capitalisation) (ibid.). An analogy can be drawn between this definition of cause and the ideas about cause in the theory of "chaos". The theory of "chaos" does not include the idea of "chance" as a factor bringing about a change in a dynamic system, but indicates that changes that affect a system may be so small as to be immeasurable (Cohen and Stewart 1994:189-190). Marsh also does not include the idea of chance, but suggests that the correlation between variables can indicate the strength of relationships and show where there are additive or indirect effects, but what is left unexplained is not "chance" but variance whose origin has not been pinned down in the model, and this is always relative to the state of knowledge at the time (1982:76-77). Marsh goes on to suggest that a small amount of variance explained can be useful, but the strength of a correlation needs to be described relative to the size of correlations usually found and conventions are needed about what is a strong correlation (1982:77). In the analysis of the questionnaire data, Cramer's V was used to test the strength of a trend, with a moderately strong trend being a result > 0.3 , a level of association also considered interesting, in social science data, when continuous data is used in regression analysis.

5.2.2 Outcome and population used in model development

To develop a causal model, a dependant variable has to be chosen that measures the outcome of interest for the model. The focus of the questionnaire survey was women's attitudes to HRT and what influenced them. Although there had been an intention to develop an attitude score, so each woman could be given a score representing her attitude to HRT, this was not done, as discussed in chapter three. The questions assessing women's attitudes to HRT did not therefore give a single numerical score to use as a measure of outcome for the development of a model. However, there was data for the use of HRT in a form that could be used for a causal model. Women were asked whether they were taking HRT or whether they had taken it in the past and had now stopped. A positive response to either of these questions can include a wide range of experience with HRT and could be affected by problems of recall, but compared to the questions about attitudes to HRT, the responses were less likely to be influenced by the research context. The outcome used for the causal model was therefore chosen as whether a woman had ever used HRT. The survey data was re-coded so women were identified as never having taken HRT, having taken HRT at some time, or having no data available.

The questionnaire survey included women aged 20-69 years. For the younger women, taking HRT would not be relevant. Those for whom HRT would be relevant include women experiencing symptoms of the menopause, women who had had a hysterectomy, and postmenopausal women. The first grouping was not used as HRT is used for prevention not just symptom relief, because of the uncertainty about the definition of menopausal symptoms, and because of the possible use of HRT for non-specific symptoms, as discussed in section 4.3. The second grouping, women who have had a hysterectomy, may include women who had various reasons for the hysterectomy, may or may not have had their ovaries removed and may have had their hysterectomy before or after going through the menopause. These factors could affect their use of HRT. The data for women identified in the survey as

postmenopausal was therefore used in developing the model. This grouping excluded all women who had had a hysterectomy, and included women whose periods had stopped and who considered themselves to be in or beyond the "change of life". A disadvantage of using data only from postmenopausal women was that this reduced the size of the sample. However, for developing a causal model, Marsh suggests identifying a particular group as the process of causal determination is not usually the same for all members of a population (1982:79).

5.2.3 Identification of causes

Having decided on the dependant variable or outcome to use in developing the causal model and the group from the survey population on whom to focus, the remaining variables in the survey data were considered as possible independent or causal variables, that is variables that may influence the outcome in the model. For a variable to be included as an independent variable, three criteria have to be met. Firstly the variable has to occur in a causal order; the independent variable has to precede the dependent variable in time. If the model was just a descriptive account of correlations in the population there would be no need to worry about causal order. However the model "purports to represent the actual process of determination it is a (philosophically) realist model" (authors' own brackets) (Marsh 1982:78). The independent variable has to come before the dependant variable for there to be a causal effect. Secondly there has to be a possible mechanism by which the independent variable may influence the outcome (Hage and Meeker 1988:13-16). The causal process may not be measurable but needs to be suggested for the model (Hage and Meeker 1988:20). Thirdly, there needs to be some measurement of the relationship between the independent and dependant variable. Each variable in the survey data was considered to see if it fulfilled these three criteria.

Cross tabulations between the dependent variable, having ever used HRT, and potential independent variables for the model were performed to measure any relationship between them. To keep the

model development statistically relatively simple, each independent variable not already in bivariate form, was re-coded as "present" or "absent". For example, each category for the responses to the open question about women's fears for their future health was re-coded to "present" or "absent", and women's responses to the knowledge questions about CVD and osteoporosis were re-coded so knowledge known was coded as "present" and no response was coded as "absent". Educational attainment was recoded as having further training after leaving school or not, a decision based on the discussion of this variable in chapter four. For age group, several ways of dividing the women were tried. Dividing them into 55 - 69 years or not resulted in the strongest correlation with use of HRT.

For many independent variables there was no statistically significant trend ($p < 0.05$) found in the cross tabulations. These included most of the knowledge questions about CVD and osteoporosis; family history of CVD; the top six health problems women fear for their future health (cancer, dementia, arthritis, heart disease, disability and stroke); the use of the media, relatives and friends or a nurse as main source of information about HRT; whether media information about HRT was felt to be correct; the image of HRT perceived from the media (coded according to whether a positive image of HRT was the first image mentioned in the woman's list of what they had heard about HRT from the media).

Where the cross tabulation showed a statistically significant trend the independent variable was considered for use in the model. These were being age 55-69 years or not; ever having used the birth control pill or not; reported experience of menopausal symptoms or not; reported family history of osteoporosis or not; naming osteoporosis as the women's main fear for her future health or not; knowing that oestrogen has a role in preventing osteoporosis or not; whether the information from the media was felt to be helpful or not; whether a doctor was the main source of information about HRT or not. There was no correlation found between education and use of HRT so this variable was not used in the initial model

development. However it was included in the second method of model development as there was a correlation between age and education and between use of the birth control pill and education, both of which were included in the model.

Where there was a measurable correlation between the independent and dependent variables, the likely time sequence and possible causal process was considered, as described below

Being age 55-69 years or not comes prior to taking HRT and the likelihood of needing HRT for symptom control or prevention is linked with the menopause and so with women's age group. Also, older women may have used HRT less as it was less available at the time of their menopause. Age was used as an independent variable in the model development.

Having ever used the birth control pill or not comes prior to taking HRT as it is used before the menopause. Women who have used the birth control pill in the past may be accustomed to taking hormones and to the use of medical interventions and medical monitoring, so may be more inclined to take HRT. This variable was used in the model development.

Postmenopausal women are likely to experience menopausal symptoms prior to taking HRT, although as HRT is used for prevention there is potential for some women to take HRT prior to experiencing significant menopausal symptoms. Women suffering symptoms may use HRT more than others because of the distress caused by the symptoms. This variable was used in the model development.

It is more difficult to be sure of the time sequence between taking HRT and a reported family history of osteoporosis. A woman may find out about a family history of osteoporosis before or after taking HRT, and a woman facing a decision about whether or not to take HRT may seek out information from her family about osteoporosis of which she was previously unaware. A parent may also be

diagnosed as having osteoporosis after a woman has started on HRT. There is a possible causal process between a reported family history of osteoporosis and taking HRT as, for postmenopausal women, a family history of osteoporosis is a medical indication for taking HRT for prevention. It was decided to use this variable in the model development despite the uncertain time sequence. This decision may have been influenced by the existence of a medical causal link.

It is not possible to be sure of the time sequence between naming osteoporosis as a woman's main fear for her future health and taking HRT. The fear may precede the taking of HRT, however the woman may only become aware of the possibility of osteoporosis once taking HRT for menopausal symptoms. There is also possible feed back as fear of osteoporosis may reinforce a woman's desire to continue taking HRT but, on the other hand, taking HRT may reduce fear of osteoporosis. The variable was included in the model development, however in retrospect the researcher is not sure it should have been included given the uncertainty about the causal process.

It is difficult to be sure of the time sequence between knowing that oestrogen has a role in preventing osteoporosis and taking HRT. A woman may learn this information after taking HRT, for example through reading information given to her by a pharmacist dispensing her HRT, or becoming aware of information about HRT in the media once she has started taking it. Knowing the role of HRT in preventing osteoporosis may prompt a woman to take HRT, particularly if she has a family history of osteoporosis or has a fear of osteoporosis. This variable was used in the model development because of this possible role in a causal process involving other variables, despite the time sequence being so unclear.

For the variable about whether information from the media was felt to be helpful or not, the researcher could see no time sequence or causal process so the variable was not included.

At the time of developing the model, the correlation between whether a doctor was the main source of information about HRT and whether a woman takes HRT or not, seemed determined by HRT being only available on prescription. The variable was not included in the model, however, it would be possible for a doctor not to be a woman's main source of information about HRT and for her to be taking HRT.

5.2.4 Development of three variable models

The cross tabulations of the independent variables with the outcome gave a level of statistical significance of the correlation between the variables and the power of the relationship could be calculated. As discussed above, a correlation does not imply a causal relationship unless there is a causal order and possible mechanism for the causation. Even when these criteria are met, the relationship between the variables may be spurious, where both are caused by the same event, or the relationship may be indirect, with the effect being mediated via other variables (Hage and Meeker 1988:23). There may also be conditional relationships where the effect depends on another variable such as age, and the absence of the conditions makes the cause ineffective (Hage and Meeker 1988:24). As the model only included postmenopausal women, the potential for conditional relationships was much less than if the whole age range for the survey had been included.

The independent variables for the model were examined for the possibility of spurious relationships between the independent variables and the outcome. For example, it is possible that the same event, and one perhaps not included in the questionnaire, could influence a woman's fear of osteoporosis and her use of HRT. There cannot be a spurious relationship between a woman being aged 55-69 years or not and her use of HRT, as age does not have an antecedent cause other than the passage of time, although there may be many intervening variables such as the availability of HRT. Use of the birth control pill and use of HRT is unlikely to be

spuriously related as women usually use the birth control pill much earlier in life than HRT, but a spurious relationship cannot be ruled out such as the emphasis given by a doctor, to the use of hormonal medical interventions. Reported experience of menopausal symptoms and use of HRT is unlikely to be spuriously related, however, it is possible that a woman's understanding of the menopause may affect both the likelihood of her interpreting and reporting symptoms as menopausal and of taking HRT. Similarly a woman's understanding of the menopause may influence her knowledge of, and ability to report, a family history of osteoporosis, as well as her decision to take or not to take HRT. These possible spurious relationships could not be accounted for in the model.

The final stage in this method of model development was to distinguish direct and indirect effects of the independent variables on the outcome. The direct effect of three independent variables was calculated; being age 55-69 years or not; ever having used the birth control pill or not; reported family history of osteoporosis or not. The calculation allowed for indirect effect via the other variables identified for use in the model. The causal sequence had to be taken into account when planning the model. The method described by Hellevik, was used and an example is presented in figure 5.1. The example uses the correlation between women being in the generation aged 55-69 years or not and use of HRT, but allows indirect effect via past use of the birth control pill.

Cross tabulation of number of women using HRT with generation (over age 55 years or not) for postmenopausal women:

	Never used HRT	Used HRT	Total
Under age 55 years	48	33	81
Over age 55 years	173	28	201
Total	221	61	282

Proportion of women who have used HRT:

under 55 years $33/81 = 0.407$

over 55 years $28/201=0.139$

Gross effect of generation membership (age over 55 years) on use of HRT = $0.139 - 0.407 = -0.268$

Generation membership also influences use of the birth control pill, and this also influences use of HRT. The use of the birth control pill can be included in a cross tabulation (incomplete data reduces number of women included):

	Used pill	used HRT	never used HRT	sum	proportion using HRT	partial effect 1	partial effect 2
Over 55 years	yes	12	28	40	0.3	-0.132	0.203
	no	15	140	155	0.097		
Under 55 years	yes	19	25	44	0.432	-0.246	0.089
	no	12	23	35	0.343		

Figure 5.1 Method of calculating the direct effect of membership of the generation over aged 55 years on use of HRT allowing for the indirect effect via use of the birth control pill (drawn from Hellevik 1984) (continued over page)

Partial effects 1 are the effects of generation membership on the use of HRT i.e. $0.3 - 0.432 = -0.132$ and $0.097 - 0.343 = -0.246$

Partial effects 2 are the effects of the use of the birth control pill on the use of HRT i.e. $0.3 - 0.097 = 0.203$ and $0.432 - 0.343 = 0.089$

The average of the partial effects would give a measure of the direct effect of the variable on the outcome, net of the control variable. However the size of the partial effect is dependant on the size of the groups therefore needs to be weighted to allow for this (Hellevik 1984:14-15). The weighting also has to allow for the distribution or variance of the causal variable (ibid:152). For models such as this example with three variables, the weighting can be calculated as follows (ibid:140):

<u>Used pill</u>	<u>Not used pill</u>
$(40 \times 44) / 84 = 20.952$	$(155 \times 35) / 190 = 28.553$
$20.952 / (28.553 + 20.952) = 0.423$	$28.553 / (28.553 + 20.952) = 0.577$

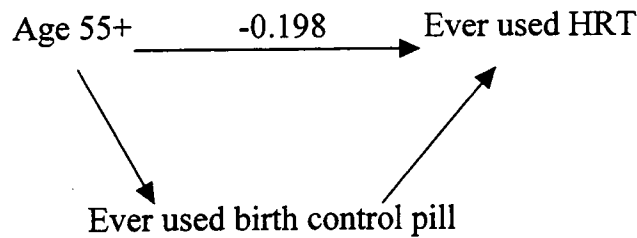
The direct effect of generation on the use of HRT, controlling for the indirect effect via use of the birth control pill, can be calculated as follows:

$$0.577(-0.246) + 0.423(-0.132) = -0.198$$

(- sign indicates a negative effect)

Figure 5.1 continued Method of calculating the direct effect of membership of the generation over aged 55 years on use of HRT allowing for the indirect effect via use of the birth control pill

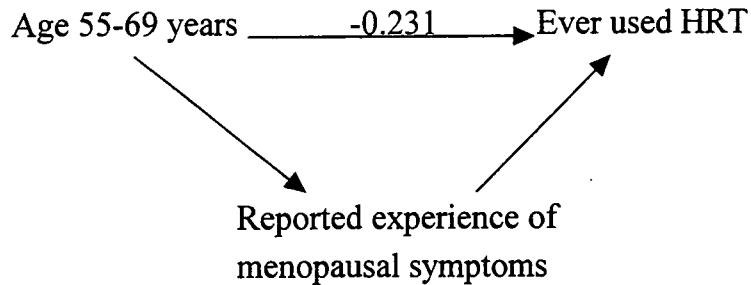
The calculation demonstrates that some of the correlation between generation membership and use of HRT seems to be mediated via whether a woman has used the birth control pill, as the gross correlation is -0.268 , but when the indirect effect is taken into account the effect is reduced to -0.198 . The causal model calculated in fig 5.1 can be represented as:



Membership of the generation over 55 years seems to have a negative influence on whether a woman takes HRT, and this effect persists when the indirect effect via use of the birth control pill is taken into account. The number -0.198 represents the amount of variation in the outcome that is accounted for by the independent variable, membership of the generation over 55 years of age, when the indirect effect via use of the birth control pill is allowed for. If the independent variable accounted for all the variation, this number would be 1. The effect of generation membership on the use of HRT is likely to be at least partly explained by the availability of HRT to women, as when women in their late 60s were going through the menopause HRT was still mostly prescribed in specialist clinics.

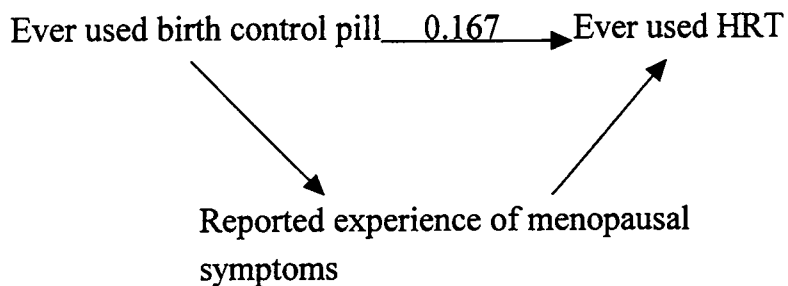
In the model presented, the values for the effects represented by the lower two sides of the triangle, have not been included as these are gross values that may be at least partly mediated via variables not included in the diagram. The above model also does not take into account any indirect effect of generation membership on use of HRT that is mediated via variables not included in the model. However a further model can be developed that does take a different variable into account. For example some of the effect of membership of the generation aged 55-69 years on use of HRT

seems to be mediated via the reported experience of menopausal symptoms. The model can be represented as follows:



The gross effect of generation membership on use of HRT (-0.268) is reduced by taking reported experience of menopausal symptoms into account, but by less than when use of the birth control pill is taken into account.

The effect of the use of the birth control pill on use of HRT can be calculated (gross effect 0.227) allowing for indirect effect via reported experience of menopausal symptoms:



It seems that previous use of the birth control pill has an influence on whether or not a woman takes HRT, but some of this influence is mediated indirectly via a woman's reported experience of menopausal symptoms. The model cannot tell us whether women that have used the birth control pill experience more menopausal symptoms, or report symptoms more, or both.

The three models presented above represent a small part of the complex interaction of variables that may influence whether or not a woman takes HRT. The three models could be combined to form a model that includes all three independent variables and the dependant variable, with indirect effects via the independent variables allowed for. The calculation involved would be complex and difficult to perform by hand, however computer programmes exist for developing models with many variables. This is discussed in the following section.

A gross correlation of 0.38 was found between reporting a family history of osteoporosis and use of HRT, a fairly strong correlation. Calculations were made to find whether any of this gross affect was mediated via the variable naming osteoporosis as the women's main fear for her future health, or via the variable knowing that oestrogen has a role in preventing osteoporosis. No indirect effect was found via either of these two variables, although each of them had their own correlation with use of HRT.

5.2.5 Development of a model with log linear analysis

To overcome the limitations of model development using the method of hand calculating weighted proportions described above, the use of log linear analysis was explored. This method is similar to the method used above as it tests models based on the cell counts from cross tabulations (Gilbert 1993:142), is specifically designed for use with categorical data, and tests models with independent variables influencing a dependant or outcome variable (Gilbert 1993:131-133). However log linear analysis can include more variables in the model and interaction between independent variables.

The theoretical considerations for the development of a model using log linear analysis are as described in the preceding section. The same outcome variable was used, that is whether women had ever used HRT, and the analysis only included postmenopausal women. For log linear analysis, the influence of all the variables is initially

calculated together so only women with data for all the variables can be included in the analysis. The model developed was therefore based on data from 232 postmenopausal women, as 69 women had incomplete data. As for the hand method of calculation, the independent variables had only two values which simplifies the model development, as although the method of analysis can cope with more than two values, the results from using more can be difficult to interpret (Gilbert 1993:139). The independent variables included in the analysis are shown in figure 5.2. The variables are drawn as a flow diagram suggesting how the variables may relate. This was then tested using log linear analysis. Fear of osteoporosis for a woman's future health was not included, as the number of women naming this was relatively small.

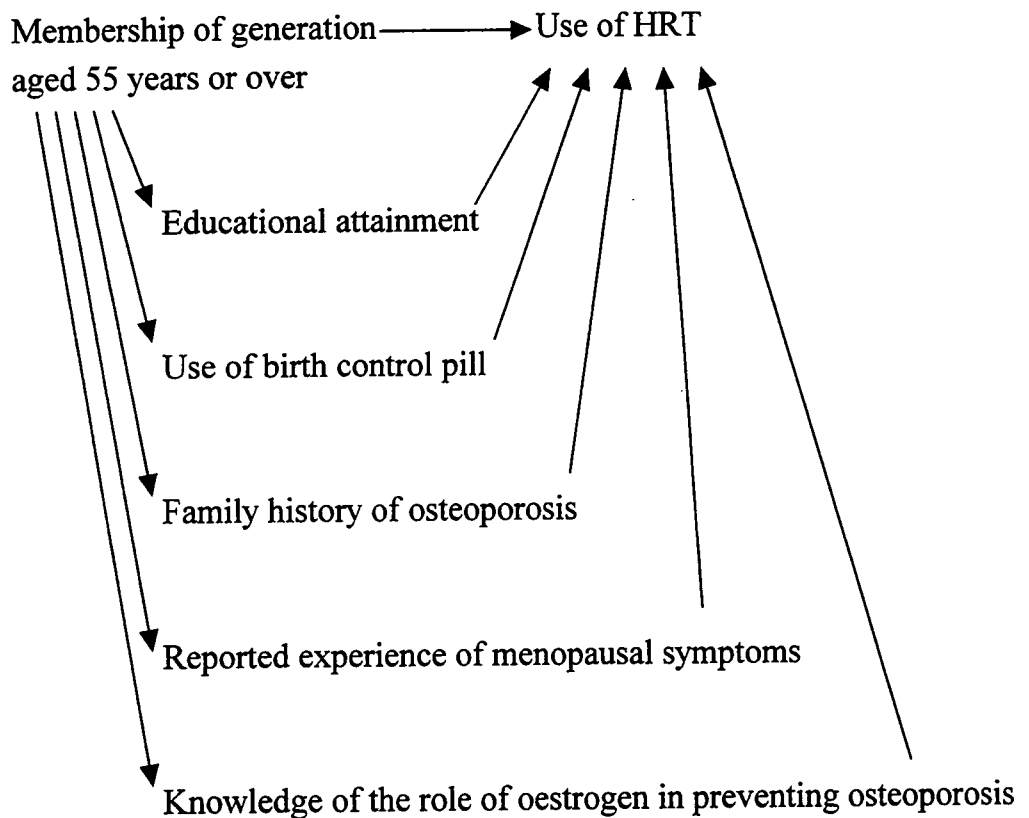


Figure 5.2 Model suggesting how variables may relate for testing using log linear analysis

The possibility of spurious relationships between independent variables and the dependent variable are the same for this method of analysis as for the hand method of calculation. The possibility of indirect effects are coped with in a different way in log linear analysis.

In log linear analysis the variables are used as though they form a mini world of their own that is called the saturated model. This saturated model is all the variables and all the possible interactions between the variables and, by definition, predicts the data totally. The interactions within the saturated model are defined according to the number of variables involved. For example, a first order interaction is the effect of an independent variable on the dependant variable, a second order interaction is the effect, on the dependant variable, of interaction between two independent variables, for example the effect of the interaction of generation membership and family history of osteoporosis on the use of HRT. A third order interaction is the effect of the interaction of three independent variables on the dependant variable. Within the saturated model there may be some interactions that are important for predicting the data of the model, and other interactions that have little or no effect. For example generation membership may have an important interaction with use of HRT that explains a significant part of the model's data, however another interaction such as the second order interaction between use of the birth control pill, education and the use of HRT may explain little of the model's data. Finding which interactions are important and which are not is an exploratory process. Models are set up that have less variables than the saturated model and the goodness of fit of the model to the saturated model is measured. The chi square of the goodness of fit is used to test the hypothesis that the model does not fit the data. If the significance level (p value) is near to zero, the hypothesis is accepted ie. the model does not fit the data. The nearer the significance level is to one, the more accurately the model fits the data (SPSS Inc. 1990:176). There was a recurring problem with this analysis. The analysis programme warned that there were "many empty cross tabulation cells or there was a mixture of large

and small observed counts", findings making it possible that the parameter estimates were incorrect. Despite this warning of potential error in the parameter estimates, many different combinations of the variables were tried. However the highest p value for goodness of fit found was only 0.167 (p value for Pearson Chi Square for goodness of fit). This p value of goodness of fit was found for the interaction of the following independent variables with use of HRT

- generation membership (over 55 years)
- educational attainment
- experience of menopausal symptoms
- knowledge of the role of oestrogen in the prevention of osteoporosis
- family history of osteoporosis
- interaction of generation membership with experience of menopausal symptoms
- interaction of educational attainment with family history of osteoporosis
- interaction of knowledge of the role of oestrogen in the prevention of osteoporosis with family history of osteoporosis.

This means that these variables, interacting with the dependant variable, use of HRT, get closer to explaining the data than any other combination of variables that was tried. The best model that could therefore be found, using log linear analysis, for what influences the use of HRT, included the above variables. However, as mentioned above, the parameter estimates may not be correct because of the data not being sufficiently evenly spread for the assumptions of the statistical analysis. The suggested model in figure 5.2, could be adapted to represent the variables listed above with the variable, use of the birth control pill omitted, and the interaction between variables added (Gilbert 1993:147-152). However, as the analysis is of questionable accuracy, this has not been done.

In addition to the p value for the goodness of fit for measuring how far a combination of variables explain the data in the model, log linear analysis can use another way of measuring the strength of the model. The total dispersion of the dependant variable is subdivided into that explained by the model and the residual, or unexplained variance. A statistic similar to r squared in regression analysis is then calculated, that indicates what proportion of the total dispersion of the dependant variable is attributable to the model (SPSS Inc. 1990:182). This is expressed as a measure of association, which is calculated as the ratio of the dispersion explained by the model to the total dispersion. For the best model found (see above), this measure of association was 0.28 (entropy method of calculating dispersion) which although not a very strong association, would be considered of interest if found in regression analysis. However, a published guide for using log linear analysis indicates that this measure of association cannot always be interpreted in the same way as r squared as the coefficients may be small when the variables are strongly related so "it appears the coefficients are best interpreted in the light of experience" (ibid.). This seems to add further uncertainty to the result obtained.

5.2.6 Discussion

The postal questionnaire survey aimed to explore what influences women's attitudes to take HRT, but the idea of establishing a causal model of these influences was not thought about when the questionnaire was designed. The questionnaire was therefore more a descriptive survey rather than an explanatory survey as it was not designed to test a causal model (Marsh 1982:83). If the questionnaire had aimed to be explanatory, the many possible causes of the outcome would have to be considered in designing the questionnaire (Marsh 1982:74), and attention given to the causal order of variables (Marsh 1982:78). The ordering of variables is a theoretical activity (Marsh 1982:83) best done prior to data collection.

The attempt to use the survey data for developing a model of what influences HRT provides examples of why the theory needs to precede the data collection. Firstly, for many variables used in the survey, it was difficult to be sure of the time sequence and so the causal order of the variables. Some of these problems could have been overcome by asking questions that help establish a time sequence. For example, when asking about a woman's family history of osteoporosis, questions seeking more detail about how a woman knows about the family history and asking when the diagnosis of osteoporosis was made. Such questions would rely on the memory of the woman, and this would limit the amount of data that could be collected using a cross sectional survey. A longitudinal study may make the measuring of causal variables easier. The Medical Research Council in the UK has a research project that has followed a cohort of women since 1946, and the longitudinal data collected is being used to study who are the women that go on HRT in the UK (personal communication D. Kuh 1993). This type of data may be useful in developing a causal model of what influences women to take HRT. A second example of why the theory needed to be developed more before collecting the data, is found in the many possible spurious relationships between variables that were identified. By identifying this prior to data collection, the questionnaire could have attempted to collect data on variables that may produce spurious relationships. For the type of data being considered, this would not be easy, for example measuring a woman's understanding of the menopause, or a woman's perception of the use of hormones. A final example is the way the variables are defined. In the survey the same response to a question may involve a range of experience, and so the data gives a relatively crude measure of these variables. This problem is compounded by the re-coding of the data into just two responses for analysis. It would give a more precise representation of women's experience to break down questions into a number of aspects, each of which could have a "yes" or "no" answer and which if necessary, could be combined during the process of analysis. In summary, the development of a causal model requires development of a theory of the causes for the outcome, and this theory is best developed prior

to collecting the data so attention can be given to the many variables that need to be included and to the ordering of variables.

The variables included in a casual model have to be ones for which it is possible to collect data relatively simply and accurately so it is clear what is being measured. The clarity and accuracy of the model may be enhanced by restricting the model to one type of experience using one particular perspective. For example Gilbert reports a model of some of the influences on voting behaviour for Senators in the US where the three independent variables used were, the voter's party identification, whether a candidate was an incumbent, and voter's attitude to party policy and performance (Gilbert 1993:131). Similarly, a causal model of the use of HRT could concentrate on events linked with a woman's reproductive system and associated medical interventions, asking about fertility, contraceptive use, gynaecological interventions, the menopause, and perhaps the experiences of the woman's mother. This type of data is relatively easy to measure compared to other aspects such as a woman's understanding of the menopause, and it may be possible to collect the data in some detail. Although such a model would take a limited perspective on why women take HRT, within that perspective it may reveal an interesting explanation. The theoretical activity prior to collecting the data for development of a model therefore needs to include clarity about the particular perspective being taken in developing the model and the limitations this imposes on the model.

When log linear analysis was used to analyse the survey data, it was found that the data was not in a form that fitted with the assumptions of the statistical processes, so these processes may not have been accurate. In planning data collection for developing a causal model, attention needs to be given to the form of data needed for the analysis process. However Hage and Meeker warn that there needs to be a separation of "the origination of causal hypothesis from the evidence by which they are tested (to) become free of some of the limitations that the statistical techniques place upon theorists" (Hage and Meeker 1988:12). The two methods of

developing a model described in this section create different images about what the analysis achieves. For both methods, only part of the cause of the outcome is identified as there will usually be influences that have not been measured. The method used to develop the three way models, following Hellevik (1984), takes separate pieces of a possible model and explores them. It is clear these are only small pieces of a possible model and that there are other processes not represented. Log linear analysis uses a theoretical model which itself is only a partial explanation, then tests which variables in the model are important and which can be left out without losing the explanatory power for the model (Gilbert 1993:150). This can give the impression that the result tells us how much of the outcome is explained. However the result tells us how close the model is to explaining that part of the outcome that the saturated model can explain. It is possible to become so involved with a statistical process that, as Hage and Meeker warn (1988:12), the theory becomes restricted by the statistical technique.

An analogy of the theory of causal models with the theory of "chaos" may increase our understanding of the value and the limitations of causal models. A woman will, at one time, not be using HRT, but then may decide to take HRT. There will be many factors influencing the woman over time but at some point she makes the decision to take HRT. A small, possibly immeasurable event may precipitate the change, such as hearing by chance a piece of information about osteoporosis and HRT, which then interacts with the woman's knowledge of her mother having osteoporosis, and so stimulates her interest to find out more about HRT and her interest in taking it. Although it may be difficult to identify the event that precipitated a woman to change from not taking HRT, to taking HRT, there will be social factors that may make the change more likely, for example the availability of information about HRT, and characteristics of the individual woman that make the change more likely such as the woman's family history of osteoporosis or her past experience of medical interventions. The process of developing the causal model is a way of measuring which individual factors make the change for women, from not taking HRT to taking HRT, more likely, expressed

in the statistics of probability. The causal models cannot determine precisely what precipitates the change or the mechanism of the change for an individual woman. An interview study with women may be able to identify what women perceive as the particular influencing factor that precipitated a decision to take HRT and the mechanism for the change. The casual model identifies what makes a change more likely but cannot predict outcome. An interview seeks to understand the processes that occur that bring about the change, and is interested in events or changes in conditions that may be too small or too complex to measure.

5.3 Cluster analysis of the questionnaire survey results

5.3.1 Introduction

The sociological question that cluster analysis seeks to answer is, can women be divided into socially meaningful groups using the survey data and, if so, what are these groupings? The researcher was particularly interested to explore whether the women could be classified into groupings, according to their approach to HRT, that cut across the standard ways of dividing groups of people, such as age and education.

The researcher had planned to follow the questionnaire survey with an interview study and the sample frame for the interview study was to be the questionnaire respondents. The interviews would collect detail from a relatively small number of women compared to the number of women involved in the survey, however the aim was to interview women with a broad range of approaches to HRT. A further reason for using cluster analysis was to explore how the women could be divided, so the sample frame for the interview study could be stratified, so the women selected were more likely to represent a broad range of approaches to HRT.

5.3.2 Cluster analysis method

Cluster analysis is an exploratory process that classifies the women according to questionnaire responses that, from statistical analysis,

appear to divide them. The SPSS command "Quick Cluster" was used for the analysis (SPSS Inc.:563-567). When using "Quick Cluster" the researcher chooses the variables to be used and the number of groups into which the analysis is to attempt to divide the women. Choosing the number of groups is a matter of trial and error, and analysis into up to six groups was tried. Analyses which resulted in some groups having almost no women in one group were discarded. This decision was prompted by the researcher wanting to find broad categories into which women divided, rather than identifying small minority groups, both to answer the question about whether women could be divided according to their approach to HRT and for stratification of the interview sample.

An outline of the process of "Quick Cluster" is as follows. If the number of groups chosen is three, the computerised statistical analysis chooses three reference points and identifies which individual data sets are in proximity to which point to give the first cluster groups. The analysis then repeats this process but using the mid points of the initial three clusters as the reference points. The individual data sets are again divided, this time according to how near they are to the new reference points, giving a new set of clusters. This process is repeated until the clusters no longer change and the clusters are described as stable. The number of runs of clustering needed to achieve stable clusters varies and sometimes no stability is achieved in which case the analysis is stopped when the changes in clustering are at their minimum. The nature of the clusters is examined by comparing the frequency of variables for each cluster with the frequency for the same variables for all respondents to the questionnaire survey.

The choice of variables was an exploratory process. Many different combinations of variables were tried: The nature of the statistical process is that, whatever data is put into the statistical process, the number of clusters, specified by the researcher, is produced by the analysis. The researcher has to decide whether the clusters have any relevance to the social world. The process and results of exploring the survey data using cluster analysis lead the researcher

to develop the following criteria for what was appropriate data to use in the analysis. Firstly the variables used in any one analysis should be about the same type of characteristic. For example, the section of the questionnaire on how far statements about HRT would persuade women to take HRT, and the section asking which were women's main sources of information about HRT. Other variables in the survey were related, and the exploration of causal models, discussed earlier in the chapter, provides examples of theoretical links between variables such as knowledge about osteoporosis and family history of osteoporosis. However these variables are not about the same type of characteristic. The second criterion related to the interests of the researcher. The variables chosen for cluster analysis were those of interest to the researcher as potential ways of classifying the women for stratifying the sample frame for the interview study. The researcher explored many combinations of variables but the two cluster analyses reported are those that fit well with the above criteria. For the cluster analysis all respondents to the questionnaire survey were included.

5.3.3 "Quick Cluster" of responses to how far each of a series of statements would persuade women to take HRT

The responses of the women to the statements about HRT (see table 5.3 for statements) were used in the "quick cluster" analysis. The women had been asked to mark on a score ranging from one to five, how far each statement would persuade them to take HRT (score one represented "would persuade me to take HRT", score three represented "would make no difference to my decision" and score five represented "would persuade me not to take HRT") The number of women marking a score for all the statements was 1007 (82.2% of questionnaire respondents), and these were the women included in the analysis. For 218 women there was a missing value in their data set so these women were excluded from the analysis.

After exploratory analysis it was found these women clustered into three groups that appeared to have some social meaning and where

none of the groups was very small. The size of the cluster groups and the mean scores for each cluster group and for all respondents is presented in table 5.3. Cluster 1 shows a mixed response to the statements. These women were less persuaded to take HRT compared to overall by the statements about living longer on the therapy, that it would make dying suddenly in old age less likely, about it working properly only if taken for the rest of the woman's life, that exercise and a good diet could prevent osteoporosis as much as HRT and that the therapy might cause monthly bleeds. Their mean scores were the same as the overall scores for the statements about the therapy not causing cancer if taken properly and about feeling younger on HRT. They were more persuaded to take HRT than overall by the statements about it preventing heart attacks, strokes and hip fractures and if a test showed the woman was prone to osteoporosis. Cluster 2 was less persuaded to take HRT than overall by all statements and Cluster 3 was more persuaded to take the therapy than overall by all statements.

The cluster groups were compared by age, education, whether they had previously thought about HRT, their use of HRT and their main sources of information about HRT. The 218 women not included in the cluster analysis were treated as a separate group and their characteristics compared to those of the cluster groups. The comparison of the clusters provides data for answering the question whether the women can be classified by characteristics not linked with the standard social divisions such as age and education, and provides data on the groups into which the women were stratified for the interview sample.

In clusters 1, 2 and 3, the proportion of women from each age group was similar but the group of women not included in the cluster analysis tended to be older than those included (chi square = 83.36, 5 degrees freedom, $p < 0.001$, Cramer's $V = 0.26$).

Statement	Cluster 1 (n =373)	Cluster 2 (n=197)	Cluster 3 (n=437)	overall ** (n=1225)
A test showed I was prone to thinning of the bones or brittle bones (osteoporosis)	1.4	2.7	1.3	1.6
I would be less likely to have a heart attack or stroke if I took HRT for five to ten years	1.4	3.1	1.2	1.7
Taking HRT for five to ten years may stop me having a fracture of the hip when I am in my 70's	1.5	3.0	1.2	1.7
HRT would not cause cancer if taken properly	1.9	3.2	1.4	1.9
I would feel younger on HRT	2.2	3.2	1.6	2.2
If I take HRT I might live longer	2.5	3.1	1.6	2.2
Taking HRT would make dying suddenly in old age less likely	2.7	3.4	1.8	2.4
For it to work properly, I would have to take HRT for the rest of my life	3.8	3.7	2.3	3.2
Exercise and a good diet could stop me getting thin or brittle bones (osteoporosis) as much as taking HRT	3.9	3.6	2.6	3.2
HRT might cause monthly bleeds like menstrual periods	4.0	4.0	3.2	3.7

The table gives the mean score for the cluster for each statement

**Overall score is for all respondents including the 218 women who did not give responses to all the statements and so are excluded from the cluster analysis

Table 5.3 Women clustered into three groups according to how far the statements would persuade them to take, or not to take, HRT.

The spread of educational attainment was very similar in clusters 2 and 3; cluster 1, the group of mixed persuasion towards HRT, included 201 women with further training (53.9%) compared with 79 (40.1%) in cluster 2, 183 (41.9%) in cluster 3 and 52 (23.9%) in the group not included in the cluster analysis; women not included in the clusters tended to be of lower educational achievement, with 132 leaving school at 16 without qualifications (60.6%) compared to 101 in cluster 1 (27.1%), 66 in cluster 2 (33.5%) and 151 in cluster 3 (34.6%); (chi square = 84.30, 6 degrees of freedom, $p < 0.001$, Cramer's $V = 0.37$), a moderate trend.

The number of women who had or had not thought about taking HRT varied in the cluster groups. In cluster 2, women less persuaded to take HRT, there were 174 women (88.3%) who had not thought about taking the therapy, in cluster 1, women of mixed persuasion, there were 246 (66.0%), in cluster 3, those more persuaded to take HRT, there were 264 (60.4%) and in the group not included in cluster analysis there were 122 women (56.0%) who had not thought about taking therapy (chi square = 49.33, 3 degrees of freedom, $p < 0.001$, Cramer's $V = 2.1$), a moderate trend. Data on whether the women had thought about taking HRT was more likely to be missing from the group of women not included in the cluster analysis than from those included (data missing for 50 women not included in cluster analysis (22.9%); data missing for 21 women included in cluster analysis (2.1%)).

There was a fairly weak trend between whether the women had ever taken HRT or not and cluster group. In cluster 2, women less persuaded to take HRT, there were 175 women who had never taken the therapy (88.8%), in cluster 1, women of mixed persuasion, there were 305 (81.8%), in cluster 3, women more persuaded to take HRT there were 337 women who had never taken the therapy (77.1%) and in the group not included in the cluster analysis there were 152 (69.7%) (chi square = 12.18, 3 degrees of freedom, $p < 0.01$, Cramer's $V = 0.10$). For women not included in the cluster analysis, data on use of HRT was missing for 27 women

(12.4%) and for women in the three cluster groups, data on HRT use was missing for 18 women (1.8%).

The main sources of information about HRT for the women were very similar across all three cluster groups. Women not included in the clusters included 45 women who had not heard of HRT (20.6%), a relatively high proportion compared to the 111 women overall (9.1%), and they reported less use of all information sources, but especially the media with only 81 women (37.2%) using magazines as their main source of information compared to an overall rate of 54.1%, and only 35 women (16.1%) using TV or radio as their main source of information compared to 30.8% overall.

Summary

The women who responded to being asked what would persuade them to take HRT can be grouped by the "quick cluster" method into those generally more likely to be persuaded to take HRT, those generally less likely to be persuaded to take HRT, and those of mixed persuasion about taking HRT with similar age, education and use of information sources. There was variation according to whether the women had thought about or taken HRT, which is perhaps to be expected. The women not included in the cluster analysis because of gaps in their responses, are a group contrasting with the cluster groups in age, education, awareness of HRT and use of information sources.

5.3.4 "Quick Cluster" of responses to question about women's main sources of information about HRT

"Quick Cluster" was used to cluster women according to their responses to the question asking which were the women's main sources of information about HRT. The question gave a list of possible information sources and the option for women to indicate they had not heard of HRT. Women were able to mark more than one information source or none (see section 4.2.5). For clustering, the data was converted to numeric form, one represented the woman

had ticked the listed item, zero represented a blank. This coding meant that all women responding to the questionnaire survey were included in the cluster analysis, although 44 women (3.6%) had not ticked any of the possible options in the question.

After exploratory analysis the women were clustered into two groups according to their main sources of information about HRT. The size of the cluster groups and the number of women that indicated each source of information as a main source for them is presented in table 5.4. Cluster A tends to use the media more than overall and friends and relations less than overall. Cluster B tends to use friends and relations more than overall and the media less than overall.

Main sources of information about HRT	Cluster A n = 535	Cluster B n = 690	Overall n = 1225
friends/relations	133 (24.9)	486 (70.4)	619 (50.5)
magazines/ newspapers	467 (87.3)	196 (28.4)	663 (54.1)
TV/radio	331 (61.9)	46 (6.7)	377 (30.8)
nurse	28 (5.2)	31 (4.5)	59 (4.8)
doctor	94 (17.6)	121 (17.5)	215 (17.6)
have not heard of HRT	3 (0.6)	108 (15.7)	111 (9.1)

(percentages in brackets)

Table 5.4 All questionnaire respondents clustered into two groups according to their main sources of information about HRT

The cluster groups were compared by age, education, whether the women had previously thought about HRT and their use of HRT. The proportion of women from each age group was similar in the two groups. The proportion of women who had left school at age 16 with qualifications was similar in the two groups; there were 268 women with further training (50.1%) in cluster A, the group who used the media more and friends and relations less for their information, and 247 women with further training (35.8%) in cluster B, the group who use friends and relations more and the media less; there were 155 women who had left school with no formal qualifications (29.0%) in cluster A and 291 women who had left school with no qualifications in cluster B (42.2%); (Chi square = 28.98, 2 degrees of freedom, $p < 0.001$, Cramer's $V = 0.16$), a weak trend.

In cluster A, 183 women had thought about taking HRT (34.2%) and 335 had not (62.6%); in cluster B, 165 women had thought about taking the therapy (23.9%) and 471 women had not (68.3%); (Chi square = 11.94, $p < 0.001$, $\phi = 0.10$), a weak trend. Data on whether women had thought about HRT was missing for 17 women (3.2%) in cluster A and for 54 women (7.8%) in cluster B. There was no trend according to whether women had ever used HRT or not and cluster group by information source.

Summary

The women can be divided by the "quick cluster" method into two groups according to their use of information sources about HRT with one group tending to use the media more and the other group tending to use friends and relations. The two groups are similar in age and use of HRT. Both groups contained a similar proportion of women who had left school at 16 with qualifications, but the women with further training were more likely to be in the group that tended to use the media more as a source of information, and women who had left school with no formal qualifications were more likely to be in the group who tended to use friends and relations more as their information source. Women who had

previously thought about taking HRT were more likely to be in the group that tended to use the media as their information source.

5.3.5 Further clustering to prepare the sample frame for the focus groups

A further step in the cluster analysis was undertaken for stratifying the sample frame for the focus groups, part of the subsequent interview study. The results of this analysis is presented here.

Each of the three groups, clustered according to what would persuade women to take HRT, were further clustered into two groups by main source of information about HRT. The resulting sub groups differed in their use of information sources but not following exactly the same pattern as when all questionnaire respondents were clustered by main information sources. The main variations between the sub clusters is summarised here. Cluster 1, those with mixed persuasion about taking HRT divided into cluster 1A (n=150) where 138 (92.0%) women used magazines and newspapers, and only 18 (12.0%) used friends and relations as a main source of information, and cluster 1B (n=223) where only 85 (38.1%) women used magazines and newspapers but 173 (77.6%) used friends and relatives. In Cluster group 1A, 53 (35.3%) of women indicated using a doctor as a main source of information but only 24 (10.8%) women indicated this in cluster group 1B. Cluster 2, those less persuaded to take HRT, divided into cluster 2A (n=120) where 101 (84.2%) women used magazines and newspapers and 65 (54.2%) used TV/radio as a main information source but only 47 (39.2%) used friends and relatives, and cluster 2B (n=77) where only 4 (5.2%) women used magazines and newspapers, only 1 woman used TV/radio, but 49 (63.6%) women used friends and relatives as a main source of information about HRT. Only 6 women (5.0%) in cluster 2A had used a doctor as information source compared to 16 women (20.8%) in cluster 2B. Cluster 3, women more persuaded to take HRT, divided into cluster 3A (n=254) where all the women had used magazines and newspapers as a main source of information and 112 (44.1%) had

used TV/radio, and cluster 3B (n=183) which included no women that used magazines or newspapers as a main source of information and only 39 (21.3%) used the TV/radio. The use of friends and relations as main information sources by cluster groups 3A and 3B was almost identical. There were no women who had not heard of HRT in cluster groups 1A, 2A and 3A; these women were all in the related cluster, 20 (9.0%) in 1B, 17 (22.1%) in 2B and 29 (15.8%) in 3B.

The results show that the pattern of the clusters, by information source, changed slightly when clustering by information source was done after clustering by what would persuade women to take HRT. However the purpose of the two step clustering was to provide stratification for sampling for the focus groups. As the two step cluster analysis still divided the women into groups that ensured a division of the women by both sets of variables, it was useful for stratification of the sample frame to try and ensure women with a range of approaches to HRT were included.

5.3.6 A comparison of clustering methods

The process of analysis used above, known as "quick cluster", has been used to categorise the women who responded to the questionnaire survey into groups. The variables used for the analysis were chosen by the researcher, as discussed. The number of groups was also chosen by the researcher, although different numbers of groups were tried in the analysis. The results may give an impression that the cluster groups are clearly separate groups. However the method of "quick cluster" analysis will always divide the women, however small the differences between the groups. There is a statistically more complex method of cluster analysis (SPSS "cluster" command (SPSS Inc.:76-83) based on Anderberg 1973) where the researcher does not decide on the number of groups before the cluster analysis, but examines the results of the analysis for where groupings occur. This cluster analysis was undertaken using the data on how far the statements about HRT would persuade women to take HRT. The results were then

examined by asking, if the women were divided into three groups, where would the division be. Of the 1007 women included in the analysis 962 would be in one group, and no women would be in the second and third groups. (This leaves 45 women unaccounted for by the analysis). Using the statistical criterion of this process of cluster analysis, there does not appear to be a statistically significant division of the women into three groups.

5.3.7 Discussion

Cluster analysis was used to explore the possibility of women being categorised into groups according to their approach to HRT, and to explore ways of stratifying the sample frame for the interview study.

The "quick cluster" method of analysis divided the women into groups that seem to fit with common sense and the researcher's clinical experience. Some women are pro HRT, others anti HRT and others have mixed feelings and are persuaded by some aspects of it and not by others and issues such as prevention of future ill health persuade them more than the possibility of living longer or not dying suddenly. Some women use mainly the media for their information and others mainly use their personal networks. Using this method of analysis, it seems that women can be divided into groups according to their approach to HRT. Table 5.3 presents the mean scores for the three groups, clustered according to how far the statements would persuade them to take HRT. The differences between the mean scores of each cluster are relatively small compared to the possible score range. There may be little difference between how far women in different clusters are persuaded by one particular statement, but when used in combination, there is a difference between clusters. However the results of the second method of cluster analysis does not support this, as using the statistical criteria of that method, the women did not divide into three groups.

The two methods of cluster analysis are tools that bring with them particular assumptions and aims. "Quick cluster" uses the data to divide the women into the specified number of groups, similar to dividing a class of children all aged five years into three groups according to when they have their birthday, but using more variables. "Cluster" analysis looks for clusters that exist in the data and was unable to divide the women, just as it would be unable to divide the class of children if their birthdays were relatively evenly spaced through the year. However the groups produced by "quick cluster" appear to be different, and the differences make sense in the social world, just as children who are just five years old differ from children who are nearly six.

The cluster groups, using "quick cluster", were found by trial and error. They were chosen because they made some sense. The second cluster method appears to be a more objective method, but the analysis includes statistical criteria for judging whether a cluster exists, so socially accepted statistical criteria are the judge of whether there are clusters, rather than the individual researcher.

Initially the method of "quick cluster" was used to explore the data, testing out possible combinations of variables for categorising women. Many of the clusters produced did not seem to make any sense in the social world. This exploratory process led to the researcher developing criteria for the variables to be used in the cluster analysis. In retrospect, the idea of only using characteristics of the same type in the cluster analysis appears to be "reinventing the wheel", given the long history of classification in the natural sciences, where characteristics of the same type are used for any one system of classification.

The "quick cluster" analysis clustered women into groups that could be used for stratifying the sample frame. The variables used for the analysis were ones of particular interest for the interviews and so this system of stratification was relevant for the interviews. The cluster analysis of the women's responses to the question about how far the statements about HRT would persuade women to take it,

excluded women who did not respond to all the statements, so this group needed to be included in the interview study as an additional sample group, to avoid missing these women altogether.

5.4 Conclusion

This chapter has presented two approaches to exploring the questionnaire survey data to its limits and contributes to the sociological understanding of women's perspectives on HRT. This conclusion draws out themes from the chapter about the use of research methods and about working across disciplines. It will then link the quantitative work of this chapter to the qualitative interview study described in the following chapters.

Both the development of causal models and the cluster analysis have highlighted the importance of the development and refinement of a theory about what is under investigation, prior to choosing a method of analysis and collecting the data. Theory can make it clear what is being done, what data is needed and the limits of the research. The model development may have been more successful if the possible causal processes had been thought out before doing the survey, and the cluster analysis may have been more fruitful if more data had been collected on characteristics of a similar type. However, theory can seem to limit the perspective taken by a researcher and impose an order on the social world that may lead to important aspects being missed. If this occurs, it may be as much the way the theory is used rather than the theory itself that causes the problem. Use of a theory does not mean that other perspectives and other theories need be rejected, nor does it mean the researcher cannot be open to possibilities not yet thought about.

In the process of model development, a theoretical model was developed then tested, a process of deduction. In cluster analysis the data was explored, but at each stage of analysis the process was one of deduction, each cluster analysis testing a hypothesis. However each stage of the analysis was informed by the earlier stages, a process also used in the analysis of qualitative data, and

the exploratory nature of the process may suggest that the process was more inductive, letting the data speak for itself, rather than testing the data against a hypothesis. The distinction between inductive analysis and deductive analysis may be more to do with the breadth of possibilities to which the researcher is open and the different theories and perspectives be brought to data in small, incremental steps, rather than a very different thought process. Inductive research may be better described as "dynamic objectivity", as described by Fox Keller (1985:117) and discussed in section 1.3.2, rather than implying that the researcher can empty their mind of theory to let the data speak for itself.

Both methods of analysis used in this chapter highlight the close link between the method of analysis to be used and the form of the data. It was very difficult to fit the survey data into the methods of analysis used in this chapter that were not planned to be used at the time of collecting the data. A process of analysis however, places restrictions on the form the data can take and the process of analysis has to be matched very carefully to the aim and theoretical background of the research. The methods of analysis also need to relate to the social context for the research, so the results make some sense in the social world.

There was a danger in both the development of the causal models and in the cluster analysis, of the results appearing to be more than they really are. The causal models are very partial explanations and the cluster groups are not distinct from each other. The account given has tried to avoid any "rhetoric" that may seem to persuade the reader of more than this, as discussed in 3.6.1, and has attempted to keep the qualifications that surround the results in view, for example by not drawing the final version of the causal model from log linear analysis, because of the uncertainty in the analysis.

An analogy with the theory of "chaos" was used to increase our understanding of the difference between causal models and an interview study. The causal model used variables about individual

women, that can be measured, to indicate the probability of a woman taking HRT. An interview study seeks to find out the details of individual women's experiences and may include finding out what the women perceive precipitated them to take HRT and the process by which they decided to take HRT. The detail of what precipitates a change may be too small to measure. The analogy can be continued into the theory of complexity as an interview study may reveal not only tiny detail, but also how many factors interact in a complex way that cannot be understood through the measurement of the detail and the calculation of interactions. The common themes that are drawn out in an interview study may represent emergent themes where the individual details may differ but the overall result is similar.

The process of analysing the survey data to its limits, as described in this chapter, influenced the interview study in a number of practical ways. Cluster analysis was used to stratify the sample frame for the interview study. As has been noted, the desire to stratify the sample frame also influenced the cluster analysis. The development of the causal model highlighted, for the researcher, the strong relationship between family history of osteoporosis and use of HRT. This relationship was apparent in the earlier analysis (see section 4.2.9) but it made a stronger impression when included in the development of the causal model perhaps partly because the women using HRT and those who had used it in the past but now had stopped, were combined into one group. The strength of the correlation found suggested to the researcher that women with a family history of osteoporosis may approach the decision to take or not to take HRT in a different way from other women. In taking the sample for the interview study, women with a family history of osteoporosis were therefore specifically selected to explore this. The process of developing the causal models also highlighted, for the researcher, the complex way variables may interact. The causal model indicated a dynamic process through time, but the data used for the development of the model was cross-sectional, collected at a certain point in time. This tension in developing the model promoted the researcher to consider the dynamic nature of the way

women consider the use of HRT when conducting and analysing the interview study.

Chapter Six

Interview study method

6.1 Introduction

The questionnaire survey, described and discussed in the preceding chapters, provided cross sectional data, from a very large number of women, about women's perspectives on HRT. This chapter describes the method used for an interview study that followed the survey, which aimed to provide detail about women's perspectives on HRT that would complement the quantitative data from the survey and lead to a deeper understanding of women's perspectives (Brody 1991; Wolff, Knodel and Sittitrai 1993). In the discussion of causal models in section 5.2.6, the difference has been highlighted between collecting quantitative data that gives an indication of the probability of a woman taking or not taking HRT, and an interview study collecting qualitative data that describes the detail of women's thoughts and experiences to increase understanding of the factors or events that may precipitate a woman to take, or not to take, HRT, and the process of how women make their decisions or develop their attitudes.

The interview study involved a relatively small number of women compared to the number of women in the survey. The aim was to interview women with a broad range of approaches to HRT, so the interviews would be representative of women in their range of approaches to HRT. The process of cluster analysis, described in the previous chapter, was used to stratify women according to their approaches to HRT.

Two methods of interview were used to provide different types of qualitative data. Individual interviews aimed to explore women's general attitudes to health, how they developed their attitudes to HRT and what influenced them, exploring the woman's personal story. Focus groups were used to provide a context where there was interaction between participants with a potential for exploration of

complex motivations or attitudes (Morgan and Krueger 1993) and where control was more with the participants of the focus group than in an individual interview (Crabtree, Yanoshik, Miller and O'Connor 1993).

In this chapter the sample frame used for the interview study will be described and the two methods of interview described and discussed.

6.2 The sample frame for the interview study

The sample frame for the interview study was formed from respondents to the survey by a question, at the end of the questionnaire, asking if they would be prepared to be approached for an interview. Of the 1225 women responding to the questionnaire, 566 women (46.2%) agreed to be approached for an interview, 595 (48.6%) did not agree to be approached and 64 (5.2%) did not answer the question. The characteristics of the women who agreed and did not agree to be approached for interview, as revealed by the survey data, are described to see if they differ. For analysis by age and education the women not responding to the question about being approached for an interview are included with those who did not agree.

The proportion of questionnaire responders who agreed to be approached for an interview varied with age (see table 6.1), being lowest for women aged under 25 years, rising to a peak for women aged 35-44 years, then dropping in the older age groups (Chi square = 53.05, 5 degrees of freedom, $p < 0.001$, Cramer's $V = 0.21$). A similar trend by age was found when the women were stratified by educational attainment. In section 4.2.1, the response rate to the questionnaire survey was reported (see table 6.1) and the trend by age calculated (Cramer's $V = 0.18$). When the number of women agreeing to be interviewed is compared to the number sent a

Age group	Number of women sent a questionnaire	Number of women responding to questionnaire survey	Number of women agreeing to be interviewed
20-25 years	178	101 (56.7)	26 (14.6)
25-34 years	416	291 (70.0)	145 (34.9)
35-44 years	374	278 (74.3)	160 (42.8)
45-54 years	315	257 (81.6)	124 (39.4)
55-64 years	249	208 (83.5)	90 (36.2)
65-69 years	117	90 (76.9)	21 (18.0)
Total	1649	1225 (74.3)	566 (34.3)

Numbers in brackets refer to the percentage of the number of women sent a questionnaire

Table 6.1 The number of women responding to the questionnaire and agreeing to be interviewed

questionnaire (see table 6.1), the power of the trend by age is similar (Chi square = 60.45, 5 degrees of freedom, $p < 0.001$, Cramer's $V = 0.19$).

Of the 515 questionnaire respondents with higher educational attainment (taken A levels or further training since leaving school), 296 agreed to be approached for an interview (57.5%); of the 249 respondents who left school at 16 with qualifications, 114 agreed (45.8%); of the 450 respondents who left school at 16 with no qualification 150 agreed (33.3%); (chi square = 56.34, 2 degrees of freedom, $p < 0.001$, Cramer's $V = 0.22$), a moderate trend.

Women who had previously thought about taking HRT were more likely to agree to be approached for an interview than those who had not, in all age groups except women aged 65-69 years. This trend was most powerful for the age group 34-44 years (Chi square = 24.54, $p < 0.001$, $\phi = 0.31$). Women who had taken HRT were more likely to agree to be approached for an interview in the age

groups 35-44 years, 45-54 years and 55-64 years, but in each age group the trend was less powerful than by whether the women had previously thought about taking HRT.

Analysis of women's personal and family history of osteoporosis with whether a woman agreed to be approached for interview revealed no trends.

The trends described above indicate that women with an interest in HRT were more likely to agree to be approached for an interview. This is not surprising as an interview requires a commitment of time, energy and thought from the participants, so those with some interest, and who may feel they may gain something such as information from the discussion, would be more likely to agree to participate. The age trend in the response rate is not surprising as for younger people HRT has not yet become relevant and older people may feel it is no longer relevant for them. Comments from the few people interviewed in the age groups at the extremes of the age range seemed to support this. The higher rate of agreement to be approached for interview by those of higher educational attainment was not surprising as these women may be more accustomed to discussing issues of this type, or feel more confident in their ability to do so.

The aim of the sampling process for the interview study was to include women with a wide range of perspectives on HRT. The sample frame is biased towards women with an interest in HRT. However, if a different recruiting system had been used, this bias may still have been present, for the same reasons discussed above, and without the survey data the bias may have been less apparent. In this study the bias, by the characteristics measured in the questionnaire survey, is quantifiable and explicit as comparison is possible with questionnaire respondents not agreeing to be approached for interview, and for age group, comparison is possible with questionnaire non-responders.

6.3 The individual interview study method

6.3.1 Recruiting for the individual interviews

The individual interviews aimed to explore how women developed their attitudes to HRT and what influenced them. The clustering described in section 5.3.2 provided a way of stratifying the sample frame to ensure women with the different approaches to HRT identified by the cluster analysis, were included. Women not included in the cluster analysis formed a fourth group, (see section 5.3.2). As these women had not completed the question about what would persuade them to take HRT, their approach to HRT may have been less well developed. As family history of osteoporosis appeared to be an important influencing factor on whether women took HRT (see section 4.2.9 and section 5.2.4), women with a family history of osteoporosis formed a fifth group for sampling.

The number of women who had agreed to be approached for interview in each of the five groups used to stratify the questionnaire respondents, is presented in table 6.2. Women in cluster 3, those more persuaded to take HRT and women in cluster 1, those of mixed persuasion about HRT were more likely to have agreed to be approached for interview than those in cluster 2, women less persuaded to take therapy, and those not included in the cluster analysis, but the trend was not strong (chi square = 27.42, 3 degrees of freedom, $p < 0.001$, Cramer's $V = 0.15$). Sampling equally from the cluster groups and those not included in the cluster analysis may have helped reduce bias towards interviewing women with very positive views on HRT, but including women with a family history of osteoporosis as a separate group may have increased this bias.

Cluster 1	
women of mixed persuasion about HRT (n=373)	182 (48.8%)
Cluster 2	
women less persuaded to take HRT (n=197)	71 (36.0%)
Cluster 3	
women more persuaded to take HRT (n=437)	228 (52.2%)
Women not included in clustering (n=218)	75 (34.4%)
Women with a family history of osteoporosis (n=78)	45 (57.7%)

Table 6.2 The number of women (percentage) that had agreed to be approached for interview for each of the groups used to stratify the questionnaire respondents for the individual interviews

The questionnaire respondents were divided into the five sampling groups then the women who had agreed to be interviewed in each group were identified. From these 25 women were invited to be interviewed individually, five women chosen randomly from each group. The number of individual interviews actually carried out was guided firstly by practical advice in the literature indicating that the number of interviews needed varies, depending on the research, but eight to ten are usually required, but sometimes more than 20 are needed (Crabtree, Yanoshik, Miller and O'Connor 1993), and secondly by the idea that sampling should cease when theoretical saturation is reached, when no new analytical insights are forthcoming (Glaser and Strauss 1967 discussed in Arber 1993). The decision to invite 25 women was based on an initial estimate of the number of interviews needed, allowing for some non-responders. After 15 interviews the researcher felt there was no new material being revealed by the interviews, but a further two

were carried out to check this and to complete interviews with women who had already agreed to interview.

For both the individual interviews and the focus groups, permission for the study was obtained from the GPs of the women included in the questionnaire survey. The GPs were invited to check the lists of women to be invited for women where circumstances might make an approach inappropriate. However, no women were excluded. Invitations for individual interviews were sent out between September and December 1994 and the interviews were completed by February 1995.

The researcher sent each woman a letter of invitation with a reply slip and stamped addressed envelope. The letter explained that the study followed on from the questionnaire survey, that the aims of the study were to increase our understanding of women's attitudes to health, ageing, the menopause and HRT, that the interviewer was a GP but doing the research as part of a PhD in Sociology, and that the woman's GP was aware of the study. It was explained that the interview would be tape recorded and the information recorded would be transcribed but kept confidential. It was suggested that the interview could be carried out in the woman's own home or, if not convenient, in an agreed meeting place, and would last approximately 45 minutes. The reply slip gave a choice of agreeing to be interviewed, being given more information before deciding or not agreeing to be interviewed, and a contact telephone number was requested where possible. It had been the researcher's intention to send no reminders to non responders to avoid putting pressure on them to agree to an interview. However, the office receiving the replies moved within the University at the time replies were expected. Few replies were received in the first two weeks after sending out the invitations so the researcher was concerned that replies may have gone astray. A reminder was therefore sent to those who had not replied.

The sample group and response of the women invited to be interviewed is presented in table 6.3.

Cluster or sample group	interviewed	not interviewed
Cluster 1: mixed response	4	1
Cluster 2: less persuaded to take HRT	3	2
Cluster 3: more persuaded to take HRT	2	2
no attitude cluster	3	2
family history osteoporosis	5	0
Total	17	7*

* does not include one woman not at listed address

Table 6.3 Sample group membership of women invited to be interviewed individually

The seven women not interviewed included two who replied saying "no" and five who did not reply.

6.3.2 Conduct of the individual interviews

The individual interviews were carried out by the researcher on a one to one basis in all but two interviews; one where the woman's husband stayed in the room, and another where a friend arrived and joined in with the discussion.

At the start of the interview the researcher introduced herself, her roles as a local GP and researcher in sociology, her institution as Durham University and the aim of the research as to increase our understanding of women's attitudes to health and HRT and to form part of the researcher's PhD thesis. The researcher explained to the interviewee that the contents of the interview would remain confidential to the researcher and the secretary transcribing the interview recording. It was also explained that extracts may be used in reports of the research but that these would be anonymised and care taken to ensure they could not be attributed to the interviewee. The researcher then gave an overview of the interview; that it would start by asking about health in general and then later focus on

HRT (Burgess 1984:117-118). The researcher opened up the interview with an open question about the woman's health "How do you feel about your health at present?" and explored the woman's attitudes to health. The researcher found it helpful to ask the woman to reflect on the health of her family and friends as well as her own health to help this exploration. After exploring health in general, the researcher asked the woman how she felt about the menopause and about getting older. This often led on to a discussion about HRT, but if not, the researcher asked the woman about her views on HRT. The researcher encouraged the woman to reflect on HRT, both for symptom relief and for prevention of osteoporosis and CVD. During the interview the researcher used open questions to allow the women to take up topics in the way she wished but the interviewer attempted to clarify and probe further where appropriate and possible (Burgess 1984:119-120). Towards the end of the interview the researcher asked if there were any questions that the woman wanted to ask. The interviews lasted approximately 45 minutes. A few were longer, but most of the extra time was while tea was being made or was spent on discussions not associated with the interview topics.

The interviews were tape recorded to provide a fuller record of the interview than if recorded only in written notes. It was hoped this would reduce the sifting of the data by the researcher in the process of the interview, as the researcher was trained and experienced in sifting interview data according to the medical model, and the process of an in depth interview without the aim of diagnosis and management was new to her.

The conduct of the interview was planned taking into account factors that could affect the interview process (Burgess 1984:103-105). The use of listening skills, eye contact and body language were familiar to the researcher from her general practice training and their use was enhanced by not taking notes during the interview. The place for the interview was left to the choice of the interviewee. The length of the interview seemed sufficient for the relatively focused nature of the discussion. The gender of the

interviewer can affect the interview and for this study the most appropriate gender probably was female.

The researcher made notes of her reflections on the interviews, focusing on the process of the interview, and these helped the researcher develop her interview technique. For example, the researcher became aware of comments lost from the transcript as they were spoken when the tape recorder was turned off, so turning the tape recorder on became the first action on sitting down and it was only turned off when about to get up to go. To begin with, the researcher had difficulty coping with being a doctor and doing this research. This was noted as being wary of asking a woman about her negative feelings about her own GP, and being worried about giving an opinion about HRT when asked, as this may affect the woman's opinion especially as the researcher was a doctor. The researcher developed a strategy for dealing with this after the first two interviews which included a clear and detailed introduction of the researcher's background, demonstrating a willingness to give information but indicating that advice on individual medical problems should be sought from the woman's own doctor and, where necessary, indicating that the researcher's role as doctor and researcher may make it seem difficult for interviewer and interviewee to discuss some things, but that the researcher was interviewing primarily as a sociologist. The researcher noted several other problems; forgetting to ask about certain issues; making assumptions in the phrasing of a question for example, "Did you have problems with the menopause?" rather than asking a more neutral question such as "How did you find the menopause?"; assuming that a woman's attitude to, for example long term HRT, might be based on her expressed attitude to long term medication in general, so missing an opportunity to look for inconsistencies; feeling concern about asking probing questions where a woman seemed defensive; feeling concern about causing increased anxiety, discomfort, anger or worry through the questions asked. These issues were discussed in supervision and the researcher records being encouraged to be as probing as the interviewee would allow, but respecting their right not to answer a question.

As the interviews progressed the researcher records feeling more at ease in the interviews, although noting this was more so with women with some similarity of background or who were experienced in being patients. The researcher notes some difficulty relating to one woman who seemed to have thought little about the future and who seemed to find questions about hypothetical situations difficult. It was at the very end of this particular interview, after the woman had asked more about the research and the researcher, that the woman finally expressed her fears and attitudes.

By the fifth interview the researcher felt more confident and began to enjoy the interviews, recording in the research notes:

I left with the feeling of how important people's stories are, how good it was to have the time to sit and listen in a relaxed way. I felt each person I interviewed had their own consistent, understandable, rational (subjectively) view on health, prevention, drugs etc. based on their own experiences, and that as a health professional, I need to understand that and be aware of clashing with that. However, I had plenty of time to listen, not the usual ten minutes of a consultation.

The process of developing the interview technique has been reported in some detail to highlight how interviews are affected by the social context in which they occur and how the process of doing the research affects subsequent research technique. It reveals some of the problems caused by crossing the boundaries of academic disciplines, in this context clinical general practice and sociology, for example the discomfort described in the first few interviews and the potential sifting of data, but it also reveals some of the rewards of crossing this boundary, for example the interest in seeing patient's accounts of their illness as stories (Brody 1987), that was prompted by the experience of doing the interviews.

6.3.3 Analysis of the individual interviews

The sensation of being overwhelmed by data from qualitative studies is identified by Dey (1993:66) and was felt in this study. Dey offers guidance to help find a focus for analysis which includes identifying the analytic objectives and the audience (ibid.). The analytic objectives for the interviews were identified as: to explore women's attitudes to HRT and their important determinants, whether these differ from women's approach to other issues about health and illness; to explore any associated dilemmas for women. The main audience was identified as general practice, with the aim of increasing GPs understanding of how HRT is best offered to women in their best interest; what is behind the questions women ask about HRT; what social forces, history and individual experience needs to be taken into account in consultations about HRT.

Exploring women's attitudes to HRT and their important determinants involves exploring women's beliefs about what led them to take the approach to HRT that they have. Draper suggests that it is difficult to be sure of beliefs about causality unless extended explanations are drawn from people, as it is important to know about pre existing background knowledge (Draper 1988). The interviews provided extended explanations and allowed some assessment of the importance of context and pre existing mutual understandings (Antaki 1988).

The idea of identifying dilemmas for women in their approach to HRT developed from work in psychology, which suggests that people can hold quite contrary ideas at any one time:

Common sense contains contrary themes and these enable the emergence of social dilemmas....the contrary themes of common sense represent the materials through which people can argue and think about their lives (Billig, Condor, Edwards, Gane, Middleton and Radley 1988:8).

Holding contrary themes may therefore not be a dilemma in the sense of a difficult decision between two choices, but a way of processing ideas. Identifying contrary themes formed an important part of the process of analysis. This is possible in qualitative research, but contrary themes are unlikely to emerge in quantitative studies or, if they do, may be interpreted as inconsistencies.

The objectives and audience for the analysis demonstrate how the study developed on the interface between the disciplines of general practice and sociology, with input from psychology, while considering a medical intervention from biomedicine and biostatistics. The process of working on the interface is also visible in the methods of analysis used. The researcher was comfortable with the idea of template analysis of the interview data, where a list of categories of themes or subjects is developed (Crabtree and Miller 1992a). This feeling probably came from the researcher's background in medical sciences which deals with categories of disease, and the researcher's knowledge of quantitative research, which often operationalises concepts such as health outcomes in categories.

The interview transcripts were checked for transcription errors by listening to the recordings of the interviews, then coded using a word processor (Reid Jr. 1992). The template approach was used initially with a list of categories, or codes developed from the researcher's ideas and the experience of the interviews. The interviews were divided into sections which were about a particular issue, and each section was given one or more codes. Additional codes were developed during the process of analysis. The following are examples of coding categories: attitude to ageing, knowledge of densitometry, doctor's attitude to HRT, exercise to keep fit, effect of medical family history on attitude, opinion of information from media, concern about long term medication. This coding process was followed for 12 of the 17 transcripts. Some of the categories became very wide as many aspects of a similar subject were included, some codes were little used because of overlap with other similar codes, and many of the codes were not

directly relevant to the research aims as the researcher was attempting to code the whole of the interviews. Most sections of the interviews had many codes, the categories interlocking with each other. This template method of analysis led the researcher to immerse herself in the interview data through a process that was familiar. However the method was abandoned, as the process and type of codes used did not seem appropriate to the aims of the analysis and did not seem to lead to increased understanding of how the women approached HRT, as it only listed the topics discussed in the interviews.

Having become immersed in the data, the researcher moved on to use the analytic approach known as immersion/crystallisation (Crabtree and Miller 1992b), attempting to see what themes crystallised from the data through reflecting on the data. The five interviews not coded for template analysis were read and re read to include them in the data pool. The immersion/crystallisation method of analysis attempts to allow the data to speak for itself although, as discussed in sections 1.3.2 and 5.4, a researcher cannot approach data with an empty mind. There were three themes that recurred in the interviews and caught the interest of the researcher. These were: dislike of medication yet being prepared to consider taking HRT; the power of the doctor and women's attitudes to this; women's attitudes to osteoporosis and future disability. The first theme seemed to emerge strongly from three interviews, and was then identified in a further five interviews. At this stage the researcher decided to focus on exploring this particular theme with its contradictory nature, so went on to examine the attitudes to medication of the seven women interviewed who were taking regular medication. This exploration then led the researcher to an awareness of the different types of factors influencing women's attitudes to medication, and in particular to HRT. Each interview was re-read to identify these factors and group them into categories. The categories developed were as follows: fear; personal experience and the experience of family and friends; doctors advice and tests, and the assessment of risk; the media; employment, training and background. By this stage the interview transcripts had

been combed several times for data relating to the theme of a dislike of medication yet being prepared to consider HRT, and the researcher had developed a model of how the different types of factor influenced a woman's attitudes to medication, with fear being the link between the influencing factors and how women viewed medication, and HRT in particular. The researcher then turned to examine the themes of the power of the doctor and women's attitudes to this, and women's attitudes to osteoporosis and future disability. As she started going through the interview transcripts identifying where these themes had been discussed, she found the relevant passages had already been identified as contributing to the analysis of the dislike of medication yet being prepared to consider taking HRT, and factors influencing women's attitudes to medication. The themes about the power of the doctor and women's attitudes to this, and women's attitudes to osteoporosis and future disability had become incorporated with the analysis already complete. These themes were not pursued further as separate themes as the researcher felt this would not add to the analysis, and she was confident that the analysis had already incorporated practically all of the interview data that related to HRT.

"Grounded theory" (Glaser and Strauss 1967) has become a widely used approach to the analysis of data such as these individual interviews, and emphasises hypothesising inductively from the data, in particular using the subject's own categories and concepts (Pope and Mays 1995). The researcher sought to develop her analysis and the model of what influences women's attitudes to medication from the data, using the concepts and expressions of the women themselves. However, on reflection it is also apparent that the interests and background of the researcher influenced the direction of the analysis. For example, the researcher's interest in contrary themes may have increased her awareness of the apparently contrary attitudes held by some of the women towards medication and HRT. The interest of the researcher in factors influencing women's approach to HRT may have been a prompt to look for these, and her clinical experience may have influenced the type of influence identified. The literature search and questionnaire survey

results, undertaken prior to the study, may also have influenced the analysis. This context for the analysis has to be taken into account when the results of the interview study are presented. However, this does not mean that the themes presented in the results of the study were not present in the data, but that the context for the research may have highlighted them. The process of the interviews will also have influenced what women said. This type of influence may bias the results of the interviews, but is present for all qualitative research although the extent of the influence of the researcher and the research process may vary. Qualitative research seeks to solve the problem of bias, firstly by reducing any artificiality from the research setting and secondly by the researcher being reflexive about their role and any bias (Armstrong 1996). Conducting the interviews in the woman's own home may have helped to remove some artificiality and, as discussed, the researcher was very aware of her influence on the conduct and analysis of the interviews.

Other ways of reducing the potential bias in the analysis of interviews have been suggested. An independent assessor may have been able to determine whether the themes picked out by the researcher were as central to women's approach to HRT as they seemed to the researcher (Mays and Pope 1995), but an independent assessor was not available. In action research the researcher may take the analysis back to the women who were interviewed to ask them if the analysis made sense to them. This possibility was not considered until well after the interviews when there seemed too much of a time lag since the interviews to go back to the women, and as the women had not been asked about this at the time of the interview, it may have been seen as an intrusion, or even putting them under pressure to help further with the research. When exploring the theme of a dislike of medication yet being prepared to consider taking HRT, the researcher attempted to check for bias in the analysis by actively looking for examples in the data which might challenge the developing analysis (Helman 1996; Mays and Pope 1995). Only one woman was identified as coming near to expressing a negative attitude to medication and to HRT, rather

than holding a negative attitude to medication and being prepared to consider taking HRT, however she did not dismiss the idea of HRT. Thus there did not appear to be examples in the data challenging this stage of the analysis. The researcher had noted how the woman who came near to being negative about HRT appeared to be looking to the researcher for guidance about HRT. The context of the research, with the interviewer being a doctor, may have impeded women from expressing a negative attitude to HRT, so explaining why no example was found to challenge the analysis. However, it is also very difficult for one researcher, having developed an analysis of a data set, to then approach the same data afresh looking for examples that challenge the analysis. The researcher may not have noticed examples that an independent researcher, new to the data, may have noticed. As an independent researcher was not available the researcher decided to rely on an awareness of the context of the interviews and their analysis, to reduce the effect of bias on the results and conclusions of the study.

6.4 The focus group study method

6.4.1 Recruiting for the focus groups

The cluster analysis described in section 5.3 was used to stratify the sample frame for the focus groups. When developing the sample frame, the researcher thought that the women not included in the clusters, because of incomplete responses in the questionnaire, would be unlikely to want to attend a focus group as this seemed to require more interest and motivation than the questionnaire. Therefore, these women were not included in the sample frame. In retrospect, it seems omitting this group of women may have missed some interesting contributions to the focus groups as these women may have brought a different perspective to the groups, and may have welcomed the prospect of discussing the subject to inform themselves and develop their own thinking on the subject.

As the focus groups aimed to explore how women developed their attitudes to HRT, including using information about it, clustering by

use of information sources about HRT was also used to ensure that both women who tended to use the media as their information source, and women who tended to use friends and relatives, were included in the focus groups. The analysis of the clusters into these sub clusters was described in section 5.3.4.

The number of women agreeing to be approached for interview in the six cluster groups is presented in table 6.4. The proportion of women agreeing to be interviewed was similar in all the groups except group 2B where it was lower (chi square = 24.01, 5 degrees of freedom, $p < 0.001$, Cramer's $V = 0.15$; with group 2B excluded there was no trend). This cluster included women who were less persuaded to take HRT and who used friends and relatives as their main source of information about HRT.

The women who had agreed to be approached for interview in each cluster group were listed, and from these the 107 women invited to attend a focus group were randomly chosen, 18 women from five of the six groups and 17 women from one group. The list of 107 women was checked to ensure it did not include any of the 25 women invited for an individual interview. Five focus groups were arranged in the period October to early December 1994. The number of groups was based on advice in the literature to have sufficient groups to ensure analysis was unlikely to be based on an unusual set of participants or an unusual group dynamic (Wolff, Knodel and Sittitrai 1993), the practical problems of getting people

Cluster 1A (n=150)	77 (51.3%)
Cluster 1B (n=223)	115 (51.6%)
Cluster 2A (n=120)	52 (43.3%)
Cluster 2B (n=77)	19 (24.7%)
Cluster 3A (n=254)	139 (54.7%)
Cluster 3B (n=183)	89 (48.6%)

Table 6.4 The number of women (percentage) that had agreed to be approached for interview for each of the groups used to stratify the questionnaire respondents for the focus groups

to the focus groups, the cost of the venue and the number of groups used by other researchers (usually four to six) (Crabtree, Yanoshik, Miller and O'Connor 1993).

A letter of invitation, similar to that used for the individual interviews, was sent to the women but inviting them to attend a group discussion in a town centre hotel. Reimbursement of any travel expenses, including taxi fares, was offered. The hotel was chosen as the venue to be as neutral as possible in its associations (Krueger 1993) and, being the best the town centre could offer for hotels, to make the participants feel considered and respected (Morgan and Krueger 1993). The women were asked to return a reply slip indicating whether they would be attending the group and a stamped, addressed reply envelope was enclosed. The researcher aimed to have six to ten women in each group (Crabtree, Yanoshik, Miller and O'Connor 1993). For the first group twelve women were invited to attend on a specific evening but only three attended. For the second group 24 were invited to attend on a specific evening and eight attended. From feedback from the women attending, and reflecting on the research process, the researcher realised that having the groups in the evening may exclude some women such as those who felt unsafe being out in the evening, those with children and needing a babysitter to go out, and those working in the evening. For the third, fourth and fifth group the letter of invitation gave a choice of a morning, afternoon or evening group, and was sent to 71 women. No reminders were sent.

The cluster group membership of the women invited to attend a focus group is presented in table 6.5 (see section 5.3.4 for details of clusters). In reply to the invitation, 31 women agreed to attend a focus group of which 25 actually did attend and two sent apologies, 38 women replied saying "no", 37 did not respond, and one letter was returned by the post office marked "gone away". The lower response rate for the focus groups compared to the individual interviews may have been partly due to the nature of the interview, but practical considerations were a problem for the focus groups, as

Cluster group	attended	did not attend
Cluster 1A	4	14
Cluster 1B	2	16
Cluster 2A	4	13
Cluster 2B	6	12
Cluster 3A	4	14
Cluster 3B	5	13
Total	25	82

Table 6.5 Cluster group membership of women invited to attend a focus group

the women had to be available at a specific time at a venue away from home. The venue for the focus groups was in the town centre to be central for access, but women attending the evening groups mentioned how they did not like coming to the town centre alone at night and most had arranged for family members to transport them.

Women from cluster 1B, those of mixed persuasion about HRT and tending to use friends and relatives as their information source, were under represented in the focus groups. The age, education and cluster group of the women attending each of the five cluster groups is presented in table 6.6. No women aged 65 or over attended the focus groups and only three women under 35 years attended. As discussed in section 6.2, the lack of women in the lowest and highest age groups was not surprising as they may not feel HRT is an issue they want to discuss. Women from all levels of educational attainment attended the focus groups although there were more with A-levels or further training after leaving school than from either of the other educational groups. This was not unexpected as women attending a focus group have to be confident about speaking in a group, and those with higher education may have more experience of this. The make up of each focus group varied according to the cluster groups of the women attending. This may have made it more likely that the different groups approached

	Age group (years)	Education	cluster group
Evening group 1	45-54	1	2B
	35-44	3	2A
	55-64	1	1B
Evening group 2	45-54	3	1B
	45-54	3	1A
	45-54	1	3B
	35-44	2	3A
	45-54	3	2A
	20-24	2	3A
	25-34	3	2A
	25-34	1	2B
Morning group	55-64	2	2A
	35-44	3	2B
	55-64	1	3B
	55-64	3	2B
Afternoon group	55-64	3	1A
	35-44	3	1A
	35-44	3	2B
	55-64	1	3A
Evening group 3	35-44	3	2B
	45-54	3	3B
	35-44	2	3B
	45-54	2	3A
	45-54	2	3B
	35-44	3	1A

Education: 1 - left school with no formal qualifications; 2 - left school at 16 with qualifications; 3 - left school after taking A-levels or further training since leaving school

Cluster groups - see section 5.3.4

Table 6.6 Age, education and cluster group of the women attending focus groups

the discussion differently so allowing exploration of the issues in a number of different ways.

6.4.2 Conduct of the focus groups

The focus groups were conducted by the researcher alone using a very high quality tape recorder and little background noise to interfere with the recording. However having a group moderator in addition to the researcher would have enhanced the data collection, as the researcher could have taken notes to complement the tape recording of the discussion (Krueger 1993). Each focus group lasted one and a half hours with coffee and biscuits to welcome the participants on arrival. The chairs in the meeting room were arranged in a circle, with the tape recorder and biscuits on a low table in the centre, so participants could see each other (ibid.).

At the start of each meeting the researcher introduced herself and the aims of the research as described for the individual interviews and explained about confidentiality and anonymity. Each woman was then asked to introduce herself to the group and this provided identification for each individuals voice on the recording. The researcher introduced the subject of HRT by asking the group what they knew or had heard about HRT, in order to establish a common knowledge base. To open up the discussion, participants were invited to discuss the statements about HRT that were used in the questionnaire survey asking women how far each statement would persuade them to take HRT (see table 4.12 for text of statements). The order in which the statements were discussed and the direction of the discussion was left to the group as far as possible. By using the statements the participants had read when filling out the questionnaire it was hoped to tap into an already familiar area so the discussion would be free flowing (Morgan and Krueger 1993).

During the focus group the researcher provided information about HRT when asked, trying not to weight the information with opinion. The researcher tried not to indicate that she held any particular position that might then influence the focus group and

used encouraging cues and neutral responses as far as possible (Krueger 1993). At the end of the group the interviewer asked if there were questions the participants wanted to ask (Krueger 1993).

Focusing directly on HRT rather than exploring women's attitudes to health in general, contrasted with the schedule used for the individual interviews. In the individual interviews the researcher was interested in hearing, in detail, the background to each woman's approach to HRT and factors that influenced her, hearing her story. In the focus group there was the opportunity to use the interaction between participants to prompt women to explore their motivations and to challenge their views. The researcher decided to focus straight onto HRT to give the group a clear boundary to the subject for discussion and so to encourage the group to discuss the issues in detail, looking at the complexity of the issue, even if this was not easy for the group.

6.4.3 Communication processes within the focus groups

The context of the focus groups and their format may affect the data collected in similar ways to individual interviews, but there is also interaction between participants which affects what is said and how it is said. The researcher's notes made at the time of the focus groups reveal her changing view of the group communication processes, from the researcher becoming aware of them, through concern about how to cope with them and then allowing them to be part of the research process and data (Albrecht, Johnson and Walther 1993). For example, after the first focus group (evening group 1), the researcher was aware of some communication processes, noting some antagonism between Mrs R and Mrs Q, as the former was interested in HRT and the latter was very against any "pills". Mrs Q was quite adamant about her view and was not to be persuaded on any grounds. Mrs R appeared to cope with this tension by putting HRT in a different category from the other "pills", thus putting Mrs Q's attitude to one side so allowing discussion of HRT to continue. After the second focus group (evening group 2) the researcher describes finding it quite difficult

to enable the woman who seemed least articulate, to speak without allowing her to bore the group or stray off the subject too much, as she often seemed to be at a tangent to the rest of the group. For the final three groups the researcher had become more aware of how communication processes seemed to affect what was said, noting that the groups sometimes formed group attitudes. For example, one group (morning group) was very positive about going into an old people's home, when they got older, to benefit from the company, while other groups did not like this idea. The morning group included one woman who had just arranged for her mother to live in an old people's home. She shared her concern and guilt about this with the group. The group attitude appears to have been a response to this, offering the woman reassurance. The process of doing the research thus influenced the researcher's understanding of the data.

There are many theories about communication processes in groups which can be used to assess how the dynamics of interactions in the groups may improve or reduce the quality of a focus group study. Which theory is most helpful depends on the purpose of the focus group (*ibid.*). For example, where the aim of a focus group is to generate a group opinion, then the model of the process of opinion giving developed by Kelman (1961) can be used to examine the quality of focus group data (Albrecht, Johnson and Walther 1993). The focus groups for this study did not overtly aim to generate a group opinion although, as in the example above, some group opinions did develop and the researcher became aware of some of the pressures and processes that Kelman's theory describes.

Kelman (1961) suggests that opinions are generated through one of three processes, compliance, identification and internalisation. Each of these processes may occur in a focus group and can reduce the quality of the data (Albrecht, Johnson and Walther 1993). When participants are compliant they respond in ways they believe are expected by the questioner, in anticipation of some immediate reward. In a focus group, compliant opinions may be very superficial and if not questioned may result in the early ending of

the group. Identification is a process where participants identify themselves with one person's opinion and this becomes a group opinion. Participants are more likely to identify with the opinion of the group leader or a powerful or attractive group member. This process can lead to the devaluing of the different contributions of other participants (Albrecht, Johnson and Walther 1993). The process of identification seems to have occurred in the morning group (described above), with the participants identifying with the woman who had recently moved her mother into an old people's home through a recognition of the possibility of being in the same situation themselves. Rather than question or criticise what she had done, they adopted an attitude that maintained the relationships in the group and gave themselves a satisfactory assessment of themselves i.e. it would be acceptable if they acted in the same way. However this identification depends on the support of the group. Outside the group the individuals may express different opinions, as the opinion expressed in the group is not necessarily integrated with the individual's value systems, as it would be if the opinion was internalised (Kelman 1961). Further analysis of the focus group data may reveal other examples of the process of identification as it is very common in focus groups (Albrecht, Johnson and Walther 1993). The researcher was very aware of trying not to express her own opinions to reduce the possibility of participants identifying with her, however discussion of biomedical aspects of HRT may have been emphasised by participants through identification with the researcher. The process of identification may have been lessened by the women being unknown to each other prior to the focus group, so there was no pre-established hierarchy, and there was no suggestion that the group had to reach an opinion or a decision (*ibid.*). Kelman's third process for the generation of opinions is internalisation (1961) where opinions are deeply ingrained and less likely to be affected by group processes. These opinions may be the most valuable yet are the most difficult to obtain using focus groups (Albrecht, Johnson and Walther 1993). Research suggests that to facilitate the disclosure of internalised opinions the focus group should start as an individual process, for example participants writing down their ideas (*ibid.*). This research

was not known to the researcher at the time of facilitating the focus groups, although she had experienced this process in group work and appreciated its value. In the focus groups the participants were not given time to write down their ideas. However, the discussion starters were the same as the statements about HRT used in the questionnaire survey one year earlier, to which all the participants had responded. Although there was a long time between the survey and the focus group, this may have enhanced the expression of internalised opinions in the focus groups.

The researcher's aim for the focus group was to explore the range of opinion held by women in the community about HRT. For this type of group, the theory of communication processes suggested as most useful for interpreting the data is that of fantasy theme analysis developed by Bormann (1972) (Albrecht, Johnson and Walther 1993). Bormann (1972) suggests that participants spontaneously construct a story or fantasy, starting with the stories participants tell the group and developing it from each others contributions into a fantasy theme. This process can help participants, unknown to each other before the group, develop a trusting group with shared understandings, for example by developing fantasy heroes or villains; an example of these from the focus groups may be drug companies or doctors. Shared fantasy can also form the basis of reasoning and discussion in the group; an example may be the acceptance of medical evidence and tests as certainties. Using Bormann's theory (1972), an analysis of the focus group data could be carried out to confirm the fantasy themes developed by the groups. While facilitating the groups the researcher aimed to question group assumptions when she saw them developing, and this may have helped reduce the development of simple fantasy themes, and pushed the group to look for a more complex understanding.

A more recent method of analysis developed in the discipline of psychology, known as discourse analysis, examines the way in which people construct what they say for specific aims:

how events are described and explained things people topicalise or orientate themselves to, or imply, in their discourse.....they are examined in the context of their occurrence as situated and occasioned constructions whose precise nature makes sense to participants and analysts alike in terms of the social actions those descriptions accomplish. (Edwards and Potter 1992:2-3)

Discourse analysis looks at how the situation or environment interacts with the way things are expressed and where an expression is being used as a management strategy. In particular it analyses discourse where there is some dispute with potential personal gain or loss (Edwards and Potter 1992:3). Discourse analysis has been used with transcripts from law courts and media interviews. These are situations which may be threatening and where gains or losses may be very large. The researcher had read an account of discourse analysis before analysing the focus group data and became aware that some expressions used by participants appeared to be a means of managing the situation. This occurred particularly where there was dispute between participants when, after some discussion of the issue, one participant would use an expression that brought the dispute to a close such as "everybody is different". The gain for the participant seemed to be the preservation of the group and keeping it comfortable. Compared to the more threatening situations where discourse analysis has been used, the focus group participants had relatively little need to use language as a management strategy, but this form of analysis helped to alert the researcher to the different reasons why an expression may be used and how the communication processes in the group may have highlighted certain themes.

The theory and analysis of communication processes in groups can be used in focus group research in several ways. As mentioned above, the focus group data could be analysed in detail using one of the theories. For the data collected, the analysis of fantasy themes may be the most relevant to the research and may produce some interesting insights. This analysis was not attempted. The research

on communication processes in groups can be used to alert those using focus groups to the potential pitfalls of the method, and practical guidance has been developed (Albrecht, Johnson and Walther 1993). The description of the conduct of the focus groups in the previous section and the discussion of communication processes above has indicated the ways the researcher tried to avoid some of the pitfalls of the method. The theory and analysis of communication processes also indicates the limitations of the focus group method and the importance of being aware of the context of data. The communication processes in the groups may have enhanced the themes drawn out in the analysis, and this is explored in the next chapter (section 7.5).

Understanding the communication processes in groups could lead to a view that the opinions expressed in the focus group may not be a true reflection of the women's opinions because they are influenced by the group process. However the group processes may make it more likely that the range of opinions that women held were expressed (Kitzinger 1994). People naturally tend to discuss issues and ideas in groups, which gives focus group data some external validity (Sink 1991 quoted in Albrecht, Johnson and Walther 1993), and any assessment of opinions through the medium of language rather than action is limited by the medium. The ability to be able to imagine events from another person's point of view and so to be able to persuade, deceive and sympathise are prerequisites of language development and one of its main uses (Aitchison 1996), so opinions may be expressed for many different purposes in all situations.

The focus group participants were aware that the aim of the group was for me to gain more understanding of women's perspectives on HRT. Having this explicit aim may have helped focus women on what they really thought about HRT. However, what women really think about HRT may not be a detailed insight:

we should not assume that focus groups will always reveal deep motivational insights. They can also show that people may be

less logical, less thoughtful and less organised than we expected. By sharing their experiences with similar others, participants often feel free to admit things like, "I really just didn't think about it. I just did it" (Morgan and Krueger 1993:17).

6.4.4 Analysis of the focus groups

The focus groups were analysed after the individual interviews so the analysis was likely to be influenced by this sequence. The researcher used three strategies to enhance the analysis of the focus groups and to avoid using the focus group data just as further confirmation of the analysis developed from the individual interviews. Firstly, themes contrasting with those identified in the individual interviews were identified. Secondly, as mentioned above, the themes identified were examined for ways in which the context of the data collection seemed to enhance them. Thirdly, to examine the way women seemed to understand the issues discussed, the data was compared to an existing model of women's ways of knowing (Belenky, Clinchy, Goldberger and Tarule 1986). This model had been developed from interviews with women and had aimed to increase understanding specifically of women's ways of thinking. There was therefore similarity between this model and the research for this thesis which also specifically focused on women

Through reading, listening to, and re-reading the focus group data, the researcher found the theme of control strongly expressed in several transcripts, which contrasted with the theme of fear identified in the individual interviews. This was likely to be enhanced by the nature of the data as control rests more with the participants in a focus group than it does in individual interviews (Crabtree, Yanoshik, Miller and O'Connor 1993). This theme was explored, with its associated issues, and added to the analysis of the individual interviews to develop a model of women's perspectives to inform general practice. Examples of how the theme was enhanced by the needs of the group were identified.

The final focus group conducted in this study was used to identify examples of the different ways in which women know and understand the world. This final focus group differed from the other four as the group discussion proceeded at such a pace that the researcher decided not to use the statements about HRT as a prompt. Women may therefore have more easily used a range of ways of knowing, with less direction from the medical model. To identify women's ways of knowing, the researcher worked through the transcript from start to finish. To support the analysis, examples of the different ways of knowing were then identified in the individual interviews and other focus groups.

The process of analysis used for the focus groups was deductive, starting with a hypothesis about what was in the data. The deductive nature of the process was more explicit than that used for the individual interviews.

6.7 Conclusion

The two methods used in the interview study complemented each other as the individual interviews focused on women's individual stories in their approach to HRT and the focus groups revealed opinion expressed in discussion and where control was more with the participants than in individual interviews.

The research methods used were influenced by the researcher's background and the aims of the study, and the research process itself influenced the research methods and how they were carried out. The influence of the context of the research is clear from the different types of data that individual interviews and focus groups provide and how being in a group can affect the way an individual expresses themselves. All research has a context which both affects what research is done and how it is done. In this study the researcher herself was acting as data collector (with the aid of the tape recorder and word processor) rather than a technical instrument or a measuring scale, such as the Likert scales used in the postal questionnaire survey. The collection of data involves making some

assumptions and dealing with a real context. In developing an instrument to collect data the assumptions and methodological problems are left at one step removed from the research process. The development of an instrument is frequently described in research papers published independently of the results of research projects that use the instrument. In qualitative research such as this interview study the assumptions and methodological problems are much closer to the actual data collection, for example the effect of the group process on the data collected from the focus groups can be seen as an interesting result or as a methodological problem: the two are not clearly separated.

All research tends to be restricted by the world view of the researcher or the discipline in which it is done, tending to see what is looked for, even if this is not explicit. The themes developed by the researcher at the very start of the research persisted throughout the research process and affected the research method, particularly the form of analysis of the interview study. Although qualitative research can be used for inductive research, the degree of induction rather than deduction is only relative, not absolute, as researchers come to the data with ideas and theories whether, implicitly or explicitly. Similarly, deductive research tends to be one part of a research process with the inductive processes separated from it, but never completely absent.

It is possible to identify bias in the research process of the interview study at many stages. For example, in the selection of women for interview, in the use of a clinician in conducting the interviews and in the form of methods used. The use of the word "bias", with negative connotations, for describing these tendencies reflects the researcher's background in quantitative research where generalisability is emphasised. The interview study results need to be presented and received with an awareness of the context in which the study took place. The data collected is about individual women and the detail of the data cannot be assumed to be the same as the detail would be for any other individual women. However it is possible to see recurring themes in the data that vary in detail for

individual women but where there is also some similarity between women. As discussed in the final section of chapter five, drawing from the theory of complexity, these could be termed emergent themes. The results of the interview study can be seen as a description of the emergent themes supported by examples from the interview data. The themes described are affected by the context of the research including, perhaps most importantly, the questions it seeks to answer (Cohen and Stewart 1994: 246, 276). From a quantitative researcher's viewpoint the "bias" of most concern may be the small number of women involved and so the possibility of them being in some way unrepresentative of the population in general. The results of the interview study, through its description of the women and examples of what they said, give detail about the individual women that can be compared to other women to assess whether the results of the interview study may be applicable in a different context. However, if the themes drawn from the data are emergent themes, then if the interview study was repeated with the same question in mind, very similar themes may emerge even if the women involved differed considerably in the detail of their situation and experience from those participating in this study.

This chapter has described the process of conducting and analysing the interview study, and has discussed the methodology used. In the following chapter the results of the analysis are presented.

Chapter Seven

Interview study results and discussion

7.1 Introduction

The previous chapter described the method used for an interview study exploring women's perspectives on HRT. The results of the study are reported here. The first section of this chapter presents a model of how women approach the decision to take, or not to take, HRT, that aims to inform general practice. The model is then compared with published models concerning health, illness and medication, to provide a check on the external validity of the interview data, and to illustrate the perspectives that can be taken in analysing the data and how this relates to the theoretical background and aims of the researcher.

The use of theories on communication processes to assess focus group data was discussed in the previous chapter. In this chapter the themes drawn out in the analysis of the focus group data are examined for how the group communication processes may have enhanced the apparent importance of the themes.

Using a model developed by Belenky, Clinchy, Goldberger and Tarule (1986), the interview data is examined for examples of the different "ways of knowing" used by women. How these may be used as a management strategy by women is explored. Analogy is then drawn between the different "ways of knowing" used by women and different scientific paradigms.

Confidentiality

All the names of women participating in the interview study have been changed to a single letter that does not correspond to their initials. This is preceded with the title "Mrs" which does not necessarily correspond to the woman's marital status. Women interviewed individually are given a small case letter and those participating in focus groups a capital letter. The quality of tape

recording of the focus group allowed each speaker to be distinguished by the sound of their voice.

7.2 An analysis of the interview study

This analysis of the interview study data aims to inform general practice of women's perspectives on HRT, particularly how they approach the decision to take, or not to take, HRT and what influences them. The results of the 17 individual interviews are presented separately from the results of the five focus groups as the data was analysed separately and they give different types of data. However the themes from the individual interview and focus groups are drawn together in developing a model of how women approach the decision to take or not to take HRT.

7.2.1 Individual interviews

7.2.1.1 Attitudes to medication and HRT

As discussed in chapter six, this analysis of the interviews started from the researcher noting how some women expressed a dislike of medication in general and yet were prepared to consider taking HRT. In the discussion of general attitudes to health, eight of the 17 women interviewed expressed a dislike of taking medication in general and were not currently taking medication. Seven women were currently taking medication and their attitudes to this were explored. In two interviews, conducted early in the series of interviews, the use of, and attitude to, medication in general was not discussed. As the series of interviews proceeded the researcher became more aware of the range of attitudes to medication and prompted women to discuss this.

The women expressing a dislike of medication saw it as something only to be used as a last resort to avoid death or severe symptoms. One woman distinguished medication such as aspirin, which she avoided, from halibut oil capsules which she took regularly. Reasons given for disliking medication included becoming immune

to them, side effects, the association of medication with illness and medication being used as a substitute for individual care and attention. (Box 7.1)

The age, sample and cluster groups of the women expressing a dislike of medication in general are presented in table 7.1 along with the attitudes they expressed to HRT later in the interview. The attitudes are fairly consistent with the women's cluster group. For some women there is a contrast between the attitude to medication in general and the attitude to HRT. Two women clearly articulated their awareness of this contrast describing how they were prepared to use HRT because they perceived its use as meeting a real need to keep themselves well (Box 7.2).

The seven women already taking medication expressed views on taking medication ranging from total acceptance of what the doctor suggested, some sadness about the effects of the medication, relief to be able to keep on living, the usefulness of medication to allow a normal life despite health problems and a desire to minimise the medication taken (Box 7.3). With two of the seven women taking medication, general attitudes to medication were not explored and one of these two women was only taking HRT. The age, sample and cluster groups of the women taking medication at the time of interview are presented in table 7.2 along with their attitudes and experience of HRT. There is a range of attitude to HRT, finding the therapy marvellous, interest in it for the relief of symptoms and for preventing osteoporosis and CVD, acceptance of therapy if a doctor suggested it, feeling it was one too many medications and feeling too old for it to be relevant. A woman's attitude to HRT is, again, fairly consistent with her cluster group.

Box 7.1 Dislike of medication in general

Nobody in the family likes taking tablets very much she (mother of interviewee) thinks it is better to take aspirin than to go through a stroke anything is better than dying really (Mrs c)

I only take something if I am really ill a headache would really have to be a boom boom one for the hay fever because I can be so poorly with it (Mrs e)

I don't like medication in general, I hardly ever remember to take a full course ... I take halibut liver oil capsules once a day if I have a headache I rarely take aspirin or anything like that (Mrs f)

I don't like it, we have paracetamol in the house and they last us from one year to the next we just take it as a last resort (I worry) that I'll just become immune to them and they won't work in the end (Mrs a)

I'd only take medicines if they were absolutely necessary ... because all medicines really have side effects (Mrs d)

There was an old lady... sat at home, the doctors just dished out pills, the pills she had, that was her day, it is so-and-so time, I've got to take a tablet, I don't want to be like that when they are ill, they become incontinent and everything, I would hate to lose my dignity like that (Mrs g)

If it is necessary it is OK ... the hospital said just take painkillers, probably a bit of physio would have been more appropriate than taking pain killers (Mrs h)

	Age group	Edu- cation	Sample group	Cluster group	Attitude to HRT
Mrs a	40-44 years	2	FH	3	in favour of taking HRT to prevent osteoporosis
Mrs b	40-44 years	3	FH	3	"not adverse" to taking HRT to prevent osteoporosis
Mrs c	20-25 years	3	1	1	prepared to consider taking HRT in the future for prevention but also interested in other forms of prevention
Mrs g	45-59 years	1	2	2	not needed for self as doctor had said this, but encouraged friend to ask about it
Mrs f	45-49 years	1	1	1	uncertain
Mrs e	35-39 years	3	1	1	not considered it, no attitude
Mrs h	65-69 years	1	NC	NC	takes too long to have an effect in the prevention of osteoporosis for it to be of use
Mrs d	40-44 years	3	2	2	not keen on taking it

Education: 1 - left school with no formal qualifications; 2 - left school at 16 with qualifications; 3 - left school after taking A-levels or further training since leaving school

cluster 1: mixed persuasion to taking HRT

cluster 2: less persuaded to take HRT

cluster 3: more persuaded to take HRT

NC: not included in cluster analysis due to missing data

FH: family history of osteoporosis reported in questionnaire survey

Table 7.1. Women expressing a general dislike of medication in general and their attitude to HRT

Box 7.2 Two women who disliked medication but were prepared to consider taking HRT*Extract 1*

Interviewer: "Is it (HRT) something you feel you would consider for yourself?"

Mrs a: "I think I would if I thought it would keep, because my mother has osteoporosis. So if I thought it would stop that I think I would take it."

Interviewer: "And do you know how long you need to take it for to prevent osteoporosis?"

Mrs a: I think you would have to take it forever wouldn't you?

Interviewer: A long time yes, and that's something you would consider?

Mrs a: Yes

Interviewer: That's in some way in contrast to.....

Mrs a: To what I said before

Interviewer: About other medication

Mrs a: Yes, but I wouldn't like to end up with - I think Mother has - is it crushed bones or broken bones in her back?"

Extract 2

Providing it was all explained to me, side effects and all the rest of it. I know I said earlier on about taking medication, but I am a realist and I believe if that is a way of keeping you well and keeping everything OK then I would have to agree to that. What I don't agree with medication, as I said earlier, is the spasmodic taking as and when, non-prescribed medication, for anything (Mrs b)

Box 7.3 Women taking medication and their attitudes to it

If it has been prescribed by the doctor, well I know I'll take it. I don't mind taking it because he must know better than I do I take the lithium, the only trouble is it means I can't express myself properly, because they are frightened I am going to go too high (Mrs m)

I take pain killers for my disc problem so that I can live a normal life medication doesn't bother me (Mrs k)

I am not in good health I have different tablets for different things. But I keep going and that's all that matters (Mrs o)

I was on HRT for about eight months and it did help some of the symptoms all the time I felt I'm on more drugs and I don't want to be on more drugs, I want to see this thing through myself (Mrs n)

	Age range	Edu- cation	Sample group	Cluster group	Attitude to HRT
Mrs i	35-39 years	2	3	3	marvellous, taking it and feeling much better (premature menopause)
Mrs j	50-54 years	3	FH	3	on HRT and keen on continuing for menopausal symptoms and osteoporosis
Mrs k	50-54 years	1	3	3	would be interested in taking HRT to prevent heart attack
Mrs l	60-64 years	1	NC	NC	interested if it improved her well being (in very poor health)
Mrs m	50-54 years	1	FH	3	if doctor suggested it
Mrs n	45-59 years	3	2	2	had tried HRT for menopausal symptoms but had stopped after nine months as already on blood pressure medication and did not want to be on more drugs but to see it through herself
Mrs o	60-64 years	1	NC	NC	too old for HRT but has encouraged children to consider it

Education: 1 - left school with no formal qualifications; 2 - left school at 16 with qualifications; 3 - left school after taking A-levels or doing or have done further training since leaving school

cluster 1: mixed persuasion to taking HRT

cluster 2: less persuaded to take HRT

cluster 3: more persuaded to take HRT

NC: not included in cluster analysis due to missing data

FH: family history of osteoporosis reported in questionnaire survey

Table 7.2 Women taking medication and their attitude to HRT

Of the two women interviewed not currently on medication, and whose views on medication in general were not discussed, Mrs q had tried taking HRT but stopped because of side effects and Mrs p had considered it, discussing it with her doctor. Mrs q was in the age group 55 - 64 years, the educational group 1, was selected from the sample group with a family history of osteoporosis and clustered in the group more persuaded to take HRT. Mrs p was in the age group 55-64 years and from the educational group 3, and was selected from the cluster with mixed persuasion about taking HRT.

7.2.1.2 Factors influencing women's attitudes to medication and HRT

Fear

Fear of illness, disability or death, what prompted or increased the fear, how women controlled their fear and what reduced the fear, were themes found in all the interviews. This theme seemed to be closely linked with the attitudes women developed, in this context specifically their attitudes to HRT. Other factors appeared to have their influence through affecting the level of a woman's fear (Box 7.4). For those women who disliked medication in general, fear seemed to influence their definition of what was really necessary when considering the question of taking medication or not. Women also described how the fear of a heart attack or cancer already experienced in the family affected their choices of lifestyle including diet and exercise. For some women the fear was very strong, for others it was less so, for example Mrs b explained that if she did fear osteoporosis, that fear would influence her decision to take HRT, however she felt, at the time of the interview, she had "a worry but it is not a genuine fear".

Personal experience and the experience of family and friends

The experiences of illness in the women themselves or among their family and friends were the major influences fuelling fear (see box 7.4 for examples). The experience of friends and relatives using HRT was occasionally mentioned but did not appear to be a major

Box 7.4 Women's fears for their future health in the context of discussing HRT

I had a sister that died of breast cancer it's a sort of inbuilt fear at the back of my mind (Mrs d)

My sister died of breast cancer ... it runs in families ... I don't dwell on it ... I'd be a nervous wreck if I sat thinking have I got this or have I got that (Mrs m)

I wouldn't risk brittle bones, if the doctor said I was very high risk I would think about taking HRT (Mrs k)

If I start off with hormones again I might have problems with breast abscesses again (Mrs f)

influence on attitudes to taking it. Mrs d had two relatives taking HRT of which one had benefited and the other had suffered side-effects. Mrs d concluded that it was hard to decide about taking HRT "because it is like an even balance". Mrs i, who had benefited from taking therapy, promoted HRT among her friends and colleagues as it had done her good, and hoped it would do everybody good, but seemed to realise this was unlikely as she added "but everybody is different".

The influence of doctors' advice and tests, and the assessment of risk

Not all the women interviewed had reasons to have discussed HRT with their doctors. The experience of those that had discussed it with a doctor varied widely (Box 7.5). Some, such as Mrs p and Mrs m, accepted the doctor's advice without question, even when it appears to have been not totally accurate. Mrs q seemed to have had a very full discussion of the risks and benefits with her GP and took her own decision based on her experience of side effects.

Box 7.5 Doctors advice about HRT

I'm having night sweats at the moment but of course I am just bearing up with it because I am on about nine tablet a day and I know if the doctor asked me if I would like to go on HRT, I would go by him (Mrs m)

I did actually once mention to the doctor about HRT and he just said not for you so I didn't pursue that any further at all My doctor said to me, "think about your mum (who died from an aneurysm), I don't think there is enough known about it and with varicose veins I am really reluctant to let you have it but of course in the end the decision is yours" I just took his advice (Mrs p)

I think if they gave you the option and say if you don't take it, this this and this could happen to you and if you take it, it won't, I'd take it (Mrs e)

He told me the pros and cons I said I'm not prepared to put up with migraine into my mid sixties he said "that's your choice, I wouldn't dream of influencing you" (Mrs q)

Mrs e had very high expectations of the predictions that a doctor could make about future health and the benefits of therapy. This expectation of prediction was also found in discussing the use of tests for measuring future health risks (Box 7.6). The test for risk of osteoporosis seemed to be seen as something that gives a definite answer rather than a probability, or, from the women's view, at least should do, although the difficulty of assessing risk accurately for individuals was acknowledged. Mrs c said "a lot of it is hit and miss really" and Mrs a said "I think different drugs affect different people (I would take HRT) only if they could say, well you'll end up like your mother, take these and you won't. I want a miracle worker I think".

Box 7.6 Women's understanding of the use of tests to predict future health problems

I would have to have the test for osteoporosis and have very strong evidence that that was the way I was going then if somebody said HRT would prevent that then I would be prepared to have some sort of therapy to reduce that risk (Mrs b)

I would (take HRT) if they could prove to me it was going to happen they would have to show me this is what your bones look like and this is what it should look like, it's starting to happen now but we can prevent it from getting worse (Mrs a)

If there was some test when you could say yes, your bones are going to need it, perhaps it (taking HRT) would be worthwhile, but to take it just on the chance that you would need it I'm not quite sure (Mrs f)

It (osteoporosis) didn't bother me I had a bone test and that was fine (on further probing the bone test was found to be a bone scan which does not measure bone density) (Mrs k)

Wouldn't you have thought they would have done a test and found out if they are susceptible to breast cancer with taking HRT (Mrs i)

*7.2.1.3 Sources of information about HRT**Media*

During the interviews the media was mentioned as a source of information about HRT by all women except two (Mrs d and Mrs c). It appeared to have raised women's awareness of therapy and sometimes prompted them to seek more information (Box 7.7). Mrs k was able to describe the advertisement run by the Osteoporosis Society on the television the previous year in some detail, which had left her with the question "I wonder how she found out she had

Box 7.7 Raising awareness of HRT by the media

A few years ago, just after I had been through the menopause and I had seen a programme on television which said you don't have to suffer this (osteoporosis) you can get HRT. I thought I wonder if I am a candidate for this with being so thin. It said thin people mainly get it, and early menopause and things like this (Mrs k)

I read somewhere that if you are on blood pressure tablets that they don't put you on HRT (Mrs m)

At the time there was a lot in the magazines and papers about side effects, I still say there is not enough literature on that. I don't fully know the side effects (Mrs i)

You get these different people, a lot of the stars, you get them on television and I always listen to what they have to say, and people like Jill Gasgoine they swear by it, they think they are absolutely wonderful, they feel so much younger and then they talk about perhaps you may start your periods again and I think well is it worth it. That is something I wouldn't want to back to so ... and there has been a lot of controversy over it. Just lately I have been reading about whether it really does do you some good, whether you are just putting something off so I just don't know (Mrs p)

Yes, I am always reading magazines and reading little bits about HRT (Mrs j)

brittle bones as her sister didn't find out until she had broken it". Mrs q had requested bone densitometry as a result of having seen, in the local paper, a report about it becoming available at the local district general hospital. Although raising awareness and so prompting the start of attitude development, media coverage did not appear to directly affect women's attitudes to HRT. Mrs a commented "sometimes in the paper they say it makes you feel

healthy and younger. It must be very nice but I don't think I would take it (I would only take HRT) on purely medical grounds". Mrs i, an advocate for therapy and who was using it to great benefit commented "They (my colleagues) say "have you read this magazine about breast cancer and HRT, you are on HRT" I feel, well, they (the magazine) can say what they want, they are not paying my rent for me, they don't keep me".

Employment, training and background

In seven interviews employment, training or background was mentioned as a factor affecting a woman's knowledge or awareness of HRT. These seven do not include Mrs e, who blamed her ignorance about the menopause partly on the age of her work colleagues all of whom were the same age or younger than her and so with no experience of the menopause. Mrs p had learnt about therapy from her work colleagues of similar age to herself, and others used their family members working in health care as sources of information (Box 7.8). Mrs j had learnt about osteoporosis "from courses and talking to the elderly" as she worked on a home care scheme. Of the seven women only Mrs p was from the questionnaire survey's higher educational grouping.

Box 7.8 Employment training and background raising awareness of HRT

Yes they (work colleagues) used to say oh go back and get it, you know, because I feel great on it (Mrs p)

My husband being a pharmacist as well. I think we would have been aware that as women got older they were more likely to suffer from fractures (Mrs q)

I've another grand-niece who is a nurse and I've asked her to check her little book what the side effects are (Mrs d)

I tell everybody about HRT. I have got half of them on it at work (Mrs i)

7.2.1.4 Summary

The interviews demonstrate a range of attitudes to medication and to HRT with fear being a major influence through which other influences, such as experience of illness in the family and medical advice, were channelled. Although the information on HRT now available to women from the media did not appear to directly influence their attitudes, it may have a powerful effect through raising women's awareness of HRT and so prompting the start of considering therapy, which may lead to seeking medical advice. Doctors will recognise much of the interview data from their clinical practice including the fear engendered by illness in the family, the request for tests and the raising of awareness about HRT by the media. Women appear to give great importance to the opinion of their doctors even where the use of HRT is seen by women as a choice they can make themselves. Many women appeared to consider tests as precise predictors for future health.

7.2.2 Focus groups

The characteristics of the individual women attending the five focus groups have been considered in section 6.4.1. The analysis of the focus group data aimed to complement the analysis of the individual interviews presented above. In contrast to the individual interviews, it was striking that women talked about control in the focus groups. Control was associated with choice about whether to take medication, in particular HRT, and seemed to be a counter balance to fear. The context may have encouraged women to talk about control as women may have felt more in control in a group situation than when interviewed individually (see section 6.1). To illustrate the themes, extracts of the focus group discussion are presented mostly, rather than only comments made by individuals, to show how they relate to what other women were saying.

7.2.2.1 Control and choice

Women discussed HRT as something they could choose to take or not but their control over this choice was restricted to varying degrees. The extracts in boxes 7.9 and 7.10 are examples of the groups exploring the area of control and choice they feel they have and what forms the boundaries of this area. Control over their choice is reduced where there is a life threatening problem, where there are serious health problems such as depression or severe menstrual flooding or other reason for needing a hysterectomy, and where there are symptoms that are very disruptive to a person's life such as distressing hot flushes. Being seriously at risk of osteoporosis, measured perhaps through the use of bone densitometry, also restricts the woman's feeling of control over her choice. Fear reduces the woman's feeling of control over her choice, for example fear of the effects of medication, including becoming addicted or dependant on them. The fear of dependence can be a fear of being like other people who appear to be addicted or a fear of not being totally in control for example, Mrs Q said "Remember the strikes when we couldn't get bread or sugar in the shops what would happen if there is some shortage and you couldn't have them (HRT)" (Evening group 1). Social attitudes affect women's sense of control over choice both directly for example, if women feel the menopause is seen as the end of their active life, and indirectly through the availability of information both informally (such as people being prepared to talk about the menopause), and formally through the media, books and the provision of information by health professionals. The boundaries of the area of control over choice are to some extent controlled by the women themselves for example, Mrs Y in the morning group went to the library to read up about the menopause to increase her knowledge. The ability to change the area of choice also depends on the woman's choices and resources in her life overall. Mrs Y was able to reduce her work to part-time and take on an exercise programme when she developed menopausal symptoms, Mrs C worked in a voluntary capacity which helped her to feel in control of the situation when having hot flushes and enabled her to choose

not to take HRT. Mrs B chose to take the therapy to enable her to continue her job, so for her, taking the therapy seems to have been used to increase her control over choice in another area of her life.

Box 7.9 Control and choice: example 1

Mrs A: My mum takes about 11 (tablets) every day - and if it keeps you well, well it is marvellous, you take them but you are alive.....

Mrs N: To live, but this (HRT) is something optional isn't it

Mrs C: I just don't like taking tablets or anything like that. If it is not really necessary.....

Mrs A: I was on a strong drug after my son's birth, I had depression and it concerned me that I was taking these tablets, I had to wean myself off them gradually the dependence of it, I hated taking tablets and yet this (taking HRT) hasn't bothered me at all

Mrs B: I think to me it would be choice. I have not had to take very many pills in my life at all so I am not used to taking pills and this I choose to take to prevent a condition. You (Mrs C) managed to work through that condition in a different way but I chose to take HRT to stop the hot flushes. Probably for me at this point in time to go down this route rather than to have the symptoms (is best). Now later on in life when I get to the age 70 say, the job I am doing at the moment will no longer be there, I will stop taking the pill and if the hot flushes come well so what, because it wouldn't be of concern to me then at all. Whereas if I was actually taking HRT because of something that I would class as serious, if I was seriously at risk of osteoporosis, then I might feel more resentful about it, having to take it for the rest of my life. But it is very tied up with being in control which probably ties up with your (Mrs A) feeling you had.

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Box 7.9 continued Control and choice: example 1

Mrs A: I had to take the others I resented it.....

Mrs D: I think we know people who become addicted to things and I think it is being frightened of getting addicted to something that you don't normally takeif I could do without taking HRT I would, but it doesn't apply to me yet My mum is going through it at the moment, getting the flushes in bed at night. It is stopping her from sleeping but it is not making her any less active it is not really doing any damage

Mrs E: I think it can be quite destructive. I had a sister who just used to strip off, she was past herself when she was having the flushes. I have two sisters one is on HRT and one isn't. They both went on it together, my eldest sister just said it is absolutely brilliant, it is the answer to my prayers. My next sister said she just didn't feel happy with it, there was just something there that she was frightened of so she has come off it. She didn't like the periods every month. Two sisters and they are both completely different.

Mrs D: It is a personal thing isn't it

Mrs A: What's good for one isn't always good for the other

Mrs F: Well my mam is getting hot flushes. She sits there and all of a sudden she is burning and she is fanning herself looking at her I say why don't you go to the doctors. No it is only the menopause I am alright, she just carries on.....

Mrs B: She will go if she wants to

Mrs N: It is down to personal choice

Mrs B: I think it is

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Box 7.9 *continued* **Control and choice: example 1**

Mrs C: Yes, I was at home, the work I did was all voluntary so I could have said at any time I am not doing any more but I think possibly it may influence you if you are at work and dealing with people all day and every day, I think it could probably influence somebody to take HRT, but as I say I could come and go as I wished and I think probably that did help me because I could just cope with it. (Evening group 2)

Box 7.10 **Control and choice: example 2**

Mrs Z: Yes you see there was nothing like that (HRT). If there was I hadn't heard about it when I got over my hysterectomy literally I didn't know what was happening to my body.

Mrs Y: I think it must be a wonderful thing for that particular problem for young people who have got no choice. Personally from choice I would not go on it, I would find an alternative if I could, unless there was a medical problem and I was advised by a GP who said this is what I suggest you do then I would consider it, but that is just my opinion.

Mrs X: Is it supposed to help with brittle bones now? ... I haven't heard a lot but I did hear mention that it was supposed to help people - really it has only just been discovered that you can get brittle bones and I guess taking HRT is also quite a new thing so I haven't heard a lot - on TV on chat shows and things.

Mrs Y: Does it depend on the individual, because I believe there are tests that you could have, like a scan, is that right, for the bone density to see if there is a problem there, which I would be prepared

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Box 7.10 *continued* **Control and choice: example 2**

to do. I decided that I would take myself in hand and would get through it myself which I have been fortunate I have done it but it has been a bit, taken a lot of doing, complete change of diet, complete exercise programme. I stopped work full time and went part time - it wasn't that easy but I decided it would benefit me to do that at the time - about 8 years ago - my periods were gradually stopping but psychologically I felt, gosh what is happening - I am going off my head here and I just was a different person - and it happened so slowly. That is what I found looking back I found it quite strange really because you just weren't the person that you were before. And I did go to my GP mainly just for a talk really to help and I didn't get a lot of sympathy. He was very busy and I mumbled my way through, getting no response whatsoever and in the end he said - well, menopause, everybody goes through it, you just have to go through it. He didn't suggest anything at all apart from he gave me a prescription for anti-depressants. I wasn't particularly depressed, so I apologised for wasting his time, gave him back his prescription and went to the library and got all the books I could find out on menopause and I thought I will try and do it myself and see how I get on. It is slow, but maybe I have been lucky because I haven't had any serious problems such as flooding.

Mrs W: Mood swings.

Mrs Y: Oh yes I had terrible mood swings - I would be standing in the supermarket with my trolley and tears just rolling down my face. I couldn't control it - I thought this is ridiculous and I had no confidence, didn't want to go anywhere in the end or do anything and that is what I couldn't understand and I think that was what really frightened me more than anything else, you just suddenly become a different person.

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Box 7.10 *continued* **Control and choice: example 2**

Mrs W: You lose a lot of confidence.

Mrs Y: Oh yes, yes - and really I think now people are talking about it which is good. Before nobody spoke about it, they didn't want to know, it was something that happened and the attitude is that people seem to come to an age and this is it! This stops and therefore this is the end, and it is not, it is the end of the reproductive cycle but it is not the end of your life or what you want to do, it could be a beginning and people just don't talk. That is what I found, I couldn't get anybody to talk to but now I find that people are talking much more.

Mrs Z: There are a lot more write ups about it in magazines.

Mrs Y: Oh yes, people are aware of it which is really good and there are clinics, well woman and health clinics which you can go to

Mrs X: You see I haven't hit the menopause yet but I would really like to know silly things really, do you think there should be someone like, - the doctor is busy, he is dealing with other things - maybe someone like the nurse who does the well woman clinic who could have a chat with you.

Mrs Z: We have.
(Morning group)

7.2.2.2 Control and fear

Fear affected women's sense of control over their decisions to take HRT or not. The factors that influenced the women's fear were similar to those described for the individual interviews, with some very similar comments made by the women about the fear engendered by other people's experiences of ill health particularly in the family, about the use of medical evidence and tests and the awareness of therapy through the media and women's employment, training and background. However at times the groups explored further the complexity and uncertainties of these areas. The experience of friends who kept fit and active yet became disabled was used as an example when discussing the uncertainties of life and health (Box 7.11), although earlier in the meeting, diet and exercise had been discussed as a positive contribution to future health. When an experience of ill health or death was from within the family, fear was greater but still tempered by uncertainty. There was uncertainty about the amount of risk, for example "my father died of a heart attack when he was 65. Whether that means it could be hereditary I don't know, as far as I know we are OK" (Afternoon group). There was also uncertainty about life itself and the difficulty of prediction for individuals, for example: "every person is totally different, everybody's body is different" (evening group 3). Discussion of the use of medical evidence and tests included discussion of women's reliance on doctors to interpret the evidence and tests, and helpful and disappointing aspects of encounters with doctors. The discussion also covered the uncertainties and limits of medical evidence (box 7.12). Women's awareness of HRT brought with it a need to make choices about it, now, in the past, or in the future. The research itself provoked in one woman some unease because of this "The result of this (focus group) is, it has made me more aware of it (HRT) but I am feeling a little bit apprehensive about whether I should be taking something" (afternoon group). The sense of control a woman felt could be increased or decreased by information.

Box 7.11 The experience of family and friends as examples of the uncertainty of life

Mrs M: If you can't get out for whatever reason, your mobility in your joints, blindness, or whatever, yes it does make old age very hard I would think

Mrs L: I wouldn't want to get Alzheimers disease.

Mrs H: I will be honest I don't think about it a lot.

Mrs K: Nor do I.

Mrs J: I am more or less one of these get on and get going. Get on with it for the day. It is something that I don't look to, like all these medications we are taking now at the moment I am not thinking of the consequences of things.

Mrs H: Because the quality of life is better.

Mrs J: I am alright at the moment. It is like what people said about the pill all those years ago. It caused this and that but people are still taking it.

Mrs G: I would have thought personally it is better to have a shorter better quality of life, it's alright prolonging life but it is quality.

Mrs L: But I think if you can invest now and look at yourself rather than just a gynaecological part of you. Look at yourself in a more holistic point of view, and look on it as a good varied diet, exercise and maybe at this stage now invest a little bit in time to keep yourself mobile, and just make sure. Surely that would pay benefits in old age.

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Box 7.11 *continued* **The experience of family and friends as examples of the uncertainty of life**

Mrs M: I am quite active in different sports and I have got friends, and as soon as they hit 50 they just drift downhill very quick. In 2 years most of them. One friend has always been fit and her husband has always been fit - 5 a side football and everything, jogging and they have just both gone downhill.

Mrs J: Is that because of the physical things? Is it the physical things, have they just rusted up?

Mrs M: They have always kept themselves fit.

Mrs G: Do you think they should say oh I am 50 now, nobody will want to know me?

Mrs M: Physically their bodies have just changed. I think they wear them out.

Mrs J: Would you say that they were very sporting, could it be a factor.

Mrs M: They played badminton 3 times a week.

Mrs J: So maybe they have worn themselves out.

Group Leader: So what is stopping them now, they are just not physically able to?

Mrs M: No, arthritis, osteoporosis. She has always been to keep fit classes, playing badminton. You are saying invest for the future, keep fit, she is strict on her diet, she is petite.

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Box 7.11 *continued* **The experience of family and friends as examples of the uncertainty of life**

Mrs L: I mean in a gentle way, I don't mean,

Mrs M: I would say they've made an investment in the way this lady (Mrs L) was saying in looking after themselves and diet, their whole outlook.

Mrs G: And it has not paid off has it.

Mrs M: It has still gone wrong.

Mrs H: This is it. At the end of the day nobody knows.

Mrs J: You don't do you. One of my neighbours died 60 years old in their garden. You don't know do you. He went out to call the dog in and he died in the garden. So nobody knows what is going to happen to them. (Evening group 3)

Box 7.12 **Medical evidence, it's limits and uncertainties**

Mrs K: This is my question - what are the side effects. Is the side effect breast cancer? There is risk in certain people.

Group Leader: It is controversial.

Mrs K: Controversial meaning half the medical profession believe it is and half believe it isn't.

Group Leader: The evidence isn't strong enough to be absolutely sure.

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Box 7.12 *continued* **Medical evidence, it's limits and uncertainties**

Mrs H: And this HRT can give you problems with breast cancer?

Mrs J: But you have to be on tablets for quite a few more years yet before they know for definite.

Mrs H: How many years has HRT been on the market? Are we still guinea pigs?

Mrs J: Exactly, we go on these things and we don't know what we are doing to ourselves.

Mrs K: Two years ago I would have said oh yes, if I have any symptoms, got any problems, straight down to the doctor and I want to go on HRT. I have a lot of reservations now and I think there are other avenues I would maybe investigate first. One of them is the fact, yes, it is man-made, synthetic. We have had all these scares in the past, Thalidomide, I think now when you talk about hysterectomies, I think a lot of women have had hysterectomies because it was the done thing at the time like tonsils were when I was a child. I think there have been mastectomies that could have been avoided.

Mrs H: I do agree.

Mrs K: So many people. There are six of us in the room now, we'll all be entirely different and I question the fact that one treatment can be a panacea for all our different things.

Discussion continued about the pros and cons of hysterectomy

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Box 7.12 *continued* **Medical evidence, it's limits and uncertainties**

Mrs G: I am here now thinking, when is the menopause going to happen. Will there be a flag saying this is it now. You have got the hot sweats at night, through the days, what are the hard and fast truths. What would the doctor be looking for..

Mrs H: There isn't because we're all different.

Mrs G: There is none is there.

Discussion continued about the menopause and the symptoms that HRT could help, including incontinence.

Mrs G: It seems as if it is, like you say a panacea. Go to the doctors, oh yes here you are, go home now, I have given you the pill, I won't see you any more.

Mrs L: Do my bunion some good! (much laughter in the group)
(Evening group 3)

7.2.2.3 Summary

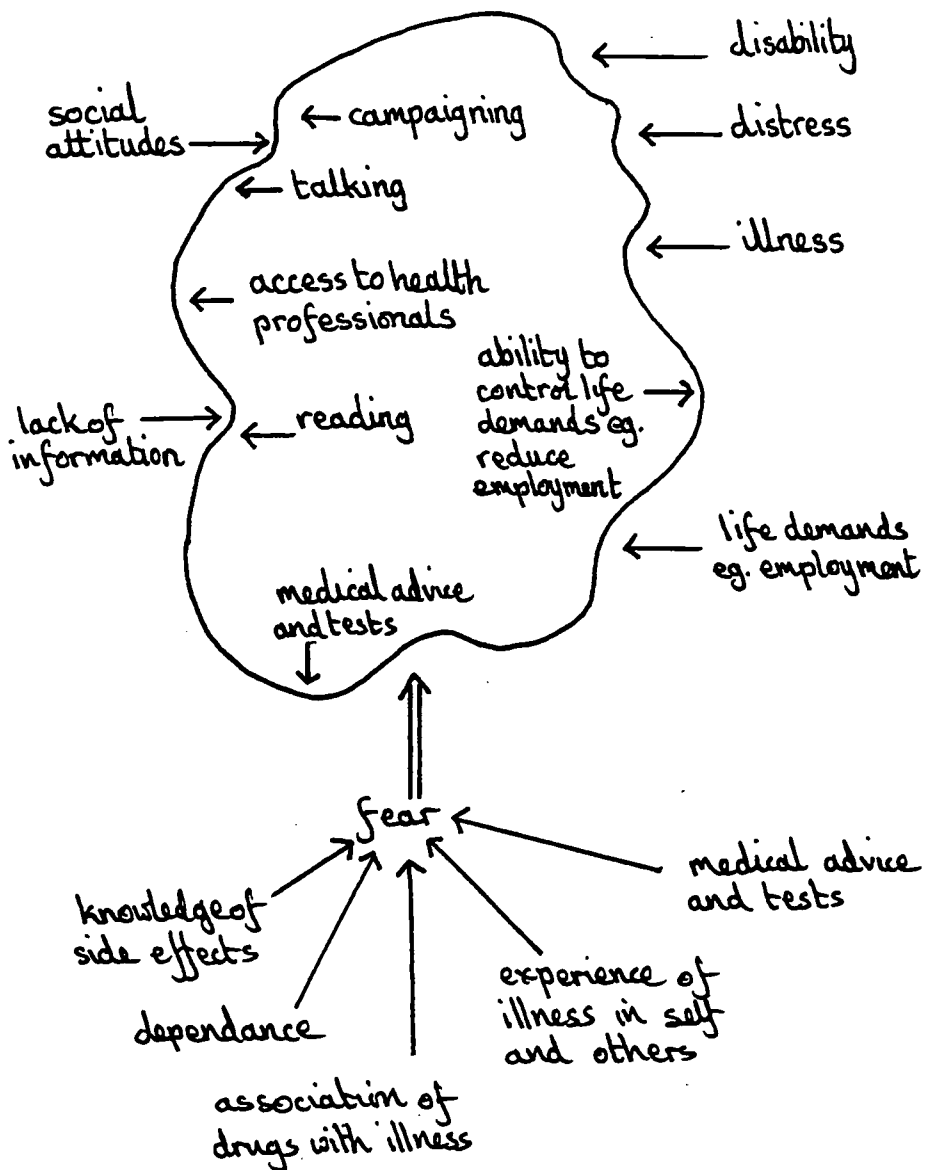
In the focus groups women explored the area of control and choice they had over the decision to take or not to take HRT. They explored what affected the boundaries of this area, including serious health problems or a risk of them, fear and social attitudes. The women also identified where the boundaries of their area of control and choice could be influenced by their own actions. The theme of control contrasted with the theme of fear from the individual interviews. Factors that influenced a woman's fear were discussed in the focus groups and were similar to those of the individual interviews. However, in contrast to the individual interviews, the focus groups discussed the complexity and

uncertainty of many issues including the uncertainties of medical evidence and the difficulty of applying it to individuals.

7.2.3 An analysis to inform general practice

The analysis of the individual interviews and focus groups is drawn together here as a model to inform general practice about how women may approach a decision to take, or not to take, HRT.

Women seem to see the decision about whether to take HRT as a choice over which they have some control, but the control is affected by outside influences which affect the type and amount of control, and this determines the degree of real choice for women (fig 7.1). Control and choice is limited by illness of a life threatening nature, or illness that causes disability or distress. Fear of ill health in the future constrains control and choice and this is influenced by experience of illness personally and in family or friends, by concerns about side effects or dependence and through associating medication with illness. The fear is controlled and so the amount of choice expanded for some women through obtaining reassuring medical advice and medical tests. Many women are aware of and take account of the uncertainties of life and health, the difficulty of applying research evidence to individuals and the limitations of medical tests. They may tend to use the results of medical tests to reduce their fears more than by the actual predictive value of the test. This may be a strategy for coping with life's complexity and uncertainty, a strategy used by GPs themselves (Willis 1995:57), as much as a misunderstanding of the role of the test. Lack of information restricts women's control and choice, but this is countered by some women through seeking out information. The increased availability of nurses in general practice providing advice and information seems to have helped this for some women. The process of seeking information has also been helped by the increased awareness of, and willingness to talk about, the menopause in the community as a whole. Social attitudes can



The enclosed area represents the area of control and thus real choice for a woman regarding whether to take HRT. The arrows inside the area indicate ways the area of choice can be expanded by the action of the woman herself or her medical advisors. The arrows outside are factors reducing the area of control for the woman.

Fig 7.1. Area of control and real choice for women in regard to HRT

restrict women's choices and some women have actively sought to change attitudes. For example, one focus group participant had been active in the Women's Institute's campaign to raise awareness of osteoporosis (evening group 2). Other demands in women's lives such as paid employment can restrict their amount of choice although some women are able to change this.

This model of an area of control where women can feel they can make a real choice, with boundaries that can change by the action of the women themselves, their medical advisors and other social factors, may help doctors identify more easily where their input can increase a woman's area of control and so increase the real choice for women. Choices made within the area of control are truly the woman's own choice. Decisions can be made outside the area of control, but these decisions may result in the woman feeling resentful, fearful or uncertain, although therapy may be taken to relieve a pressing need. The choices women make may need to change as their circumstances change, so the decision to take, or not to take, HRT needs to be conditional and appropriate for re-examination at intervals by the woman alone or with her doctor.

7.3 Models of health, illness and medication and their level of analysis

The interview study results will be compared with published studies of health, illness and medication to show how far the interview data appears to support the published studies, so providing some evidence for the external validity of the interview study data. The comparisons will also be used to highlight the different perspectives and levels of analysis used in the studies.

7.3.1 Categorising individuals

The interview study results are similar to those from Calnan in his 1987 study of lay perspectives on health and illness (Calnan 1987:42-44). His study involved interviews with 60 women about health and illness in general, so was not focused on specific health

issues as in the study reported here. It is also difficult to draw comparisons between Calnan's results and what women said in this study about taking HRT for menopausal symptoms, as these symptoms are not necessarily seen as an illness. More precise comparison can be made with what women said about future illness. Calnan grouped the women according to their assessment of health threats. The first group included women who felt there was an illness they would get, and these women had either experienced the illness previously or had what they considered to be signs of it (Calnan 1987:42). The woman who feared a recurrence of a breast abscess could be included in this group, although she was aware that the risk was reduced by avoiding HRT (Mrs f, Box 7.4). Future illness was discussed in the interviews, particularly osteoporosis and CVD conditions that can be totally asymptomatic until, for example, the fracture of an osteoporotic bone or a myocardial infarction. It is therefore not surprising that few women seem to fall into Calnan's first group, but more would fit into his second group where women felt there was an illness they might get (1987:42). This group could include the woman interviewed who was on treatment for high blood pressure to prevent CVD (Mrs n, Box 7.3 and table 7.2). Calnan notes that women in this group also referred to "temporary feelings of vulnerability when they experienced signs and symptoms" (1987:43). This seems similar to the idea developed from the interview study that women's attitudes change according to the situation (fig 7.1). For example, a woman might reduce her feelings of vulnerability by seeking a medical test or medical evidence (Mrs k and Mrs i, Box 7.6). Calnan's third group were those for whom there was an illness they feared getting or worried about getting (1987: 42). The reasons women gave for worrying about the illness included family history, experience of symptoms or signs that they associated with the disease, because they had a risk factor such as smoking, information they had learnt from the media (Calnan 1987:44), and from the experience of a relative or friend having the illness (Calnan 1987:46). These factors are very similar to the factors identified as influencing women's fear of illness in the interview study. Calnan notes that "the disease that was almost exclusively referred to was cancer"

(1987:43). This was not the case in the interview study where the focus of the discussion was HRT, CVD and osteoporosis, however the results of the questionnaire survey agree with Calnan's finding (see section 4.2.3). Calnan's fourth group were those who believed there was nothing that they were likely to get, "the majority of these women associated thinking or worrying about illness as a form of hypochondria or neurosis that was considered "unhealthy" in it's own right" (1987:44). This idea of worrying about illness being unhealthy was mentioned by the woman who had a sister with breast cancer and who felt she would be a nervous wreck if she worried about her health (Mrs m, Box 7.4). The nature of the interviews, focusing on HRT and prevention, probably made it less likely for women to express the idea that there was nothing they were likely to get. However, some women said they would want to have strong evidence that they were likely to suffer from osteoporosis before considering taking HRT. This may indicate that they believed there was nothing they were likely to get (Mrs b, Mrs a and Mrs f, Box 7.6). Although the aims and focus of Calnan's study (1987) differed from the interview study reported here, there are many similarities between the results. The level of analysis in Calnan's sociological study was the individual, exploring individual's perspectives on health and illness, although Calnan was able to categorise them as described. This use of data about individuals to develop categories of lay perspectives on health and illness, is a form of process similar to categorising women according to their responses to statements about HRT using cluster analysis, described in section 5.3, although the method of data collection and analysis is different. Both use individual data to develop categories of individuals.

7.3.2 Models of how individuals function

Themes similar to those developed from the interview studies are discussed by Cassell in his book *The nature of suffering and the goals of medicine* (Cassell 1991). Cassell develops a theoretical perspective with reference to other research and his experience of clinical medicine, rather than reporting one specific research study

and his analysis focuses on people with a disease, rather than those considering prevention. However, the interview study revealed interesting similarities with Cassell's analysis. Cassell discusses the link between pain and suffering (1991:35-36) and from this develops the idea that "suffering has a temporal element. For a situation to be a source of suffering, it must influence the person's perception of future events Fear itself always involves the future" (Cassell 1991:36). The interview study identified fear as a major influence on women's approach to HRT (section 7.2.1.2). This raises a question about whether consideration of the future always involved some fear, particularly when the future is being considered in terms of ill health and ageing, so this finding may have been inevitable. Two women dismissed HRT for themselves, as it did not come into their view of the future (Mrs h, Table 7.1 and Mrs o, Table 7.2). Mrs h saw a future which she feared, but her fear was focused on not receiving personal care (Box 1), and Mrs o seemed to consider the future very little (Box 7.3). Cassell goes on to describe "Another aspect essential to understand suffering is the relation of meaning to the way in which illness is experienced" (Cassell 1991:37). The same word, object, event, person, may have simultaneously many different meanings, including a cognitive meaning such as the understanding of the effect of a drug on the body, an emotional meaning such as fear, a bodily meaning such as the experience of side effects of a drug and a transcendent or spiritual meaning about a power beyond our understanding or control or the idea of God intervening (ibid.). These meanings were also found in the interview study, where an example of cognitive meaning would be discussing whether and how HRT prevented osteoporosis, an example of emotional meaning would be fear of breast cancer with HRT (Mrs d, Box 7.4), and an example of the bodily meaning of HRT is the experience of migraine as a side effect of taking it (Mrs q, Box 7.5). An example of transcendent meaning may be a comment from the afternoon group when discussing cancer and HRT "I think if you are going to get it (cancer) you are going to get it", that life is determined by something beyond what we know, and HRT would have little effect. Cassell goes on to describe how suffering is affected by the

disruption illness causes, distinguishing disruption to the roles a person has in life such as family and work roles, the disruption to relationships with others, disruption to the relationship with himself or herself and disruption to the person's political being which includes feelings of powerlessness and lack of representation (1991:40-41). These themes can be found in the interview data. For example a woman's role at work can be disrupted by menopausal symptoms (Mrs B, Box 7.9) especially when the work involves dealing with people (Mrs C, Box 7.9), the sister of Mrs E (Box 7.9) seems to have found HRT disrupted her relationship with herself producing fear and Mrs Y and Mrs Z (Box 7.10) found menopausal symptoms disrupted their relationship with themselves making them feel out of control. A feeling of powerlessness and lack of representation is reflected in Mrs Y's comment (Box 7.10) about people seeing the menopause as the end. Although Cassell's analysis focuses on a different aspect of illness, the model he develops about suffering includes issues which the women in the interview study talked about in considering HRT. As a physician Cassell is considering the individual, and developing a model of the meaning of suffering for individuals, with each individual likely to fit fairly closely with the model, but not perhaps exactly. The level of analysis is the individual patient, thus similar to the level of analysis of the interview study which considers individual women, and the type of model developed is similar, models of how individuals function in general, to which specific individuals have a fairly good but not exact fit.

7.3.3 Individual's relationships contributing to social trends

Other research has focused on the meaning and function of drugs rather than the meaning of symptoms or illness. Although a drug may have a particular physical effect, its manifest function, it can also have other dimensions of meaning known as latent functions, for example it may symbolise that a person is ill and that a person deserves sympathy (Helman 1990:177). In Helman's study of long-term users of psychotropic medication he found that the drugs were often taken for their believed effect on relationships with others, as

they were seen as bringing the user's behaviour and emotions into conformity with an idealised model of "normal" behaviour (1990:178). The use of HRT could be similarly described, with menopausal symptoms being seen as the abnormal behaviour. Data from the interview study, such as the dialogue in Box 7.9, supports this, but shows the women are aware of how the demands and restrictions of their life may make menopausal symptoms appear abnormal and so lead them to take HRT.

Helman's study also revealed the importance of the drugs being socially acceptable, and that this both enables people to take them and brings about "fashions" in drug taking (1990:178-179). HRT may be seen as a "fashionable" drug, attracting women to take it, but "fashion" in drug taking can also put people off, as expressed by Mrs K (evening group 3, Box 7.12). In the interview study, colleagues, friends and family were all mentioned as sources of enthusiasm or not for HRT, and Mrs i was herself active in persuading women to try HRT (box 7.8). These discussions about HRT would keep it in mind for women and help it to be seen as fashionable. The media also raised women's awareness of HRT, keeping it in fashion (Box 7.7). Helman points out that the social values that support this normalisation of drug taking may be partly learned from doctors who in turn may be influenced by colleagues and the advertising of pharmaceutical companies (1990:179). Doctor's advice and medical evidence were given considerable weight by the women interviewed, when discussing HRT (Box 7.5). Thus the themes of Helman's analysis can also be drawn out from the interview studies. The level of analysis in Helman's anthropological study is the individual, but in particular the individual relating to others, and brings in the idea of the social world, but looking at the individual relationships that form social trends such as fashions in drugs.

7.3.4 Conclusion

The similarity between the published models and the data provides some proof of external validity for the interview study data, as

themes similar to those found in other published studies can be identified in the interview data.

The comparison with published studies also provides examples of how the data could have been analysed if different perspectives had been taken. The interview study and each of the studies with which it was compared used data collected from individuals. Calnan used the data to develop categories of women. The comparisons made with the interview study data and the consistency between the cluster groups and women's attitudes expressed in the individual interviews suggest that it would have been possible to categorise the women using the interview data. Helman's study considers the individual in relation to social trends or culture, and again comparison with the interview data suggests this type of analysis may have been possible with the interview data. If the aim of the researcher had been similar to that of Calnan or Helman then the interviews would have been conducted to draw out these perspectives. However the interview study, and the model developed from it, takes a perspective closer to that used by Cassell. Both models try to incorporate themes that are common to most individuals, but cannot be an exact fit for any one individual. They try to reflect a particular aspect of being a person. Cassell describes how a person copes with suffering. The model developed in this chapter describes how a person carves out an area of control and choice over the decision to take, or not to take, HRT. Both models describe an aspect of an emergent phenomenon, that is the individual. Neither use reductionist explanation. Both models were developed by practising physicians with the aim of increasing understanding of individual patients by physicians.

The model of women's control and choice over the decision to take or not to take HRT, as discussed above, focuses on the level of analysis of the individual and examines one aspect of being an individual. However the model includes influencing factors from other levels of analysis. From a lower level of analysis there is illness that could be seen in terms of physiology and pathology, and from a higher level of analysis social organisation such as

employment and health care services. These factors impinge on the individual and the individual is closely interrelated with them. In chapter one, the idea of different levels of analysis was introduced. Harvey and Reed (1994) distinguish different levels in a hierarchy of organisation from the chemical basis of life, through simple organisms and then humans, to social phenomena and social institutions. The different levels of the hierarchy, such as society and individuals, are not clearly distinguished, with interaction between levels and an indistinct boundary between levels. The model developed in this section provides an example of interaction between the levels of analysis. It also supports the idea of an indistinct boundary between levels. For example employment may be seen as a social system, but it is also an individual experience. Harvey and Reed (1994) go on to suggest that social systems evolve because as there is interaction between the different levels in the hierarchy, there is potential for changes to occur. The interactions are amplified through the process of deterministic chaos which they argue, is built into the structure of these hierarchies. The process of a drug becoming fashionable, for example the huge interest in HRT at present, may be a good example of a change that occurs firstly at an individual level, but becomes amplified into an emergent social phenomenon.

7.4 Themes from the focus groups enhanced by the group process

The effect of communication processes on focus group data was discussed in section 6.4.3. This section will examine how participants appeared to use what they said to manage the group process, and how this may have enhanced the themes drawn from the focus groups in this study.

The theme of control contrasted with the theme of fear from the individual interviews. This theme may have been enhanced by the group process as individual women sought to take some control of the group. For example, Mrs Y (morning group) dominated the discussion early in the focus group (see box 7.10 for example). She

described her experience of taking control of herself during the menopause, and also seemed to control the group. The researcher noted that she appeared to be sure of her own opinions and understanding and was skilled in influencing groups. As the group proceeded the amount of control women have, and what influenced this, was discussed. The extract in box 7.13 is taken from later in the same group. The participants, including Mrs Y raise uncertainties about the control they have, for example questioning the value of available foods. Mrs Z seems to offer the group a positive way forward, that helps them feel in control, through discussing her garden produce. Seeking the feeling of being in control may have been because of a desire to keep the group in control as much as exploring control in their lives beyond the group. Earlier in the group, seeking information and advice was discussed as one way of taking control of a situation. Mrs W appears to challenge the control of the group by challenging the idea of the group participants taking control of their life situation, through describing her sister who did not seek information or advice about her loss of height. The group did not respond to this, leaving a pause, after which the group leader took control of the group by inviting someone to place a statement about HRT down on the table for discussion. The group then expressed positive views about having a test for osteoporosis, and when Mrs W challenges this by informing the group that the tests are not available at the moment, Mrs Y seems to grasp for a way to feel back in control by seeking an alternative test. It is difficult to know how much Mrs Y's tendency to want to be in control and Mrs W's tendency to challenge feelings of control and certainty are personal characteristics or roles they have taken in the particular context of the focus group. The story Mrs Y tells about her personal approach to the menopause (box 7.10) indicates she may tend to want to be in control in other situations, however her emphasis on this may have been enhanced by being in the focus group. Thus, the process of the focus group and the control exerted on it by participants may have enhanced the expression of the theme of control in the groups, although individuals' stories indicate the theme is also important in everyday life.

Box 7.13 Control and the group process

Mrs Y: I would like to know more about that (diet, exercise and osteoporosis) and I would also like to go and have a test, a scan or whatever they do, and then if they said no you are okay then I would carry on as I am doing because that is something I would not like to have. I think it can happen to anybody, I can imagine.

Group Leader: So you don't actually know from your reading whether exercise and a good diet would make any difference.

Mrs Y: Well I would say it makes a difference yes, definitely I would say no doubt about it.

Mrs X: I think it is a longterm thing surely, with diet especially it has to be quite a longterm thing you can't suddenly change your diet and...

Mrs Y: I think it has to be in your system as well.

Mrs X: You see what I mean.

Mrs Y: You have got to keep to it.

Group Leader: When you say longterm for the diet, how long are you thinking of?

Mrs X: Oh years.

Mrs Y: Permanently.

Mrs W: It is changing your habit isn't it?

continued over page

Box 7.13 *continued* **Control and the group process**

Mrs X: If something is going to happen you would put the change of diet quite early I would say for it to prevent or to make some difference. If your diet has been bad before hand then things....

Group Leader: You mean if you have a bad diet up to your 50's then you....

Mrs X: I think it has got to be before that, before it starts and say a good 5 years before you would think about that and change a lot of things for it to make any difference.

Mrs Y: I think a lot depends on perhaps what sort of - I am more like a vegetarian anyway so it doesn't really bother me so much but I know a lot of people who are not and who like a lot of sweet things and who like quite a heavy diet with lots of fat and it is difficult if that is what you have been used to wean off that sort of thing, so I understand that is. The other thing that I do take is multivitamin supplements and minerals, and Vitamin C. Now there is a lot of talk about that isn't there as to whether it is a waste of time. On television the other night; if this is something that makes you feel better carry on, is it something psychological, because I have taken them for years.

Mrs Z: I take cod liver oil tablets.

Mrs W: I do. I take cod liver oil I have done for years.

(general noise of agreement)

Mrs W: For arthritis.

Mrs Y: Maybe it is a waste of time.

continued over page

Box 7.13 *continued* **Control and the group process**

Mrs W: I don't know. I said maybe it is the way you feel yourself.

Mrs Y: I agree if you have a balanced diet but I think with so much of the foods being, - you don't know what they are spraying on the vegetables and all the sort of hormones that are being popped into beasts and all the rest of it, if you are able to get organic stuff then great but I think a lot of the natural must be well and truly out of most of what we eat.

Mrs W: Mine is not a great diet.

Mrs Z: My husband's a great gardener.

Mrs Y: If you have an allotment or something and can grown your own, it's brilliant, even the taste of that is different

Mrs Z: We have had literally hundreds and hundreds of pounds of tomatoes, potatoes....

Mrs Y: It is brilliant if you can do that.

Mrs Z: I'm using cabbage, I've got broad beans in now.

Mrs Y: And you can get them if you want to.

Group Leader: That is something you value because of the good diet.

Mrs Z: Yes I do.

Mrs X: And taste is also different .

continued over page

Box 7.13 *continued* **Control and the group process**

Mrs Y: Yes, no doubt about it.

Mrs Z: Once a year the man comes and brings a load of manure. You might think it is daft but it is the way we garden

Mrs Y: It is natural isn't it.

Mrs Z: He loves his garden, what with his garden and his art work, he is 69 years old and never has a minute. But we grow in the greenhouse all year round so we get a lot of our own stuff.

Group Leader: You still feel you need cod liver tablets.

Mrs Z: Yes I do. I like the cod liver oil.

Mrs X: Addictive isn't it?

Mrs Z: I will tell you a story about this. (Story about cod-liver oil and pregnancy) I have a son like myself who is absolutely crucified with arthritis, this is my mother's side of the family and what is in families, what is in genes, comes out.

Mrs Y: Is that a fact, would you say there is a lot to be said for hereditary problems?

Group Leader: Certainly things to run in families, osteoporosis seems to run in families. You said you mother had osteoporosis.

Mrs W: Well we summarize she had but she would never go to a doctor, never would.

Group Leader: What made you think she had osteoporosis?

continued over page

Box 7.13 *continued* **Control and the group process**

Mrs W: She had the hump. And then I have my older sister she won't go to the doctors. She used to be as tall as me and now I look down at her. I know I am not all that tall but - and I said to her one day and she said, No I wouldn't bother going to see about anything like that.

(Pause in group discussion)

Group Leader: Anyone else want to put another statement down?
(on the table for discussion)

Mrs Z: Like that lady there, I didn't know a lot about osteoporosis, I know more about arthritis, but I think "A test shows I was prone to thinning of the bones or brittle bones" I have quite strong bones my doctor told me.

Group Leader: But if you had a test that showed you had or were likely to get osteoporosis, would that push you towards to taking HRT

Mrs Z: Yes it would if it was going to do me any good, yes.

Group Leader: What about other people.

Mrs X: Yes.

Group Leader: Would that be quite important the test?

Mrs Z: Yes.

Mrs Y: I think so yes.

Mrs W: They have stopped doing the tests now haven't they.

continued over page

Box 7.13 *continued* **Control and the group process**

Mrs Y: Have they I didn't know that.

Mrs W: I think on account of money.

Group Leader: Stopped completely?

Mrs W: For a while they have yes. Those who have already had, like my younger sister, she has it and she goes for a test.

Mrs Y: Is that the only way then that they can find out?
(morning group)

Another contrast with the individual interviews was that the focus groups discussed the complexity and uncertainty of issues. The extract in box 7.14 is an example of the participants exploring the uncertainties about cancer. The researcher noted that the women appeared to be listening very carefully to one another as if seeking to understand the dilemmas. However it is also possible to trace how the participants may also have been speaking in a way that enabled the group to survive comfortably for the time of the focus group. Mrs A has lost three of her family with cancer and Mrs D suggests cancer is something that is inherited. Mrs A rejects the idea that cancer can run in families because of the fear it would engender. Mrs D brings in more evidence using diabetes as an example, but then softens her argument with her comment that it may not apply to everyone. This may have been added to avoid a dispute with Mrs A or avoid distressing her, although Mrs D seems sure that illness runs in families. At the end of the extract Mrs E provides a balancing philosophical comment which had the effect of easing the tension between Mrs A and Mrs D as they went on to share experiences of the side effects of the oral contraceptive pill. There was then a pause and the group leader moved the group onto a new subject. Expressions such as "I'm not saying it applies to everyone" and "you have to weigh up the pros and cons" were often

used in the focus groups. A similar type of idea concludes the debate in box 7.11. These ideas may be what the women believe, but the expression of these ideas seems to have been enhanced by the context of a focus group.

Box 7.14 Complexity, uncertainty and the group process

(The group leader had invited Mrs E to comment on the statement "HRT would not cause cancer if taken properly".)

Mrs E: Yes it would be one factor that I would question. I have really really lumpy boobs, I have had a couple of - I had a mammogram a few years ago, and that was brought up as a side effect, the breast cancer and that would make me think seriously, the pros and cons about it with my boobs being so lumpy anyway. I would be quite worried.

Group Leader: So it might actually stop you taking it.

Mrs E: I think I would seriously have to weigh up the pros and cons, and go on the doctor's recommendations really because he knows you and he knows your body but it would be something that I would question.

Mrs A: I told my doctor I had lost three of my family with cancer when I started on HRT and she didn't say anything so, I plunged in.

Mrs F: There is a leaflet going around - a yellow one - all about your breasts and in one of the questions it said "would HRT give me cancer". The answer underneath said no.

Mrs P: It can't give you it but it can trigger it off.

continued over page

Box 7.14 *continued* **Complexity, uncertainty and the group process**

Mrs F: But it is very very rare that it could give a side effect, beginning of cancer, but it just said straight that HRT shouldn't give it unless certain circumstances in our bodies trigger it.

Mrs P: I think if I was offered HRT because I needed it for various reasons, I think if I was offered a mammogram every other year, or something like that, as a precautionary measure I think that would.

Mrs D: I only know of one person who, in the immediate family close to us, that took HRT and she had one breast removed, and that is one of my aunts. She is the only one of a big family, mum had 7 sisters and 2 brothers, and she is the only one who didn't have a family. But when she got older you realise that she wasn't a suitable person for to have a family. She didn't have the patience and that but it might have been that her body wasn't capable of accepting a baby in the first place, because the cancer must have been, it must be a hereditary thing in our family. I know that strokes run in our family rather than heart attacks. She had a breast removed about 7 or 8 years ago....

Mrs A: I don't think you can say that - it would contribute. My mam and dad didn't smoke or drink. You can say don't eat this, don't eat that. My dad was a creature of habit, out every day at the same time, and he was active, walked everywhere, and mum died at 58, dad died at 67, and my sister died at 28, all of cancer, all different types of cancer. So none can say. I can say oh it runs in my family, I could be living with a death threat.

Mrs D: We have got diabetes in the family, that runs through the family and we have also got - I had a problem with my eyes when I

continued over page

Box 7.14 *continued* **Complexity, uncertainty and the group process**

was a child. I have one eye longsighted and one eye shortsighted and I have got a cousin who is exactly the same. That's why I am going by my experience. I am not saying that it applies to everybody.

Mrs A: It mightn't necessarily be the HRT the reason why she got the breast cancer.

Mrs D: It might have triggered it off, it might have started off.

Group Leader: What does your aunt think?

Mrs D: I don't know, because I don't see much of her .

Mrs A: Sometimes with a pregnancy, that can trigger things off as well. My sister had a melanoma which grew while she was having the baby, she was pregnant, again that's a time when your hormones are disrupted isn't it. When you are having a baby. And I suppose when you are going through the menopause your hormones are disrupted again, that could trigger it off. The fact that you are levelling off, that is how I see it. You are replacing something and you can be weaned off gradually. I don't know how you come off HRT.

Mrs D: I am not one to take medicines unless I really have to

Mrs A: I am not.

Mrs D: I am a coward when it comes to needles or anything, hospitals make me feel ill.

continued over page

Box 7.14 *continued* **Complexity, uncertainty and the group process**

Mrs A: Well I am not but it did make a difference to me - made a big difference.

Group Leader: You mean the HRT did.

Mrs A: Yes.

Mrs E: I think you have to weigh up the pros and cons and just make a decision at the time.

(evening group 2)

In conclusion, two themes drawn from the focus groups, both which contrasted with the individual interview data, the theme of control and the exploration of the complexity and uncertainty of issues, seem to have been enhanced by the group process.

7.5 The interview data and women's "ways of knowing"

7.5.1 Introduction

Belenky et al. (1986) developed a model of the ways in which individual women understand and find out about the world, as revealed by what women said about themselves in individual interviews. The "ways of knowing" identified by Belenky et al. (1996) are: silence, received knowledge, subjective knowledge, procedural knowledge and constructed knowledge. A brief description of each of these "ways of knowing" is given in each of the following sections. Belenky et al. (1986) describe how women can move from one form of thinking to another and see this process as a progression, some women reaching the final stage and others not, or not yet. The idea of progression is based on what women

said about themselves in the interviews rather than on a study that followed women up over many years.

The model developed by Belenky et al. (1986) is used in this section to examine the data from the individual interviews and focus groups conducted for this thesis. Firstly one focus group (evening group 3) was examined for the different "ways of knowing" identified by Belenky et al. (1986), starting early in the discussion and moving through towards the end. The progression that Belenky et al. (1986) describe for individual women seemed to occur in the focus group, with the women using more complex ways of knowing as the group progresses. Examples of the "ways of knowing" were also then identified in other individual interviews and focus groups.

7.5.2 Silence

Silent women have no more confidence in their ability to learn from their own experience than they have in learning from the words that others use. Because the women have relatively underdeveloped representational thought, the ways of knowing available to them are limited to the present (not the past or the future); to the actual (not the imaginary and the metaphorical); to the concrete (not the deduced or the induced); to the specific (not the generalised or the contextualized); and to behaviours actually enacted (not values and motives entertained). (Belenky, Clinchy, Goldberger and Tarule 1986:26-27)

In Belenky et al.'s study (1986), this description was based on a very small number of interviews which is not surprising as researchers probably find these women the most difficult to access. The description has great resonance with the researcher's experience with some women in general practice where the researcher is aware of being, for these women, an authority that "bellow(s) but do(es) not explain" (Belenky, Clinchy, Goldberger and Tarule 1986:28).

The focus group used initially for this analysis did not reveal an example of this "way of knowing" and the interview study data as a whole also reveals few examples. This is probably because the research methods asked women to volunteer to talk about issues so "silent" women may not have volunteered. The research notes about the interview with Mrs g include the comment: "Mrs g lived for the present, the future was rarely thought about". This seems to fit with the category of "silence". It was also noted that she was nervous and seemed unsure of what to say as she had not thought widely on the issues. Mrs g's apparent lack of thought for the future may, however, have been because of inhibitions in the interview situation, as at the end of the interview, after the researcher had reassured her about the usefulness of the interview, she explained her fear of dependency and losing her dignity (Box 7.1). The apparent silence may have been Mrs g's way of managing the interview situation rather than a persisting "way of knowing".

7.5.3 Received knowledge

Belenky et al. describe women who rely on received knowledge as those who learn by listening, but have little confidence in their own ability to speak. They think of words as central to the knowing process, look to authorities to tell them what is right and wrong, assume there is only one right answer for each problem and that truth is something absolute (1986:36-41).

An example of what seems to be a received way of knowing is presented in box 7.15 and is taken from early in the focus group. Mrs G is confident there is a test, measuring oestrogen, that can guide women and their doctors about their need for HRT. Her confidence in this leads her to see the doctors, who "do not bother" to perform the test, as the problem. From a medical perspective, there is a test for hormone levels in the blood that can show whether a woman has been through the menopause or not, but not whether she is currently nearing it or having problems from it. Mrs G seems to be using the received "way of knowing". However this may be her way of managing uncertainty, perhaps about the menopause.

Box 7.15 Received knowledge

Mrs G: You mentioned that your doctor gave you the blood test to see what your oestrogen levels were, did he actually give you a figure?

Mrs H: Yes, but I couldn't tell you what it is. He did give me it.

Mrs G: And obviously as you say that is how he decided that you needed it.

Mrs H: He said I was in the change. He said, I would say by that if you were still having periods you would have stopped by now. I have still got my ovaries, but he said I think if you were on your periods they would have stopped.

Group Leader: But of course you had had a hysterectomy so you weren't having periods.

Mrs H: That's right. That's one of the reasons I couldn't tell as well.

Mrs G: I've just found out a very interesting point, the fact that apparently there are a lot of GPs who do not bother to give these blood tests to find out when women are having problems. It would seem a natural event to give them a blood test to ascertain what the levels of oestrogen are and it is amazing how many doctors don't. They actually just put you on the HRT. I am not speaking from personal experience. I know some ladies who are on it.

Mrs H: He didn't put me on that until the results came back. I had to wait until I got the results because I went on holiday and came back.

(evening group 3)

She gives the impression, to herself and others, of certainty about a test and attributes any uncertainty to the shortcomings of doctors. This process of attributing blame is seen in discourse analysis as part of a strategy that is "used to stabilise and make factual seeming, particular versions of events in the world" (Edwards and Potter 1992:129). This would suggest that using "received knowledge" may be a management strategy for coping with uncertainty in life. The use of this strategy may be enhanced by the context; early part of a focus group, meeting with people unknown to each other. As the group proceeds there were further examples of this "way of knowing" but often mixed with other categories of "ways of knowing", indicating the group was moving on to other "ways of knowing".

An example of received knowledge from another group is in box 7.14 where Mrs F says

There is a leaflet going around - a yellow one - all about your breasts and in one of the questions it said "would HRT give me cancer". The answer underneath said no.

Mrs F sees words as central to the process of knowing and uses authority, in this case a health education leaflet, for knowing what is right. During this focus group, Mrs F often seemed to speak about issues at a tangent from the rest of the group, and seemed to find it difficult to express herself. Mrs F may have found it difficult to remain engaged with the group as it moved on from a "received way of knowing", and this may indicate she tended to stay with this "way of knowing". There were examples of women interviewed individually also using received knowledge (e.g. Mrs i, Box 7.6). The "received way of knowing" may therefore be a strategy for understanding the world that is used by most women, but is more persistently used by some who may find it difficult to move on to other ways of knowing. It can be viewed as a management strategy for coping in a discourse, and the context of a discourse may affect whether this strategy is used or not.

7.5.4 Subjective knowledge

Women in this category tend to see truth as something personal, private and subjectively known or intuited, although they still use the received way of knowing to some extent (Belenky, Clinchy, Goldberger and Tarule 1986:54). "When faced with controversy, subjectivist women become strictly pragmatic - "what works best for me"" (Belenky, Clinchy, Goldberger and Tarule 1986:70). The following may be an example of this way of thinking

But I can't class me like everybody else and I would say every person is totally different, everybody's body is different (evening group 3).

As discussed in the preceding section, this form of comment seemed to be made in the focus groups as a way of reducing tension within the group. This may be a pragmatic approach to enable the group to survive, and the individuals in it to remain fairly content. Again this "way of knowing" may be used as a management strategy by women when talking and one that is particularly useful in a focus group. Similar comments were also made by women in individual interviews (e.g. Mrs i about the media in section 7.2.1.3) and may be a "way of knowing" used more by some women.

7.5.5 Procedural knowledge

Belenky et al. describe how women can move from subjective knowing to using procedures to develop ways of knowing or analysing. They learn from their teacher's methods of looking at or analysing things, situations or people, but they do not reject authority completely (1986:87-93).

They have learned that truth is not immediately accessible, that you cannot "just know". Things are not always as they seem to be. Truth lies hidden beneath the surface and you must ferret it out. Knowing requires careful observation and analysis. (Belenky, Clinchy, Goldberger and Tarule 1986:93)

In both individual interviews and the focus groups women talked about finding out about, and weighing up, risks and benefits. In a section of dialogue from evening group 3 (first part of dialogue in box 7.12), Mrs K asks about the risk of breast cancer and seems to be asking a procedural question, indicating some idea that there are ways of finding out about the risk of breast cancer through observation and analysis. Mrs J seems to move towards the category of knowledge, constructed knowledge, described below, but, in the dialogue there is also an element of received knowledge with the idea that there is, or will be, a truth, and an element of subjective knowledge with the comments on what is happening to the individuals themselves.

Belenky et al. comment on women using the "procedural way of knowing" as follows: "as these women become increasingly skilful at executing procedures for obtaining and communicating knowledge, many of them experience an increasing sense of control" (1986:96). The use by women of information, experience and results of medical tests to increase their sense of control was included in the model of women's control and choice with regard to decisions about taking HRT or not (section 7.2).

Thus, there are examples of the "procedural way of knowing" in the interview study, but this "way of knowing" was often used by women together with other "ways of knowing". The model developed from the interview study data reflects a "procedural way of knowing". As the model was developed from the interview data it may reflect women's use of this "way of knowing". However, the aim of the model was to understand how women develop their perspective on HRT and what influences them, which assumes that there is a process that women use and there are factors influencing the women. The procedural nature of the model was therefore implicit in the aim of developing it and so may be more a reflection of the researcher's way of thinking than the women's way of thinking.

7.5.6 Constructed knowledge

Women constructivists show a high tolerance for internal contradiction and ambiguity there is an impetus to try to deal with life, internal and external, in all its complexity, and they want to develop a voice of their own to communicate to others their understanding of life's complexity the basic insights of constructivist thoughts are: *all knowledge is constructed* and *the knower is an intimate part of the known* (authors' own emphasis). (Belenky, Clinchy, Goldberger and Tarule 1986:137)

Comments that seem to be constructivist in nature become more frequent towards the end of the focus group and are used by women who also used the other categories of "ways of knowing". In the second part of the dialogue presented in box 7.12, the women seem to be developing an acceptance of the uncertainties about HRT, using a way of knowing similar to the "constructed way of knowing" described above. The dialogue in box 7.11 also moves towards an acceptance of uncertainty.

A final extract demonstrates both procedural and constructivist ways of thinking and comes from near the end of the focus group, from a discussion about whether to take HRT to prevent a hip fracture when older:

Mrs G: It is a gamble, whether to gamble or not. Are you a gambler or not?

Mrs F: If it's proven safe I can't see why not.

Mrs K: But that's loaded isn't it?

Mrs H: But we don't know do we?

Mrs K: But that's the reservation, if it's safe.
(evening group 3)

The women may feel more able to question knowledge and information, and accept the limits of knowledge once the group has established itself and perhaps even more when the end of the group is drawing nearer. The use of the "constructed way of knowing" may be enhanced by the group process. This was demonstrated in the analysis, as when the focus group data was examined for contrasts with the individual interviews, the exploration of complexity and uncertainty by women in the focus groups was identified (see section 7.2.2.3). The "constructed way of knowing" may also be used more by women who are prepared to volunteer to attend a focus group. Women able to use a "constructed way of knowing" are also likely to be able to use other "ways of knowing", as Belenky et al. (1986) suggest they will have moved through the different "ways of knowing".

7.5.7 Conclusion

Each of the "ways of knowing" described by Belenky et al. (1986) can be identified in the interview data. Only a few women seem to use mainly one "way of knowing" such as "silence" or "received knowledge". This may be because women lacking confidence about discussing issues may not have agreed to participate in the study. Many of the women included in the interview study used several different "ways of knowing". Their use seemed to be influenced by the context. For example, during the focus group, the women seemed to progress through the "different ways of knowing" towards a "constructed way of knowing". The women able to use several different "ways of knowing" seemed to use them as a management strategy in the focus groups. The complexity of discussion between people can be manipulated as an impression management strategy, for example to avoid expressing dislike or to avoid making a decision (Tetlock and Snedfield 1988).

The model developed by the researcher from the interview study uses predominantly a procedural way of knowing yet the researcher also uses a constructed way of knowing in this thesis. This is an example of similarity between the different "ways of knowing", and

different scientific paradigms used in research, and is explored in the following section. Just as researchers use different paradigms depending on what they are doing and why, so research participants can move between different ways of thinking. Edwards and Potter point this out for the discipline of psychology:

(research) participants themselves can do what psychologists do, offering either objective or constructive notions of reality. these theoretical positions (can be) deployed flexibly as options, with participants moving from one version to another, as context and pragmatics require (1992:65).

7.6 Women's "ways of knowing" and scientific paradigms

This thesis has developed on the boundary between academic disciplines and has used and explored different ways of seeing the world used by different disciplines. The analysis of the focus groups in the preceding section illustrates how the research participants moved between different "ways of knowing". Belenky et al. (1986) suggest that women can progress from simpler to more complex "ways of knowing", implying a developmental process. The researcher found progress from simpler to more complex "ways of knowing" as a focus group discussion progressed, so the "ways of knowing" developed as the focus group developed. However the different "ways of knowing" may be used as management strategies by both researchers and research participants. In this section the similarities between the categories of women's "ways of knowing" described by Belenky et al. (1986) and scientific paradigms will be explored and the use of different "ways of knowing" as part of a developmental process or as a management strategy will be discussed. This may increase understanding of how different disciplines understand each other.

The model of women's "ways of knowing" was developed in a context that included existing scientific paradigms and so the similarities between scientific paradigms and women's "ways of

knowing" may be a consequence of this context. It is however a useful tool to aid the discussion.

In the description of silent women Belenky et al. (1986) include examples of the type of thought processes that these women do not seem to use (see section 7.5.2). These contrasts reflect some of the methodological problems for medical research. For example the women limit themselves to what is known in the present, rather than the past or the future. For research, using retrospective data raises questions about the reliability of the data and how the context may have been different and so affected the data. There are similar problems for predicting the future, and research methods may have to make assumptions about the similarity between present and the past, or future, or develop a way of allowing for changes over time. Focusing on the present provides a management strategy for coping with this methodological problem. Women using "silence" are described as limiting themselves to the actual, concrete and specific. Medical research often focuses on an actual, concrete and specific item, although often has to use a marker or representation of the item being researched. For example, a biological marker may be used in laboratory research or a scale of measurement for symptoms may be used in clinical research. Sophisticated methods have been developed to examine how closely the markers represent what is the actual or concrete item, but this assumes that there is something that is "real" or "true". Women using "silence" are also described as limiting themselves to behaviours actually enacted, (not values and motives entertained). Medical research limiting itself to enacted behaviour avoids the methodological problems of the assessment of values and motives.

For individuals, there may be times when "silence" as a way of knowing is useful. For example in describing the nature and control of suffering, Cassell describes a way of someone controlling suffering by "root(ing) themselves in the absolute present", something that is difficult to achieve (Cassell 1991:36). Belenky et al.'s silent women may be "silent" as a way of controlling suffering (Belenky, Clinchy, Goldberger and Tarule 1986:34).

"Silence" may be used by some women as a strategy for managing a situation, and similarly medical research appears to have a "silent way of knowing" as a management strategy for doing research in a complex world. This strategy can be very successful, as demonstrated by many areas of medical research. However, the use of this strategy may become a problem if it is forgotten that it is only a strategy, and if it becomes accepted as the only way of coping with the complex world.

Received knowledge is described as assuming there is an absolute truth and that authorities know the answers. As mentioned above, the assumption that there is a truth to be discovered, may be found in some positivist, experimental and reductionist science. This type of science has tended to portray itself as an authority that can provide answers.

The subjective way of knowing comes closest to the way of thinking used in qualitative methods where induction is emphasised, and detailed data on specific situations is collected. Qualitative research aims to make use of the subjectivity of the researcher rather than trying to minimise it.

Procedural knowledge resembles the recommendations to doctors to use "evidence based medicine" with an emphasis on learning, from experts, the methods of assessing research data and how to apply them. This type of knowledge is also recommended for patients. For example, in research published in academic medical journals about women's knowledge and attitudes to HRT, it is suggested that doctors should ensure women have knowledge of the risks and benefits of HRT (Ferguson, Hoegh and Johnson 1989; Kadri 1991) and that the doctor should help women in balancing the risks and benefits (Sinclair, Bond and Taylor 1993).

The insights that Belenky et al. emphasise in constructed knowledge, i.e. that all knowledge is constructed and the knower is an intimate part of the known (1986:137), are insights of the

sociology of science. The toleration of contradiction and ambiguity found in constructed knowledge is also found in disciplines applying knowledge to practical, individual situations such as in clinical general practice, which also deal with the complexity of life.

These analogies suggest that different scientific paradigms may be used as a management strategy to allow specific types of progress in research. Thus understanding the detailed aims of a piece of research, including the practical and political aims, and understanding the context for a piece of research, including the motivation for the research and the values used by the researcher, should make clear why a particular paradigm is being used, that is, why a researcher may want to use a particular strategy for managing the world to further the research process.

The analogies also suggest that there may be some development from one paradigm to another. For example the sociology of science developed as a critique of reductionist science and the current interest in qualitative methods in medical research seems to be a response to the emphasis on procedural knowledge in medicine. However this progress is not of a linear form with one "way of knowing" being left behind once science has progressed to another. For example, qualitative, observational studies of disease provided the disease categories on which reductionist medical science developed. However, different paradigms seem to come to the fore at different times and historical study can reveal the political, economic and cultural influences on their use (Griffiths 1996a).

7.7 Conclusion

The interview data was analysed to inform general practice of how women approach the decision to take HRT, to enable GPs to provide the most appropriate advice, support and understanding for women in consultations about HRT. The model developed from the interview data clarifies what may influence the amount of control

women feel over the decision to take, or not to take, HRT, to enable GPs to help increase this control as far as possible. The model provides a more complex and comprehensive idea about women's feelings of control, and so more ideas about how GPs may be best able to advise women to increase their sense of control, than the exhortations in medical papers to explain the risks and benefits of HRT to women, although this may form part of what is needed. Familiarity with this model may help improve the "therapeutic alliance" between a GP and a patient, leaving most of the control with the patient, so achieving a better concordance between GP and patient over prescribing (Marinker 1997). The model is very similar, in general, to the models already used in general practice and taught to GPs in training, as it includes taking into account a patient's physical, psychological, social and spiritual needs. However it makes the process more explicit, providing detail that is specific to HRT, and this may make it easier for GPs to use in this context. The interview study may have revealed something that was already known but this is true of much research as explained for mathematics:

By definition, all mathematical statements are tautologies. Their conclusions are logical consequences of their hypotheses. The hypotheses already "contain" the information in the conclusions. The conclusions add nothing new to what was implicitly known already except ... that it makes things explicit rather than implicit.

It is not enough for something to be true; you have to know it is true, and be able to explain why. Otherwise, you do not know whether it is safe to use it. (Cohen and Stewart 1994:234)

The comparisons of the model developed from the interview data with models from published research in sociology, anthropology and clinical medicine provides a test of validity of the interview analysis but also helps to clarify the different perspectives that can be taken in analysis of qualitative data, although the focus is at the same level of analysis, that of the individual. This also helped to clarify those factors that are from a different level of analysis,

although there is interaction between levels and the boundaries between the levels of analysis are unclear. As the model of what affects women's control and choice about HRT is specifically for individual women, the model is accessible to general practice and can be used in the clinical setting, as it suggests specific areas that can be explored with individual women.

There are necessary prior conditions to the development of the model about the control and choice women have over the decision to take, or not to take, HRT. These include the existence of HRT, the regulation of its provision through the medical profession by it being only available on prescription, and the acceptance of its use for relatively mild menopausal symptoms and for prevention. If HRT was only used for the relief of severe distress or illness then choice would be limited by the distress or illness. A woman in severe distress or who is ill may not see any option but to take HRT to relieve the distress or illness. The model of women's control and choice over the decision to take, or not to take, HRT assumes that not all women considering HRT are in extremis. This, along with HRT being available only on prescription, means that the model assumes that for many women there is some degree of medicalisation of the menopause, as discussed in chapter two, as without medicalisation of the menopause there would not be the same choice facing women about HRT.

The interview data was collected in a specific context and the context influenced the data collected. This has been explored for the focus groups where the context appears to have enhanced themes such as control and the acceptance of uncertainty. These were themes that were found to contrast with themes from the individual interviews. The analysis of the interview data using the model of women's "ways of knowing" from Belenky et al. (1986) revealed the use of the different ways of knowing by the women, but that many women used several different "ways of knowing" and that these different "ways of knowing" could be used as a management strategy. Women able to use many "ways of knowing" were probably more likely to agree to participate in the interview

study. The context for the interview study influenced the data collected and therefore the context needs to be taken into account when interpreting the data, but the context also forms an important part of the research data itself. This can be at the level of a particular comment made by an individual woman, where the preceding comment, or whether the comment was towards the beginning or end of the group, may be important for understanding the comment. The importance of the context may also be at the level of the social context for a particular interview or group, or for the research as a whole.

Just as research participants can use different forms of expression depending on the context and needs, so researchers can use different strategies for dealing with the world in their research. There are analogies between the different "ways of knowing" and different scientific paradigms used in research. The use of different "ways of knowing" and of different research paradigms is influenced by the context of the research, including the aims and motivations of the research participants and of the researcher. Understanding how research itself influences research data can make it seem more difficult to be sure research has any results or conclusions as they depend on the social context and the perspective taken by the research. However, the inclusion of the research context as part of the research data means the research results and conclusions can be more accurately assessed. For example, for a GP interested in using the model developed in this chapter, about how women approach the decision to take, or not to take, HRT, it is important to know that the issue about control came from the focus groups rather than the individual interviews. A general practice consultation would be more like an individual interview than a focus group. This does not mean that the issue of control is not important for the consultation, but the GP needs to know this may not be overt, as it was only expressed in the research study when women were in a group.

The following chapter concludes the thesis by reviewing the results of the research, including examining the value of the interview

study results presented here, and the themes of social context and different research perspectives that have recurred through the thesis.

Chapter Eight

Conclusion

8.1 Introduction

This thesis has provided a narrative of the journey taken by the researcher through a process of research. This journey has illuminated issues about researching women's perspectives on HRT particularly from the researcher's perspective as a GP. This final chapter traces that journey and discusses what it may mean for general practice and future research. Firstly, the themes of the thesis are described, in particular how they fit together to answer the three research questions. In the thesis the analysis of the research methodology and the use of different perspectives and levels of analysis has raised questions about whether the results and conclusions of the field work are an accurate representation of women's perspectives on HRT. This is discussed in the subsequent section. Then the themes of the influence of social context and of the use of different perspectives and levels of analysis are brought together and provide a conceptual model for going on to look at areas for future research arising from this thesis.

8.2 The themes of the thesis

The research for this thesis started with the researcher, as a GP, wanting to understand women's perspectives on HRT and to inform other GPs about women's perspectives on HRT. The first research question developed as: *what are women's attitudes to HRT and what influences them?* The thesis has described the research which was carried out for this question, from the development of the research question and an analysis of the background and context of the research, through the questionnaire survey including using the questionnaire data to its limits in model development and cluster analysis, and through the interview study. At each stage of the research, the implications for general practice have been considered. The use, in general practice, of biomedical and

biostatistical models and their evidence on HRT was discussed. The results of the questionnaire survey provided general practice with a description of aspects of women's perspectives on HRT, as measured by the questionnaire, and the intellectual and practical challenges this raised for general practice were discussed. The interview study provided a model of how women approach the decision to take, or not to take, HRT, which reflected theory commonly used in general practice, but which showed how this applied to the specific issue of HRT. This was drawn from, and so could be illustrated by, examples of what women said from their individual perspectives in their particular contexts. The details of the results and conclusions of the field work are not presented here as this would involve repeating the account of the analysis described for each stage of the field work. However, section 8.3 discusses whether the results and conclusions of the field work are an accurate representation of women's perspectives on HRT.

The exploration of women's perspectives on HRT formed the starting point for the thesis, and the process of this research gave the thesis its overall structure. However the thesis also considered the research question: *what are the methodological questions raised by trying to answer the first research question and how can they be addressed?* This led, in particular, to identifying the influence of social context on the research participants and the research process and the interaction between the research and the process in a number of ways. The background and experience of the researcher influenced the development of the research question and the way the research was carried out. The research methods influenced the research results both in the questionnaire survey and the interview study. The interpretation and presentation of the research results were influenced by the aims and motivation of the researcher, and similarly the responses of the research participants may have been influenced by their own aims and motivation. Social factors influenced the development of the use of hormones in medicine, which then prompted the development of this research. This research, in turn, aimed to influence the medical use of hormones. Social organisation such as the provision of medical services, the

availability and type of employment, the provision of welfare and the process of dissemination of information through the media, influenced the process of the research, the data collected and the interpretation of the results. Prevailing political and cultural ideas such as the emphasis in society on individual action, particularly for health promotion, the importance given to measurement and numbers, and the incorporation of biomedical ideas into lay perspectives on health, influenced both the research participants and the research process. The way both the researcher and the research participants viewed the world influenced the research both as a background influence and by being actively used by the researcher, for example through using a theory or model to examine the results of the research, and by being used as a way of understanding or managing a situation. Thus, although the thesis followed a research process aimed to understand women's perspectives on HRT, it also explored the influence of the social context on the research participants, the research process, and the interpretation of the research results.

The research idea for this thesis originated in the discipline of clinical general practice, but was progressed within the discipline of sociology. Working within two disciplines highlighted the different ways of viewing the world used by different disciplines and led to the research question: *what have the disciplines of sociology, clinical general practice and biomedicine with biostatistics to offer each other in terms of answering the first two research questions and developing relevant understanding of each other, and how can an interchange between disciplines further understanding?* The thesis examined the biomedical and biostatistical paradigms with reference to HRT. The results of the research were discussed from the view of general practice and sociology, and theory from psychology was also used in understanding the research process and results. The theories of "chaos" and complexity were used to increase understanding of uncertainty, the limits of measurement and the different levels of analysis used by different disciplines and how these levels of analysis interact. The disciplines that contributed to the thesis each focus mainly on one level of analysis,

although there is interaction between the levels and disciplines may use evidence from other levels of analysis. Biomedicine traditionally focuses on the detail of individuals such as their physiology and biochemistry. General practice focuses on individual patients although taking into account their physiology and biochemistry, their relations with other individuals and their social context. Psychology tends to focus on individual beings, but may consider them as groups rather than as separate individuals. Biostatistics is also concerned with individuals but only as a member of a group of individuals. Sociology focuses on social organisation and social phenomena although this may be informed by contributions from individuals. The questionnaire survey results and the interview study results have been considered from both the level of analysis of individuals, as particular individuals or individuals grouped together, and from the level of analysis of social organisation or social phenomena. This has provided examples of the interaction between the levels of analysis and how the boundaries between the levels of analysis are not clearly defined.

8.3 Do the questionnaire survey and interview study give an accurate representation of women's perspectives on HRT?

Working on the boundary between different disciplines led the researcher to see the research from different perspectives and to analyse the methods and results from these different perspectives. This led to questioning of the research including asking whether the results and conclusions of the field work were an accurate representation of women's perspectives on HRT. For example, chapter three examined the questionnaire survey method to reveal its many limitations, the uncertainties about what was measured and the compromises made. Chapter six explored how the process of the research influenced the data collected in the interview study, and in chapter seven, different ways of interpreting the same data were described. This critical analysis of the detail of the research methodology could lead to a conclusion that the research results are too flawed to be representing women's perspectives on HRT. This

conclusion could be reinforced by looking at the research context more widely. For example, chapter one described the social context influencing the development of the research question. It could be argued, from a perspective that sees research as something objective, that as the research is so clearly a social product that its results are too affected by the context to be representing women's perspectives on HRT. During the course of the research, the researcher considered this conclusion and frequently felt it may be right!

However, although the research methods have many limitations, both in the questionnaire survey and the interview study, the researcher listened, as carefully as she knew how, to the women. This listening was at the core of the original research question, and a desire to do this well was the researcher's main guiding value. Knowing that the research data was what women had said, drew the researcher back from the conclusion that the research results were not representing women's perspectives. There also began to appear some consistency in the results. For example, the attitudes to HRT expressed in the individual interviews were consistent with the characteristics of the women's cluster groups. Results from the survey such as the widespread fear of cancer and the importance given to medical tests, were also expressed in the interview study. There was also consistency with other published research.

The researcher had to view the data from a perspective new to her, in order to see some of the consistency. The survey results, presented in chapter four, provide a description of women's use of HRT and many issues associated with this. The data is about individual women and is analysed treating the women as members of a large group that can be subdivided in various ways, to tease out trends within the data. For example, women were subdivided by age or menopausal status as these variables were thought likely to affect how women view HRT and how they respond to the questions in the survey. Although the aim of the research was to discover women's attitudes to HRT, the researcher had most conceptual difficulty with the section of the questionnaire dealing

with this. Moving away from the descriptive cross tabulations to cluster analysis gave the researcher a new perspective on the data. This time the women were not divided up before doing the analysis. It took the researcher some time working with the data to realise the women need not be subdivided. Cluster analysis sought to answer the question: are there ways in which women can be categorised using the data about their approach to HRT? This sees the data as something that describes women as they are, rather than in terms of the probability of holding a particular attitude or of taking HRT. To use the language of the theory of complexity, this type of characteristic could be termed an emergent property of the women. Cluster analysis revealed that women could be divided according to their approach to HRT, and later the different approaches to HRT emerging from the cluster analysis were found to be consistent with the interview data. Characteristics such as age and menopausal status also describe women as they are and can also be termed emergent properties. However, when any of these properties are used as a way of dividing the women for measurement they can seem to lose their importance as a description of the women. Although the characteristic remains the same, its use can alter the meaning and value it is given.

The interview study aimed to complement the questionnaire survey and this was thought to be by providing detail from individuals. However, analysis of the data involved identification of common themes, including women's fear for their future health, feelings about control, the power of medical evidence and coping with uncertainty. These describe aspects of women as individual people and could again be termed emergent themes. The themes are common to women across a wide range of context and experience but the detail for individuals, for example the level of fear or control and what influence this, will vary between individuals. The themes emerge from the details about individuals and the detail can be used to illustrate themes. The interview study complemented the questionnaire survey by identifying emergent themes that were consistent with the results of the questionnaire survey. The details

about individuals illustrated these themes and the variation in women's experience.

As with the questionnaire survey, discussion of the influence of the research context on the results and conclusions of the interview study questions whether the study was too affected by the context to be accurately representing women's perspectives on HRT, but as discussed above, the researcher drew back from this conclusion. However, the interview study method and how the results are presented added to the researcher's doubt. The method relies on collecting accounts from individual women, separately or in groups. From a medical perspective, medical practice gives importance to listening to individual patients, but medical research dismisses accounts from individuals as a form of evidence (Helman quoted in Griffiths 1996a:S30). This uncertainty about the value of the data as research evidence was compounded by the use of quotations from individuals women to illustrate the themes that emerged from the data. As the quotations are from individuals and so are specific to the individual's context, this may give the impression that the emergent themes are also context specific. However, if the themes identified are emergent themes then they would emerge even where the details of the context vary within certain limitations. These limitations are likely to include aspects of Western thinking, culture and social systems. However, the limitations are unlikely to include, for example, whether the context is the north or south of England even though the details of the women's accounts may vary between these areas. This is discussed further in section 8.5. In summary, the method and form of presentation of the interview study results can give the impression, from the medical perspective, of being too context specific to be accurately representing women's perspectives.

The similarity between the model developed of women's control and choice over the decision to take HRT and other models of how individuals function, supports the idea that the model is describing themes that represent women's perspectives. The comparisons, explored in chapter seven, also demonstrate how the model

describes just one particular aspect of women as revealed by the data, and that the research question being asked determined the aspect that was described. The data may be analysed differently if approached with different questions and different motivations. The most important influence on the results of the research seems to be the research question itself, and the social context has its strongest influence on the research process through its influence on the research question.

The original research question was developed in the context of increasing promotion and use of HRT. This social context gives the research results their importance. The aim was to use the results of the questionnaire survey and the interview study to prompt GPs to reflect on their practice and encourage them to take women's views into account.

The interview study provides a model, specific to HRT, that suggests ways in which a GP may enable a woman to take as much control as possible over the decision to take, or not to take, HRT. This model seems a small offering, particularly as the themes in the model have been written about extensively, although not specifically in relation to HRT. Many GPs will be well used to exploring these issues in consultations already. However, in the context of the increasing promotion of HRT and an emphasis on the use of biostatistical evidence for making decisions in clinical medicine, the model may be a timely reminder that the exploration of the issues included in the model, is as important when considering HRT as for any other general practice consultation.

The questionnaire survey results and the study of women's use of HRT in the researcher's own practice provide quantitative data that may prompt reflection by doctors about the promotion of HRT. Knowing the number of women taking HRT can be useful when considering prescribing policy in general practice and planning service provision. Understanding women's knowledge of HRT and their sources of information can be helpful for developing strategies for the clinical situation. The results may also prompt GPs to

reflect on their part in a social phenomenon. However, the results are only of importance in the context of the increasing promotion and use of HRT.

In summary, criticism of the research methodology and looking at the research from different perspectives can make it seem that the results from the questionnaire survey and interview study cannot represent women's perspectives on HRT. However, care was taken to listen to women and the themes that emerged from the data were consistent using different research methods and were supported by other research. This suggests that the results are representing women's perspectives, but the results are limited by the research question asked. Conclusions can be drawn about women's perspectives on HRT which, in the current context of general practice, may be important in influencing the way GPs respond to women asking about HRT and which may prompt reflection about the role of GPs in the provision of HRT. This use of the research results is context specific.

8.4 Social context, perspectives and levels of analysis

The themes that have emerged from what women say about HRT can be looked at from different perspectives. These different perspectives may be at the same level of analysis, for example looking at women as individuals, as explored in section 7.3, when comparisons were made between the interview study data and other qualitative studies. However, different perspectives often use different levels of analysis. The major perspectives discussed in the thesis that use different levels of analysis are those of the disciplines of sociology, general practice, biostatistics and biomedicine. In chapter seven, different "ways of knowing" used by women were explored in the interview data, and analogy made with the different ways of dealing with the world used by different academic disciplines.

The type of question asked in research influences the way a researcher copes with the complexity of the world and the use of

different levels of analysis and different perspectives is a part of the management strategy used to narrow the research field sufficiently to develop hypotheses, theory or models that can be conceptualised as an entity, explored and tested. In the process of narrowing the research field, disciplines tend to leave questions beyond their narrow field to other disciplines. For example, in biomedical research, where experimental methods are used, for a particular piece of research, the context is controlled and the description of the research focuses on how this is achieved. A commentary on the influence of social context on biomedical research and its research questions is left to other disciplines such as sociology, as explored in chapter 2, which by focusing on the level of analysis of social organisation and social phenomena, can demonstrate how social context influences the research processes of biomedicine including which research questions are asked. However, once a research question is formulated and an experimental method devised, the social context may not have an effect on the results, although it may influence the conclusion and the presentation and use of the results. The discipline of biostatistics studies groups of individuals and is interested in the probability of outcomes. It takes into account differences between individuals and their social context as far as this may affect the measurement of the probability of the outcomes, Sophisticated methods for doing this have been developed including the process of taking a random sample, as used in the questionnaire survey, and using control groups. Biostatistics focuses on the level of analysis of individual people but only as members of a group. Although biostatistics has to take account of the social context for its research, it requires the level of analysis used by sociology to demonstrate how biostatistical research is influenced by its social context and is a product of a way of thinking of a particular time and place. For the questionnaire survey, which used a biostatistical approach, these influences were explored in chapters one and two.

Biomedical and biostatistical research have been successful in developing some very useful medical interventions and demonstrating some particular causes of ill health. HRT was developed through biomedical research and has been, and still is

being, tested with biostatistical methods. The development of medical interventions such as HRT are influenced by the social context, but they also interact with the social context to change it. Analysis of the effect of a medical intervention on the social world needs the perspective taken by disciplines such as sociology to study the effect on social organisation such as the provision of health services, and the effect on social and cultural phenomena such as society's view of menopausal symptoms, ill health and ageing.

General practice is concerned with people as separate individuals. Heath describes the key role of general practice, serving individual patients, as follows:

the key roles of the general practitioner are firstly to serve as an interpreter and guardian at the interface between illness and disease; and secondly to serve as a witness to the patient's experience of illness and disease (1995:26).

Individuals are complex entities which biomedicine tries to understand in a reductionist way. General practice uses biomedicine but sees individuals as emergent phenomena with characteristics as individual people. General practice theory suggests the characteristics of individuals important for clinical practice include the individual's hopes, fears, feelings and expectations (McWhinney 1989: 87-110 discussed in Royal College of General Practitioners 1996: 2). The model developed in chapter seven, of women's control and choice about HRT, attempts partly to reflect an aspect of women seen as individuals. General practice is a discipline with its own perspectives, theory and models, but primarily exists to work with patients. Therefore, it can also be described as a craft which brings together the understanding provided by many different disciplines for the individual patient. For example, general practice considers the social context and social systems that affect individuals (*ibid.*), and these were also included as influencing factors in the model of women's control and choice with regard to HRT.

The craft of general practice is informed by sociological perspectives, it uses disciplines that study individuals in groups including biostatistics and psychology, and it uses studies of particular relationships of the individual including studies of the family and the doctor patient relationship. The craft is influenced by its social context, which includes the perspectives, theory and evidence from other disciplines, and general practice influences the social context. An understanding of these influences requires the study of general practice as a social organisation or phenomenon.

Drawing these ideas together, the main disciplines contributing to this thesis use different levels of analysis as a way of coping with the complex world so ideas can be conceptualised and tested. Results of research are limited by the perspective taken and the level of analysis used. An awareness of the limited nature of research results and any models or theory developed from the results, highlights what is not known, i.e. what is around the theory or model that we do not know enough about to include or cannot be included in the particular perspective of the theory or model. Each discipline needs other disciplines to use different levels of analysis and different perspectives to increase our understanding of the world. General practice is primarily a craft developed for serving individual patients which uses understanding developed by many different disciplines. As an academic discipline, one particular contribution of general practice could be to the understanding of individuals, particularly themes common to individuals that relate to health and healing including fear, control, power of influence and coping with uncertainty.

There is interaction between different levels of analysis, for example, individual people contribute to the organisation and development of a society but are also influenced by that society (Reed and Harvey 1992). The boundaries between the levels of analysis can not be clearly drawn even though the different levels of analysis can be distinguished. For example, in chapter five, the data from the questionnaire survey was used to develop a model of what

influences women to take HRT. The data came from individual women, but was collected in a form that allowed the data from individuals to be put together so the individuals could be treated as a group. The outcome, whether women took, or did not take, HRT was expressed in terms of a probability for the group of women. However this probability can also be seen as a social phenomenon. This phenomenon of women taking HRT is created by the individual acts of the women and the phenomenon may influence social organisation and social attitudes. The effect of the phenomenon on social organisation and social attitudes may influence other individual women to take, or not to take, HRT, and may influence the women already taking HRT. Whether the measure of women taking, or not taking, HRT is seen as a statistical outcome measure for a group of women or as a social phenomenon that raises sociological questions, depends on the aims of the research.

Within one level of analysis it is also possible to use data in different ways. The comparisons made between the interview study data and other interview studies (chapter seven) and how the focus group data could also be used to study communication processes in groups (chapter six) demonstrates how the results of analysis of data depends on the research question asked and the perspective taken by the researcher.

In summary, the level of analysis used in research will depend on the aims of the research, which will be influenced by the social context. Models and theory relate to particular levels of analysis. Data however can be used by neighbouring levels of analysis, although it would be used with different aims. Within one level of analysis data can also be used from different perspectives. The different levels of analysis are influenced by other levels and these influences need to be acknowledged whether by controlling them or accounting for them.

8.5 Directions for future research

The previous section has drawn together the themes from the thesis of the influence of social context on research, the different perspectives used in research and the different levels of analysis. I now look to directions for future research that emerge from the thesis. My experience and interests continue to influence the thesis so the themes for future research are those seen from my perspective.

Firstly I suggest research questions about HRT that have been raised in the thesis. These research questions arise in the current social context and, in particular, from clinical care where doctors are facing questions and decisions about HRT. The research questions accept the social context and aim to find practical answers to uncertainties in this specific context. This may be termed applied research, but to emphasise the effect of context it is referred to as "context accepting research". The research questions are divided according to the different levels of analysis used

Then I suggest future areas of research that explore the effect of social context on issues such as health and HRT and raise questions about the social order. This is referred to as "context questioning research". The research questions suggested are not free of the influence of social context themselves.

Finally I explore the possibility of research that may be, to some degree, context non-specific. This builds on the suggestion in section 8.3 that the themes emerging from the interview study may not be specific to the context, within broad limitations. The themes included fear, control, power of influence and coping with uncertainty. The interview study discussed aspects of these themes relevant to HRT, but the themes themselves are not limited to this context. The themes may be found in other contexts, and in a sense transcend context. In section 8.4 it was suggested that as an academic discipline, general practice could focus on the level of analysis of the individual, and seek to understand themes such as

those identified in the interview study and that are common to individuals, particularly as they relate to health and healing. This area of research is referred to as "relatively non-context specific research". The choice of this title helps to contrast this area of research with the others described in this section, in terms of the influence of the social context. This research may not be specific to a context in the sense that themes about individuals and how they function may be very similar despite variation in detail. For example the nature of suffering as explored by Cassell (1991) may be similar in the US and in Europe despite different health care systems. The need to be cared for when ill is a theme that occurs in all cultures (Hart and Dieppe 1996). The themes of fear and control may be similarly experienced across different contexts although the detailed manifestation may vary. Although this thesis points towards the idea of non-context specific research, it cannot demonstrate that is totally non-context specific, and the effect of context may depend on the way the research is formulated.

8.5.1 "Context accepting research"

There are unanswered questions about how HRT has its effect at the level of biochemistry, including its effect on hot flushes and how it acts to help prevent osteoporosis and CVD (Oldenhave and Netelenbos 1994). This research would require a biomedical approach. The social influences on biomedical research on female hormones in the past was discussed in chapter two, and social context would continue to influence such research. The thesis explored the theory of medicalisation of the menopause and how the data from the questionnaire survey supported the theory. A social context where the menopause is seen as a medical problem treatable with hormones will act as a stimulus for medical researchers to find out more about these issues, as they are socially accepted as within their remit.

As HRT is being used more widely, there is some concern that some women may become dependent on HRT (Bewley and Bewley 1992a,b). This concern comes from the context of clinical practice

where HRT is being used. Collecting a case series would help to clarify if women are becoming dependent, and this has already been started in a gynaecological clinic setting using psychological measures of dependence (personal communication S. Bewley). The level of analysis here is the individual. If the case series confirms the clinical impression that women may be becoming dependent on HRT, a biostatistical approach could then be used to measure the frequency of the problem and factors that may affect the likelihood of women becoming dependent. This would provide information about women as a group and may help guide policy decisions about the availability of HRT. An interview study with women who appear to have become dependent on HRT would increase understanding of individual women's experiences, from which common themes could be drawn, which may then increase the understanding of the problem by health professionals.

The model of the area of control and choice for women in regard to HRT, developed from the interview data in this thesis, was at the level of analysis of the individual. This model could be tested further using a process derived from action-research, taking it to individual women for their comments, amending it and then taking it back to them again for further feedback. This could improve the validity of the model and may reveal other factors that women feel affect their approach to HRT. The model was aimed to inform general practice and it may be possible to test it in general practice, assessing whether the issues are the ones women bring to a general practice consultation, or are issues they appreciate having raised by the GP in a consultation. There would be a number of practical problems to be overcome to do this as, unless women are attending a particular "clinic" in general practice, the content of general practice consultations cannot be predicted as it is mostly a reactive service.

Biostatistics is committed to long term controlled trials of HRT to try to establish the probability of benefit and risks from different forms of HRT (Medical Research Council's General Practice Research Framework 1996) giving results at the level of analysis of

individuals in groups. Information from this type of trial is used by clinicians in advising individual women about HRT, even though the results cannot be applied directly to individual women. These trials have become of great importance in the current social context, with more women interested in taking HRT, with the emphasis on prevention of future health problems, with the medico-legal responsibilities for HRT as a prescription only drug, and the acceptance of information from this form of trial as being the most robust form of medical evidence.

A biostatistical approach could also be used to collect data on the use of HRT by women, perhaps using a brief questionnaire, for comparison with the data presented in the thesis, to reveal any changes in the number of women using HRT. This data could be used in planning health service provision and so would be research for a very specific context. However, the data could also contribute to a sociological analysis of the phenomenon of taking HRT which would be more context questioning. This type of research is considered further in the next section.

At all levels of analysis, involving many disciplines, there are potential areas for future research linked with the use of HRT that could be explored further. In developing research questions in the areas described above the researcher accepts the social context as given and is seeking to increase our understanding of one issue, probably with the ultimate aim of improving people's health in some way, but within the given social context. This can be important for informing the decisions of health professionals and patients. However, looked at from other perspectives the research can seem very limited. For example, why not question the medicalisation of the menopause rather than research the long term effects of HRT? A sociological perspective would also question why certain research is done and who has the power to decide what is done. However, clinicians and patients value context specific medical research where it informs their decisions on medical concerns in their particular context.

8.5.2 "Context questioning research"

Examples of research questions were used to contrast context accepting and context questioning research in the previous paragraph. Throughout the thesis the context for the research into women's perspectives on HRT has been explored and questioned. This section suggests some potential areas of future research that have been raised by the thesis and that question the social context.

The social influences on the development of female hormone therapy were discussed in chapter two. Now hormone therapy is in common use, a divide seems to be developing between hormone therapy that is under patent and that which is not and so can be produced by any drug company. From a clinician's perspective, therapy under patent, which includes more or less all HRT, seems to be promoted and researched far more than non-patent therapy. The reasons for this will include the way pharmaceutical companies develop drugs and behave as commercial organisations, the regulations about drug licences and patents and the way research is funded generally. Social, economic and historical research may be able to make more explicit the differences in research on patent and non-patent hormone therapies, raise awareness of potentially fruitful areas of research that are not being funded, and highlight ways in which the social system may be maintaining a rather narrow drug research agenda.

The medicalisation of the menopause was discussed in chapter two and women's views on the use of HRT were explored in the questionnaire survey and interview study. Women used the media as a major source of information about HRT, so a study of images of the menopause in the popular media may increase our understanding of how the medicalisation of the menopause is being promoted. This may form an interesting comparison with the work by Bridgewater (1994) on the images of HRT used in the medical press.

Although this thesis has considered the use of HRT in general it has put more emphasis on exploring women's attitudes to the use of HRT for the prevention of future illness, than on the use of HRT for menopausal symptoms. Some of the possible effects on attitudes to ageing were explored using sociological theory in chapter two, and women's fears for their old age were explored in the survey and in the interviews. A sociological study could further explore attitudes to ageing and how medicalisation influences this. Women and men in their mid 40s to mid 60s may form a particularly interesting group for such a study as they may be facing several relevant issues at the same time including the menopause, starting medication for the prevention of future ill health (for example, for men, treatment for CVD), seeing their own parents reaching old age, and planning for their own old age. In the social institutions given the task of caring for the elderly or planning for future care needs, those with most power and influence are also likely to be in this age group. A study could also examine how social institutions are changing in response to changing attitudes to old age.

The three areas for future research described above are areas the researcher sees as important, particularly from the experience of writing this thesis. There will be other areas of research of importance that other experiences would suggest. The areas suggested for research question the social context and so would raise, implicitly or explicitly, political questions about society and how it operates. The motivation for developing this type of research question may include particular political values.

8.5.3 "Relatively non-context specific research"

Research always has a social context and, as discussed in section 8.3, the context influences the research question asked, including the questions for future research discussed here. The researcher's particular interest in individuals, both from experience in clinical general practice and from the experience of research for this thesis, influences the subject of this section. This influence is emphasised rhetorically through these ideas being discussed last, at the end of

the thesis. The thesis started in general practice and ends in general practice. In this section the idea of "relatively non-context specific research" will be explored, firstly summarising the idea of themes about individuals, then exploring the idea of relatively non-context specific themes in general practice, and finally suggesting a particular role for academic general practice.

In this chapter it has been suggested that there are themes about people, such as fear, control, the power of influence, coping with uncertainty, suffering and the need for care, that are relatively non-context specific. The themes are likely to be found in many different contexts although the details of how they are expressed will vary. Many disciplines in the social sciences and the humanities contribute to the understanding of this type of theme. General practice has developed theory that includes similar themes about individuals, from the perspective of health and healing (see section 8.4 for examples).

The activities of trying to assist with healing and trying to prevent or relieve suffering are activities of general practice and other health professions that have been present down the ages and across cultures (Taylor 1997: Hart and Dieppe 1996). These activities seem to be relatively non-context specific, although their detailed manifestations are context specific.

In a philosophical exposition on "What is good general practice?" Toon (1994) suggests there is a core of good practice that may need rediscovery. In his exposition he describes four models of aspects of good general practice which have equivalence with the levels of analysis explored in this thesis. Toon describes his four models as follows:

According to the biomechanical model good general practice is characterised by technical expertise in the diagnosis and treatment of the diseases which the patient presents. According to teleological/hermeneutical models such as Balint good general practice is characterised by the quality of the relationship

between doctor and patient In the anticipatory care model good practice means structures for screening and health education .. and ultimately reducing the incidence of disease. In the business/consumerist view, the good practice is efficient and profitable, and provides the services which patients want. (1994:47-48)

Toon's biomechanical model would use research evidence mainly from biomedicine but also biostatistics and his anticipatory care model would use research evidence mainly from biostatistics. Teleological/hermeneutical models use research evidence from studies of the doctor patient relationship. The business/consumerist view would use evidence from research into social organisation, probably of an applied form, but sociological theory may also be used. Toon goes on to consider the way forward in developing good general practice:

Since our view of good general practice depends on our philosophical position, as well as our scientific judgement of how best to achieve the ends we desire, there is a limit to the extent to which our difficulties can be resolved by more and better research and more sophisticated clinical skills, necessary though these may be. *What we need is not better research data but better philosophy.* We need to consider the philosophical differences between the models and reconcile them in order to produce a more coherent view of good general practice (author's own italics) (Toon 1994:49).

Toon then goes on to explore whether the four conflicting models he described may be philosophically reconciled. One of his conclusions is as follows:

It may be that within the co-operative human activity that is general medical practice there is a sufficiently strong tradition which, because of superficial and external moral fragmentation, finds it hard to articulate standards of excellence but nevertheless has deep within it a intuitive concept of what the goods internal

to the practice are. If this is so then our task is more akin to archaeology than to architecture, uncovering what is already there and filling in the gaps, rather than building bridges from new material. (ibid.)

The task of "archaeology" as suggested by Toon, seems to be a rediscovery or remembering of what we know about the healing craft of general practice that is relatively non-context specific in that it will include ideas or themes that are similar across cultures and down the ages. However, within our current social context the healing craft will have a particular manifestation, and Toon suggests that our social context may be making it very hard to be clear about what is central to good practice.

In summary, there are relatively non-context specific themes about individuals and about the healing crafts that are important for clinical general practice and so may be important areas for research by academic general practice. However, it could be argued that this type of theme has been so well studied in the past that there is nothing new to say. In one sense this may be true. However, changes in social context can make it appear that everything has changed, that people are different, that the healing crafts are different. In one sense this may also be true. In each social context it seems necessary to rediscover, or at least remember, what we know about individuals and about the healing crafts, and so seeing what is relatively non-context specific, yet seeing it within its particular context. For example, this thesis has pointed to fear and to control as important themes when women consider HRT, but fear and control are important in many contexts. The power of medical evidence in influencing women has been explored in the current social context where biostatistics is seen as very important, yet the theme of the power of medicine is not new to this social context. Academic general practice may be able to contribute to the understanding of individuals and to the understanding of its healing craft from its clinical experience and context specific research, by developing its own theory and models and through dialogue with other disciplines, including philosophy. This may require a

widening of the research focus from the issues of primary care that concern general practice such as dealing with common health problems, the differentiation of serious illness and the prevention of illness, to include what is general in the experience of health, illness and healing.

8.6 Final conclusion

The practical research for this thesis which explored women's perspectives on HRT, using a questionnaire survey and an interview study, was research done in a specific social context. It was influenced by that context and, in turn, it aimed to influence that context. Questioning the methodology used in the research made explicit some of the influence of the social context, the imprecision of apparently precise measures such as in the survey, how data could be used in different ways depending on the research perspective and the research question, how the research results and conclusions are limited by their context and how research results, by adding in a small way to our understanding, also reveal how much is not understood or cannot be brought into the research perspective used. Developing the thesis on the boundary of academic disciplines prompted the researcher to look at the research process and results from different perspectives and using different levels of analysis, employing those used by different disciplines as a way of managing the complexity of the world in order to conceptualise and conduct research. Although disciplines need to restrict their perspective, they rely on other disciplines to use different perspectives and different levels of analysis from themselves in order to increase our understanding of the world. Of the main disciplines contributing to this thesis, biomedicine, biostatistics and sociology seem to have distinguishable boundaries around the perspectives and level of analysis they use, although these boundaries are not clear cut. General practice as a craft uses many perspectives and levels of analysis and this may benefit the individual patient. However, as an academic discipline general practice may benefit from a clearer focus with more distinguishable boundaries. A particular contribution could be to the understanding

of themes about individuals in relation to health and illness, and to the understanding of themes about healing, that are relatively non-context specific, naming these themes and discussing them in our current social context. Thus the researcher's journey has finished back in general practice, where it started, bringing an understanding about social context and levels of analysis to contribute to the future of general practice research.

Appendix 0

The clinical use of HRT

HRT is a medication currently available in the UK only on prescription of a doctor. It is prescribed mainly in general practice and by gynaecologists. Other specialists that have an interest in it include rheumatologists and cancer specialists.

There are four main uses for HRT, the most common being the treatment of menopausal symptoms which are symptoms that some women develop around the time of the menopause (when menstruation stops). HRT can alleviate hot flushes and dryness of the vagina, two common menopausal symptoms. There is more variable evidence about whether HRT helps other symptoms that may occur at the time of the menopause such as depression, although there will be some indirect effect on symptoms through the relief of hot flushes and dryness of the vagina, by improving sleep and sexual well being.

The bodily changes and symptoms of the menopause are brought on if a woman's ovaries are removed surgically (oophorectomy) and is referred to as a surgical menopause. Women are given HRT to replace the oestrogen hormones that would be naturally produced by the ovaries. This helps to prevent the changes and symptoms of a surgical menopause. The symptoms of a surgical menopause are similar to the natural menopause but can be more severe. If a woman has a hysterectomy (surgical removal of the womb) the ovaries are often left in place and continue to function. However the ovaries seem to stop functioning more quickly after a hysterectomy than if the womb is in place. HRT is therefore given to some women following hysterectomy even if the ovaries are left in place especially if they develop menopausal symptoms.

HRT is also used to prevent two types of disease. These are osteoporosis (brittle bones) and CVD (diseases of the heart and blood vessels, in this context mainly heart attacks).

As all humans age, the density of their bones gradually diminishes. After the menopause (natural or surgical) the rate at which the bones of women become less dense increases compared to before the menopause. HRT appears to slow down this loss of bone density. Osteoporosis refers to bones which have become relatively low in density and more easily fractured. By slowing down the rate of loss of bone, HRT postpones the time when the bones become liable to fracture. There are three main clinical problems for which this is relevant. Fracture of the hip is a relatively common problem for elderly women. Although the fracture can be successfully fixed surgically, this involves risk of illness and death and mobility may be limited even after successful operations. Crush fractures of the vertebrae can occur when bone is low in density, which are very painful and can result in deformity of the back. Fracture of the wrist is more likely for women with osteoporosis, for example when they fall on ice in the winter. These fractures usually heal well but can exacerbate the difficulties of coping for an elderly person while healing takes place. Having a relatively early menopause (natural or surgical) starts the increased rate of loss of bone early and so this increases the risk of osteoporosis for women while they are otherwise still alive and well. This is one of the reasons women with an early menopause are offered HRT. Osteoporosis tends to run in families, having a first degree relative who has had osteoporosis means a woman's risk of getting it herself is increased compared to the population as a whole. Other risk factors seem to be lack of exercise, low calcium intake, being thin and smoking. These risk factors seem to be important for young women, affecting their risk of osteoporosis as they age. There are other medical conditions that predispose to osteoporosis, but these are relatively rare.

It is possible for women to have their bone density measured (bone densitometry). This gives a measure of current bone density which is then used to predict a woman's future bone density and so her relative risk of osteoporosis.

As all people age, their risk of developing CVD also increases. Before the menopause the risk of CVD for women is less than men. However after the menopause a women's overall risk becomes the same as for men of the same age. There are other risk factors for CVD apart from age include smoking, obesity, lack of exercise, family history of CVD, diabetes and a diet high in saturated fats. There is evidence that HRT may help prevent CVD and may be particularly important for women who have already developed CVD. For example, if a woman has had a heart attack, HRT may reduce the risk of further illness or premature death.

There is a range of preparations and ways of giving HRT. The action of the different preparations seem to be equivalent although different women tolerate different preparations better. The types of preparation include tablets, patches, implants and gels for rubbing into the skin. However there are two major groups of HRT which have important differences. In one group, the HRT contains only the hormone oestrogen which relieves menopausal symptoms and prevents osteoporosis and CVD. However oestrogen was found to increase the risk of developing cancer of the endometrium (lining of the womb) when given alone. For women without a womb, this is not a problem, so they usually receive oestrogen alone. For women with a womb, another type of HRT is used, that containing oestrogen and progesterone, as the progesterone seems to prevent an increase in the risk of endometrial cancer. Until the last few years the progesterone was given in the final ten days of each monthly packet of HRT and produced a withdrawal bleed, that is a bleed like menstruation but brought on by giving, then stopping progesterone. Recently preparations have been developed that give the progesterone throughout the month and usually do not produce a withdrawal bleed.

Oestrogen alone has been widely used in the USA and the increased risk of endometrial cancer was identified there. In the USA some women still use oestrogen alone even if they have their womb but they may have their endometrium checked each year looking for malignant changes by taking a sample of endometrium for

laboratory testing. In the UK, the use of oestrogen alone is generally restricted to women with no womb and the combined preparations containing oestrogen and progesterone are used for all other women. Endometrial sampling has recently become widely available in the UK, but its use is restricted to diagnosis of endometrial pathology rather than screening of women on HRT.

The oestrogen used in HRT was originally produced for pharmaceutical use from mare's urine. However, many forms of HRT now contain chemically synthesised oestrogen. The dose of hormones in HRT is very much lower than that in the combined oral contraceptive pill (birth control pill).

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Appendix 1

Concepts and terminology from the theories of "chaos" and complexity

The use of the term "chaos" in describing the original theory can be confusing as the word in this usage does not refer to disorder, confusion or randomness but to a dynamic system where orderly behaviour can destabilize and become unpredictable. The phrase "deterministic chaos" has been coined to try and clarify the meaning of the term "chaos" (Harvey and Reed 1994). According to "chaos" theory, the outcome of a system, for example a weather system, would be predictable if the elements of the system could be measured in sufficient detail, to infinite accuracy, and the outcome of the interaction of different elements could be calculated. However, in reality the outcome is not predictable because it is impossible to measure small differences to infinite accuracy and the calculation of outcome, even if measurement was infinitely accurate, may be too difficult (Cohen and Stewart 1994:189-190). The study of thermodynamics has revealed that most systems, including biological systems, are "chaotic" in nature, as energy can freely flow between the system and the environment. The few that are not "chaotic" include inert substances such as crystals and systems such as a thermostat (Harvey and Reed 1994).

In a "chaotic" system, small differences in initial conditions can become magnified to produce very different outcomes. This characteristic of a "chaotic" system has become known as the "butterfly effect" as one of the earliest expressions of the idea came from the work of the meteorologist Lorenz who had developed a computer model that he hoped would be able to predict the weather when provided with appropriate data. Lorenz discovered that tiny differences in initial conditions could produce radically different outcomes in his model. The size of the difference in initial conditions he likened to a butterfly beating its wings, so a butterfly beating its wings in China could cause a hurricane in New York a week later. If the butterfly had not beaten its wings there may have

been no hurricane. The difference in initial conditions that can give such different outcomes is so small as to be essentially immeasurable in most real life situations. It could be equivalent to a difference in tone of voice of the doctor in a general practice consultation (Pruessner, Hensel and Rasco 1992).

Two other phrases used with meanings specific to "chaos" theory are "phase space" and "attractors". Phase space is the space of the possible; everything that could possibly happen not just everything that has been known to happen in the system being investigated. In meteorology, phase space would include all possible measures of variables such as wind speed, atmospheric pressure and temperature. The phase space for an individual human would include the space of the possible for variables that include physical, psychological, social and spiritual measures. Our ability to conceptualise and measure variables limits the phase space that we can investigate. When a chaotic system is represented in a computer model the system is seen to settle in one position in phase space, the boundaries of which are known as an "attractor". This term can be confusing as there is no predetermined pulling of the system towards a known point, the "attractor" can only be identified by watching a system until it settles on a position in phase space, so is only known after the event (Cohen and Stewart 1994:204-207). This boundary or "attractor" is determined by a number of variables which can be many or few, but is usually less than the total variables that determine phase space. Computer models have shown the "attractor" tends to be torus shaped (the shape of a jam doughnut). The system is dynamic, constantly testing its boundary, changing shape over time as the environment changes and variables change and interact with each other, however it usually returns to more-or-less its original shape.

A "chaotic" system can evolve in unpredictable ways. A change in the environment or an interaction within the system of sufficient magnitude to overcome the system's tendency to remain stable can precipitate a major change in its configuration and position in phase space. When the system begins to become unstable, it fluctuates

between two or more new positions in phase space. This oscillation continues at what is known as a "bifurcation", until the system takes one of the alternative positions around which to stabilise. Once the move is made there is still potential for further changes to other alternative positions or even back to the original position. However the longer the system remains in a new position the more likely it will remain there. In a computer model the shape of the two potential new positions for the system look like a butterfly, the wings being the potential new positions for the system. The final position of the system cannot be predicted in advance nor is it possible to be sure of all the variables that contribute to the change in position in phase space as it is impossible to measure variables to infinite accuracy. A medical example of a bifurcation is the crisis point of untreated pneumococcal pneumonia, when it is uncertain whether the patient will rally and live or succumb and die.

A development from "chaos" theory in the discipline of mathematics was that of fractals, including the famous Mandelbrot set. A fractal is a pattern that has a complex and distinctive structure on all scales of magnification. Keep magnifying it and you see ever-new detail, yet the computer command that gives rise to it is very short (Cohen and Stewart 1994:196). This idea of complex patterns emerging from simple rules forms the basis for the science of complexity. Complex systems display emergent properties that cannot be explained by reference to the components of the system. This is similar to the idea from Gorovitz and MacIntyre (1976) that, for example, an individual is more than the sum of the multitude of complex biochemical structures and reactions taking place in their body. The complex system, the individual, has emergent properties. At one level of complex organisation, such as the individual, there are patterns of behaviour that individuals have in common. Similarly, at the level of the cell, there are patterns of behaviour in common for cells, and so on down the levels of complexity. However, the details of behaviour at one level of complexity cannot fully explain that at the level above. Biomedicine has found many very useful, but only partial explanations for individual behaviour based on an understanding of

the lower levels of organisation. Similarly, the study of social systems reveals phenomena that cannot be fully explained in terms of the individual actions of the people in the social system. There is interaction between the levels of organisation and a change at one level can affect another and may precipitate changes characteristic of "chaotic" systems (Cohen and Stewart 1994:438-443; Harvey and Reed 1994).

Appendix 2

The use of HRT by women in one general practice

Method of data collection

This study was conducted in the researcher's own practice which was described in chapter one. In December 1993 the women who had received HRT on computerised repeat prescription, either currently or in the past were identified. Women who received one prescription for therapy and did not continue with repeat prescriptions were not included. At the time of the data collection, records of past computerised repeat prescriptions had been kept for 8 years. For patients joining the practice since then, all current users were included, but not those who had been on HRT and stopped before joining the practice. Data were available on the frequency of prescriptions being requested by the women. From this it was possible to calculate whether women appeared to be taking breaks from therapy. The length of apparent breaks was calculated as a percentage of total time on therapy.

Data were collected from the practice morbidity register on the number of women with a history of hysterectomy with or without bilateral oophorectomy. The number of women who had had a hysterectomy was verified by cross checking with cervical cytology records. For the women taking HRT and who had a hysterectomy, the time of starting therapy relative to the hysterectomy was established. The continuity of treatment was estimated and any reasons recorded for stopping therapy noted.

A search was made for women with risk factors for osteoporosis. Women with a previous fracture of the hip or forearm before the age of 65 were identified from the morbidity register, updated from hospital reports. Bone densitometry results and the computerised record of family history of osteoporosis were searched. An attempt was made to identify women at risk through their use of oral

steroids, but this proved complex and was abandoned. The use of HRT by women at risk of osteoporosis was recorded.

For women taking therapy for menopausal symptoms, the records were searched for menopausal status on starting therapy. The length and continuity of treatment was estimated and any reasons recorded for stopping therapy noted.

For the analysis, women who had received HRT were divided into groups according to whether they had had a hysterectomy, and if so, whether their ovaries had been preserved and whether the hysterectomy had been done before or at the average age for the menopause (i.e. under 52 years) or after, and whether they were using HRT primarily for menopausal symptoms or for other reasons.

Results

There were 608 women in the practice with a record of having taken HRT. Of these 141 had stopped taking it (23.2%). For comparison with other studies the number of women aged between 40 and 59 years and currently taking therapy was extracted from the total. Of women in the practice aged 40 to 59 years, 348 (19.9%) were currently taking therapy.

For the 608 women, the main reason recorded for starting therapy was menopausal symptom relief for 321 women (52.8%), post-hysterectomy for 225 (37.0%), prevention of osteoporosis for 24 (3.9%) and prevention of CVD for one woman (0.2%); other reasons were recorded for 25 (4.1%) and no clear reason was recorded in 12 cases (2.0%). Included in the total group of 608 women were 275 women who had used HRT and had had a hysterectomy. Of these, 225 had started on the therapy because of the hysterectomy, 37 had done so to relieve menopausal symptoms, seven for prevention of osteoporosis and six for menstrual problems.

HRT use by women who had had a hysterectomy

There were 265 women who had had a hysterectomy when aged under 52 years. Of these, 107 had had their ovaries removed and 158 had not.

Of the women who had had a bilateral oophorectomy, 76 were currently taking therapy (71.0%), nine had taken it in the past but had then stopped (8.4%), and 22 had never taken it (20.6%). HRT had been started before the operation for 14 women (16.5%), immediately afterwards for 43 (50.6%), within one year for 16 (18.8%) and more than a year later for 12 (14%).

Of the 158 women who had not had their ovaries removed, 39 were currently taking therapy (24.7%), 11 had taken it in the past but then stopped (7.0%), and 108 had never taken it (68.4%). HRT had been started before the operation for 14 women (28.0%), immediately afterwards for four women (8%), within one year for 24 women (48%) and more than one year later for eight women (16%).

For the 20 women who had had a hysterectomy before the age of 52 years who had stopped therapy, the reasons recorded for stopping were breast symptoms (two women), side effects (two) and other reasons (three). No reason was recorded for 13 women.

There were 92 women who had had a hysterectomy and bilateral oophorectomy when aged 52 years and over and 48 women who had had a hysterectomy with preservation of the ovaries when aged 52 years and over who were taking or had taken HRT. The timing of starting therapy in relation to surgery was similar to that for the women aged under 52 years.

For women of all ages who had had a hysterectomy and had taken HRT, 214 had taken it continuously (77.8%). This proportion varied little when women were divided into groups of current and past users, women with or without ovaries, and women aged under 52 years or older. For the 52 current intermittent users, the estimated break times were as follows: 10% or less of total time on

therapy for 18 women (34.6%), between 10% and 20% for eight (15.4%), between 20% and 50% for 14 (27.0%), and over 50% for 12 women (23.1%).

HRT use for relief of menopausal symptoms

A total of 321 women had taken HRT for menopausal symptoms at some time. A date for the woman's menopause was found in only 13 records. The proportion of women in each age group in the practice taking HRT is shown in table A2.1. The use of therapy was highest in the 50-54 years age group but a substantial number of women continued to take it when aged 60 years or more. Five women aged 70 years or more were taking HRT. The majority of women took HRT continuously for up to five years (table A2.2).

Of the 69 women who took it intermittently, the estimated break times were as follows; 10% or less of total time on therapy for 20 women (29.0%), between 10% and 20% for 16 (23.2%), between 20% and 50% for 14 (20.3%) and over 50% for 14 women (20.3%), data missing for five women.

For the 89 women who had stopped HRT no reason was recorded for 54 women (60.7%). Recorded reasons were: weight gain (seven women), return of monthly bleeds (four), breast symptoms (three), other side effects (14), concern over long term side effects (two), and other reasons (five).

Age (years)	Number of women	Percentage of women in each age group on practice list
35-39	4	0.8
40-44	22	4.9
45-49	78	15.6
50-54	93	23.7
55-59	67	16.5
60-64	30	7.4
65-69	22	7.2

Five women were over 70 years.

Table A2.1 Women taking HRT for menopausal symptoms

Number of years of continuous use	Number of women	percentage of all women taking HRT for menopausal symptoms (n=321)
0-1	18	5.6
1-3	129	40.2
3-5	74	23.1
5-10	28	8.7
10-20	3	0.9
Intermittent use	69	21.5

Table A2.2 Length of time women took HRT for menopausal symptoms

Risk of osteoporosis and use of HRT

There were 47 women aged between 45 and 59 years with a risk factor for osteoporosis recorded in their notes: fracture of arm when aged less than 65 years (34 women), past history of osteoporosis (eight women), fracture of hip when aged less than 65 years (three) and family history of osteoporosis (two). Of these, 20 were on therapy but the reasons recorded in the notes for taking HRT did not include osteoporosis. However, there were 24 women not included in the group with a risk factor for osteoporosis who had taken HRT and for whom the recorded indication was osteoporosis, but no specific risk factor had been noted. Of these 24 women, four had stopped taking it (one because of side effects, no reason was recorded for the other three). Of those women still taking it, 17 had taken it continuously, of whom two had taken it for less than one year, eight had taken it for between one and three years and seven had taken it for four to five years. Of the three women who had taken it intermittently, estimated break time was 10% or less of total time on therapy for one woman and between 20% and 50% for two women.

Problems for the study methodology

The study highlights gaps in the recording of data that would be useful in any future survey of HRT use. Some women who had had a hysterectomy may have been receiving HRT implants from the hospital before transferring to prescriptions from the practice. The practice is rarely informed of when implants are given. The lack of information on women receiving implants at the hospital may have caused an underestimation of the number of women on therapy following hysterectomy. The recording of family history of osteoporosis was probably incomplete as this had not been systematically recorded by all members of the practice team during the period of time covered by the study. For women using therapy for osteoporosis there was a low level of recording of risk factors. The reasons for stopping therapy may never be known to the doctor as women may not return for review. Questionnaire surveys of reasons for stopping HRT are likely to give a more accurate picture

(Ryan, Harrison, Blake and Fogelman 1992; Wren and Brown 1991). The estimates of the percentage of time the women appeared to be taking HRT are probably overestimates as not all prescriptions collected are then redeemed (Beardon, McGilchrist, McKendrick, McDevitt and MacDonald 1993) and those redeemed will not all be taken. The use of vaginal oestrogen cream to relieve menopausal vaginal dryness was not included in this study.

Appendix 3.1

Pilot questionnaire and covering letter

On the covering letter the text in brackets << >> indicate "print merge" fields for the word processor.

The reference number on the covering letter was also hand written onto the top right corner of the first page of the questionnaire.

NORTON MEDICAL CENTRE

J.R. THORNHAM, MBBS, FRCCP, DOBstR/COG
 R.A. HORNE, MBBS, FRCCP, DR/COG
 D.H. WHITE, MBBS, MRCCP, DR/COG
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Dr. Frances E. Griffiths, 243 Darlington Lane, Stockton-on-Tees TS19 8AA

«TITLE» «FORENAME» «SURNAME»
 «HOUSE_NAME»
 «STREET»
 «AREA»
 «TOWN»
 «COUNTY»
 «POSTCODE»

14th May 1993

«PATIENT_NUMBER» «AGE_GROUP» «WARD_CODE»

Our ref

Dear «TITLE» «SURNAME»

Health Survey

I am conducting a survey of women's views on health issues and in particular on women's health issues. I shall be using the results of this survey to contribute the views of women to the current debate about priorities in health care. It is very important that the views of women as users of health care services are represented in this debate rather than only professionals' views, and so I am asking for your help with this survey.

Please could you fill in the enclosed questionnaire and return it to me in the stamped addressed envelope provided.

Your answers to this questionnaire will be kept strictly confidential to me and my clerical assistant.

This survey is being funded by the Northern Regional Health Authority.

Many thanks for your help.

Yours sincerely

Dr. Frances E. Griffiths

Health survey

Thank you for your help with this survey. Please fill in the questionnaire from the beginning. Your answers will be kept strictly confidential.

1. What single health or welfare problem do you feel deserves the highest priority at the moment?

(Please write the one problem here) _____

2. The following is a list of health and welfare services. For each one please circle the number which best shows how high a priority you would give the service. (1 is highest, 5 is lowest)

	High priority		Neutral		Low priority
Provision of premature baby units	1	2	3	4	5
Transport system for the elderly and disabled	1	2	3	4	5
Higher taxes on cigarettes	1	2	3	4	5
Cycle lanes	1	2	3	4	5
Promotion of long term HRT (hormone replacement therapy)	1	2	3	4	5
Safe play areas for children	1	2	3	4	5
Advice and advertising about safe sex	1	2	3	4	5
Research into a cure for dementia	1	2	3	4	5
Screening for osteoporosis (brittle bones)	1	2	3	4	5
Research into the cause of childhood leukaemia	1	2	3	4	5
Sports facilities in all housing areas	1	2	3	4	5
A national food policy so healthy foods are relatively cheap	1	2	3	4	5

3. What health problem are you most worried will affect you as you get older? (Please write one health problem here) _____

4. The following statements are about screening for health problems (checking for health problems so they can be treated early). For each statement please circle the number which best shows the extent to which you agree or disagree with that statement.

	Agree		Neutral		Disagree
Screening people is a worry as it can make people feel they are below standard	1	2	3	4	5
Women should be encouraged to have screening tests	1	2	3	4	5
I like to have the available screening tests to put my mind at rest about my health risks	1	2	3	4	5

5. This question asks your views about the menopause (change of life). I am interested in the views of women of all ages so please fill in this section even if you are not near the menopause yourself.

For each of the following statements, please circle the number which best shows the extent to which you agree or disagree with that statement.

	Strongly agree		Neutral		Strongly disagree
The thing that causes all women their trouble at the menopause is something they can't control- changes inside their bodies.	1	2	3	4	5
Male partners of menopausal women regard them as less sexually desirable following the menopause.	1	2	3	4	5
Because the menopause is brought on by diminished hormone levels, it should be viewed as a medical condition and treated as such.	1	2	3	4	5
Women who are having trouble in the menopause are those who are expecting it.	1	2	3	4	5
A woman feels like less of a woman following the menopause.	1	2	3	4	5
Psychological problems that women experience around the menopause are more greatly affected by life changes at that time (i.e. children leaving home, death of parents) than by hormonal changes.	1	2	3	4	5

6. This question is about health problems common in older women, osteoporosis (thinning of the bones or brittle bones), strokes and heart attacks. Please answer whatever your age.

Which of the following do you think make osteoporosis or heart attacks and strokes more likely? (Tick only those you think apply)

Osteoporosis	Strokes and heart attacks
<input type="checkbox"/> Smoking	<input type="checkbox"/>
<input type="checkbox"/> Low dietary calcium	<input type="checkbox"/>
<input type="checkbox"/> Inactivity	<input type="checkbox"/>
<input type="checkbox"/> Family history of osteoporosis	<input type="checkbox"/>
<input type="checkbox"/> Overweight	<input type="checkbox"/>
<input type="checkbox"/> Lack of oestrogen hormone	<input type="checkbox"/>
<input type="checkbox"/> Family history of strokes or heart attacks	<input type="checkbox"/>
<input type="checkbox"/> High blood pressure	<input type="checkbox"/>

_____ Other (please write here) _____

6. *continued.* Which of the following would be helpful in trying to prevent osteoporosis, strokes and heart attacks? (Tick only those you think apply)

Osteoporosis

Strokes and heart attacks

- | | | |
|--------------------------|--|--------------------------|
| <input type="checkbox"/> | Decrease fat in the diet | <input type="checkbox"/> |
| <input type="checkbox"/> | Take HRT (hormone replacement therapy) | <input type="checkbox"/> |
| <input type="checkbox"/> | Loose weight if overweight | <input type="checkbox"/> |
| <input type="checkbox"/> | Increase exercise | <input type="checkbox"/> |
| <input type="checkbox"/> | Stop smoking | <input type="checkbox"/> |
| <input type="checkbox"/> | Eat adequate calcium in the diet | <input type="checkbox"/> |

Other (please write here) _____

Which of the following symptoms do you think are warning signs of osteoporosis? (tick any you think apply)

- Arthritis-like pain
- Depression/irritability
- There are no warning signs
- Hot flushes
- Dry vagina (front passage)
- Other (please write here) _____

The next section asks about yourself and your own health.

7. What is your age today? _____ years old

8. How many years of education have you completed? (Tick one only)

- Left school on reaching 16 years or younger
- Left school age 16-18 years
- Vocational training beyond secondary school
- Higher education, not university, e.g. HNC, HND
- University education

9. Have you ever attended a 'Well Woman Clinic'?

Yes

No

10. Have you ever taken birth control pills?

No, I have never taken them

Yes, I am taking them now or have taken them at some time in the past

11. Have any of your parents, brothers or sisters had osteoporosis (thinning of the bones or brittle bones) as they became older?

No

Yes

Don't know

12. a. Do you consider you are going through, or have gone through, the menopause (change of life) ?

No

Yes

b. If yes, have your menstrual periods stopped?

No (go to question 13)

Yes at age _____ years old

13. a. Have you had a hysterectomy (womb removed) ?

No

Yes at age _____ years old

b. If yes were BOTH ovaries removed?

No

Yes

Don't know

If you have answered No to 12a or 13a please go to question 15.

If you have answered Yes to 12a or 13a please answer question 14.

14. Do you feel you have experienced significant symptoms related to your periods stopping or to the menopause (change of life)

No

Yes

If yes, have you experienced any of the following symptoms? (tick all that apply)

Hot flushes

Dryness of the vagina (front passage)

Depression

Insomnia (difficulty in sleeping)

Just didn't feel well

Other (please write here) _____

15. Have you ever heard of HRT (hormone replacement therapy)?

Yes. Please answer the following section of questions. I am interested in the views of women of all ages. You do not need to know anything about HRT nor do you need to have taken it to answer the questions.

No. If you have never heard of HRT (hormone replacement therapy) please stop here and return the questionnaire in the stamped addressed envelope provided. Your answers so far are valuable for the survey, thank you for your participation.

16. What has been your main source of information about HRT (hormone replacement therapy)? *(tick all that apply)*

Friends/relations

TV/radio

Magazines

Doctor

Other *(please write here)* _____

17. The following questions ask about what you may have heard about HRT (hormone replacement therapy) in the media, i.e. TV, radio, magazines and newspapers.

Please tick any of the following aspects of HRT which you have heard about from the media:

HRT makes you youthful

HRT can prevent strokes and heart attacks

HRT does not suit everyone

HRT can be taken for short periods or long periods of time

HRT prevents the aches and pains of old age

There are side effects from HRT

HRT can improve your sex life

HRT may increase the risk of cancer

HRT can prevent osteoporosis (thinning of the bones/brittle bones)

HRT helps to keep you active in old age

You are less likely to fracture your hip if you take HRT

Have you found the information from the media helpful?

No

Yes

Do you feel the media gives accurate information about HRT?

No

Yes

If you have answered no to either of the above two questions please could you tell me more about what you have found unsatisfactory about the information in the media.

(Please write here) _____

18. This section asks about what would affect your decision as to whether or not to take HRT (hormone replacement therapy) after going through the menopause. I am interested in the views of women of all ages so please answer even if you do not feel HRT is relevant to you at the moment.

For each statement please circle on the scale 1-5 how much it would affect your decision.

	would persuade me to take HRT		neutral	would persuade me not to take HRT	
Taking HRT may prolong my life	1	2	3	4	5
HRT would not relieve the aches and pains of old age	1	2	3	4	5
To be effective HRT would have to be taken for the rest of my life	1	2	3	4	5
Exercise and a good diet could reduce the risk of developing osteoporosis (thinning/brittle bones) as much as taking HRT	1	2	3	4	5
HRT might cause periodic bleeding like a menstrual period	1	2	3	4	5
I would feel young on HRT	1	2	3	4	5
I would be less likely to have a heart attack or stroke if I took HRT for ten years	1	2	3	4	5
A test could be done to determine my risk of osteoporosis	1	2	3	4	5
HRT may prevent me having a hip fracture in my 70s	1	2	3	4	5
HRT would not cause cancer	1	2	3	4	5
Taking HRT would make dying suddenly in old age less likely	1	2	3	4	5

19. I am interested in your experience of HRT (hormone replacement therapy). Please tick the statement (a. b. or c.) which best describes your situation, and then answer the other questions in that section.

a. I HAVE NEVER TAKEN HRT

Which best describes the reason you are not taking HRT? (tick one only)

I am not old enough for HRT (go to question 22 on the last page)

I have never thought about taking it (go to question 22 on the last page)

My doctor told me I should not

I thought about taking HRT but decided not to (please write reason here) _____

b. I AM CURRENTLY TAKING HRT

Why was HRT prescribed for you? (please write reason here) _____

c. I HAVE TAKEN HRT IN THE PAST BUT HAVE STOPPED

Why was HRT prescribed for you? (please write here) _____

Which best describes your reason for stopping? (tick one only)

My doctor told me to stop

I was feeling better

They were too inconvenient

I was having side effects (please list) _____

Other (please write here) _____

20. With which of the following people did you discuss HRT (hormone replacement therapy)? (Please tick all that apply)

General Practitioner

Husband/Partner

Hospital doctor

Relative

Nurse at doctor's (GP) surgery

Friend

Which of the people in the above list was the most important in helping you decide whether or not to use HRT? (please write here) _____

21. These questions are about your own General Practice. Your answers will be kept strictly confidential.

Do you feel your own General Practitioner (GP) is in favour of using HRT (hormone replacement therapy) for the following? (*tick all that apply*)

- for symptoms of the menopause
- for preventing osteoporosis (thinning of the bones/ brittle bones)
- for prevention of strokes and heart attacks

If you have discussed HRT with a doctor or nurse at the GP surgery, do you feel:
(*please tick all that apply*)

- you received enough information about it
- the doctor or nurse seemed uncertain if it would work for you
- you received enough time to discuss it
- confused as different health professionals told you different things
- the doctor or nurse was uncertain about using HRT for longer than a few years
- you would have had to apply pressure to be started on HRT

22. Have you heard of 'bone densitometry', a test that measures the thickness of bone and so can measure a person's risk of developing osteoporosis (thinning of the bones/ brittle bones)?

- No
- Yes

Have you yourself had bone densitometry?

- No
- Yes

If yes, who suggested the test? (*tick one only*)

- yourself
- Nurse at GP's surgery
- General practitioner
- Hospital doctor

Thank you for completing the questionnaire. Please return the questionnaire in the stamped addressed envelope provided.

Appendix 3.2

The questionnaire and covering letter used for the main questionnaire survey

The covering letter was reproduced on the letterhead of the woman's general practice. The original copy of the letter was signed by one doctor from the woman's general practice.

On the covering letter the text in brackets << >> indicate "print merge" fields for the word processor.

The reference number on the covering letter was also hand written onto the top right corner of the first page of the questionnaire.

The questionnaire was in the form of an A4 booklet, printed on both sides of each page.

1st September 1993

«practice»«identificationnumber»
«title». «initial». «surname»
«housename»
«number_and_street»
«estate»,«town»
«country»
«postcode»

Dear «title». «surname»

A survey of women's attitudes to health

I am writing to ask your help. Enclosed is a questionnaire which asks about your views on health, especially women's health as they get older. **Please fill in the questionnaire and return it in the envelope provided. No stamp is needed.** Your answers to the questions will be used, along with those of other women, to tell the people running health services what you feel is important for your health.

Your name was chosen at random from patients that use our surgery.

The survey is being run by Dr. Frances Griffiths and is funded by the Northern Regional Health Authority. Dr. Griffiths needs to hear the views of women of all ages and opinions, so please fill in the questionnaire. Your individual answers to questions will be kept strictly confidential to Dr. Griffiths.

Many thanks for your help.

Yours sincerely

Dr.

A survey of women's attitudes to health

Thank you for your help with this survey. Please fill in the questionnaire from the beginning. Your answers will be kept **strictly confidential**.

1. What single health or welfare problem do you feel deserves highest priority in Britain today?

(Please write the one problem here) _____

2. What health problem are you most worried will affect you as you get older?

(Please write the one problem here) _____

3. The following is a list of things that could be done to improve health. Please tell me how important you think each one is for the health of people in Britain today.

Please circle the numbers (1 means very important, 5 means not at all important)

	Very Important		Undecided		Not At All Important
Provision of premature baby units	1	2	3	4	5
Transport system for the elderly and disabled	1	2	3	4	5
Higher taxes on cigarettes	1	2	3	4	5
Cycle lanes	1	2	3	4	5
Promotion of long term HRT (hormone replacement therapy)	1	2	3	4	5
Safe play areas for children	1	2	3	4	5
Health checks to prevent heart disease	1	2	3	4	5
Advice and advertising about safe sex	1	2	3	4	5
Research into a cure for dementia	1	2	3	4	5
Screening for thin or brittle bones (osteoporosis)	1	2	3	4	5
Research into the cause of children's leukaemia	1	2	3	4	5
Sports centres on all housing estates	1	2	3	4	5
Making healthy foods cheap to buy	1	2	3	4	5

4. This question asks your views about the change of life (menopause). I am interested in the views of women of all ages *so please fill in this section even if you are not near the change of life yourself.*

For each of the following statements, please circle the number which best shows the extent to which you agree or disagree with that statement.

	Strongly agree		Neither agree nor disagree			Strongly disagree	
	1	2	3	4	5	6	7
Natural things such as eating healthy food and taking exercise are better for problems of the menopause than HRT (hormone replacement therapy).	1	2	3	4	5	6	7
A woman feels like less of a woman following the menopause.	1	2	3	4	5	6	7
A woman who experiences distressing menopausal symptoms such as severe hot flushes should be on HRT (hormone replacement therapy).	1	2	3	4	5	6	7
Psychological problems that women have around the menopause are more because of life changes at that time (i.e. children leaving home, death of parents) than changes in their hormones.	1	2	3	4	5	6	7

5. This question is about health problems common in older women: thinning of the bones or brittle bones (osteoporosis), strokes and heart attacks. *Please answer whatever your age.*

Which of the following do you think make thin or brittle bones (osteoporosis) or strokes and heart attacks more likely? *(Tick only those you think apply).*

Thin or brittle bones (osteoporosis)	Strokes and heart attacks
_____ Smoking _____	_____
_____ Low levels of calcium in what you eat _____	_____
_____ Lack of exercise _____	_____
_____ Having a parent who has (or had) osteoporosis _____	_____
_____ Being overweight _____	_____
_____ Lack of female hormones (oestrogen) _____	_____
_____ Having a parent who has had a stroke, angina or heart attack _____	_____
_____ Having high blood pressure _____	_____
_____ Other (please write here) _____	_____

Question 5 continued overleaf...

Question 5 continued ...

Which of the following symptoms do you think are warning signs of osteoporosis? (*tick any you think apply*)

- | | | | |
|--------------------------|----------------------------|--|----------------------------|
| <input type="checkbox"/> | Arthritis-like pain | <input type="checkbox"/> | Hot Flushes |
| <input type="checkbox"/> | Depression/irritability | <input type="checkbox"/> | Dry vagina (front passage) |
| <input type="checkbox"/> | There are no warning signs | Other (<i>please write here</i>) _____ | |

The next section asks about yourself and your own health

6. Please tell me about your education, put a tick next to which of the following best describes your education.

- I left school with no formal qualifications (exam passes or certificates)
- I left school at 16 with qualifications (exam passes or certificates)
- I left school after taking A-level or equivalent exams
- I am doing or have done further training or education since leaving school

In the following questions please circle your answer

7. Have you ever attended a "Well Woman Clinic"? No Yes
8. Have you ever taken birth control pills?
- No - I have never taken them
- Yes - I am taking them now or have taken them at some time in the past
9. Have you suffered from any of the following ?
- | | | | |
|--------------------------------------|--------|--------|--------------|
| thin or brittle bones (osteoporosis) | stroke | angina | heart attack |
|--------------------------------------|--------|--------|--------------|
10. Have any of your parents, brothers or sisters had thin or brittle bones (osteoporosis) as they became older? No Yes Don't know
11. Have any of your parents, brothers or sisters had a heart attack, angina or stroke before the age of 60 years? No Yes Don't know
12. Do you consider you are going through, or have gone through the change of life (menopause)? No Yes
13. Have your menstrual periods stopped? No Yes
14. Have you had a hysterectomy (womb removed)? No Yes

15. Do you feel you have experienced significant symptoms related to your periods stopping or to the change of life (menopause)? No Yes

If **Yes**, have you experienced any of the following symptoms? (*tick all that apply*)

- | | |
|--|--|
| <input type="checkbox"/> Hot flushes | <input type="checkbox"/> Dryness of the vagina (front passage) |
| <input type="checkbox"/> Depression | <input type="checkbox"/> Difficulty in sleeping |
| <input type="checkbox"/> Just didn't feel well | |

Other (*please write here*) _____

The next section of the questionnaire asks about HRT (hormone replacement therapy). I am interested to find out what you have heard about it and your views. You do not need to know anything about HRT to answer the questions. I am interested in the views of women of all ages.

16. What has been your main source of information about HRT (hormone replacement therapy)? (*tick all that apply*)

- | | |
|---|---|
| <input type="checkbox"/> Friends/relations | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Magazines/newspapers | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> TV/radio | <input type="checkbox"/> I haven't heard of HRT |

Other (*please write here*) _____

17. The following questions ask about what you may have heard about HRT (hormone replacement therapy) in the media, i.e. **TV, radio, magazines and newspapers.**

What are the most striking things you have heard or read about HRT in the media?

(*please write here*) _____

Have you found the information from the media helpful? (*please circle*) No Yes

Do you feel the information about HRT in the media is correct? No Yes

If you have answered **no** to either of the above two questions please could you tell me more about what you have found unsatisfactory in the media.

(*please write here*) _____

18. This section asks about what would affect your decision as to whether or not to take HRT (hormone replacement therapy) after going through the menopause. I am interested in the views of women of all ages so please answer even if you do not feel HRT is relevant to you at the moment.

For each statement please circle on the scale 1-5 how much it would affect your decision to take HRT or not.

	Would persuade me to take HRT		Would make no difference to my decision		Would persuade me not to take HRT
If I take HRT I might live longer	1	2	3	4	5
For it to work properly, I would have to take HRT for the rest of my life	1	2	3	4	5
Exercise and a good diet could stop me getting thin or brittle bones (osteoporosis) as much as taking HRT	1	2	3	4	5
HRT might cause monthly bleeds like menstrual periods	1	2	3	4	5
I would feel younger on HRT	1	2	3	4	5
I would be less likely to have a heart attack or stroke if I took HRT for five to ten years	1	2	3	4	5
A test showed I was prone to thinning of the bones or brittle bones (osteoporosis)	1	2	3	4	5
Taking HRT for five to ten years may stop me having a fracture of the hip when I am in my 70's	1	2	3	4	5
HRT would not cause cancer if taken properly	1	2	3	4	5
Taking HRT would make dying suddenly in old age less likely	1	2	3	4	5

19. Have you ever thought about taking HRT before now? (please circle) No Yes
 If yes, who did you discuss HRT with? (please tick all that apply)

_____ Your family doctor (GP)	_____ Husband/Partner
_____ Hospital doctor	_____ Relative/friend
_____ Nurse at doctor's (GP) surgery	_____ No one

Other (please write here) _____

Who was the most important in helping you decide whether or not to use HRT? (please write here)

20. I would like to know if you have used HRT (hormone replacement therapy).
Please tick which is true for you (a. b or c.) and then answer any other questions in the section you tick.

a. I have never taken HRT .

b. I am currently taking HRT

Why was HRT prescribed for you? (please write reason here) _____

c. I have taken HRT in the past but have stopped

Why was HRT prescribed for you? (please write here) _____

Why did you stop taking HRT? (please write here) _____

21. This question is about your family doctor (GP). Your answers will be kept strictly confidential.
(Please circle your answers)

a. Do you feel your own doctor (GP) is in favour of using HRT for the following?

Symptoms of the menopause e.g. hot flushes	No	Yes	Don't know
Stopping women getting thinning of the bones or brittle bones (osteoporosis)	No	Yes	Don't know
Helping to make strokes or heart attacks less likely for women	No	Yes	Don't know

b. Have you discussed HRT with a doctor or nurse at the GP surgery?
If yes, do you feel:

	No	Yes	Don't know
I was given enough information about it	No	Yes	Don't know
The doctor or nurse seemed unsure if it would work for me	No	Yes	Don't know
There was enough time to discuss it	No	Yes	Don't know
I felt muddled as different nurses and doctors told me different things	No	Yes	Don't know
The doctor or nurse was uncertain about using HRT for longer than a few years	No	Yes	Don't know
I would have had to persuade them to start me on HRT	No	Yes	Don't know

- 22. There is a test that measures the thickness of bone and can tell whether a person is likely to suffer from thinning of the bones or brittle bones (osteoporosis)?
The test is called bone densitometry.

Have you heard of bone densitometry? *(please circle)* No Yes

Have you had the test called bone densitometry? No Yes

If yes, who suggested the test? *(tick one only)*

Yourself Your family doctor (GP)

Nurse at your doctor's (GP) surgery Hospital doctor

Have you heard of the bone densitometry service at South Cleveland Hospital? No Yes

Thank you for completing the questionnaire.

A further stage of this research will be to ask women to be interviewed.

Would you be prepared to be asked to be interviewed? *(please circle)* No Yes

If you have any comments you would like to make please write them here:

Please return the questionnaire in the envelope provided. No stamp is needed.

Address for return of questionnaires;

**Dr. Frances Griffiths, Women's Health Survey,
Freepost MI 751
Stockton-on-Tees, Cleveland, TS16 9BR**

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