

Information Behaviour in Accounts of the  
Menopause Transition

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## DECLARATION

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## ABSTRACT

This study examined women's information behaviour and decision-making during the menopause transition. The findings were compared with expectations from McKenzie's Model of Information Practices in Everyday Life Information Seeking (developed from a study of twin-pregnancy). **Methods:** There were two strands to the study: 1) An evaluation of the service provided by a community menopause clinic. For this strand 199 patients registered at the clinic completed questionnaires (response rate 92.1%) giving their views about the clinic and data about their information practices relating to the menopause. Six GPs based locally to the clinic were interviewed by telephone. 2) Thirty-five telephone/face-to-face interviews were carried out with midlife women to investigate their information behaviour relating to the menopause. **Analysis:** Descriptive statistics were used for the questionnaire, the interview transcripts were analysed qualitatively using NVIVO software. **Findings:** The menopause can be a challenging time and finding advice/information that is tailored to a woman's individual set of circumstances can be challenging in itself. Women particularly value other women's 'menopause stories' which provide validation and context for their own experiences. Testing the McKenzie model in a different, yet related, context demonstrated that it is robust and flexible enough to permit adaptation. However it did not provide sufficient scope for the fluidity of information practices in the complex context of the menopause in which women often engage in mutual exchanges of support and may themselves take on the role of 'expert'. **Conclusions:** This study looked beyond information-seeking to how women use information to inform their decisions. The process of testing the McKenzie model contributes to theory development. Further testing in different contexts would support the development of a more generic model and could contribute to a discussion of whether gender can justifiably be considered as a variable in information behaviour.

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## LIST OF ABBREVIATIONS

BMS	British Menopause Society
CAM	Complementary and Alternative Medication
CHD	Coronary heart disease
ELIS	Everyday Life Information Seeking
FMP	Final menstrual period
GP	General practitioner
HERS	Heart and Estrogen/progestin Replacement Study
HRT	Hormone replacement therapy
ICT	Information and communication technology
LIS	Library and Information Science
MHRA	Medicines and Healthcare products Regulatory Agency
MMR	Measles, mumps, rubella
MS	Multiple sclerosis
NHS	National Health Service
PCOS	Polycystic Ovarian Syndrome
PCT	Primary Care Trust
PMT	Premenstrual tension
R&D	Research and Development
RCT	Randomized Controlled Trial
REC	Research Ethics Committee
STRAW	Stages of Reproductive Aging Workshop
UFE	Uterine fibroid embolization
WHI	Women's Health Initiative
WHO	World Health Organization



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# Chapter One: Introduction

## 1.1 Background to the study

The idea for this research grew out of two opportune, though unconnected, incidents. The first was meeting a Consultant in Reproductive Health who had set up a community-based menopause clinic funded ‘on a wing and a prayer’ after realizing that local women were so desperate for information about the menopause that they were coming to her contraceptive clinic or, if they could afford to, travelling to private clinics in London. The second incident was a discussion with a friend who was bemoaning the lack of useful information about the menopause having discovered that she was entering the perimenopausal stage of life. Out of the first meeting grew the service audit that forms part of this PhD study, out of the second came a wish to investigate the availability and genuine usefulness to women of information about the menopause.

During the early stages of the research Pamela McKenzie’s call for her Model of Information Practices in Everyday Life Information Seeking (McKenzie, 2001; McKenzie, 2003) to be tested in different situations was identified. This model was of particular interest because it looks beyond simple location of information to how users interact with and value sources of information. Furthermore it had been developed out of research in a contrasting area of women’s reproductive health (pregnancy), The decision was taken to consider how the McKenzie model could be applied to information behaviour during the menopause transition as a further outcome of the study.

This study has provided the opportunity to talk to many women, both formally and informally, about their experiences of looking for and using information about the menopause. Having set out with the preconception that the menopause would be a somewhat taboo subject (Hall and Jacobs, 1992) the willingness of women to tell their menopause stories, particularly to a stranger, has been surprising. Another preconception, based on early discussions with friends, was that there would be limited information available to women. In fact the opposite is true, there is an overwhelming amount of

readily-accessible information about the menopause but women are faced with the problem of making sense of all this information and of selecting those items that are relevant for their own situation, health-status and outlook. The result of this is that, although most women do have access to a range of information sources, it is still difficult for them to make a truly informed decision about preparing for and managing their menopause experience.

A researcher approaching the field without medical training encounters a world of unpredictability, subjectivity and shifting medical and lay opinion and is immediately confronted by a bewildering array of terms: 'climacteric', 'premenopause', 'perimenopause', 'postmenopause', 'natural menopause', 'induced menopause', 'premature menopause'. Added to this are the alternative variations favoured by lay writers struggling to find a less intimidating label for a potentially emotive experience, the most popular being 'the change', favoured by, amongst others, Greer (1991) and Ojeda (1998). From an initial stage of searching for clear-cut technical definitions in an attempt to pin down the meaning of menopause emerged an understanding that this is not a topic to be easily contained. The 'meaning' of menopause is different for individual women, as is their experience of it, and goes beyond pure biological functioning to encompass psychological and emotional issues, lifestyle choices, self-image, relationships both interpersonal and with professionals, and a reflective process born out of a period of transition and life-change. This research has been guided by a desire to consider not just the mechanics of information-seeking behaviour during this life-change but also how women value the information they find and how they use it in the context of their lives to make decisions about living with the menopause.

## 1.2 Research question, aim and objectives

The research question is: how does women's information behaviour relating to the menopause transition support their decisions about managing this life event?

The aim is to take a qualitative approach to investigate the information behaviour of perimenopausal/menopausal women, exploring the findings in the context of work previously conducted in a related topic.

The objectives are to explore:

- What prompts women to start looking for information on the menopause;
- Whether they have preferences for different sources of information at different stages of the life transition;
- Whether they rely on different types of information source to meet different needs (e.g. emotional support, medical facts, lifestyle issues etc.);
- How women judge the authority and helpfulness of information sources;
- How they use information to inform decisions about managing their menopause transition (e.g. whether or not to take hormone replacement therapy);
- What happened during and after the information encounter;
- How the study's findings relate to the McKenzie Model of Information Practices in Everyday Life Information Seeking.

## 1.3 Structure of the thesis

This report is divided into eight chapters each with references. A full Bibliography can be found at the end along with a set of Appendices.

Chapter One, gives an Introduction to the study, explaining my interest in the topic and stating the research question and the aims and objectives.

The purpose of Chapter Two is to provide a context for the study. It gives an overview of the menopause and the issues that can affect women's experiences at this time. It also

gives an introduction to Pamela McKenzie's study of Canadian women pregnant with twins and explains her information model.

Chapter Three reviews the literature relating to information behaviour with particular emphasis on everyday life information behaviour and the role of information models. It also considers broader topics with relevance to the current study, exploring women's relationship with the healthcare providers and factors that can impact on the decision-making process.

Chapter Four describes the methodological approach and the methods used to carry out the study. This study had two elements: firstly a feedback survey of patients from a community menopause clinic and of local general practitioners (GPs), and secondly in-depth interviews with a subsection of the clinic patients, and with women who were experiencing/had experienced the menopause transition but who had not attended the clinic.

Chapter Five presents the findings from the questionnaire survey and from interviewees' accounts of their menopause transitions. Chapter Six explores these findings in the context of other research about information behaviour and the issues impacting on midlife women. Chapter Seven then considers how the findings relate to McKenzie's Model of Information Practices in Everyday Life Information Seeking.

Chapter Eight contains the conclusions and implications for future research.

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# Chapter Two: Context

The aim of this chapter is to provide a context for the study: firstly to describe McKenzie's Model of Information Practices in Everyday Life Information Seeking since this current study sought to test the McKenzie model, and secondly to explain how the menopause transition has been interpreted by the medical and lay communities: to consider some of the ways it can impact on women's lives and to explore the help and support available during this life event. The literature review (Chapter Three) will situate the study within the context of library and information studies research.

## 2.1 The McKenzie Model of Information Practices in Everyday Life Information Seeking

McKenzie, herself a mother of twins, carried out a small-scale study of twin pregnancy in southern Ontario for her 2001 PhD thesis and subsequent publications (McKenzie, 2001; McKenzie, 2003). The study used a combination of techniques: initial and follow-up interviews and regular telephone check-ins to collect data on the information behaviour, or, to use McKenzie's preferred term, 'information practices' of 19 women. Study participants ranged from 19 to 40 years of age and were between 11 and 35 weeks pregnant at the time of the initial interview. Using a constructionist discourse analysis approach to interpret the data, McKenzie devised a two-dimensional model of everyday life information seeking which sought to 'reflect the idiosyncrasies of multiple pregnancy as an information-seeking context and to identify the patterns and concepts that might translate to other contexts.' (McKenzie, 2001, p.164). This current study is an attempt to explore the extent to which the patterns and concepts identified by McKenzie can indeed be translated to a related yet different context.

The starting point for McKenzie's study was an awareness that women pregnant with twins are going through a life transition and facing a new situation. She acknowledges that previously-existing support networks may be insufficient to help the women cope with the transition due to a mismatch between individual and society's understandings and assumptions about the pregnant woman's experiences. McKenzie suggests that the

journey to negotiate other people’s understandings and to find help that fits a woman’s own experience of the situation can provide ‘an excellent context for studying information behaviours’ (2001, p.1). McKenzie’s thesis charts her research from her initial intention to explore the characteristics of two modes of information behaviour (‘active’ and ‘incidental’ information seeking), through a realization that the data emerging from the women’s accounts was so rich and contained so many different dimensions that the original dichotomous goal seemed inadequate, to the development of her final model which portrays four modes of information practice that can themselves figure in either of two stages of the information process (Figure 2.1).

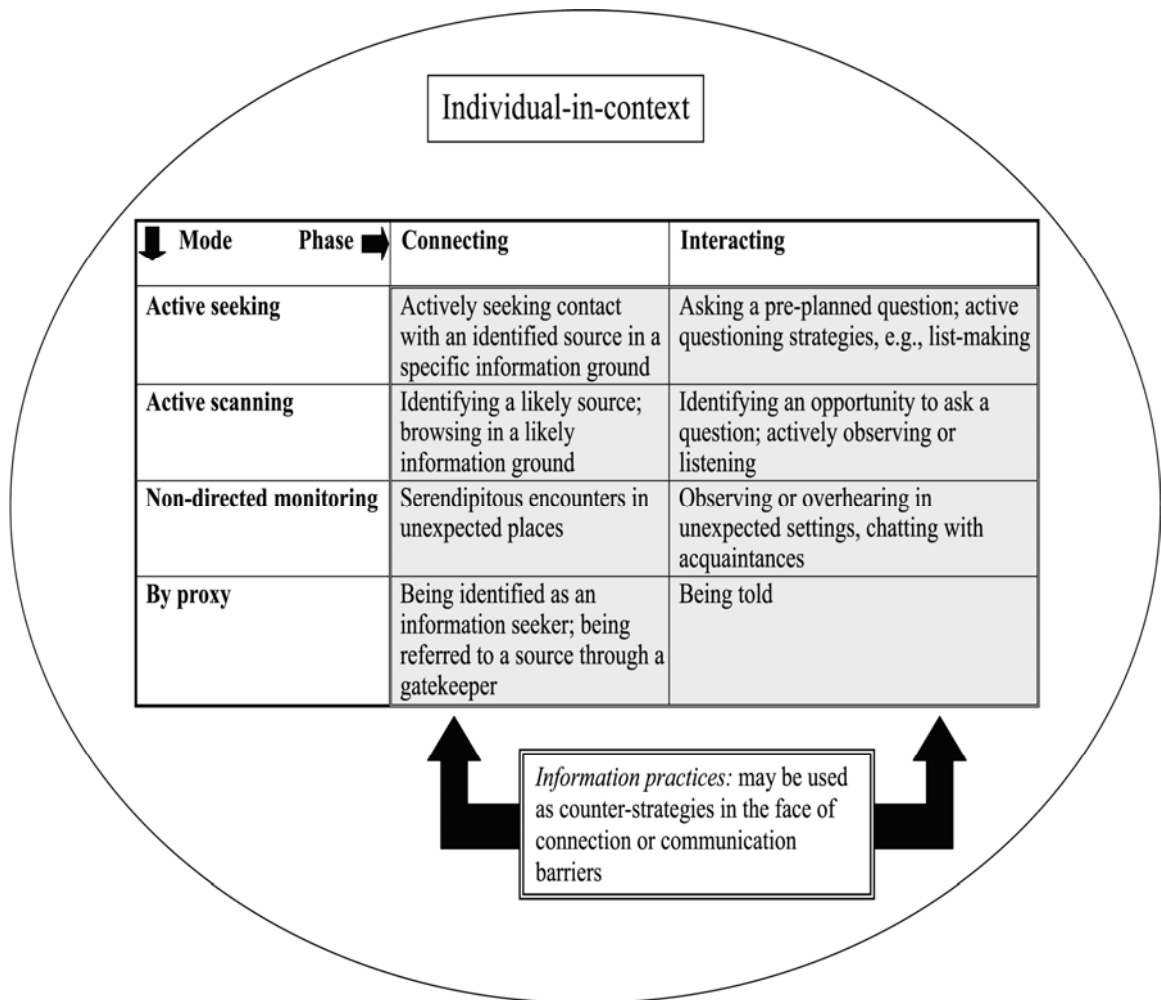


Figure 2.1 McKenzie’s Model of Information Practices in Everyday Life Information Seeking (Reproduced from McKenzie, 2003, p.26).

In McKenzie's model, participants were found to have engaged in four modes of information behaviour:

**Active seeking** – a directed process in which they, for example, specifically sought out a known source, conducted a systematic known-item search or asked a planned question etc.

**Active scanning** – in which they identified a particular source as likely to be helpful or a particular location as a potential information ground (Pettigrew, 1999). This activity involved practices such as semi-directed browsing or active listening to conversations etc.

**Non-directed monitoring** – in which participants serendipitously encountered a source in an unlikely place or whilst monitoring information sources such as newspapers. In these cases there was no initial intent to look for information and examples included overhearing a conversation rather than actively listening to one or chance encounters in a public place.

**By proxy** – in which participants encountered sources through the initiative of another agent. Examples included being identified as an information seeker by another individual or being referred to a source through a gatekeeper or intermediary.

McKenzie then distinguishes two stages of the information encounter: Connecting with sources and Interacting with them. When making connections, participants described the practices involved in identifying (or being identified by) and making contact with (or being contacted by) potential sources and the barriers that could inhibit the process (Phase One of the model). After initial contact with a source the quality of the actual interaction with that source (practices/barriers) forms Phase Two of the model. For example, making connections through non-directed monitoring could involve a chance meeting with a woman who had several young children, non-directed monitoring in information encounters could involve watching a parent struggle through a department store checkout with a side-by-side double buggy.

To combat barriers in either stage of the model McKenzie suggests that information practices can be used as counter-strategies. In the active seeking and active scanning modes participants displayed a range of tactics for pursuing information. In active



seeking participants used the techniques of list-making (described as an on-going activity to aid memory but also to ensure the successful communication of their concerns during all-too-brief consultations), asking direct questions (this involved judging not only which questions to ask but also how to ask them), keeping the process 'on track' (using active information seeking to ensure that an anticipated next step occurred even when a practitioner was failing to initiate it), and persistence (the repeated asking of questions often over several days and to different sources in an attempt to extract a response). In the active scanning mode participants described opportune questioning during prolonged encounters with healthcare practitioners, observation and listening (e.g. observing how long a sonographer was taking over an ultrasound exam), and a process of trying to stay connected (e.g. during a prolonged silence from a sonographer concentrating on the screen) and monitoring what was happening around them.

The aim of this current study is to investigate everyday information practices relating to the menopause and to consider how the data collected might work within McKenzie's model.

## 2.2 Twin pregnancy and the menopause transition as information-seeking contexts

McKenzie sees twin pregnancy as an unexpected situation in which an expectant mother's pre-pregnancy network of friends, family, medical caregivers and other providers of help and information may not understand or be able to meet her needs. Even if a woman was planning to become pregnant a twin pregnancy itself is not planned and it exposes a woman to a whole range of emotional and physical demands. McKenzie explains that multiple pregnancies, births and early parenthood are generally regarded as more physically and psychologically taxing than singleton pregnancies, with mothers of twins reporting extreme lack of sleep, financial strain, postpartum depression, marital conflict and lack of time for other children. Twin babies are also at a higher risk of disabilities and language delays, and have been shown to perform significantly worse than singletons on measures of intelligence. She also points out that the relative rarity of twin pregnancy can lead a mother to feel the weight of societal perceptions of what twins

are like and of what mothers of twins ought to do. 'A woman pregnant with twins is likely to have few peers to turn to within her existing social network. Comparing herself with mothers of singletons may result in feelings of abnormality or inadequacy and may lead to reluctance to disclose needs, seek help or ask questions.' (McKenzie, 2001, pp.2-3). McKenzie's interviewees reflected many of these concerns, displaying ambivalent feelings about their situation:

Rachel: 'The first week I was so depressed. I was **so** depressed. My husband would come home at lunchtime and I said, "I'm not happy. I'm sorry. I should be ecstatic. I should be, like, jumping up and down I'm so happy I'm pregnant.... I was losing sleep. Like I thought oh my gosh I can't do this. I don't know if I can do this.'" (McKenzie, 2001, p.90)

or expressing, for example, concerns about finances, the breastfeeding of twin babies or the logistics of looking after older siblings as well as the new babies. McKenzie's interviewees felt themselves to be 'knocked through a loop' or at risk of 'falling into a hole'. (McKenzie, 2001, pp. 92,94). From her interviews and her review of published sources of information about pregnancy and twinship, McKenzie identified two interpretative repertoires that described the characteristics of twins or multiple pregnancy. The first focussed on the commonality of the experience, i.e. the fact that women in this situation are all more likely to encounter similar challenges and attitudes (physical symptoms and risks, increased medical attention, changes to postpartum plans, consciousness that popular images of twinship are ambivalent, etc.). The second interpretative repertoire stressed the concepts of uniqueness and individuality: not only is each mother an individual and will she have her own experience of the pregnancy, birth and motherhood but also each twin is a separate identity from his/her sibling.

Other authors, including feminist writers, have pondered the state of pregnancy and how it affects society's perception of women and their interaction with the medical establishment (Graham and Oakley, 1981; Oakley, 2007; Wolf, 2001). In a study from the 1970s Taylor and Langer (1977) explored society's response to pregnancy and found that a pregnant woman is subjected to both staring from other people (particularly men)

and avoidance. For men avoidance behaviour was found to be linked to the fact that pregnancy is a novel visual stimulus but for women it was tied to role expectations about the pregnant woman's behaviour: a pregnant woman is expected to be passive but is simultaneously rejected for her passivity. For Oakley, pregnancy disturbs others because it disrupts dualist thinking and draws attention to the unpredictable: 'In the body of a pregnant woman, there is at least one other body, and the point of its emergence is the most extreme splitting of one into two... pregnant and postnatal bodies constantly threaten to break boundaries because they're disturbingly non-stable entities: leaking and seepage are routine, uncontrollable events.' (Oakley, 2007, p.122). If this is so for pregnancy in general, how much more pertinent is it for women pregnant with twins in their state of heightened visibility and their potentially unsettling influence on the sensibilities of others? Wolf (2001) explores 'the hidden truths behind giving birth in the developed world today' through the eyes of women, including herself, on the journey to first-time motherhood. She concludes that although the journey is fulfilling it is also 'undersupported, sentimentalized, and even manipulated at women's expense'.

In a collection of essays reflecting on the social, cultural, philosophical and ethical issues that surround the menopause (Komesaroff et al., 1997), Australian feminist Philipa Rothfield notes certain parallels between the states of pregnancy and menopause: 'Pregnancy and menopause are similar in some respects. Each is experienced by women. They are both culturally and biomedically defined in relation to notions of reproductive femininity. Both are medically managed in industrialized countries, and both are commonly described in hormonal terms.' (Rothfield, 1997, p.35). In their analysis of three qualitative studies on women's healthcare decisions, Brown et al. (2002) also note common ground between pregnancy and the menopause: 'Although childbirth and menopause are natural events occurring in the cycle of a woman's life, they have been medicalized to the extent that many women feel unequipped to actively participate in decisions regarding interventions or treatments impacting on their health and well-being.' (Brown et al., 2002, p.225). Returning to McKenzie's study of pregnancy, in her discussion of the commonality of experience of twin pregnancy McKenzie lists five temporal characteristics of pregnancy:

1. It has a finite duration. In the absence of complications it involves fairly extensive contact with the healthcare system for a relatively short period of time, after which time contact with formal health providers returns to the former level.
2. A pregnancy becomes increasingly visible to others as it progresses, inviting comments and questions from other people.
3. A Canadian pregnancy at the end of the 20<sup>th</sup> century follows a particular time-line of medical care.
4. Pregnancy is an opaque condition (i.e. there is a substantial amount of time during which the outcome, good or bad, is not directly evident).
5. Pregnancy, particularly first pregnancy, is seen as a period of transition to motherhood. (McKenzie, 2001, p.110).

The next section (2.3) will explore the menopause as an information-seeking context in more depth to demonstrate how the menopause can make a valuable contribution to the testing of McKenzie's model. There is much common ground between the two states of pregnancy and menopause: both reflect the dichotomy of commonality of experience (the menopause occurs for the vast majority of women) and uniqueness of the individual (each woman's experience of the menopause is different), both, as indicated by Rothfield and Brown et al., are phases of a woman's reproductive life-cycle and represent periods of transition, both are influenced by the interaction of hormones and have been subjected to a process of medicalization in Western societies, both also propel women into an unknown arena where they must take decisions about their health and wellbeing and must interact with a number of agencies, in particular members of the healthcare professions. On the other hand, although both states can induce ambivalent feelings on the part of individual women, there are differences in society's perceptions of and reactions to pregnancy and menopause. Menopause is not necessarily visible to others and in fact women often strive to keep it a private matter. There are different cultural expectations of a woman's behaviour during the menopause to those placed on a pregnant woman. There are many negative associations with menopause and indeed towards ageing in general and often particularly towards ageing women. Furthermore although the menopause usually has a finite duration, it is often much longer than that associated with pregnancy

and can last for several years. During this period the time-lines of care may not be as distinct as those experienced in pregnancy with women's needs changing over time and with levels of and approaches to care depending very much on the individual woman's encounters with individual representatives of the healthcare professions.

### 2.3 What is the menopause and what does it mean to women?

This section covers two questions: 'What is the menopause?' and 'What does it mean to women?'. At the start of the research process, initial explorations of the topic centred on attempts to pin down a definition of 'the menopause', to contain it and explain it, and focussed on the question 'What is the menopause?'. However, finding the answer to this question is not sufficient to understand the context of the study. Reading medical texts can provide an explanation of the physical aspects of the menopause and definitions of the terms associated with it but even within the medical community it is a topic that is full of uncertainties and where opinions are constantly changing and hotly debated.

Furthermore, although certain symptoms are deemed to be common to the menopause transition, each woman's experience of the menopause is unique to her (cf. McKenzie's interpretative repertoires of the commonality and uniqueness of twin pregnancy, Section 2.2). Although many studies in the medical literature, and many lay writers, concur that certain 'symptoms' are typically associated with the menopause (classically: hot flushes, sleep disturbance, 'mood swings', loss of libido, irregular menstrual cycle), these 'symptoms' are experienced with a greater or lesser degree of frequency and intensity by individual women. Some women claim to have 'sailed through' the menopause with very little discomfort or disruption to their daily lives whereas others claim to be incapacitated by severe and/or recurrent episodes of, for example, hot flushes and sweating, heavy bleeding, or emotional stress (Albertazzi, 2002).

The World Health Organization (WHO) (1996) states that the health and wellbeing of all menopausal women are strongly influenced by their cultural and economic situation, with health status being determined by experiences in prior life such as reproductive history, access to health care, diet, and work patterns. Since this mix is different for each individual it is not surprising that there are as many 'menopause stories' as there are

women to tell them. This is especially true because the perimenopausal period can cover several years of a woman's life, often at a time when outside factors such as returning to work after taking time out to raise children, older children leaving home, elderly parents requiring increased levels of care, etc. may also be demanding a woman's attention and energies, and impacting on her physical and emotional wellbeing (Coope, 1979). Another element in the mix, discussed in both the medical and lay literature, is the role of the partner during the woman's perimenopause. Since male partners may themselves be approaching midlife, couples may enter a stressful period as each partner takes stock of their own life and of the state of the relationship (World Health Organization, 1996).

Since for many women identity is inextricably linked to reproductive status, the onset of the perimenopause can be an unsettling event, or series of events. Not only does the woman have to adjust to a different body rhythm and cycle, she may also be forced to confront any anxieties she has about ageing, her changing role in the family and society, or altered body-image. 'Empty nest' syndrome may set in if children are leaving home and the woman may have to reassess what has previously been a pivotal role at the centre of the family (Coope, 1979; Greer, 1991). Some women may begin to feel insecure and may fear, or discover, that their partners are turning to younger women in an attempt to recapture the essence of their own youth. Even if a woman's experience of the menopause turns out to be similar to that of other women, she will have her own preferences for dealing with it.

At one end of the scale is the approach, taken by many feminist authors, that the menopause is a natural life event and that it should not be over-dramatized or medicalized into an illness requiring treatment. Feminists argue that throughout history the medical profession, mainly dominated by men, has taken over the previously exclusively female domain of female reproduction and has manipulated the system so that essentially natural events such as childbirth have become medicalized to the extent that women are dependent on the offices of (male) doctors and are thereby repressed. The menopause is seen as being another casualty of this process with women encouraged by the medical profession to feel that they are suffering from an oestrogen deficiency disease that can

and should be brought under control through the administering of hormone replacement drugs. Feminists suggest that the ‘symptoms’ of the menopause are simply the result of natural changes in the ageing body and do not warrant medical intervention. Women are seen as battling with the medical profession for control of their bodies (Gardner, 1981) in a network of power relations (Sybylla, 1997).

At the other end of the scale, many medical professionals argue that although menopausal symptoms are not life-threatening and are self-limiting they are unpleasant and for some women can be disabling. Measurement of the extent to which a symptom is incapacitating is subjective and individual women have different tolerance levels for discomfort and inconvenience, and different degrees of willingness to seek advice from the medical profession. The medical profession also point to research examining the consequences of diminishing levels of oestrogen, the main examples being: increased risk of coronary heart disease, increased deterioration of bone mass and loss of bone tissue, and vaginal atrophy. Some within the profession claim that the correct use of hormone replacement therapy (HRT) can be successfully applied to reduce the impact of these changes. HRT is itself a contentious topic that will feature throughout this thesis since it represents a key area of decision-making for perimenopausal women.

Between the feminist viewpoint and that of the medical profession lies a whole range of alternative approaches to managing the menopause. These can often be found in magazine articles and consumer-health books and may advocate ‘holistic’ approaches to managing the menopause. These include dietary advice, the role of exercise, the use of complementary medicine, and addressing the emotional issues associated with this time of life.

This section will provide, as much as is possible given the complex and dynamic nature of the topic, answers to the questions ‘What is the menopause?’ (i.e. What are the physical reasons for and symptoms of the menopause?) and ‘What does it mean to women?’ (i.e. How do women imbue the menopause with meaning that can go beyond the physical to affect their whole lives, relationships and perceptions of self?). The

section begins with a brief overview of the menopause as generally accepted by the medical profession, an interpretation which does indeed focus primarily on the physical aspects of the transition.

### *2.3.1 What is the menopause? The 'medical' interpretation of the menopause transition*

The WHO has estimated that in 1990, 467 million women worldwide were aged 50 or over, a figure that is expected to rise to 1200 million by the year 2030. Given that the average age for reaching a natural menopause in developed countries is 51 years and that life expectancy is increasing – in 2002 female life expectancy at birth was 81 years in the UK (Office for National Statistics, 2004) – growing numbers of women will be able to expect to live for many years in a postmenopausal state (World Health Organization, 1996). The menopause itself is a distinct physical event: the final menstrual period (FMP). There is currently no way of accurately predicting when that event will happen and, indeed, it can only be established in retrospect since when a woman experiences her final period she does not know that it will be her last. Changes in menstrual patterns and the presence of symptoms thought to be associated with the menopause can however occur for some time before and/or after the actual FMP.

As an indication that the impact of the menopause on a woman's life can be far greater than implied by the concept of one neat event marking the end of her fertile years, a whole range of terms relating to 'stages' of the menopause can be found in the literature. According to the WHO (1996), the 'premenopause' can be used either to mean the one or two years immediately preceding the menopause or to the entire reproductive period prior to the menopause. 'Perimenopause' includes the period immediately before the menopause (when the endocrinological, biological and clinical features of approaching menopause appear) and the first year after the menopause. 'Menopause transition' should be reserved for that period of time before the final menstrual period (FMP) when variability in the menstrual cycle increases, and 'postmenopause' is defined as dating from the FMP regardless of whether the menopause was 'induced' or 'natural'. A premature menopause is held to be one that occurs at an age less than two standard deviations below the mean estimated for the reference population. The WHO advises



against the use of the historical (Greer, 1991) term 'climacteric' as it is felt to be confusing. So bewildering is the nomenclature that in 2001 a group of reproductive ageing specialists met in Utah at the Stages of Reproductive Aging Workshop (STRAW) to attempt to address the absence of a staging system for female reproductive ageing and develop a definitive terminology. They recommended a seven-stage system:

- 5: early reproductive stage following menarche
  - 4: peak reproductive period, when menses occurs every 21-35 days
  - 3: late reproductive period, not clearly different from stage -4
  - 2: early menopausal transition, with noticeable variable cycle lengths
  - 1: late menopausal transition, with two or more skipped cycles and a cycle of amenorrhea lasting at least 60 days
  - +1: early postmenopause, lasting for 5 years following the last menses
  - +2: late postmenopause, lasting from 5 years postmenopause until death (p.222).
- (Mansfield et al., 2004).

The STRAW system confines use of the term 'menopause transition' to the stages immediately preceding the actual FMP (i.e. date of the menopause itself). The term is applied more broadly in this thesis to refer to the whole life-phase during which a woman realizes that she is approaching the menopause, reaches her FMP, and then may continue to experience symptoms or go through a time of adjustment to her new state. There are precedents for the use of this term both in the literature (e.g. Im et al., 2008) and in usage by women's health specialists (as at Women's Health Concern 'Women's Health Issues: Particular reference to the Menopause'. Symposium, November 2003). The term reflects the intention to examine 'the lived experience of menopausal women' (Im et al., 2008) through their menopause stories, not simply focussing on physical symptoms but exploring how the menopause has impacted on their lives and how they have coped with it. Use of the term 'menopause transition' also links to McKenzie's view of pregnancy as a life transition during which a woman has to come to terms with a new situation and a new role for herself.

Since menopause is defined as the final monthly period, it marks the end of the fertile phase of a woman's life. Although 51 is the average age for this event in developed countries it can occur earlier or later. If a woman experiences a natural menopause before the age of 40 it is classed as a 'premature menopause' (although some gynaecologists use the age of 45) and most women (80%) can expect to have reached their menopause by the age of 54 (MacGregor, 2006; World Health Organization, 1996). In some women menopause is induced by the effects of radiotherapy or chemotherapy or by oophrectomy (surgical removal of the ovaries).

Each female child is born with a finite number of follicles in her ovaries. Counts of follicles have shown that the number is greatest in the foetus at seven months and at birth is typically around 700,000. Numbers decline steadily until about the age of 40 at which point the decrease becomes more rapid until after the menopause when there are no follicles left (World Health Organization, 1996). Studies have shown that age at menopause can be affected by factors such as smoking or never having been pregnant (Brett and Cooper, 2003). As a woman approaches the menopause 'the ovaries become less efficient, resulting in irregular and often heavy periods. Eventually they stop functioning, no further eggs are released and periods stop. At the same time, the monthly hormonal cycle becomes more erratic. Blood levels of oestrogen fluctuate – low levels give rise to hot flushes, night sweats and many other symptoms' (MacGregor, 2006). Dr MacGregor, in her book aimed at consumers and published in association with the British Medical Association, lists the following symptoms of the menopause:

- |                              |                       |
|------------------------------|-----------------------|
| Anxiety                      | Irritability          |
| Changes to skin and hair     | Joint and muscle pain |
| Depression                   | Loss of libido        |
| Disrupted sleep              | Painful intercourse   |
| Dry vagina                   | Heart palpitations    |
| Fatigue                      | Poor concentration    |
| Headaches                    | Poor memory           |
| Hot flushes and night sweats | Urinary problems      |

Irregular periods (MacGregor, 2006, p.6).

Of course, as MacGregor points out, not all women experience all, if any, of these symptoms yet it is hardly surprising that many women approach the menopause with feelings of trepidation. Since increasing life expectancy means that women will be living longer beyond their FMP, medical texts draw attention to the long-term effects of reduced oestrogen levels. MacGregor suggests that the risk of fractures, strokes and heart disease increases with each year after the menopause.

Some authors using a more ‘holistic’ interpretation of the menopause, many of them feminists, accuse the medical profession of helping to stigmatize the menopause and turn it into an illness rather than a natural life-event by framing it in negative terms of loss of function and breakdown of the reproductive system (Campioni, 1997; Martin, 1997). Health professionals talk about ‘diagnosis’ of the menopause (through a blood test to check levels of follicle-stimulating hormone and luteinizing hormone) and some authors even argue that the medical profession and pharmaceutical companies have invented a disease in order to develop a ‘cure’ – hormone replacement therapy (Coupland and Williams, 2002; Oakley, 2007). Although menopause books written by health professionals but aimed at lay readers may provide a lot of information about HRT they often explain the potential risks of taking it as well as the potential benefits and they may also give advice about other ways of controlling menopausal symptoms (e.g. through exercise, weight loss, dietary guidance and other lifestyle changes) (Brewer et al., 2007; Coope, 1996; Hunter and Coope, 1993; MacGregor, 2006).

### *2.3.2 What does the menopause mean to women? The ‘natural’ interpretation of the menopause transition*

In an article in the journal *Discourse and Society* Coupland and Williams (2002) identify three different discourses of the menopause, each with its own lifespan and health ideologies and each with its own economic and/or political agendas. The authors argue that these discourses can influence a woman’s interpretation of her menopause transition. Each discourse uses a different ‘voice’ to persuade women to adopt a particular viewpoint. The authors argue that ‘a woman’s interpretations of her menopause, and therefore its “symptoms”, are highly subject to discursive constructions of the menopause

she encounters' (p. 427). For Coupland and Williams Discourse 1 is represented by the leaflets supplied by pharmaceutical companies and available in primary care practices. These leaflets construct the menopause as a disease caused by failure of the female reproductive system and generally advocate treatment with HRT. This discourse tends to present information using a 'medical voice' to confer authority (using strategies such as presenting ideas as though they have achieved expert medical consensus through the use of phrases such as 'doctors seem now agreed'), often without substantiation, to further the ends of what is essentially a marketing exercise. Discourse 2 is represented by many popular printed texts and rejects that idea that women should placidly accept intervention from the medical profession and pharmaceutical companies. Women are urged to take personal and active control of their menopause experience through the use of 'natural' remedies and by making lifestyle changes. Despite the different perspective, Coupland and Williams identify similar persuasive techniques to those used in Discourse 1 with reliance on appeals to experts (e.g. herbalists) the presentation of statistical 'evidence'. In Discourse 3, feminist writers construct the menopause as a rite of passage and propose 'breaking away from the need to recreate the younger (better) self towards claiming a different, stronger, older self'. Two approaches are noted from feminist authors: the 'essentialist' stance which emphasizes spiritual power and the celebration of the changing states of womanhood; and the 'materialist' viewpoint which centres on negating the focus on youthful attractiveness and sexual availability.

Coupland and Williams's Discourses 2 and 3 both reject the concept of the medicalization of the menopause and the perceived reliance on HRT. They support a more 'natural' and 'holistic' view of the menopause that seeks to overturn negative attitudes towards menopausal women, and indeed towards ageing women in general. Feminist writers from across a range of disciplines have been drawn to the menopause from the mid-1970s onwards, having previously shown little interest in it (Houck, 2003). Despite the disparity of their backgrounds (e.g. literary studies for Greer, sociology for Oakley, anthropology for Martin) and differences in style of presentation, they are consistent in their claims that ageing is a 'profoundly gendered experience' (Oakley, 2007) with older women seen as invisible or ridiculed by stereotypical portrayal as the

‘batty old hag’ or as ‘a “frustrated”, bitter, cruel, dried-up envious old stick’ (Greer, 1991). According to Oakley (2007, p. 97). ‘The redundant nature of post-menopausal breasts (and uteruses) stands for the obsolescence of older women themselves. Their bodies and lives are retired characters in a script that is best kept hidden from public view altogether’. Feminists argue that it is in men’s interest to perpetuate the myth that postmenopausal women have no function in society and can therefore be passed over for younger women who still depend on men (Kaplan, 1997). Depicting the menopausal woman as ‘prone to all sorts of erratic and disturbing behavior’ and ‘flawed’ allows men to sustain their power over women, fighting off competition in midlife and to benefit passively from the double standard of culturally-constructed attitudes to ageing (Campioni, 1997; Gullette, 1997; Sybylla, 1997).

Women themselves have been shown to have an ambivalent attitude towards midlife and the menopause. Price et al. interviewed women in rural Canada about their menopause experiences. They found that the ‘historical and social construction of the menopause experience has persistent stereotypes that portray it as a time associated with loss of youth and sexuality and a negative experience filled with undesirable physical and emotional symptoms’ (Price et al., 2008, p. 504). Their interviewees were often surprised by the intensity of the experience and found themselves coping not just with the physical challenges of the menopause itself but also with the concurrent stresses of midlife such as perceptions of ageing, death of family or friends, changes in relationships, changes in employment or finances, or caring for ageing and ailing parents. Im et al. (2008) took a feminist approach to explore the lived-in experience of menopausal white women in the USA. They chose an online forum as a survey method having identified it as ‘a mechanism commonly used among middle-aged women to provide electronic emotional and informational support’ (p. 542). Four main themes emerged: redefining self, laughing at suffering, differences within sameness, and talking to the wall. These themes encapsulate many of the ideas common to interpretations of the menopause.

### 2.3.2.1 Redefining self

Most of the participants in Im et al.'s study reported that they had not given any thought to the menopause until they started to experience it. It acted as a stimulus for reflection on their lives, prompting them to think about ageing and to re-think their life and redefine themselves. They saw it as an inevitable natural process and, on the positive side, felt that it freed them from the pressure of striving to meet society's expectations. Although they acknowledged that it was sometimes a struggle they felt that they had ultimately dealt with it and had moved on in their lives. Although women may see the postmenopausal state as freeing them from cultural expectations, some of the women in Price et al.'s study from rural Canada felt an expectation that they should respond in certain ways to the menopause experience itself: that they should not 'dwell' on their challenges and concerns. Feminist writers urge women to use the menopause as a time to take stock and move forward into a new phase of life. Mackie (1997) calls for the menopause to be spoken of as a more 'joyous experience' and notes that social constructions create a situation where very few women will be enabled to experience a joyous transition at this phase of their life when midlife pressures take their toll. She recounts her own menopause as a time of 'increasing awe, delight, rejuvenation – an awakening to bodiliness, asserting itself through difference, as it did at adolescence...' and talks of moving towards 'new realizations, releasings, displacements, a new restfulness [that] imbues the body, so that it is not inertia, but an equal energy, differently deployed that comes as the reward.' (p. 27). From a more pragmatic viewpoint, The Boston Women's Health Book Collective (2005) note that the menopause can mark the end of familiar roles and ways of being and the beginning of a different way of life since it often coincides with other major life-changes such as children leaving home and/or the decline of a parent. In the final chapter of her book *The Change* entitled 'Serenity and power' Greer (1991) calls for women to understand that the new 'invisibility' that follows the menopause can be a desirable condition. For her, only when a woman ceases the fretful struggle to *be* beautiful [italics in original] can she look outward to find the beautiful and feed upon it. 'She can at last transcend the body that was what other people principally valued her for, and be set free both from their expectations and her own capitulation to them' (p. 430). The book ends

by describing the menopause as ‘the end of apologizing’ and with the image of the ‘chrysalis of conditioning’ breaking to allow the female woman to emerge.

### **2.3.2.2 Laughing at suffering**

In Im et al.’s study, participants said that the menopause added an extra dimension to lives that were already stressful simply with the demands placed on women, (running the household etc.). The stress levels they experienced exacerbated their symptoms but most felt that they could cope since they knew it would free them from concerns about pregnancy and from the discomforts of menstruation. They reported using humour to boost their inner strength and turning to friends and family members for support. Price et al.’s interviewees also cited humour as a coping mechanism and relied on friends and family for support. They particularly valued contact with other women and their most valued sources of information were women of menopausal age who had medical experience. They spoke of the menopause as a bonding opportunity for women and expressed a desire to make things better for younger women. Although some women did explain that their male partners were sympathetic to their needs they claimed that men could never fully understand the menopause experience and so preferred contact with other women who had experienced or were experiencing the menopause. Mansfield et al. (2003) investigated the social support husbands provided to their perimenopausal wives. They found that midlife provided its own challenges for men which, the authors concluded, may encourage them to empathize with their wives during the menopause transition or may create personal stress that diminishes the levels of support they feel able to provide. Many of the husbands were ill-informed about the menopause but two-thirds believed they played a supportive role. Price et al. found that the key to women’s sense of health and wellbeing was ‘validation from others that what they were feeling and experiencing was “normal”, that they were not “going crazy” and that they were not alone.’ Suter et al. (2007), in a study of twenty-two Canadian women, also found a need to establish what is ‘normal’ so that women could stop worrying that their symptoms were ‘abnormal’ and indicative of an illness.

### **2.3.2.3 Differences within sameness**

The concept of ‘difference with sameness’ reflects McKenzie’s interpretative repertoires of commonality and uniqueness. From a menopause perspective, some of Im et al.’s participants thought that it would be a universal experience and that every woman’s experience of it would be the same. Others acknowledged that there would be commonalities but thought there would be cultural and ethnic differences, particularly relating to expression of symptoms. Others again felt that generational differences were most likely to affect perception of menopause experiences, claiming that menopause was not discussed freely in the past but that women now felt able to talk about their symptoms. Price et al.’s interviewees also rejoiced in the new-found freedom and permission to talk about a taboo subject and the authors call for menopause talk to become more commonplace and less taboo, suggesting that this could be driven by community leaders with personal menopause experience. In 1995 Foster argued that until older women felt able speak out about the menopause it would remain a stigmatized event and women’s overall attitudes towards it would be shaped by (negative) media images (Foster, 1995). Just over ten years later ‘Hot Flush!’, a musical about the menopause, was touring theatres in the UK (Flood, 2007; Munro, 2007).

Cultural differences in interpretation of the menopause have provided a rich environment for reflection about the menopause transition and attitudes towards ageing women. One commonly-cited example is that of Japanese women who report fewer hot flushes than Western women (BBC Radio 4, 2006; Fu et al., 2003; Lock, 2002; Nagata et al., 2001; Zeserson, 2001). Studies have indicated that the reason for this may be higher consumption of soy-based foods by Japanese women since soy is a source of isoflavone a naturally-occurring oestrogen. Nagata et al. studied 101 Japanese women over a six-year period and concluded that consumption of soy products can have a protective effect against hot flushes. Lock surveyed midlife Japanese women who had been without periods for over one year and found that 24% reported no menopausal symptoms. In fact there was no everyday language term for ‘menopause’ in the Japanese language. There was no specific term to describe a hot flush and Japanese women tended to talk in terms ‘stiff shoulders’, ‘headaches’, ‘ringing in the ears’ or ‘tingling sensations’. A few years



later Zeserson noted that a term for hot flush (*hotto furasshu*) had been adopted from English and suggests that this term is likely to subsume all the vague sensations previously communicated by ambiguous terms. He points out that the presence (or not) of concise words for things in a given society tells us less about the (non)existence of the phenomenon than about the social relations within that society.

Although there does appear to be some justification for claims that soy intake reduces the incidence of hot flushes (*see* Section 2.4.1.3), there is debate about the extent to which social and medical influences impact on women's interpretations of what is happening to them. There is plenty of literature exploring experiences of the menopause in different cultures (e.g. Chim et al., 2002; Doyal, 1995; Fu et al., 2003; Grisso et al., 1999; Kowalcek et al., 2005; Mumtaz and Rauf, 1997; Stewart, 2003). In some cases the presence or absence of symptoms is attributed to physical factors like the presence of phyto-oestrogens in the diet (as for Japanese women or the Mayan women of the Yucatan and Guatemala) or increased body mass (as for African-American women). However other factors are implicated in perceptions of the menopause experience. These can include lower socioeconomic status (again relevant for African-American women), strength of personal and social support networks (e.g. Fu et al. suggest that the high level of social functioning in Taiwanese women may help reduce menopausal symptoms when compared to Australian women), and cultural attitudes towards ageing women. Although Western culture portrays the menopause as a time of reduced social status due to loss of reproductive ability, other cultures celebrate the ageing process and the menopause is seen as a time of transition to a higher status. This is seen, for example, in Asian cultures where prestige increases with age and postmenopausal women may enjoy greater respect in the community, greater independence and freedom of movement (Fu et al., 2003; Mumtaz and Rauf, 1997). In her study of highland Guatemala Mayan women, Stewart (2003) noted that the menopause not only liberated women from pregnancy but it allowed them the opportunity to participate in village ceremonies and religious activities, socialization and governance. Fu et al. conclude that 'women's attitudes to the menopause evolve over the lifecycle and are affected by societal attitudes, observations of older women, attitudes towards ageing and personal experiences' (p.81).

#### **2.3.2.4 Talking to the wall**

Participants in Im et al.'s study reported generally negative experiences interacting with their physicians during their menopause transition. Some had not contacted their doctors because they felt the doctor would not care about their symptoms. Many of the women expressed a wish for healthcare professionals to start listening to women and not to rush into decisions about treatment, although they acknowledged that doctors were often constrained by tight clinic schedules. Again, Price et al.'s interviewees had similar criticisms and found physicians, particularly male physicians, to be dismissive of their concerns. Most had access to the Internet but were dubious about its reliability and the overwhelming amount of, often conflicting, information available online. They had similar doubts about media representation of the menopause and about hardcopy literature such as magazines and books, and from choice turned to other women for advice. Women's interaction with the medical profession is discussed more fully in Chapter 3, and Section 2.4 below considers the sources of support and advice that are available to women facing the menopause transition and the potential problems women might face in finding information.

### **2.4 Where can women turn for help and advice?**

Before starting this study it was hypothesized that only limited information would be available to women experiencing the menopause. This inference came from informal discussions with women who had struggled to find the information they needed in order to take informed decisions about living through their menopause transition. As explained in the Introduction, there quickly followed a realization that there is in fact a plethora of information available; the challenge is not so much to locate it but to interpret it, assess its credibility and understand its implications for the individual woman.

Health information studies of midlife (though not necessarily menopausal) women (e.g. Marmoreo et al., 1998; Price et al., 2008; Wyatt et al., 2005; Yoo and Robbins, 2008) reveal the wide range of resources accessed by women and also some of the barriers that constrain that access. Women are shown to place high value on interpersonal sources such as family and friends, especially if those individuals also have relevant expertise or

have been through similar experiences (e.g. Price's interviewees valued the advice of menopausal women with medical backgrounds and members of focus groups in Marmoreo et al.'s study of decision-taking about HRT placed high significance on the health status and experience of their own mothers). Other resources identified by midlife women include healthcare professionals, online resources (e.g. chat rooms and Websites), media broadcasts and print materials like books and magazines. Marmoreo et al. talk about 'information networks' in which support groups play an important role, revealing 'the intricate process of networking undertaken by women to further their knowledge, understanding, and management of menopause' and demonstrating 'the remarkable support that women provide for each other' (p. 295). Wyatt et al. interviewed midlife women and men who were seeking information about the menopause or erectile dysfunction and about HRT and Viagra. This study focusses on their use of the Internet in the context of the 'digital divide' debate and concludes that having access to online information goes beyond simply being in the vicinity of the right equipment, it also includes 'the gendered and generational social relations which form the context in which people's daily interactions or non-interactions with the internet take place' (p. 213). For example, some female respondents reported that they did have computers at home but that they were unable to go online because the computers were dominated by sons or male partners.

Huston et al. used a postal questionnaire survey to investigate trust in and use of information sources in the treatment of menopausal symptoms. This study was part of a larger project which focussed on factors related to the use of HRT in women with and without diabetes from a not-for-profit managed care organization in the USA. Analysis of the 765 eligible questionnaires confirmed that women use several different sources of information about menopausal treatments and that use varies with self-assessed menopause stage and HRT-use status. Doctors were identified as the most important source of information although women who had never used HRT were less likely to discuss the topic with a healthcare professional or watch a television programme about HRT than current- or past-users. HRT-use status also impacted on perceptions of the trustworthiness of information resources. Never-users rated doctors, pharmacists and

other healthcare providers as significantly less trustworthy than did current users. The authors suggest that this may reflect current-users' positive experiences with healthcare professionals perhaps owing to more regular visits or that it may be due to never-users deciding against HRT without a visit to a healthcare professional thereby missing an opportunity to build trust. The authors concluded that perceptions of knowledge and helpfulness played an important role in influencing trust in healthcare providers and recommend that professionals wishing to build trust consider seeking contact in non-traditional settings (e.g. by giving educational talks) thus giving them the opportunity to display their knowledge and willingness to help (Huston et al., 2009).

The menopause is a particularly challenging topic for women seeking health information. There are plenty of sources of information available, interpersonal, online and literature-based but women may have to overcome barriers to accessing these sources and to interacting with them. Furthermore, as discussed above, there are competing constructions of the menopause each with its own agendas and interpretations (Coupland and Williams, 2002). Nowhere is this more palpable than in information about ways of controlling menopausal symptoms. The debate about HRT is salient to any discussion of the menopause. It is complex, dynamic, elusive and contentious, even within the medical profession. A woman wishing to make an informed decision about how to deal with her symptoms is bombarded by conflicting opinions and by a barrage of media reports giving the results of studies that constantly reshape views on the benefits and risks associated with hormone replacement drugs or the alternatives.

#### *2.4.1 The HRT debate*

Hormone replacement therapy literally replaces the ovarian hormones, oestrogen and progesterone, that are no longer produced after the menopause (MacGregor, 2006). Proponents of HRT suggest that it is the most effective treatment for symptoms of oestrogen deficiency (e.g. hot flushes, night sweats, vaginal dryness, etc.). It is also considered to be beneficial for women at risk of osteoporosis – in which bones become more fragile and likely to fracture (National Osteoporosis Society, 2007). However osteoporosis is itself a contentious issue with claims that, for example, the osteoporosis

phenomenon has been used to justify increased medical intervention in the ageing female body through screening programmes and medication when in fact it is not an exclusively female preserve (Oakley, 2007) or (by self-acknowledged anti-establishmentarian author Vernon Coleman) that it was redefined as a disease to broaden its scope and hence increase numbers of ‘sufferers’ in order to provide a market for HRT drugs (Coleman, date not given). Negative views of HRT centre on the belief that potential harms outweigh potential benefits and that the menopause transition is a natural stage of a woman’s life which pharmaceutical companies have attempted to exploit. Feminist authors tend to identify HRT with the pressure exerted on women to remain youthful and fight off signs of ageing. They are particularly vocal in their criticism of Robert Wilson whose book *Feminine Forever* (1966) was a watershed in the modern HRT story.

#### **2.4.1.1 A brief background to HRT**

Accounts of HRT-use predate the twentieth century (even going back as far as the ancient Egyptians) with the first documented prescription dating from 1896 when a German gynaecologist gave ‘ovarian therapy’ to a woman whose ovaries had been removed. However the 1930s saw the first successful attempts at developing synthetic oestrogen along with natural conjugated equine oestrogens (extracted from the urine of pregnant mares) and HRT became available commercially. Despite uncertainties about the risks/benefits it was used by US and British consultants through the 1940s and 1950s with the connection between osteoporosis and oestrogen deficiency (made in the 1940s) prompting increased demand (MacGregor, 2006; Murray, 2001).

The popularity of HRT boomed in the 1960s following the publication of Wilson’s book. In *Feminine Forever* Wilson, a British-born gynaecologist based in New York, described the menopause as ‘a serious, painful, and often crippling disease’ induced by oestrogen deficiency and advocated the use of oestrogen therapy to prevent the inevitable ‘living decay’:

*‘From a purely biologic point of view, estrogen therapy can hardly be regarded as altering the natural state of life. On the contrary...it merely restores a natural harmony that has been disturbed by the lengthened life-span of modern women. It*

*is the untreated woman – the prematurely ageing castrate – that is unnatural. That which is common is not necessarily normal. The mere fact that such women castrates are prevalent – and getting more so every day as the world fills up with older women – does not make them biologically natural.’ (p. 47)*

Today Wilson’s book is considered contentious partly because of his descriptions of ageing women and their supposed loss of femininity, and partly because of his classification of the menopause as a ‘disease’. Houck has surveyed feminist responses to the book from 1963 to 1980. This is a complex topic but it is interesting to note that, according to Houck, feminists did not initially reject the message of *Feminine Forever*, the widespread use of HRT, or even the disease model of the menopause. In the period to 1975 some feminist health activists saw it as a weapon in the fight for women’s liberation and welcomed it as a means of proactively fighting the received wisdom that women were doomed to feel ill at certain times of their lives. British feminist Wendy Cooper saw it as a way for women to control their bodies and praised Wilson for taking women seriously and pushing the subject into the public arena (Houck, 2003; Murray, 2001). Other feminists during this period were less enthusiastic but although they rejected Wilson’s negative images of the menopause they still embraced HRT as a valuable tool for alleviating suffering. Even feminist writers had previously neglected the menopause. Houck cites the example of The Boston Women’s Health Book Collective whose first edition of *Our Bodies, Our Selves* in 1971 omitted any mention of it. Over time and through many editions this has evolved with the 2005 edition containing a full chapter on the menopause and an entire book devoted to it was published in 2006. Between 1976 and 1980 concerns about safety began to excite a more critical examination of HRT, reflected in concerns expressed by the medical establishment and the general public, and an acknowledgement that it cannot be a panacea for all the effects of ageing. From this point feminists turned to a broader reconsideration of the significance of the menopause and the need for a social solution to the dilemmas of ageing women (Houck, 2003; MacGregor, 2006).

The concerns about safety that proved the catalyst for a change in attitudes towards HRT occurred in response to publication of reports about increased risk of endometrial cancer. During the first half of the 1970s numbers of HRT prescriptions rose steadily in the UK and by 1977 they were almost two and a half times greater than in 1972. Between 1977 and 1980 use of HRT fell by around 30 percent due to the concerns about endometrial cancer and then remained steady through the early 1980s with the introduction of opposed therapy (taking progestogens to oppose the action of the oestrogens on the endometrium) to reduce the risk of cancer (Greer, 1991; MacGregor, 2006; Murray, 2001). In the late 1980s and early 1990s uptake of HRT rose again to reach over 4.5 million prescriptions in England by 1992 (Hunt, 1994). From the late 1990s a series of major clinical trials began publishing results that were widely reported by the media. These reports questioned the safety of HRT leaving women and their doctors more uncertain than ever about the risks and benefits of taking it. Following the publication of these results the numbers of women taking HRT fell, either because women themselves decided to cease treatment or because their doctors recommended it. Women's Health Concern (2007a) estimate that the number of women taking HRT (presumably in the UK although this is not stated) fell by 66% after the reports from two of the trials (the Women's Health Initiative, or WHI, study from the USA and the Million Women Study from the UK). In the USA, Haas et al. (2004) looked at the changes in HRT-use following the results of the WHI study and the Heart and Estrogen/progestin Replacement Study (HERS) and found that whereas the publication of the HERS results led to a temporary modest decline in HRT-use, the results of the WHI study provoked a substantial decline in use, particularly among subgroups of women. Section 2.4.1.2 will consider the implications of the trials for women taking decisions about managing their menopause and will summarize recent guidance on the relative risks and benefits of taking HRT.

#### **2.4.1.2 The risks and benefits of HRT**

MacGregor explains that there are numerous brands of HRT available through prescription in the UK. Some contain oestrogen only and others contain both oestrogen and progestogen to reduce the risk of endometrial cancer. Oestrogens can be either synthetic or natural. The natural types of oestrogen have fewer side effects and are the

preferred form for HRT whereas synthetic oestrogens which are more potent are used in contraception. Systemic oestrogen-based HRT can be taken orally in the form of tablets, or as patches, implants, gels, or in a vaginal ring. Oestrogen-based HRT can also be applied locally to the vagina using creams, pessaries, tablets or a vaginal ring. Progesterone is also available in tablet form but it is unstable and sedative. Furthermore, to be effective, tablets must be taken several times a day. Alternative methods of taking natural progesterone include vaginal gel, pessaries and suppositories but these methods are considered messy and, for convenience, synthetic forms of progesterone (progestogens) are available orally (tablets to be taken once a day), through a Mirena coil (netdoctor.co.uk, 2006), or combined with oestrogen in patches.

The majority of women starting HRT before or shortly after their menopause will be offered oestrogen with a cyclical use of progestogen over 10-14 days. For many women a disadvantage of this form of HRT is that the cyclical use of progestogen, which mimics the natural hormone cycle, results in a monthly bleed or 'period'. Women who have been postmenopausal for longer (e.g. typically from around the age of 55) can take both oestrogens and progestogens on a daily basis thus avoiding the withdrawal bleed. Women who have had a hysterectomy can take oestrogen-only preparations since they do not need to protect their uterus against endometrial cancer.

Different combinations and ways of taking hormone therapy suit different women and the process of adjusting dosages and methods of delivery can take time. Tablets are easy to take and if a woman decides to stop the treatment the effects are quickly reversed. However dosages are necessarily higher in tablet form because there is more wastage as the drug passes through the digestive system and side effects can therefore be stronger. Women must also remember to take their tablets. Patches can deliver drugs in smaller doses thus reducing the severity of side effects. Hormone levels are also more constant with patches but some women develop an allergic reaction to the patches themselves or have difficulty sticking them on. Adjusting doses can also prove difficult since there are limited versions of patches available. Gel is convenient and easy to use and the dose is



easy to adjust. However only oestrogen is available in this form and many women need to take progestogen in addition to oestrogen. Each method has its own set of advantages and disadvantages which must be weighed up on an individual basis.

MacPherson (writing in 1993) characterized the history of HRT from the 1960s as having three phases or ‘false promises’: the first phase (1966-1975) promised eternal beauty and femininity as extolled in *Feminine Forever*; the second (1975-1981) a safe, symptom-free menopause; and the third (1980 onwards) escape from chronic diseases. HRT has at times been linked with protection from a range of diseases including Alzheimer’s disease, Parkinson’s disease, osteoporosis and coronary heart disease (CHD). Of these, current guidance only recommends the use of HRT for treating osteoporosis although there is also some evidence to suggest that it may reduce the risk of colorectal cancer and improve symptoms of arthritis (MacGregor, 2006; MHRA, 2008b; Murray et al., 2001; Parker-Pope, 2007). The situation is complex and much depends on the individual woman’s age, medical history, and the type of HRT taken, but consensus of current opinion appears to be that HRT is beneficial to certain groups of women: those who have experienced a premature menopause, those suffering from menopausal symptoms, and those at risk of or suffering from osteoporosis (British Menopause Society, 2008b; MacGregor, 2006; MHRA, 2008b; Pines et al., 2007).

Much of the media interest in HRT has been sparked by the publication of the results of clinical trials that have focussed attention on the risks of taking hormone therapy. Again this is a complex topic but since awareness of risks is a key factor in women’s perceptions of HRT and in their decisions about managing the menopause it is important to consider briefly the most high-profile trials that have impacted on public and professional opinion about HRT.

**The Heart and Estrogen/progestogen Replacement Study (HERS):** a randomized double-blind (i.e. neither the patient nor the doctor knew whether HRT or a placebo was given), placebo-controlled trial in the USA designed to test the efficacy and safety of oestrogen plus progestin therapy for the prevention of recurrent CHD events in women.

Participants were post-menopausal women with an intact uterus who suffered from CHD (Grady et al., 1998). The 2763 participants were studied for an average of four years. The trial found that taking oestrogen plus progestin for up to four years did not prevent further heart attacks or death from previous heart disease in women who were already known to have CHD. There were no significant differences in heart problems between the active hormone and placebo groups. For the first year of the study there was an increased number of heart problems in women taking HRT but after two or more years the active HRT group had fewer problems than the placebo group. The researchers concluded that HRT should not be started to inhibit heart problems but that it might be appropriate for women to continue taking HRT if they developed a heart problem whilst already using HRT (MacGregor, 2006; Women's Health Initiative, 1998).

**The Women's Health Initiative (WHI) study:** this study, again from the USA, was set up by the National Institutes of Health in 1991 to look at the most common causes of death, disability and impaired quality of life in postmenopausal women including cardiovascular disease, cancer and osteoporosis. The study was intended to last for 15 years and had three strands: a randomized controlled clinical trial of promising but unproven approaches to prevention; an observational study to identify predictors of disease; and a study of community approaches to developing healthy behaviours. (Women's Health Initiative, 2009). The hormone trial element had two strands (daily oestrogen and progestin for women with a uterus and daily oestrogen only for women who had had a hysterectomy). The trial was intended to assess the effects of hormone therapy on risks of CHD (thought to reduce) whilst also considering the effects of HRT on breast cancer (thought to increase with duration of hormone use). The oestrogen/progestogen strand of the study was stopped three years early in 2002 amidst high publicity because a greater number of cases of breast cancer than expected occurred in women taking the hormones. The National Institutes of Health considered that the potential risks of this type of HRT for this group of women outweighed the benefits. The widely-reported results also suggested that women taking HRT had more heart attacks, strokes and blood clots than their counterparts taking placebos (BBC News, 2002a; BBC News, 2002b; Laurance, 2002; MacGregor, 2006). The oestrogen-only strand of the WHI

study was also stopped prematurely in 2004 since the National Institutes of Health felt that sufficient information on outcomes had been gathered (Stevenson et al., 2004). Shortly after the termination of the oestrogen/progestogen strand of the WHI trial a study based in the UK, Australia and New Zealand also ceased. The WISDOM study had been set up to assess the level of protection HRT could provide against heart disease but the study was stopped in the light of the WHI results which appeared to show increased risks of heart disease and breast cancer amongst participants. Despite this, the WISDOM team have recently published their results based on the findings available when the study ceased (Duckworth, 2002; Welton et al., 2008).

**The Million Women study:** This is an ongoing study from the UK. It launched in 1997 and by 2001 had recruited 1.3 million women. Participants responded to an initial questionnaire and have subsequently been monitored for health events through follow-up questionnaires, attendance at breast screening centres and through National Health Service (NHS) central registries. In 2005 a new strand was introduced which asked participants to provide a blood sample to allow analysis of genetic and biochemical factors. Researchers from The Million Women study have published widely but key topics have included the relationship between HRT and ovarian cancer (results suggest a small increased risk), HRT and endometrial cancer (results indicate that oestrogen-only HRT does increase risk of endometrial cancer in women with an intact uterus but that combined, or opposed, HRT may decrease the risk of endometrial cancer) and HRT and breast cancer (results suggest that use of HRT is likely to increase risk of breast cancer and this may be substantially greater for those using combined HRT). The authors claim that use of HRT by women aged 50-64 in the UK for the period 1993-2003 resulted in an estimated 20,000 extra breast cancers (Beral, 2007; The Million Women Study Coordinating Centre, 2008).

Several studies have noted that use of HRT dropped following publication of trial results suggesting increased risks, particularly in the aftermath of the initial WHI findings. Schonberg et al. found that the majority of women taking HRT in a large US academic practice ceased taking it an average of 13 months post-publication of the WHI results. Of

the 30% that continued with HRT about half reduced their dose (Schonberg et al., 2005). In New Zealand, Lawton et al. (2003) found that 58% of women surveyed (as part of the recruitment process for WISDOM) stopped taking HRT after the WHI results but 18% of them subsequently restarted. Haas et al. (2004) related average household exposure to newspaper coverage of the WHI results in July 2002 to use of HRT. They found that women had an average exposure of 1.4 articles and that greater household exposure to newspaper coverage was associated with large population-based decline in HRT-use.

It seems clear that some women and their doctors respond to new 'evidence' by changing their behaviour yet the evidence in this area, and with it the guidelines, is constantly being revised with new studies reporting and longer-term effects becoming evident as cohorts of participants age. Women in the UK are urged to treat results with caution since trials may have been conducted using types of HRT not commonly used in the UK or at different doses. Criticisms levelled at the WHI study include the fact that it included women with an average age of 63 which is not truly representative given that most women start taking HRT at around the age of 50 and that the majority of participants were overweight which is a known risk factor for heart disease and breast cancer. The methodology used in the Million Women Study has also been criticized. It was not a randomized controlled trial and the women were self-selecting and self-reporting HRT-users. These women were also already having a mammogram which may make them at higher risk for cancer or more aware of potential cancer risks because they were taking HRT. Furthermore, follow-up was done by reports from national cancer registries, not by subsequent questionnaires, so changes in HRT-use after initial registration were not recorded (MacGregor, 2006; Women's Health Concern, 2007a).

A 2009 Comment in *The Lancet* suggested that ongoing reanalysis of results is bringing the findings from observational and randomized controlled studies into line. According to Vandenbroucke, the data from both types of study suggest that the cardiovascular risk is real and is slightly stronger in older women and that the breast cancer risk is also real but is stronger in women closer to the menopause (Vandenbroucke, 2009).

#### **2.4.1.3 The ‘alternative’ approach to managing the symptoms of the menopause**

Some women prefer to take what they perceive to be a ‘natural’ approach to the management of menopausal symptoms. This may include lifestyle changes such as giving up smoking, taking more exercise or losing weight but may also encompass the use of complementary or alternative treatments. In their discussion of the three discourses of the menopause (*see* Section 2.3.2 above) Coupland and Williams (2002) explain that the label ‘complementary’ designates therapies that can be used in conjunction with medical treatments whereas ‘alternative’ treatments are used instead of medical preparations. The authors link complementary and alternative treatments to women’s desire to ‘take control’ and to no longer be subject to the influence of the patriarchal medical system.

Gollschewski et al. (2008) carried out a small-scale study of Australian women’s perceptions and beliefs about the use of complementary and alternative medications (CAMs) during their menopause. These women echoed the wish to have ownership and control over their menopausal experience and the treatments used. They wanted to be aware of their body’s individual needs during this transition and to self-manage their needs. Between them the women had used a range of CAMs and believed that lifestyle factors such as healthy eating, exercise and taking vitamins were helping them control their symptoms, improving their current health and ensuring long-term health benefits. Although some of the women found that CAMs could not control their symptoms sufficiently and were also taking HRT they were uneasy about this and continued to search for alternatives. The high cost of CAMs and of alternative practitioners was seen to compromise women’s beliefs and their ability to control their body and the treatments used. It has been estimated that in 1998, 10.6% of the adult population of England had visited at least one CAM therapist in the previous year and that 90% of the cost was borne by the patient (Thomas et al., 2001). In Gollschewski et al.’s study, negative attitudes of doctors and lack of reliable information were also identified as barriers to the use of CAMs: these women equated knowledge with control over their choices and were sceptical about research that did not support the use of CAMs for menopausal symptoms since their own experiences had been positive. Dew et al. considered how the topic of CAMs is broached in the general practice consultation. This study from New Zealand

found that patients would use a variety of strategies to introduce the subject of CAMs and that doctors reserved judgement about CAMs but were cautious in how they presented their concerns to patients (Dew et al., 2008).

Suter et al. looked at how Canadian women gathered, evaluated and used information about CAM options for managing their menopause. The women in this study located information through a range of sources including CAM practitioners, doctors, personal contacts and staff in health food shops and then used a combination of intuition and systematic analysis to judge the validity of the information they had found. They particularly valued first-hand accounts from personal contacts such as friends and family but continued researching many sources until they felt satisfied that they had enough trustworthy information to validate their experiences and make an informed decision. The majority of interviewees stated that they had faced challenges including limited access to resources (for those living in smaller communities), lack of time to do the searches and evaluate information, and the perceived unwillingness of health professionals to advise about CAM approaches (Suter et al., 2007). Concerns about the safety and side-effects of HRT, belief in the safety of 'natural' products, and a desire for a more holistic and personalized approach to care have all been identified as reasons for women turning to CAMs instead of or in addition to HRT (Gokhale et al., 2003; Gollschewski et al., 2008; Meadows et al., 2001; Seidl and Stewart, 1998).

The types of treatment available for the alleviation of menopausal symptoms can be broadly grouped into:

- botanicals (including phytoestrogens such as soy and red clover, and herbal treatments like black cohosh, dong quai, evening primrose, kava kava, St John's wort, and Chinese medicinal herbs),
- homeopathy,
- steroids (e.g. progesterone creams),
- vitamin supplements,
- diet and nutrition,

- non-oestrogen-based treatments for hot flushes (such as Clonidine and progestogens),
- physical treatments (acupuncture, reflexology, magnetism, Alexander technique, etc.) (British Menopause Society, 2008a; Rees, 2009; Royal College of Nursing, 2006).

Despite the attraction of CAM approaches there is limited evidence of their effectiveness and authors caution against the perception that anything ‘natural’ is by definition ‘safe’ (Gokhale et al., 2003; Greenhalgh, 2004; Rees, 2009). The two main issues are 1) a shortage of good quality research about benefits/risks of CAMs and 2) the lack of standards and controls in what has become a large and lucrative industry.

Although researchers have investigated the effectiveness of specific types of CAMs (e.g. Booth-LaForce et al., 2007; Briese et al., 2007; Carpenter and Neal, 2005; Low Dog, 2005; Nir et al., 2007), many of these studies are small-scale and the results are often inconclusive. Some researchers have carried out systematic reviews of the topic (Geller and Studee, 2006; Howes et al., 2006; Huntley and Ernst, 2004; Kronenberg and Fugh-Berman, 2002; Nedrow et al., 2006; Palacio et al., 2009) but these are constrained by the low numbers of high-quality trials acceptable for review. Of these systematic reviews, one of the more recent and more wide-ranging was produced by Nedrow et al. (2006). Seventy randomized controlled trials (RCTs) met the inclusion criteria for this study: randomized placebo-controlled trials and meta-analyses published in English using alternative therapies categorized by the National Center for Complementary and Alternative Medicine. Like other authors (e.g. Huntley and Ernst, 2004; Palacio et al., 2009). Nedrow et al. point to weaknesses in the trials they assessed: ‘Current published trials are generally small, of short duration, and have inadequate methods, such as not reporting between-group differences. Standardization of biologic products is poor, making direct comparison difficult. Nearly half of the studies in this review were rated as being of poor quality owing to these and other methodological shortcomings.’ (n.p.). The Nedrow review included studies relating to phytoestrogens and other biologically-based agents which showed mixed results, and to mind-body, manipulative, body-based and

whole-system approaches which showed little benefit in treating menopausal symptoms. The authors conclude that individual trials suggest a benefit for certain therapies but that ‘data are insufficient to recommend any CAM as effective for the management of menopausal symptoms’ (n.p.). A search of the reviews in the ‘complementary medicine field’ on the Cochrane Collaboration Website revealed no systematic reviews specifically covering CAMs and the menopause, although there were a few reviews of related topics such as treatments for postmenopausal osteoporosis and depression (Cochrane Collaboration, 2009).

Lack of robust evidence about the potential benefits and risks of taking CAMs means that health professionals often have poor knowledge of this area and about the interactions between herbal preparations and any pharmaceutical drugs a patient may also be taking. Health professionals may omit to ask about CAMs when taking the patient’s history or women may themselves be reticent for fear of meeting disapproval from the medical establishment (Gokhale et al., 2003; Gollschewski et al., 2008). In their guidance on complementary approaches to menopausal symptoms for nurses, midwives and health visitors, the Royal College of Nursing (2006) point out that herbal treatments may cause side effects (for which there is at present no effective reporting mechanism) or contain potential harmful contaminants. The guidance gives the example of black cohosh which has been linked with a risk of liver disorders in some (though rare) cases with the result that it must now carry a safety warning with information about the symptoms of liver problems (MHRA, 2006a). Kava kava has also been linked with liver damage and has been withdrawn by regulatory authorities (Greenhalgh, 2004; MHRA, 2006b; Rees, 2009).

As a result of a European Union Directive all over-the-counter herbal medicines in the UK will be subject to a registration scheme by April 2011. Under the terms of this directive, herbal medicine producers will be required to demonstrate the safety of the medicine by providing evidence of a minimum of 30 years of traditional use of which at least 15 years must have been within the European Union. Additionally, medicines must now be manufactured under Good Manufacturing Practice with the enforcement of safety



and quality-control standards with a further requirement to provide systematic patient information and a statement on labels/advertisements to the effect that the medicinal claim is based on traditional usage (MHRA, 2008a).

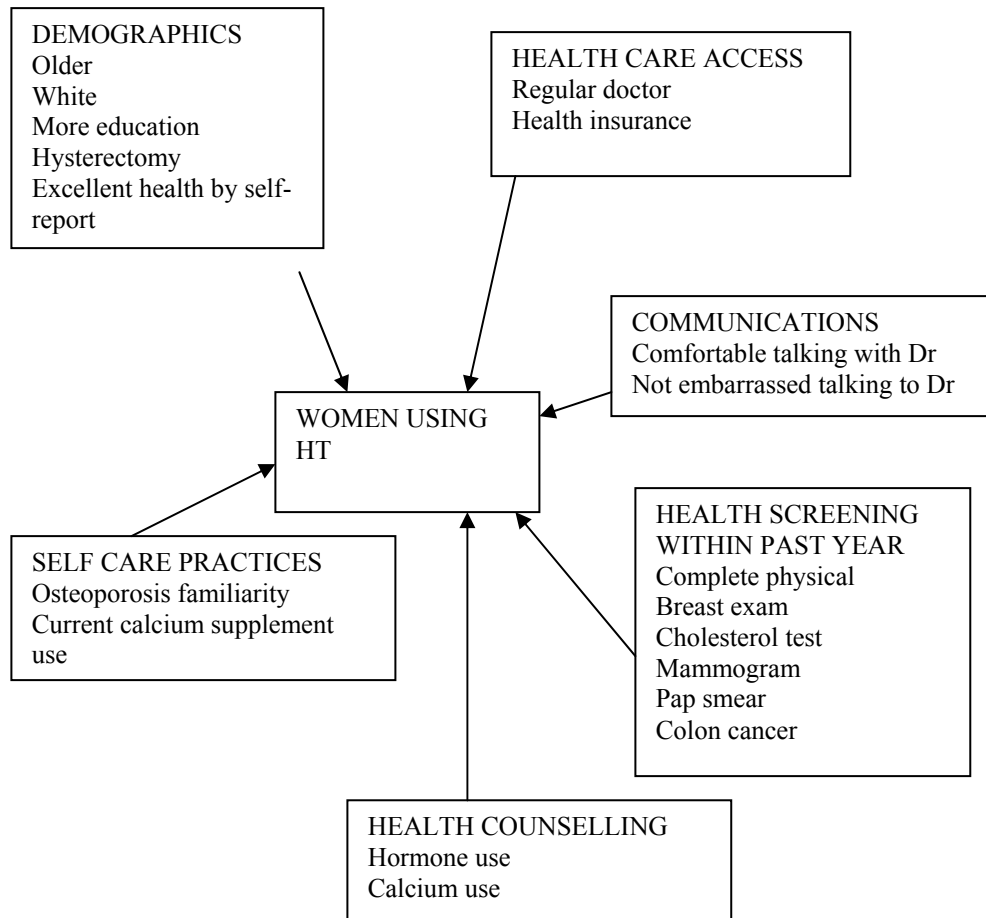
Nedrow et al. conclude their systematic review of CAMs with a call for further high-quality research and for health professionals to encourage open communication that allows patients to disclose treatments they are using and to share in decisions about managing their menopausal symptoms. The Royal College of Nursing however adds a note of caution in its guidance to practitioners: 'If nurses are to remain accountable they should be aware of the benefits, side effects, evidence base and interactions as well as the cost of treatments that they might discuss. You should not recommend products or therapies over others without a good evidence base, and we should all remember that verbal recommendations can carry the same weight as a written prescription.' (Royal College of Nursing, 2006, p.5).

So, given the competing influences that women may encounter as they attempt to make decisions about their menopause transition, what do they base their decisions on and where can they turn for help?

#### *2.4.2 What resources are available to help women make sense of their menopause?*

Research into women's decision-making during the menopause is dominated by HRT and the choice of whether or not to take it. This is understandable since experiencing symptoms that need management (either by HRT or other means) is a key trigger point for women to begin searching for information and advice. It is also the area which is most likely to bring women into contact with the medical establishment from within which many of the journal articles on this topic are produced. MacLaren and Fulgate Woods (2001) used data from The Commonwealth Fund 1998 Survey of Women's Health to explore HRT-use and the factors relating to women's decisions about HRT-use in the USA. They found that uptake of HRT was associated with certain socioeconomic markers, and was affected by attitudes to self-care, and by access to and communication with healthcare professionals (see Figure 2.2). Of the women using HRT, 57% reported

that their decision was based on discussions with health professionals, 36% reported that relief of menopausal symptoms influenced their decision, disease prevention (CHD/osteoporosis) was cited by only 13% of women and 4% had undergone a hysterectomy. The authors found that women who were white, with a higher level of education, who visited their doctor regularly and who assessed their own health status as very good/good to excellent were more likely to be taking HRT. These findings are in line with those from other studies (e.g. Neuner et al., 2003; Pansini et al., 2000; Shah et al., 2001; Strinić et al., 2002,). One study from the UK (Kuh et al., 2000), by contrast, found no strong evidence of healthy lifestyle or higher socioeconomic group being a predictor of HRT-use. In this study, women who, by the age of 50, had smoked in earlier adult life, were of lower socioeconomic status, had more reported health problems and who had chosen oral contraceptives through their fertile years were more likely to be using HRT.



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 Figure 2.2 Factors associated with hormone use. Source: analysis of Commonwealth Fund 1998 Survey of Women's Health. (Reproduced from MacLaren and Fugate Woods, 2001).

Other studies have focussed on women's understanding of the risks associated with the menopause and HRT (e.g. Ballard, 2002; Walter and Britten, 2002) or on the use of specific decision aids (combinations of tailored booklets, printed summaries, audiotapes and worksheets) to help women as they negotiated the information needed to make a decision (Bastian et al., 2002; Légaré et al., 2003; Murray et al., 2001). These studies have found that decision aids can help patients play a more active part in the decision-making process and can reduce anxiety but that different methods of delivery work best for different individuals. Schapira et al. (2004) developed a model to identify the relative

importance that women attribute to various factors that contribute to decisions about HRT. They established that weighting varied for different groups of women: for example, among women taking HRT at the time of the study, heart disease and osteoporosis received high weightings whereas breast cancer was considered less important yet among never-users concerns about breast cancer were a strong issue weighting against use of HRT. Women's participation in the decision-making process and the quality of their interactions with the medical profession is discussed in more detail in Chapter 3.

A wide variety of other resources are available to women looking for general or more targeted information about the menopause. Books are easily accessible through bookshops and libraries and range from those written by authors from within the medical profession (e.g. MacGregor, 2006; Rees et al., 2003), through those written from a more popular stance (e.g. Brewer et al., 2007; Murray, 2001), to those with a feminist pedigree (e.g. Greer, 1991; The Boston Women's Health Book Collective, 2006). Others focus on specific issues, frequently HRT or 'natural' approaches to the menopause transition (Hall and Jacobs, 1992; Parker-Pope, 2007; Stoppard, 2003). However, in this fast-moving environment where opinions and recommendations are constantly changing, books can quickly become outdated and women may need to access more dynamic forms of information.

Television, newspapers and other media resources can respond more quickly than can books to new developments in the field and a lot of information about the menopause can be gleaned both from active information-seeking practices such as searching archives of radio broadcasts for women's health topics or non-directed practices like browsing through magazines. The amount of information and the speed with which it appears in the media can, however, be overwhelming and confusing. An example of this is the appearance of a newspaper article on 20 May 2008 claiming that 'HRT is given the all-clear' by 'an international panel of experts' who said that the health risks had been 'greatly exaggerated' (Hope, 2008a). The same issue of the newspaper carried a profile of a well-known female television presenter with the headline 'I pop 25 pills a day but I would never risk HRT' (Hunniford, 2008). Just three days later the same newspaper in a

second article written by Jenny Hope claimed that ‘a study’ had found that women taking HRT pills doubled their risks of blood clots (Hope, 2008b).

An Internet search on ‘menopause’ will produce many millions of results. A woman looking online for information must be willing and able to search effectively and be selective in order to retrieve reliable, up-to-date and accessible information. She needs to be able to judge the authority of a Website and differentiate between those providing information/services and those simply trying to sell symptom-relieving products.

Informal networks of family, friends, colleagues etc. are known to be highly valued information resources for women (e.g. Ankem, 2007; Im et al., 2008; McKenzie, 2001; Meadows et al., 2001; Price et al., 2008; Raupach and Hiller, 2002). The Internet can provide a forum for social contact and support through chat rooms and discussion groups (e.g. EarlyMenopauseUK, 2007; Good Housekeeping, 2008). It can also provide access to digests of information (factsheets etc.) from organizations like the British Menopause Society (BMS), Women’s Health Concern, or The Menopause Amarant Trust (The Menopause Amarant Trust, 2009), although there is sometimes a fee for leaflets.

Patient information leaflets can be found in primary care practices and pharmacies. However many of these leaflets are produced by pharmaceutical companies and may promote the medicalized view of menopause as a disease that needs treating or may be little more than adverts for that company’s products (Coupland and Williams, 2002).

For a woman seeking an intermediary to help her make sense of the conflicting evidence, of the different approaches to the menopause and of her own personal set of risks and values, options depend on levels of support in her geographical area and/or on her skills at locating appropriate resources. As part of the information-gathering process for this study interviews were carried out with representatives from a range of organizations providing support and advice to women during their menopause transition. A brief overview of these organizations is given below. Appendix 1 contains a rich-picture that includes representation of their objectives and concerns as identified through the interviews (Checkland and Scholes, 1990).

**The NHS menopause clinic:** This clinic provided the site for part of the data-collection element of the study and for an evaluation of clinic services (the Executive Summary of the report of this evaluation can be found in Appendix 2). The clinic was set up by a Consultant in Reproductive Health who found that women going through the menopause were so frustrated in their attempts to find the information and advice they needed that they began visiting the consultant's contraceptive clinics thereby blocking the clinics for those who needed contraceptive advice. The consultant identified a gap in services since at that time none of the gynaecologists in local hospitals had a special interest in HRT and if a woman's own general practitioner (GP) was not able to give her the time and information she needed then she had nowhere obvious to turn. The clinic was set up with no funding and medication provided through the clinic was supplied free of charge by pharmaceutical companies in the anticipation that if a woman settled with a particular drug she would adhere to it and return to her GP for further prescriptions. The consultant's ethos was that HRT is a prophylaxis for life and that a woman must feel comfortable with her prescription even if it takes time to settle on the right product. By not charging prescription costs the clinic was able to offer flexibility in the early stages so that women could try different products without having to pay each time they changed. Since many women need to take a combination of hormones, prescription costs can be expensive. The consultant also hoped to introduce an educative element for GPs through discharge letters that detailed the decision-making process.

Awareness sessions had been held at local hospitals for hospital staff wanting information about their own menopause. These sessions were always crowded, with large numbers of women contacting the clinic immediately afterwards and others following on having heard about it by word of mouth. About 50% of clinic patients were referred by GPs, often because the GP had been unable to find an HRT preparation to suit the patient. The remainder of the patients were self-referrals, contacting the clinic to request an appointment. Clinic appointments lasted 30 minutes which gave patients time to discuss their options and seek explanations to help them make decisions about treatment. At the

time of initial contact with the clinic, sessions ran for one afternoon a week and at times the clinic had a waiting list of several months.

At that time the consultant was semi-retired and hoped to find a colleague to continue and expand the service. When the consultant took full retirement the service was in fact disbanded. Contact with the local Primary Care Trust (PCT) established that, following discussion, it was felt that a combination of low through-put, no medical input (after retirement of consultant), and inequity of service (since there was no similar provision elsewhere in the local area) justified the closure of the service. The two alternative routes to menopause advice (i.e. through primary care and specialist gynaecology services) were deemed sufficient to replace the clinic.

Hanlon et al. (1996) and Obeid (2001) have also evaluated community menopause clinics. For Obeid the clinic was attached to an inner-city general practice in an area with high levels of social disadvantage and non-white ethnicity and had been set up in response to a recognized lack of service provision for the sexual health needs of mature women registered at the practice. Obeid, a nurse in the clinic, dedicated one session per week to menopause management and breast awareness. The clinic was found to have the advantages of providing women with the opportunity to discuss their individual circumstances and of communicating the message that the practice took the implications of the menopause seriously with the expectation that this would result in increased rates of self-referral for menopause-related problems. Hanlon et al. carried out their evaluation in 1996 but the Johnstone Community Menopause Clinic is still active (NHS Greater Glasgow and Clyde, 2006). The authors found that levels of satisfaction with the community menopause clinic were significantly higher than the general population's reported levels of satisfaction with their GP's care. They also found that clinic patients were more likely to be given relevant literature after the consultation than those attending GP consultations. Hanlon et al. asked participants what services women would like to see at a menopause clinic. The most popular responses requested more time with the doctor, information about the menopause, HRT, the premenstrual syndrome and diet. The authors point out that the study has limitations, particularly in terms of comparisons between GPs

and the clinic, since women who attended the clinic were likely to have been members of a self-selecting group who may have been more likely to have been dissatisfied with GP services in the past. However, they conclude that high levels of satisfaction with the community clinic and evidence that there is a minority of patients who are reluctant to contact their GP to discuss menopause issues is justification for the continuation of the clinic.

**The Wellwomen Information centre:** This inner-city organization was founded in 1983 and had evolved from a group of women meeting from the late 1970s to discuss women's health. Gradually women began to contact the group for advice about issues such as abortion or hysterectomy and a role for the exchange of health information and support was identified. Wellwomen Information was formed and began to advertise services. Initially premises were provided by the local health promotion department for a few hours each week and women were waiting by the door first thing in the morning to gain access to the support and information provided by the centre. It took four years for the centre to secure any substantial funding which was eventually supplied by community outreach and women's committee groups within local councils. Acquiring funding forced the group to re-evaluate services and organization; a management committee was set-up and a constitution devised. The culture had to change from one of collectivism to a hierarchy with employers and employees and this was a testing time for the centre. At the time of interviewing, fundraising was a continuing problem with levels from local councils dependant on which political party controlled the budgets. Services to women were free but donations were welcome. The centre provided information and counselling services as well as outreach services (e.g. sessions with Asian women's groups to discuss issues including the menopause) and worked on the basis that while people do need information what they probably need even more, especially at a time when information is relatively easy to acquire, is help to think about what is going on for them – help exploring their personal situation and options.

**The women's health charity:** Women's Health Concern had been established as a charity for 32 years at the time of interviewing. It was started by a nurse and originally



provided factsheets about women's health issues. The information resources gradually expanded to include larger booklets and videotapes and by running training sessions for nurses to facilitate the flow of information towards the public. Gradually the training sessions grew into hosting Women's Health Concern days for nurses from gynaecology departments or primary care practices which were run under the auspices of hospitals. The study days covered various aspects of women's health including a session about the menopause. Members of the public can access the charity through its Website (Women's Health Concern, 2007b) and through a nurse-led telephone helpline. Contact details for the charity can be found on information provided by drugs companies, in magazine articles and books (e.g. in the Useful Addresses section of Jenni Murray's book *Is it me or is it hot in here?*) At the time of the interview they were hoping to expand into 'roadshows' to take information out to women. Along with providing information and advice about women's-health issues through the helpline and information available on the Website, the charity can help women locate support services and clinics (e.g. specialized menopause clinics) in their local area.

**The community healthy-living centre:** This healthy-living centre in the north of England aims to bring together a range of activities and initiatives that will improve the health and quality of life of the local community. The centre provides access to CAM activities (e.g. acupuncture and reflexology) and support groups (e.g. 'caring about cancer' and breast feeding). Funding has also allowed the provision of additional services including relationship counselling, stress awareness/relaxation courses and training for counsellors. A practice nurse working in collaboration with the centre suggested menopause workshops and, at the time of interviewing, one had been held with another planned. A bid for lottery funding was made under the umbrella of mental health which stressed the need to provide opportunities for women to share experiences and to tackle feelings of isolation that can have a negative impact on women's mental health during the menopause. A second element of the workshop was to provide advice about nutrition as a means of managing wellbeing and each participant was offered a one-to-one session with the nutritionist (the workshop facilitator) as a follow-up. The workshops had been promoted through posters and brochures to primary care practices but this method had not

been very successful. Other promotion efforts focussed on the local press and local radio station which stimulated more interest. Several participants had heard about the workshops through word of mouth or by visiting the centre for other activities. Post-workshop feedback questionnaires revealed that participants felt less isolated and had benefited from the opportunity to share experience with other women.

## 2.5 Summary

The aim of this chapter was to lay a foundation for the rest of the thesis by introducing McKenzie's Model of Information Practices in Everyday Life Information Seeking and by explaining the relationship between twin pregnancy and the menopause transition as information-seeking contexts. The context of the study was further explored through discussion of the medical interpretation of the menopause and of women's attitudes towards midlife and the challenges implicit in this life transition. Appendix 1 contains a rich-picture summary of some of these challenges and of possible implications for organizations seeking to provide services, information, and/or support to women during their menopause. Chapter Three widens the discussion through a review of the literature covering topics identified as central to the core concepts in the study.

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# Chapter Three: Review of the Literature

## 3.1 Introduction

The initial approach to the literature was to read widely around the subject from both a clinical and consumer viewpoint, to identify the main issues and areas that would require investigation in greater depth. Many of the menopause texts introduced a feminist perspective which then broadened the scope to include consideration of what feminist writers have written about women's health issues, the medical model and about researching women's issues. A key element of the menopause discussion highlighted in both the clinical- and consumer-focussed texts is the issue of making an informed decision about HRT. Exploration of this topic not only pointed to the literature on HRT and related clinical trials but to the questions of informed decision-making and presentation of risk. Concurrently the literature on information-seeking models and, in particular, studies of everyday information-seeking behaviour was accessed and evaluated. This was a long and iterative process, with every opportunity being taken to access potential information sources both formal and informal.

The literature searches were carried out at Aberystwyth University libraries, The National Library of Wales, The Wellcome Library for the History of Medicine, The King's Fund library, and several other academic/health libraries including the University of Bristol Medical Library, the University of Bath, and Bath Royal United Hospital NHS Trust. Subscriptions were made to a number of alerting services (e.g. the British Library's Zetoc Alert service) specifying journals relating to 'women's health', 'ageing', and 'library and information studies' with searches on the terms MENOPAUSE, HRT and "HORMONE REPLACEMENT THERAPY". Not surprisingly, the literature searches carried out in academic and other specialist libraries tended to yield results in the form of journal articles or academic books. Methods used to survey the literature available to the consumer included visiting public libraries and checking the press and relevant media broadcasts (e.g. Woman's Hour).

Findings were often serendipitous and the approach was frequently that of ‘berrypicking’ (Bates, 2005a; Bates, 2005b). Bates applies this term to online searching, but the concept of an evolving search that can begin with one feature of a broader topic or with one reference and then move through a variety of sources with each new encounter giving further ideas and directions to follow reflects much of the experience of working with an unfamiliar topic.

More structured searching was carried out using library catalogues and web-based electronic information services such as ISI Web of Knowledge, MEDLINE, LISA and LISTA. Careful selection of search terms was particularly important for literature relating to the menopause since an array of terms can be used in this context and a useful title can be easily missed: a search for ‘menopause’ on the MeSH database of medical subheadings (National Library of Medicine, 2008) gave ‘perimenopause’, ‘menopause, premature’, ‘premenopause’, ‘pre-menopause’, ‘postmenopause’ and ‘post-menopause’ as possible alternatives. Similarly ‘hormone replacement therapy’ may also be referred to be several terms including ‘HRT’, ‘menopausal hormone therapy’, or ‘oestrogen/estrogen replacement therapy’. In a database such as MEDLINE where huge quantities of results would be generated by simple use of the term ‘menopause’ a careful search strategy and use of the ‘limiting’ facility proved invaluable.

As the study progressed scope was refined and this review is therefore structured around those topics that were identified as being central to the core concepts in the study.

### 3.2 Theoretical approaches to information behaviour

Library and Information Science (LIS) is relatively new field that has at times been criticized for a lack of real theory (Case, 2005). Despite this, the theoretical foundations are being laid by researchers developing their ideas within LIS and borrowing from other fields. The result has been that we now have ‘a confusion of many approaches competing for attention’ (Bates, 2005b). LIS authors have used various ways to present the research trends in an ordered and accessible manner but there are many different approaches to classifying the studies (e.g. from a historical approach, grouped by philosophical outlook,

by type of study participants, etc.) and through the organic process of research the field is continually branching out in all directions. Finding reading matter pertaining to LIS theory was not difficult, selecting sources most appropriate to my discussion and working out how to present the discussion concisely was more of a challenge. The literature is presented here as a discussion of the concepts related to theoretical approaches and, firstly, as an explanation of the choice of ‘information behaviour’ as the preferred term for exploring women’s relationship with information as they face the transition of the menopause.

### *3.2.1 Why ‘information behaviour’?*

Early LIS studies talked, somewhat narrowly, in terms of patterns of information-seeking behaviour but the more general term ‘information behaviour’ gained favour as researchers turned their attention to the wider view of information acquisition and use. Pettigrew et al. (2001) explain that there has been debate about whether ‘information behaviour’ is an appropriate term for describing the body of academic study. ‘Arguments for using the term were based largely on observations that the field has broadened to include such concepts as information need and information giving, in addition to the basic concepts of information seeking and information use. Others argued that the term information behavior is inappropriate because people outside the field might associate it too closely with the behaviorist paradigm in psychology and thus not consider the broad range of contextual factors of interest to information behavior research’ (p. 44).

The process of broadening out the interpretations and scope of IS research has seen a shift from the traditional view of early work which examined the highly specialized needs of user groups such as engineers and scientists and focussed on information sources and how they were used. ‘Surveys of individuals made such strong assumptions about their needs, motivations, habits, and behaviors that the range of responses they could make was severely constrained; what mattered in these early investigations was how *formal information systems* served the serious (e.g., work, health, or political) information needs of the population studied’ (Case, 2007, p. 6). A sea change occurred through the 1970s as authors began to question the traditional systems viewpoint, moving towards a person-

centered approach with the individual as ‘finder, creator, and user of information’ (Case, 2007) and becoming more sensitive to people’s perceptions of, and attitudes to, information (Dervin, 1976). With this questioning of the perception that information studies research should focus primarily on active, problem- or task-driven information seeking came an appreciation of the complexities of people’s relationships and interactions with information.

Researchers began recognizing that the traditional idea of information seeking as an intentional and directed process produced a ‘narrow conceptualization of information seeking [that] may in fact be the last, most easily observable, perhaps not even primary stage of a complex set of activities – ongoing, conscious as well as unconscious, intentional as well as serendipitous, and social as well as political and cognitive’ (Rice et al., 2001, p. 2) and that individual personality traits could bring much to bear on the information-seeking process (Heinström, 2005). Furthermore, the concept of ‘information’ itself could no longer be confined to ‘useful symbols stored and represented in some medium’ but had to be expanded to encompass the whole process of communication and creation of meaning for different social groups (Rice et al., 2001). Accepting that directed information seeking is only one aspect of people’s experience of ‘information’ in their lives, researchers began to explore other ways of ‘encountering’ information, to look at how people use information and pass it on to others (Rioux, 2005), and to acknowledge that people not only have a multiplicity of current needs but also past and future needs (Erdelez, 1999). Wilson (1999) introduced a nested model, in which information behaviour is a general field of investigation within which lies the field of information-seeking behaviour which, in turn, contains the more specialized field of information search behaviour.

The term ‘information behaviour’ (as opposed to ‘information-seeking behaviour’) as a way of describing the broader scope of LIS research has received general acceptance and is now widely used in the literature (Pettigrew et al., 2001). The label is open to interpretation and Erdelez explains that there is no formal definition of what constitutes information behaviour. For her study of accidental information discovery she defined

information behaviour as: ‘an all-encompassing term that involves various forms of users’ conceptual and physical contacts with information’ (Erdelez, 1996, p. 412). No longer confined to directed information-seeking activities, examples of contact with information (with varying degrees of structure and purpose) now embedded in the literature include: information encountering (Erdelez, 1996; Erdelez, 1999; Erdelez, 2005) described as a ‘memorable experience of unexpected discovery of useful or interesting information’ (2005 p.179), browsing in which people ‘meander from topic to topic’ and ‘seem to seek information in a purposeless, illogical and indiscriminate manner’ (Toms, 1999, p. 191), serendipitous discovery (Toms, 2000), incidental information acquisition (Williamson, 1998), and ‘information grounds’ (Pettigrew, 1999).

### *3.2.2 Everyday life information behaviour*

Since early research into information needs and uses, scientists and engineers have proved popular choices as study participants (e.g. Mick et al., 1980; Palmer, 1991a; Palmer, 1991b) with the share of other academics and professionals gradually increasing as trends and levels of funding changed over time (Case, 2007). Many authors have explored information behaviour within many different work environments (Byström, 2005; Ellis, 1993; Ellis et al., 1993; Leckie et al., 1996; Urquhart, 1999), indeed there are many practical reasons for choosing a study group which, if not totally homogeneous, at least has a certain number of common factors and identifiable needs. However, an interest in the informal ways in which people interact with information has naturally prompted researchers to explore beyond the task-oriented environments of the workplace and to probe the realities of people’s wider social worlds.

Savolainen (1995) sought to legitimize the nature of non-work contexts and developed his model of Everyday Life Information Seeking (ELIS) to illustrate ‘the various informational (both cognitive and expressive) elements which people employ to orient themselves in daily life or to solve problems not directly connected with the performance of occupational tasks’ (p. 266). In this model, ELIS receives its meaning through the values, attitudes and interests characteristic of the individual’s way of life. For Savolainen, *Way of Life* is a concept in its own right and refers to ‘order of things’ where

‘things’ are various activities taking place in the daily world (e.g hobbies, running the household) and ‘order’ refers to the preferences given to these activities, determined on both objective and subjective grounds. The major factors involved in the concept of way of life include the structure of time budget (work/leisure), models of consumption of goods/services, and the nature of hobbies. To ensure that the meaningful order of things is sustainable individuals must take active care of it. Savolainen calls this care *Mastery of Life*, explaining that it is ‘the central point of departure for the model’ and ‘provides a broad context for investigation of individual and social factors affecting ELIS’. He associates it with pragmatic problem-solving, particularly in instances where the order of things is under threat (Savolainen, 2005, p. 144). If all is well, mastery of life continues as a routine process supported by passive monitoring of everyday life events. When the order of things is unsettled, mastery of life can evolve into active problem-solving ‘which aims at restoring the disturbed order, usually requiring *active seeking of practically effective information*’ (italics in original) (Savolainen, 1995, p. 272). Savolainen’s model suggests that way of life and mastery of life determine each other and that they are affected by the values, conceptions and phase of life of the individual. However, he stresses that way of life can provide only general criteria for choosing and using information sources. Similarly an individual’s approach to mastery of life should only be seen as a tendency to adopt a certain information-seeking strategy in problem-solving situations.

In her study of a lower-working-class population (university janitors) Elfreda Chatman (1991) explored information behaviour in the context of gratification theory. Although the survey questions were job-related, they were not specific to tasks undertaken at work and rather focussed on the ways in which participants looked for work opportunities. Chatman’s results confirmed the existence of a lifestyle focussed on present reality and with an orientation towards immediate gratification. The janitors lived in an environment in which financial and psychological resources were consumed in meeting current needs and dealing with frequent and unexpected problems. She concluded: ‘What is most real to the janitors are those experiences that take place in a small world. Furthermore, there is minimal link to the activities or persons who reside outside their social milieu. Finally,



things of most interest to them are those that are most accessible, have a firm footing in everyday reality, and respond to some practical concern.’ (p. 447). Chatman later expanded on her concept of ‘life in a small world’ in a study of life in a maximum security prison for women. To Chatman, life in a small world is one in which activities are routine and predictable. There is a strong element of social control and the horizons of the world are bounded by social norms. In such a society mutual opinions and concerns are reflected by its members and language and custom bind participants to a common worldview. ‘In its truest form, a *small world* is a community of like-minded individuals who share coownership of social reality.’ (Chatman, 1999, p. 213). To survive in such a world, members adopt a policy of ‘life in the round’. Despite the predictability of small-world existence, members accept that life contains an enormous amount of imprecision and uncertainty, of approximation. Chatman describes it as ‘life taken for granted’ which works most of the time with enough predictability that, unless a critical problem arises, there is no point in seeking information. In a small world, legitimized others (‘insiders’) set the boundaries on behaviour, social norms force private behaviour (including information-seeking behaviour) to undergo public scrutiny, this results in a communal worldview that includes language, values, meaning, symbols and context. It is this worldview that Chatman defines as life in the round and members subscribing to this worldview will not cross the boundaries of their world to seek information unless it is perceived as critical, there is collective expectation that the information is relevant and a perception that life in the round is no longer functioning.

Following on from Chatman’s work, the notion of ‘place’ as a element of information behaviour has formed the basis Fisher’s theory of the existence of ‘Information Grounds’. Fisher (née Pettigrew) first identified the concept during her fieldwork at community foot clinics in Canada. She used Granovetter’s strength of weak ties framework (Granovetter, 1982; Granovetter, 1973) to explore the flow of everyday information between community nurses and the older people they tended at the clinic (Fisher and Naumer, 2006; Pettigrew, 1998; Pettigrew, 1999). Granovetter’s theory argues that our acquaintances (weak ties) are ‘more likely to move in circles different from our own and will thus have access to information different from that which we receive’ (1973, p.

1371). 'It follows that individuals with few weak ties will be deprived of information from distant parts of the social system and will be confined to the provincial news and views of their close friends.' (1982 pp. 105-106). Granovetter's theory has been criticized for, amongst other things, his lack of strong evidence to support his premise, his use of a single information event to support his theory (acquiring job information), and his tendency to impose his own definition of information on participants (Dixon, 2005) but some of these weaknesses may be symptomatic of the time he was writing and the theory provided Pettigrew with a hypothesis that nurses (as weak ties) would supply the seniors with information from outside their own social circle but that seniors would confer with their peers before using that information.

Fisher (Fisher and Naumer, 2006) explains that the situation was more complex than she had anticipated. She quickly learned that the seniors were themselves a ripe sources of information for the nurses, that multiple persons participated in exchanges and that seniors shared information whilst waiting for their treatment or afterwards. This led her to explore the clinic itself as a physical and social setting for the exchange of information, which in turn led to her definition of an information ground as '...an environment temporarily created by the behaviour of people who have come together to perform a given task, but from which emerges a social atmosphere that fosters the spontaneous and serendipitous sharing of information' (Pettigrew, 1999, p. 811). In information grounds, information flow is a byproduct of social interaction (Fisher et al., 2004) and can be affected by contextual factors such as, in the case of the chiropody study, the physical environment, clinic activity and the participants' respective situations.

Sonnenwald (2005) expresses the relationship and interplay between information resources (including social networks) in terms of 'information horizons' which are determined socially and individually and are dependent on context. Study participants were asked to draw a graphical representation, or map, of their information horizon and to verbally explain the importance and role of each element whether a physical information resource or a person. This concept has been further developed by Savolainen and Kari who propose that material objects such as colleagues or libraries do not *per se*

constitute an information horizon but that the horizon can be defined as an imaginary field into which the individual places sources so that those that appear most significant are closest and the potentially least useful are further away. (Savolainen, 2007; Savolainen and Kari, 2004). In a small-scale study of the selection and use of information sources in everyday life situations, Julien and Michels (2000) used diary and interview techniques to explore both formal and interpersonal sources in the context of day-to-day and crisis situations. Participants prized human sources for the ability to make value judgements based on life experience and expectations of usefulness varied with the information seeker's gender and the source characteristics.

By the nature of the environments they are investigating, studies of everyday life information behaviour often follow a naturalistic approach such as that used by Sönnenwald (Lincoln and Guba, 1985). This approach demands an appreciation of the importance of context and an understanding that findings are context-specific since information-seeking does not occur in isolation from surroundings and these surroundings can have a profound influence on information behaviour (Hargittai and Hinnant, 2006; McKenzie, 2001). Furthermore, Johnson (2003) argues that individuals can themselves shape contexts by how they activate and interpret them. McKenzie (2003) states that the intent of her study of pregnant women was to 'focus holistically on the role of information practices in accounts of the individual within her context' (p. 28). This style of research identifies McKenzie with social approaches to metatheory, i.e. approaches that concentrate on social contexts with the attendant focus on 'the meanings and values associated with social, sociocultural and sociolinguistic aspects of information behavior' (Pettigrew et al., 2001, p. 54).

### *3.2.3 Metatheories, theories and models*

This section will begin by considering some of the relevant terms that occur in discussion about theoretical approaches to information behaviour: metatheories, theories and models. Bates (2005b) warns that these concepts are often, but erroneously, used interchangeably and defines them as:

- Metatheory – a theory concerned with the investigation, analysis, or description of theory itself;
- Theory –
  - a) the body of generalizations and principles developed in association with practice in a field of activity....
  - b) a system of assumptions or accepted principles, and rules of procedure devised to analyse, predict, or otherwise explain the nature of behavior of a specified set of phenomena;
- Model – A tentative ideational structure used as a testing device... (p. 1).

According to Bates, metatheory is the philosophy behind the theory. It is the fundamental set of ideas about how phenomena of interest should be thought about and researched. Theories on the other hand, are systems of assumptions, principles and relationships posited to explain phenomena. While theories often carry with them an implicit metatheory and a methodology to provide the ‘rules of procedure’, the core meaning of theory relates to the development of understanding and explanation of a phenomenon. Models, are a tool in the development of theory, a kind of proto-theory that can be tested for validity and may endure for many years until further research transforms them into something more akin to true theory. For Bates, most current LIS ‘theory’ is really still at the modeling stage.

### **3.2.3.1 Models**

Case (2007) defines the concepts in terms of perspectives, paradigms, theories and models. Here again, models are viewed as a stage en route to the development of theory. Both models and theory are simplified versions of reality but models are tied more closely to the real world and typically make their content more concrete through the use of diagrammatic representation. Järvelin and Wilson (2003) suggest that conceptual models should map reality, guide research and systematize knowledge. They propose a set of criteria for judging the comparative merits of conceptual models (n.p):

- Simplicity (simpler is better, other things being equal);
- Accuracy;
- Scope (a broader scope is better, other things being equal);
- Systematic power (the ability to organize concepts, relationships and data in meaningful systematic ways);
- Explanatory power (the ability to explain and predict phenomena);
- Reliability (the ability, within the range of the model, to provide valid representations across the full range of possible situations);
- Validity;
- Fruitfulness (the ability to suggest problems for solving and hypotheses for testing). (Järvelin and Wilson, 2003)

Although models have the advantage of presenting ideas in a succinct and accessible format, it is advisable to treat them with caution since there can be a tendency to overgeneralize and apply them out of context (Case, 2007). The simplicity of models can also lead us to infer a logical progression that can be deceptive: information seekers do not necessarily follow ideal, optimized routes (Godbold, 2006). It is in the rigorous testing of existing models to ascertain how far their validity extends beyond the original, often very limited, context as well as in the creation of new models that the research basis of LIS consolidates and advances. A comprehensive review and comparison of every model that has been produced in the LIS literature would warrant an entire thesis in its own right but some examples of how different models reflect the broadening scope of LIS research (e.g. to recognize the importance of context and of the full spectrum of information-acquisition activities including those that can be classed as ‘passive’) will help to contextualize this study.

An example of an early model, Krikelas’s (1983) information-seeking behaviour model, though easy to understand, has been viewed as over-simplistic and too redolent of a library search model. It has been criticized for omitting any reference to characteristics of the information seeker and for a direct refusal to consider unconscious information needs (Case, 2007; Williamson, 1998). However, despite the model’s deficiencies authors

acknowledge Krikelas's desire to unify the field of user studies, his introduction of a holistic approach allowing for the use of a range of information sources, his belief that the individual user defines 'information', and his role in 'signaling a turning point in the field of user studies, establishing new criteria to guide our research into information seeking, as well as laying the groundwork for the development of models and theories of information behavior in the years to come' (Henefer and Fulton, 2005, p. 225).

Although Kuhlthau's 1991 model was still grounded in the trend of assigning stages to the act of searching for information (i.e. Initiation, Selection, Exploration, Formulation, Collection and Presentation) – making it into a process of construction, Kuhlthau strove to look beyond the purely physical and cognitive aspects of the process and to include affective elements that impact on each stage of the process. She acknowledged that people experience the Information Search Process holistically with an interplay of thoughts, feelings and actions which influence the choices made during the process. (Kuhlthau, 1991; Kuhlthau, 1998; Kuhlthau, 2005). 'The feelings of uncertainty, confusion, optimism, frustration, relief and satisfaction cut across searching context. Each is also a fundamentally unique response by an individual at a point in time, engaging in a particular information-seeking episode.' (Pettigrew et al., 2001, p. 50). For Kuhlthau feelings such as uncertainty and the associated anxiety are to be expected in the early stages of looking for information and are an essential and natural characteristic of the process that should not be stifled.

Another early model by Ellis (Ellis, 1989; Ellis, 1993; Ellis et al., 1993), grounded in studies of the information-seeking patterns of academic researchers (social scientists and, later, physical scientists), identified a series of activities undertaken by information-seekers during the course of the search process (starting, chaining, browsing, differentiating, monitoring, extracting, verifying, ending). Ellis's activities, or 'features' have been incorporated into a revised version of the second of Wilson's models from 1981 since Wilson viewed them as demonstrating an awareness of both the micro-analysis of search behaviour (illustrated by starting, chaining, verifying etc.) and the wider view of information (typified by browsing, monitoring, differentiating) compatible

with Wilson's own revised approach. In an article in the *Journal of Documentation*, (Wilson, 1999) Wilson looks back to his earlier models (two from 1981 and one from 1996). In the first model he attempted to outline what he, at the time, called 'information-seeking behaviour' suggesting that an information user perceives a need and consequently makes demands on formal or informal information sources or services resulting in success or failure to find relevant information. Wilson reflects that this model acknowledges that other people may be involved in the information-seeking process through exchange or by passing on useful information and also that 'information use' was an area requiring further study. The author himself concedes that such a model does little more than provide a map of the area and draw attention to gaps in research with no suggestion of causative factors and consequently provides no hypotheses to be tested. In the second model Wilson proposes that information need is a secondary need that arises out of needs of a more basic kind and that someone looking for information is likely to encounter barriers. These potential barriers are categorized as: personal, impersonal and environmental, and include factors such as the importance of satisfying the need, lack of full information, availability and cost of sources (Wilson, 1981). In 1996 Wilson revised his original model and, whilst adhering to the basic framework of the original, extended it to include theoretical evidence from other fields (e.g. stress/coping theory, risk/reward theory). This model recognizes that there are different types of search behaviour, both active and passive and introduces an evaluative feedback loop allowing for the process to start again if necessary (Case, 2007; Wilson, 1999). Wilson's readiness to test and rework his models and include elements of other author's work provides an example of the organic nature of research.

When Johnson developed his 1997 model it was his intention that it should be tested to ensure that it could apply across a wide range of contexts. After applying it in the everyday context of health-information seeking by the general public and in the very defined context of a technical organization, Johnson and colleagues concluded that a variety of contingent factors need to be more systematically incorporated into the model such as stage of illness (in the health-information context) or existing information base (in the work-based context). Johnson's model is pictured as a causal process which

begins with four ‘antecedent’ factors (demographics, experience, salience and beliefs) which motivate an individual to seek information. Beliefs about the topic constrain the individual’s thinking and levels of motivation. Johnson stresses the significance of context and grapples with the difficulties associated with research into information behaviour – how does the researcher establish whether information was found actively or passively? (Case, 2007; Johnson, 2003).

Foster’s (Foster, 2004; Foster, 2005a; Foster, 2005b) Nonlinear Model of Information Seeking is based within the work environment (interdisciplinary academic researchers and postgraduate students) but it deliberately rejects the tendency to present a linear, progressive, image of information seeking. Foster’s core processes of Opening, Orientation and Consolidation are nested within three levels of contextual interaction (External Context, Internal Context and Cognitive Approach). The author stresses that the core processes should not be considered in a sequential light but rather as options to be dipped into as appropriate with the relationship of core processes and developing context freely interacting to allow a reiterative flow between core processes.

Savolainen’s work with his ELIS model has been described above in Section 3.2.2, along with some approaches taken by other researchers interested in everyday life information seeking. McKenzie’s two-dimensional model of information practices lies with these in the domain of everyday life information behaviour and focusses on the individual-in-context. Like Foster, McKenzie moves away from a purely linear representation of a systematic search process and developed her flexible two stage model (*see* Chapter Two) to ‘preserve the fluidity of the practices [interviewees] described while at the same time systematically describing both the practices and the process’ (McKenzie, 2003, p. 27). In this model, four modes of information behaviour are identified ranging from Active Seeking (which includes the type of directed, intentional, behaviour explored in many of the early information-seeking studies), through Active Scanning (including the concepts of browsing and locating likely information grounds), and through Non-directed Monitoring (which includes serendipitous encounters in unexpected places), and finally to ‘By Proxy’ encounters (where an individual is recognized as an information seeker and



is referred to a source by someone else). McKenzie considers these four activities firstly in terms of how individuals locate and connect with information sources and then in terms of the quality of experience of interacting with the sources. She reflects on the barriers her study participants faced when attempting to connect with or interact with the sources and on the information practices participants employed as counter-strategies to attempt to overcome the barriers. McKenzie acknowledges that her findings are context-bound and that testing of the model in other contexts would be necessary to establish how robust it is and potentially to add to the development of a more general two-dimensional model of everyday life information practices. However, the literature search did not reveal any other study that has attempted to apply the McKenzie model in a different context. McKenzie herself has pursued her interest in information behaviour in the context of pregnancy and childbirth in a study of the use of documentation in a midwifery clinic which aims to provide ‘an understanding of the web of texts and social relations within which individual information seekers in local contexts are located’ (McKenzie, 2006, p. 90). A further naturalistic study amongst the members of a Canadian knitting group offers a collectivist analysis of the ways that members of a setting together construct ‘information itself’, negotiate and express ‘information needs’ and evaluate the authority of information sources (Prigoda and McKenzie, 2007).

### **3.2.3.2 Theories and metatheories**

As explained above (Section 3.2.3) the distinctions between theories and metatheories are often blurred and dependent on the interpretation of different authors. Most authors seem to agree with Bates’s description of models as tentative ideational structures used as testing devices (Bates, 2005b), but the boundaries between theory and metatheory are more fluid and are further complicated by use of the term ‘paradigm’. According to Bates, metatheory has a lot of overlap with paradigm but paradigm has a broader meaning, although metatheory is central to any paradigm. For Case (2007), ‘paradigm’ is an overarching concept that highlights the connections between research and the purposes and beliefs of the investigator and that permits us to articulate the competing approaches to information-seeking research. Bates and Case agree that theories are essentially ‘explanations’, they are generalizations that are more specific than paradigms and that attempt to explain the relationships between different phenomena. Case does not pursue

the concept of metatheories but instead refers the reader to Bates and, amongst others, to Pettigrew et al. (2001). Returning to Bates's definitions, Metatheory can be seen as the philosophical underpinning of theory. Metatheories present a viewpoint on how theories and methodology are inter-twined, they refer to the nature of research and propose research methods appropriate to a particular metatheoretical approach.

Bates gives brief descriptions of some of the most popular metatheories developed or adopted by LIS researchers but cautions that individual researchers should not be assumed to be always and unequivocally associated with a particular metatheoretical approach. She explains that each approach is part philosophy and part methodology although the weighting given to each depends on the tenets of the individual metatheories. Other authors have also provided classifications of metatheories or conceptual frameworks, for example Talja et al. (2005) and also Pettigrew et al. (2001) who divide conceptual approaches into:

**Cognitive approaches:** researchers who follow this approach focus primarily on the attributes of the individual and on the importance of the individual's model of the world. Characteristics of the individual and of the processes in which the individual is involved are seen to account for variations in information behaviour. Pettigrew et al. cite Ellis, Kuhlthau, Wilson and Erdelez as examples of researchers identified with this approach.

**Social approaches:** these approaches encompass the work of authors like Pettigrew herself, Chatman, and Williamson, looking beyond the cognitive frameworks to focus on 'the meanings and values associated with social, sociocultural and sociolinguistic aspects of information behavior' (Pettigrew et al., 2001, p. 54). Within this category lies the naturalistic, constructionist, approach taken by McKenzie when developing her two-dimensional model. From the constructionist viewpoint, knowledge and identities are constructed in discourse that categorize the world and bring phenomena into sight (Talja et al., 2005).

**Multifaceted approaches:** some researchers have noted the limitations of models based on one viewpoint, whether cognitive or social, claiming that only a multifaceted approach can explain and predict such a complex phenomenon as human information behaviour. Dervin's work with the Sense-Making metatheory is given as an example of a multifaceted approach. Dervin rejects the traditional model of information transmission in which people are seen as static entities passing messages from sender to receiver in favour of a methodology that sees communication as a dialogue requiring open-endedness and an appreciation of the differences and contests in human beings' understandings and experiences (Foreman-Wernet, 2003). The Sense-Making project has grown since 1972 with the aim of improving design of practices and systems for communication and deliberately calls itself a 'methodology for the communicative study of communication' to reflect the relationships between the research methods, the working concepts (substantive theory) and the underlying philosophical assumptions (or metatheory) during the research process (Dervin, 2003; Foreman-Wernet, 2003). Dervin describes Sense-Making as 'methodology between the cracks' and sees both reality and individuals (body-mind-heart-spirit beings) as ordered in part, chaotic in part and evolving in part. Rather than focusing on characterizations of situation or context, Sense-Making considers movement through time-space with individuals engaged in a constant journey through sense-makings and sense-unmakings, constantly building interpretive bridges over a 'gappy' reality. For Dervin, Sense-Making inhabits the space between 'so-called realist, foundational conceptualizations of information and so-called constructivist, subjectivist conceptualization. In research questions, Sense-Making attends to this by addressing, for example, the conditions leading to differing interpretations of the same material circumstances; or how people use "information" to make sense differently in the same material conditions' (Dervin, 2003, p. 150). Dervin, like Coupland and Williams cited in Chapter Two for their exploration of the three conflicting discourses of the menopause, is grounded in communications studies. Sense-Making theory lies at the intersection between communications science and LIS and is particularly relevant to a study of information behaviour during the menopause transition since making sense of their experiences is known to be a key factor in women's information behaviour during this life-stage (Coupland and Williams, 2002; Im et al., 2008; Price et al., 2008). Further

research into the overlap between communications studies and LIS research would perhaps shed further light on the extent of the overlap between the two fields but is not within the scope of this current study.

#### *3.2.4 Summary*

Section 3.2 has provided a narrative view of theoretical approaches to information behaviour judged relevant to this current study. It has been used to site McKenzie's Model of Information Practices in Everyday Life Information Seeking within the context of LIS theory. It has traced the emergence of 'information behaviour' studies as part of a process of broadening the interpretations and scope of LIS research through to a recognition that it is insufficient to focus on the formal, task-oriented, world of the workplace and that information behaviour in the informal context of everyday life is equally valid and more inclusive, if less ordered. From this grows an appreciation of the intricacies of everyday information behaviour, of the, sometimes surprising, directions in which information flows between individuals and of the way worldview and the limitations of one's physical and social world can shape attitudes and behaviour with the work of Chatman (1991, 1999) and Pettigrew (1998, 1999). McKenzie's interest also lies in the context in which information behaviour takes place, in how an individual's interpretation of a life event and their interaction with the social networks that surround them can influence their information behaviour.

Unlike Chatman and Pettigrew, however, McKenzie chose to develop a conceptual model to illustrate her findings. The next step in the narrative was therefore to place McKenzie's model within the context of other models of information. Early models illustrated a desire to 'contain' information behaviour, to restrict it to formalized stages with an inference of structured progression through each stage. Despite an increasing awareness that an interplay of affective elements can direct choices, that each choice is a unique response made by an individual in a particular set of circumstances, and that the individual elements of an information behaviour model need not necessarily occur in a rigid sequence but may be dipped into as necessary (Foster, 2004; Kuhlthau, 1991, Pettigrew et al., 2001), many models still constrain information behaviour to a process of locating

information. McKenzie's model moves beyond this to place equal emphasis on the interaction that takes place with an information source (whether an object or an individual) once it has been located. For this reason it could be argued that McKenzie provides a link between the concept of 'the information model' and the non-model-based theories of Chatman and Pettigrew. McKenzie's appreciation of the importance of information grounds – physical locations such as waiting rooms identified by participants as likely places in which to find things out either actively (e.g. by reading information or asking questions) or passively (e.g. by listening to conversations) – and her understanding of the power dynamics inherent in interactions with health professionals moves away from the idealized vision of sterile information encounters. McKenzie's concept of information grounds is broadened into 'settings' and goes beyond purely physical locations to encompass interaction with groups of individuals likely to be able to provide information such as twin-parenting support groups. Here the accumulated knowledge of the group is independent of the actual physical setting in which a meeting takes place. It is for this openness, the appreciation of the fluidity of encounters and for the fact that there is acknowledgement that the encounter does not end the moment a potential source of information is located that McKenzie's model appealed. The model was presented in 2003 after the menopause had been selected as the topic for this current study. However, the fact that the model had been developed from investigations in a related yet different area of women's reproductive health suggested that it would be useful to take up McKenzie's call for it to be tested in other contexts as a step towards the creation of a more generic model.

As discussed above, there is a somewhat confusing array of approaches to LIS research and, within that, a plethora of models that for the most part have done little to add to the generation of real theory. For Bates (2005b) models are a tool in the development of theory, they must be tested for validity and it is this process alone that can turn them into true theory. Understandably it may be gratifying for an individual researcher to see his/her name attached to a new model but as very few existing models are being tested the process of theory generation is likely to remain static as ever-increasing numbers of models stack up. It is also possible that, since Information Science is a relatively new

discipline researchers are seeking to provide it with some gravitas through the constant generation of models that give an illusion of objectivity in a field that is in reality vulnerable to the unpredictability of human behaviour: to the fact, for example, that an individual may make a particular choice on a certain day simply because of how they are feeling. It is therefore important to acknowledge the subjectivity of much research and the impact that the researcher herself can have on the study (it is impossible to be entirely objective in qualitative research of this sort and this must be acknowledged). These models are often based on very small studies that are context-bound. To move forward and consolidate the research base it is necessary to encourage a process of testing of existing models in different contexts so that more useful conclusions may be drawn.

Having explored approaches to LIS research, the next section examines studies relating specifically to the information behaviour of women. This includes consideration of women's interaction with healthcare providers/resources and of how this has been interpreted by feminist researchers. It also considers issues impacting on all consumers of healthcare services: shared decision-making, the provision of consumer health information, and the communication of clinical risk.

### 3.3 Women's information behaviour

#### *3.3.1 Sources*

My initial attempts to locate literature relating to the 'information needs of women' proved surprisingly challenging. Further searching revealed that there is a body of literature but that it is related to specific groups of women – since the U.S. Census Bureau (2007) currently estimates that there are over three billion females in the world (mid-2007), it would not be practical to investigate the information behaviour of such a large and diverse population. Within the field of information behaviour studies as whole, the trend towards focussing less on sources of information and more on the encountering and seeking of information and the interpretation of meaning from that information (Case, 2007) has resulted in studies looking at groups of people (often based on occupations, demographic background or social role). Research into girls'/women's information behaviour has reflected this with studies focussing on: professional and

educational settings (Baker, 2004; Burdick, 1994); on women from different ethnic groups (Davies and Bath, 2002; van Wersch and Uniken Venema, 1994) or in the developing world (Valk et al., 1999); or on other discrete social groups, for example, lesbians (Whitt, 1993) or battered women (Dunne, 2002; Harris, 1988; Harris et al., 2001). Other authors have considered women's relationship with information and communication technology (ICT) and the role of specialized libraries for women (Heimrath and Goulding, 2001; Lorence and Park, 2007; Marcella, 2002; Simon, 2004; Simon, 2005; Simon, 2006; Tyler, 2006).

An advantage for this current study is that several authors have considered women's information needs in a health context, although as Ankem points out, much of it has been 'pursued in medicine, nursing, and allied disciplines such as psychology' and is 'focused on patients with breast or ovarian cancer' (Ankem, 2007, p.164). Huber and Cruz (2000) looked at the information needs and behaviours of both HIV-positive men and women and found that women sometimes had different needs and behaviours from their male counterparts, possibly because the socioeconomic status of HIV positive men and women is unequal, as is disease manifestation and progression. In her work looking at the coping strategies of people with multiple sclerosis (MS), Baker (Baker, 1996; Baker, 1997) chose to focus on women because greater numbers of Canadian women than men suffer from MS – at a ratio of 3:2. Warner and Procaccino (2004) assessed the process of seeking health information and the awareness of specific health and medical information resources of 119 women in New Jersey and Pennsylvania through surveys distributed by mail or in person at public venues such as health centres, shopping centres, libraries and churches. Meadows et al. (2001) interviewed 24 women from rural areas in Canada as part of a project on midlife women's health.

Other health-information researchers have focussed on women by definition because their chosen topic is one that primarily or uniquely affects female patients, for example, McKenzie's work on women pregnant with twins (McKenzie, 2001; McKenzie, 2002; McKenzie, 2003). Avery and Braunack-Mayer (2007) carried out interviews with ten women with Polycystic Ovarian Syndrome (PCOS) to establish whether they had

different information needs at different periods of their lives, how and where they obtain information and the consequences of the information for their future treatment and health outcomes. Other gynaecology-based research includes a retrospective study by Ankem (2007) tracking the information behaviour of women who had been treated by uterine fibroid embolization (UFE), Stewart et al.'s (2000) work with women suffering from ovarian cancer, and a Dutch study (Weijts et al., 1993) which focussed on the process of the patient–health professional interview in a gynaecology clinic. Genuis (2006) looked at a range of publications available to Canadian women and physicians in the years prior to and immediately following the publication of the WHI study results which claimed that long-term preventive use of HRT was unsafe. In the context of these results Genuis used Diffusion of Innovation and the Strength of Weak Ties theories (Granovetter, 1973) to explore the role of published literature in the diffusion of new information.

The field of breast cancer research has provided a rich environment for information-behaviour studies. Breast cancer can affect men as well as women with approximately 250 men diagnosed with the disease each year in the UK (Cancerbackup, 2003). However, since over 99 percent of breast cancer cases are women most research focusses on this group. Rees and Bath (2000) reviewed the literature on the information needs and source preferences of women with breast cancer and their family members between 1988 and 1998 and found a number of methodological limitations associated with such research. These studies tended to use small sample sizes or were based on fairly homogeneous groups. Most of the literature also came from the UK, USA or Canada and the review authors felt that there was a lack of research evidence from other countries where, despite differences in healthcare systems, the range of individuals' information needs may be similar. Subsequent work by Brown et al. (2000) and Raupach and Hiller (2002) has introduced the Australian perspective. Brown et al. looked at women who had undergone surgery for non-invasive breast cancer but, in an echo of the criticism from Rees and Bath (2000), they used a small sample group of only six women.

Brown et al. conducted in-depth interviews with their six participants. A qualitative approach (or at least an approach containing some qualitative elements) has been the



preferred choice for the breast cancer studies, and indeed for most of the work on women's information needs and behaviour discussed here. In a study designed to pilot-test The Information and Support Needs Questionnaire, Chalmers et al. (2001) used postal questionnaires to contact women from the North West of England who had one or more primary relatives (i.e. mother; sister; or mother and sister) with breast cancer. Forty-two questionnaires were sent out with 39 responses. Follow-up telephone interviews were carried out with 37 women. Luker et al. (1995; 1996) carried out an initial study exploring the information needs of women newly diagnosed with breast cancer and continued with a follow-up study in which 105 women from the same consultant's practice were interviewed twice: initially in the hospital prior to treatment and then later in their own homes. Raupach and Hiller (2002) sent postal questionnaires containing both closed and open-ended questions to 266 women diagnosed with breast cancer at a South Australian hospital. Galloway et al. (1997) developed and tested a 73-item questionnaire (the Toronto Informational Needs Questionnaire-Breast Cancer) designed to identify the information that women with a recent diagnosis of breast cancer need to cope with their illness. Each participant was interviewed for 30 minutes with the interview comprising administration of the questionnaire and a final open-ended question asking women to identify areas of need not covered in the questionnaire itself.

Williams-Piehotka et al. (2005) used a brief baseline telephone survey to assess the coping styles of women who contacted the New England regional office of the Cancer Information Service but who were not themselves current cancer patients. Participants then listened to a randomly assigned message promoting mammography which was tailored to either a 'blunter' or 'monitor' coping style. Participants were contacted at a later date to determine whether they had elected to have a mammogram. The authors of this study, based on work by Miller (1987) to assess styles of information seeking under threat, concluded that messages matched to a woman's monitor-blunter coping style encouraged mammography after six months more effectively than mismatched messages and that they were significantly more effective for blunTERS but not so for monitors.

Appendix 3 contains a Characteristics of Studies table giving details and a critical assessment of the main studies cited in Section 3.3.

### *3.3.2 Discussion of women's information behaviour*

In her study of women who had received innovative treatment for symptomatic uterine fibroids Ankem (2007, p.169) developed a preliminary information-behaviour model with five stages:

1. Awareness
2. Conscious exploration of options
3. Self-education
4. Probing, discussion, and decision
5. Procedure

At the awareness stage women expressed a preference for obtaining information from interpersonal sources such as friends or maybe colleagues and, to a lesser extent, from the mass media (e.g. television programmes or magazine articles). In the following stages women explored their options with their gynaecologist and then moved into a phase of self-education in which they relied heavily on active searching of the Internet and on passive information seeking through popular magazines that they came across in everyday life. As the women moved towards a decision about treatment they returned to their gynaecologists and other healthcare professionals and, to a limited extent, their friends for further discussion. Finally, at the procedure stage the women obtained most of their information from radiologists.

Ankem's findings reflect the results of the other studies of women's information behaviour both within the health field and beyond it, particularly the fact that information needs can evolve over time (Baker, 1997; Luker et al., 1996; Rees and Bath, 2000) and the value placed on social networks (Davies and Bath, 2002; Dunne, 2002; Harris, 1988; Harris et al., 2001; McKenzie, 2001; Raupach and Hiller, 2002; Warner and Procaccino, 2004). Women consistently rate friends and family members as key sources of support and information. In Raupach and Hiller's (2002) survey of 266 women diagnosed with breast cancer the most frequently-cited sources of support were family (81%) followed by

friends (71%) and the surgeon (70%). The least frequently mentioned source of support was the Internet at just two percent.

Perhaps surprisingly, given the women's appreciation of interpersonal sources of support and information, 'peer support programme volunteer' and 'breast cancer support group' also ranked very low in Raupach and Hiller's study with just three and five percent of women respectively saying they had accessed these services. The authors found that although use of support groups and peer support programmes was low, satisfaction with the services was high and conclude that 'Many breast cancer support groups include both an informational and supportive component and expansion of these services is likely to be valuable in meeting women's information and support needs following the primary treatment of breast cancer' (p.299). Seven of the ten women with Polycystic Ovarian Syndrome interviewed by Avery and Braunack-Mayer (2007, n.p.) had been involved in a clinical trial which had effectively provided them with a support network in the form of contact with other sufferers and information/exercise sessions designed by a fertility clinic. The interviewees claimed that this had been a positive experience since it gave them 'opportunities to share experiences with other sufferers , and for finding information regarding their condition on both an individual and a more general level'. The authors surmised that this enabled the women to compare themselves with others thus giving them a frame of reference for their own symptoms. Networking with other sufferers allowed the women to validate their own experience. Such findings are in contrast with Luker et al. (1996, p.494) who interviewed women with breast cancer and found anecdotal evidence suggesting that membership of a support group or contact with voluntary support services was felt to be a negative experience. 'Many women commented that they wanted to put the breast cancer experience behind them and get on with their lives, and felt that membership of a support group would involve reliving their own painful experiences and listening to others recalling stories of "doom" and "gloom".'

The PCOS sufferers in Avery and Braunack-Mayer's (2007, n.p.) study found Internet chat groups and email lists useful. They felt that this interaction was similar to that found via support groups but that it had the advantage of anonymity. Participants in this study

found the Internet to be well-suited to fulfil their information needs and gave three reasons for preferring this form of searching:

- Frustration at the paucity of information available about such a complex condition via traditional mechanisms;
- Desire for privacy and access from home since certain aspects of the condition can be considered embarrassing (e.g. hirsutism, obesity);
- Appreciation of the sense of being able to control the amount, level, type and timing of information received.

The authors point out, however, that a degree of skill is required in using the Internet and that the women who were most proficient were also the more highly-educated. In general the participants appeared to be aware of the need to assess critically information found via the Internet. Since many did have a high level of education they were in a position to access information aimed at users with medical knowledge and were keen to share information retrieved from the Internet with their doctors thus increasing their involvement in healthcare decisions. In common with much research into women's information behaviour the Avery and Braunack-Mayer study was conducted on a small scale (10 in-depth interviews). The Characteristics of Studies table in Appendix 3 provides a critical assessment of the main studies cited in this section and identifies potential limitations including sample size.

Women's somewhat ambivalent relationship with new technologies is a thread picked up in other information-behaviour studies, and research on usage of and attitudes towards the Internet provides some examples of comparisons between female and male information behaviour (e.g. Harbour and Chowdhury, 2007; Hupfer and Detlor, 2006; Ilie et al., 2005). Heimrath and Goulding (2001) considered the role of gender in attitudes to Internet use. Their study, carried out in 1999, found that female use of and interest and confidence in the Internet was high but that, in comparison to males, females had not taken to the Internet as rapidly. The authors were surprised to find that the women who responded to their questionnaire appeared more ready to take advantage of a wider range of locations offering Internet access than the men. Another interesting finding was that although males assumed that women would be put off by the perception that the Internet

is male-oriented in terms of design and content, female respondents did not in fact report this view. It should be noted however that this was a small-scale survey and the majority of participants were Information Studies students and thus may not reflect the attitudes of the general population. Hargittai and Shafer (2006) administered a questionnaire to and then observed a randomly selected sample of Internet users as they searched for information. The purpose of the study was to investigate how perceived Internet-use abilities equate to actual abilities and, in particular, how these are related to gender. They found that overall there was little difference in actual abilities between men and women but that women were more likely to undervalue their abilities. The authors suggest that women's perception that they have weaker skills may significantly affect the extent of their online behaviour and the range of uses they find for the Internet. In an employment context, Sun et al. (2007) considered how gender can affect trust building in virtual environments and concluded that gender can influence the expectations and perceptions of communicators and that managers should consider the gender mix when developing teams.

In a retrospective study Lorence and Park (2007) compared two datasets from the Pew Internet and American Life Project which contained an extensive set of questions about the demographic profile of randomly selected adult users of computers, the Internet, and other online services. The datasets were from March 2000 and December 2002. Overall, 1509 participants were categorized as being online health information users (i.e. they had at some point looked for information pertaining to healthcare on the Web). The authors found that although the implementation of National Telecommunications and Information Administration programmes designed to improve Internet access across the USA had led to an increase in the overall usage rates during this period, disparities in the use of the Internet and of online health information remained statistically constant with males dominating overall use of the Internet but more females than males searching for health information. Dholakia (2006) looked at the factors that contribute to gender differences in adoption and use of computers and Internet applications in US homes. This later study found that women had overtaken men as users of computers and the Internet but that use in the home context was restricted for women due to competing demands. Dholakia

suggests that future developments in the use of the computer and the Internet will depend not only on levels of skill and income but on the ways household tasks and time are divided between men and women.

Simon (Simon, 2004; Simon, 2005; Simon, 2006) carried out in-depth one-to-one interviews and focus-group interviews with fifty women ranging in age from early twenties to over seventy. Almost 50% of the interviewees were employed in the information and library sector. Other participants were recruited from the teaching profession and from a group of women known to have little or no experience of ICTs. The author explored women's perceptions of technological change in the context of their 'lived relationship with technologies' (Simon, 2006, n.p.) and found that despite initial scepticism, many of the participants felt positive, or at least comfortable, with new technologies. Interviewees cited experiences of learning something new, making contacts or accessing information for themselves which made them feel more in control and 'may mean that for the first time, for many women, computers seem worth the effort' (n.p.). This enthusiasm was tempered by doubts and concerns about some aspects of computer-use and by fears of being 'left behind' where experience was limited but Simon argues that 'ambivalent or contradictory attitudes are integrated or made sense of by the participants who see ICT as both positive *and* negative' and that women's ambivalent relationship with ICTs can be seen as an active and critical response to technological change.

Marcella (2002) carried out a systematic evaluation of ten Internet sites aimed at women and covering a range of sectors including health, business and technology. She concluded that such sites can offer women an approachable, alternative electronic space in which women can set the agenda and communicate in ways with which they feel most comfortable. She did however note a lack of protection for the female environment with there being nothing to prevent men from accessing and participating in all aspects of the sites and with only limited rules for acceptable use and behaviour. Tyler (2006) also considered the role of an alternative space for women, though this time within the

physical setting of women's libraries but concluded that there may be a movement away from this concept given current pressures on staffing and resources.

Steinerová and Šušol (2007) conducted a large-scale questionnaire survey in Slovakian academic libraries to explore how gender influences information behaviour. Reflecting findings from other studies, they established that women perceived themselves to be less experienced in the use of electronic information resources. Looking beyond electronic resources to the whole information-seeking process, they found that men preferred independent approaches to information seeking with women turning more frequently to librarians and library catalogues. Women were found to be more cautious in their approach to the information seeking process and to experience stronger initial feelings of uneasiness and anxiety. They expressed more doubt and were more likely to cooperate with colleagues. The authors conclude that different voices in communication and gender-sensitive feelings may control the process of information seeking.

To return to Ankem's (2007) five-stage model of information seeking by women with symptomatic uterine fibroids, the high levels of confidence placed in friends and colleagues as providers of support and information and the acquiring of information by informal, often passive, means are themes that recur throughout the literature on women's information behaviour. Ankem's participants relied on different sources of information depending on the stage of their decision process and the type of information they needed. At the awareness and self-education stages the women turned to interpersonal sources and to television, magazines and the Internet but when approaching the decision point participants tended to return to healthcare professionals for discussion and further exploration of their options. Meadows et al. (2001) used Kleinman's model of the popular and professional healthcare sectors to examine the results of their study of 24 rural Canadian women in midlife. Kleinman (1980), a psychiatrist and medical anthropologist, discussed attitudes to illness and healthcare within both Chinese and American cultures and considered the interplay between the popular and professional health sectors. From his work in Taiwan Kleinman identified the popular sector as potentially embracing the individual, family, social network and community. In the USA he defined this sector as

encompassing alternative health professionals including ‘non-licensed practitioners of various forms of meditation and occult religious practices’. Meadows et al. note that in Kleinman’s model ‘laypeople move in and out of the popular sector as the anchor from which they evaluate services from the professional sector and make decisions about further access and evaluate success of interventions from the professional sector’ (p.451). They argue that both the popular and professional sectors have their own fundamental assumptions regarding health and illness and their own language through which knowledge is imparted. For them, messages from different sectors often clash which can complicate decision-making and action, leaving individuals to negotiate between the sectors as they strive to decide what constitutes good health and how to action on information related to it. In contrast to Kleinman’s definitions, the authors found that participants in this more recent study tended to include non-allopathic practitioners in their definition of the professional sector, though with clear distinctions and evaluations between allopathic and non-allopathic professionals.

Meadows et al. found that the transfer of knowledge between the two sectors was not always successful and that when women tried to transfer their knowledge from the popular sector into the professional encounter they were often ‘silenced’ by dismissive statements. The authors argue that women are losing trust and confidence in the allopathic medical profession that does not respect their flexible approach to finding effective care by looking beyond traditional healthcare sources. This research focussed on preventive care only but other studies echo concerns that interaction with professionals can confound women in their search for information.

Baker (1997), in her study of women with MS, proposes that ‘communication problems between a doctor and a chronically ill person may stem from the physician’s continuous adherence to the traditional biomedical model of disease’ – i.e., from a failure to consider the social and psychological implications of health and ill-health (p.252). Baker suggests that physicians may become frustrated when they have to deal with non-medical questions. Many feminist writers have questioned the adequacy of the traditional medical model to satisfy the holistic health needs of women (for example, Doyal, 1995; Foster,



1995; Greer, 1991; Martin, 1987) but women's information-behaviour researchers also stress the value women place on a two-way dialogue with a professional who is seen to have a sympathetic demeanour even if the desired outcomes are not necessarily achieved (Davies and Bath, 2002; Harris et al., 2001).

McKenzie (2001, p.194; McKenzie, 2002) identifies four ways in which the communication process between pregnant women and their sources of information tended to break down: failure to ask questions; disclosure barriers (source unable/unwilling to disclose an answer); lack of realization or comprehension; and connection failures during the communication process. These headings can be applied to group loosely other barriers encountered by female information-seekers in different contexts.

#### *Failure to ask questions*

Luker et al. (1996, p.487) note that in a life-threatening situation, such as following a diagnosis of breast cancer, levels of attention and recall can be low. They explain that 'with shorter hospital stays there is a limit to the information which can be imparted and assimilated, women may return home with many unanswered questions, or questions may arise as the breast cancer experience unfolds'. Weijts et al. (1993, p.423) considered the patient-health professional interview and suggest that on the whole 'most information-seeking actions elicit adequate responses. Only indirect requests for information run a high risk of resulting in minimal answers'.

#### *Disclosure barriers*

Baker (1996, p.77) found that some of the questions asked by her participants could not be answered by health professionals: 'their questions may reflect the fact that what they want to know is just not available, because science has not found the answers'.

#### *Lack of realization or comprehension*

Several studies identify time constraints as barriers to successful information seeking, especially in a health context (Avery and Braunack-Mayer, 2007; Meadows et al., 2001; Raupach and Hiller, 2002; Warner and Procaccino, 2004). Medical consultations are

considered too short to ensure that patients understand the information they have been given. Women are aware that medical practitioners are busy and frequently overworked and talk of not having enough time to ask questions and of not wanting to bother their doctors with anything but external health problems. Raupach and Hiller found that the demands of women's own hectic lifestyles also contributed to problems in locating information and/or support.

### *Connection failures*

Dunne (2002, p.350) discusses a perceived unwillingness of US physicians to become involved with the female victims of domestic violence and an 'ethos of remaining detached from their own feelings and those of their patients'. She claims that 'a code of silence' exists in battered women's exchanges with their physicians. Harris et al. (2001, p.126), who also studied abused women, found that those seeking help often struggled to connect with official agencies. They cite five factors that discourage successful help-seeking:

- Help seekers cannot find the service they need because it does not exist where they live;
- Help seekers do not know which agency to contact;
- Help seekers do not reach an appropriate service agency because of language difficulties or other forms of social isolation resulting from cultural differences, literacy problems, and physical or developmental disabilities;
- Help seekers who succeed in reaching appropriate service agencies encounter obstacles that are deliberately or inadvertently constructed by the agencies;
- Help seekers fail to receive assistance because the services they contact are not adequately funded or staffed.

McKenzie's participants developed counterstrategies such as list making, actively asking questions, persistence and observing and listening to try and work around such barriers. Successful communication during the medical consultation is a key element of shared decision-making which is itself part of a move towards empowering patients towards a

greater involvement in, and responsibility for, their own healthcare. This process is discussed in Section 3.4.

### 3.4 The empowered patient

In a study of 19 younger (i.e. aged 50 and under) women with breast cancer Allen et al. used Grounded Theory to identify four emergent core themes regarding the nature of problems in doctor–patient communication:

1. Women’s realization of medical uncertainty;
2. Their rejection of physician paternalism;
3. Women’s desire for information; and
4. Their preference for a greater role in decision-making. (Allen et al., 2001, p.40)

These women, interviewed in a series of focus groups, were based in the US and were therefore interacting with a different healthcare system (e.g. they faced issues relating to the lack of medical insurance cover for mammograms in younger women) but their concerns echo those of female patients in the UK and illustrate the movement towards renegotiation of the traditional doctor–patient relationship that has taken place within Western medicine over recent years.

This section of the literature review will explore this shift and with it the concept of ‘the empowered patient’, drawing sources from a wide range of fields including: feminism, sociology, philosophy, healthcare policy, medical practice, and information studies. Clearly, both men and women can find themselves at times in the position of ‘patient’, a role which ‘imposes certain patterned conditions and requirements on all persons who are defined as sick’ (Fox, 1959, p.248), but much of the discussion will concentrate on women since they are the focus of this thesis and are considered by many (particularly feminist) writers to have been disproportionately disadvantaged by the traditional model of Western medicine. For this reason the section will begin with an exploration of the feminist view of women’s relationship with their health and with the healthcare system which maps to Allen et al.’s theme of women’s ‘rejection of physician paternalism’. It will then look at the role of the empowered patient, with particular reference to desire for ‘a greater role in shared decision-making’ and consumer health information (women’s

‘desire for more information’). Finally, it will explore the concept of ‘medical uncertainty’ through a discussion of the presentation of risk.

### *3.4.1 ‘Women’s problems’ – the feminist perspective*

In her book *Fracture* (Oakley, 2007) charting her journey through ill health following a fall, Ann Oakley reflects on her own experiences as a patient and beyond this to wider questions around having a human body, what happens when this body ‘lets us down’, and how cultural views about women’s bodies, and about ageing bodies, affect the subjective experience of fracturous events. From the starting point of a moment’s slip on an icy path, Oakley’s personal story extends out to encompass many of the issues key to feminist arguments about women and health. Central to the feminist approach is a rejection of the so-called ‘medical model’ employed in modern Western clinical practice which reduces illness to biological or psychopathological entities resulting from dysfunction and producing signs (that can be measured by clinical and laboratory procedures) and symptoms. Feminists contend that the medical model serves to objectify the human body, and hence to disenfranchise the patient, denying them the opportunity to tell their story and to participate in decisions about their healthcare.

Feminist writers further contend that the medical model has historically served to reinforce the subjugated position of women in relation to the male-dominated medical profession. Women are seen as being reduced to nothing more than their bodies by a paternalistic system. Women have been systematically portrayed as left at the mercy of bodies that ‘govern themselves in irrational and uncontrollable ways’ and that lead them to ‘states of nervous frenzy, hysteria or lassitude’ whereas men have been able to transcend this state through rationalized thought (Oakley, 2007, pp. 96-7, 152). The association of women with corporeal matters and of men with intellectual matters puts women at a disadvantage in a world where the brain is prized above all else and the ‘mind’ is installed as ‘emperor over all that lies below the neck’ (Mackie, 1997, p. 17).

Doyal (1995) argues that although the tendency of modern medicine to reduce the complexity of sickness and health to matters of specific biological causation has the

potential to affect both sexes, it is women who have been especially damaged by the narrowness of the approach since it has allowed problems to be blamed on hormonal disturbance, leading not only to inappropriate treatment but to a 'mistaken naturalisation of gender divisions that are essentially social in their origin' (p. 16). She explains that at the heart of all feminist critiques of medicine is the recognition that women lack power in healthcare institutions. This not only limits their ability to determine medical priorities etc. but affects their individual experiences as users of health services, constraining their capacity to play an active part in their own treatment and leaving them feeling uncared for. The number of female doctors has increased greatly in latter years with women comprising over half of UK medical school graduates in 2006 (British Medical Association, 2006) but debate about the impact this will have on the medical profession continues (e.g. BBC Radio 4, 2004; British Medical Association, 2004). With its focus on scientific proof and a tangible evidence base, feminists see the medical model as stifling women's attempts to speak for themselves and devaluing traditions of passing advice from one woman to another (Graham and Oakley, 1981; Roberts, 1981).

Overall, women are known to make more frequent use of primary care services than men (Morris et al., 2004; National Assembly for Wales, 2004). According to Gardner (1981), this may be partly due to a difference in approach to healthcare with women more willing to visit a GP than men but the main reasons are: women's responsibility for contraception, their encounters with the medical profession during pregnancy and childbirth, their responsibility for sick children, that fact the women's anatomy is viewed as more complex than men's and hence more likely to suffer complications, and doctors' willingness to capitalize on the traditional view that women are frail. Reproduction-related issues and childrearing do indeed seem to explain the statistics and it is only above the age of 65 that the numbers of men and women attending primary care practices evens out (Morris et al., 2004; National Assembly for Wales, 2004).

Women, therefore, are seen as being at the mercy of the medical profession where cultural assumptions influence even allegedly value-neutral research (Haraway, 1991). They are to be 'routinely monitored, screened and tortured, to no purpose except the

enactment of control' (Greer, 2000, p. 17). Not only do feminists argue that the medical model perpetuates patriarchal definitions of women with an assumption that they and their bodies (i.e. their ovaries) would be completely unruly without medical gaze and masculine intervention (Leng, 1997), they are also seen as being vulnerable to the demands of the cults of 'youthism' and beauty (Greer, 2000; Mackie, 1997; Oakley, 2007; The Boston Women's Health Book Collective, 2005). Feminists contend that the pressure to remain young-looking and conventionally attractive makes women susceptible to claims made by pharmaceutical companies and healthcare providers about drugs and procedures and to a general over-medicalization of women's lives (Foster, 1995; Hunt, 1994). Martin (1997) suggests that throughout much of the twentieth century women's bodies were conceptualized as machines designed to produce products where menstruation can be seen as a breakdown (i.e. a failure to produce a baby) and menopause as the final breakdown, inaugurating an inexorable slide into disrepair. In this context it is hardly surprising that feminist writers claim that the menopause is vilified by Western society as representing only loss: loss of womanliness, of childbearing, and potentially of sexuality and that older women are perceived as having no useful role in society, becoming 'crones' and the very opposite of 'all that is deemed worthy and good' (Mackie, 1997, p. 21).

The more polemic feminist writers use emotive phrases to evoke an image of women's bodies as 'battlefields' where they must fight for liberation from attempts to oppress them (Greer, 2000). Leng (1997) explains that many feminists view the biomedical approach to the menopause as 'an assault to the autonomy and integrity of women's normal bodily existence' perpetrated by a 'patriarchal conspiracy'. Whilst talk of a 'conspiracy' may seem excessive there is general agreement amongst those writing from a feminist perspective (including from an established academic perspective) that women have long been disadvantaged by a medical system designed by men and dominated by male values that ignore women's understanding of how bodily experiences affect identity and result in women feeling like items on an assembly line excluded from decision-making processes (Doyal, 1995; Graham and Oakley, 1981; Martin, 1987; Oakley, 2007).

### 3.4.2 *Shared decision-making*

Medical sociologists and anthropologists, including those taking a feminist approach, have explored the nature of health and illness and have contemplated the individual's role and responsibilities as a patient. Oakley (2007) explores her own perceptions of her body in its unfamiliar state after her accident and considers her interaction with the healthcare system: 'This isn't my first time in hospital, and I do what I've learnt to do before, which is to concentrate on negotiating my route as a compliant patient through the hospital system.' (p. 8).

Strauss et al. (1985) talk in terms of 'illness trajectories', referring 'not only to the physiological unfolding of a patient's disease but to the total *organization of work* done over that course, plus the *impact* on those involved with that work and its organization.' [italics in original] (p.8). Although much of this work is carried out by healthcare professionals, the authors devote a chapter to 'the work of patients' in which they discuss the different types of work patients carry out, including not only the physical work involved in tending to themselves or to technology but also obeying commands, maintaining composure, monitoring for potential error, or coping with identity problems precipitated by illness. Predicting the role of the 'expert patient' Strauss et al. note that 'there is a paradox that involves chronically ill persons whose heads, and often hands, are well endowed with experiential knowledge and skill' becoming wards of health professionals who may discount the patients' knowledge, regarding them as 'medically innocent' (pp. 193-4). They warn of future conflict between patient and staff if this patients' knowledge base is not acknowledged and of increased challenges to staff as patients expect a greater share in the management of their own illnesses.

The last two decades have seen a shift towards the recognition of patients' entitlement to participate in decisions about their health as predicted by Strauss et al. with the development of the role of 'expert patient' (Department of Health, 2001) and the drive towards shared decision-making in health and social care. Shared decision-making is defined by Towle and Godolphin (1999) 'as decisions that are shared by doctor and patient and informed by best evidence, not only about risks and benefits but also patient

specific characteristics and values' and that occur 'in a partnership that rests on explicitly acknowledged rights and duties and an expectation of benefit to both' (p. 766). Despite these government-driven initiatives (Department of Health, 1999; Department of Health, 2006; Department of Health, 2007), the process has not been entirely smooth. In 1994, Helman identified the disparity that can exist between the way in which doctors and their patients view ill-health. Their perceptions can be 'based on very different premises, employ a different system of proof, and assess the efficacy of treatment in a different way' (p. 101). He proposes that in order for a medical consultation to be a success, there must be a consensus between doctor and patient about the cause, diagnostic label, physiological processes involved, prognosis and optimal treatment for the condition. The success of a consultation can be further jeopardised by the internal and external contexts of the consultation itself. The internal context comprises the prior experience, expectations and cultural assumptions that each party brings to the encounter whereas the external context includes the setting and the social influences acting on each party (e.g. dominant ideology, class/gender/ethnic divisions etc.). Helman states that all of these factors help to define who has the power in the consultation and can greatly influence the types of communication possible between doctor and patient (Helman, 1994). As seen in the previous section, feminist sociologists have long stressed the social inequality in the healthcare system that is seen to limit the influence of women within institutions and to impact on their experiences as individual health service users (Doyal, 1995).

To return to Allen et al.'s four core themes, the women in this study expressed their preference for a greater role in decision-making. In choosing to focus on younger women with breast cancer (i.e. those aged 50 and under), the authors acknowledged that they had selected a study cohort from a generation of US women accustomed to medical consumerism and to the idea of being able to choose physicians that met their needs for compatibility as well as having good credentials and reputations.

Despite an acknowledged ideal of the empowered patient with increased responsibility for his/her own healthcare and with greater facility to participate in decisions about that healthcare, several researchers have chosen to investigate the extent to which theory has



been carried effectively into practice. Researchers' lines of investigation can be broadly grouped under the following three questions:

- Do patients really want to be involved in decision-making anyway?
- What can inhibit effective shared decision-making?
- How can shared decision-making be encouraged?

#### **3.4.2.1 Do patients really want to be involved in decision-making anyway?**

Coulter and Ellins (2006) in a report forming part of the Quality Enhancing Interventions component of the Quest for Quality and Improved Performance initiative from The Health Foundation (The Health Foundation, 2003) conducted a literature review of patient-focussed interventions including those aimed at improving clinical decision-making. They found that most patients expect to be given information about their condition and the treatment options and they want clinicians to take account of their preferences. Some patients are willing to take this a step further and become involved in the decision-making process themselves. The authors found that this willingness tended to vary by age, educational status and disease severity but that this could not be taken as an absolute rule and therefore concluded that clinicians should ask patients what level of participation they would prefer to have.

McKinstry (2000) carried out primary research to determine patients' preferences for a shared or directed style of decision-making across five GP practices in Scotland. The 410 participants were shown video presentations of actors portraying consultations on a range of problems (lifestyle advice, mental health, serious acute, minor acute and chronic). The vignettes were presented in two styles using the same actors: one that involved the patient in a shared approach and one that contained a more directed approach from the GP. Patients were shown both styles of consultation for one topic and were then asked which scenario they liked best, which was most like their own doctor's style and what they thought was the biggest difference between the two presentations. McKinstry found that preferences for shared or directed versions of the consultations were significantly associated with the patients' age, social class, smoking status (particularly with reference to the smoking scenario), the scenario, and their perceptions of their own doctor's

consultation style. Overall, a large number of patients preferred directed consultations although the author points out that it can be difficult for participants to imagine a situation with which they are not familiar: the chronic illness scenario (rheumatoid arthritis) was intended to show an ‘expert patient’ but most participants viewed it as a complex medical situation and assumed that a patient with this condition would be as ignorant as they were.

With particular reference to decision-making about the menopause, Daly (1997) found that clinicians in an Australian menopause clinic preferred to explain the risks and benefits of HRT to women and then offer them a ‘choice’. Some women found this unhelpful and felt they had come to the clinic for specialist advice on issues that lay outside their knowledge. They felt that the offer of a ‘choice’ was merely placing the responsibility for the decision on their own technically inexperienced shoulders. HRT take-up and adherence rates are acknowledged to be generally low but doctors’ opinions and attitudes have been found to influence women’s decisions about whether or not to try the therapy (Hunter et al., 1997; Rees and Purdie, 2002).

#### **3.4.2.2 What can inhibit effective shared decision-making?**

With the current shift away from the traditional doctor-centred model of healthcare provision towards a more shared or partnership-based model ‘in which the doctors and the patients share all the steps of the decision-making process’ and which has legitimized the expression of patients’ views, preferences and values (Daghio et al., 2003, n.p.), the very nature of the doctor-patient relationship has been put under scrutiny. Earlier authors such as Strauss et al. and Helman identified the importance of culture and social/personal ideologies in the consultation process and acknowledged that these can influence the success or otherwise of communication between patient and health professional. The field of medicine is fraught with dichotomies and doctors can be regarded with ‘ambivalence and suspicion’ by patients (Komesaroff, 1997, p.54): patients may have high expectations yet both they and their doctors must accept the limitations and uncertainty of medical interventions; doctors are entrusted with confidences and personal information, yet the relationship remains formal and impersonal; doctors can be appealed to as allies against the problems of everyday life and yet they are themselves representatives of privilege and

power (Allen et al., 2001, p.43; Daghighi et al., 2003, n.p.; Komesaroff, 1997, p.54). Understanding that every encounter is a learning experience for both patient and doctor (Herxheimer, 2001) and establishing the physical and cognitive conditions conducive to good communication are essential to the success of the consultation.

In a study exploring women's perceptions of and satisfaction with aspects of decision-making related to hysterectomy, Skea et al. (2004) found examples of how sensitive confidence in the decision-making process can be to perceived inadequacies in communication and/or to the internal and external context of the consultation. The authors received 104 responses to a structured questionnaire which focussed on information provision, communication and decision-making during recent visits to hospital clinics. They then interviewed a purposive subsample of 20 women (selected from questionnaire responses to ensure variation in terms of health problems, treatments etc.) about their experiences of decision-making. Although questionnaire responses relating to information provision and helpfulness of doctors were generally more positive, some interviewees felt that they had not been given a balanced view of the advantages/disadvantages of hysterectomy as opposed to other possible treatments with less information being made available to them about other options or with those options being presented as inferior or temporary. Women also felt disadvantaged in not knowing enough in advance to be able to identify the kind of questions they wanted to ask during the consultation, feeling put 'on the spot', and 10% of questionnaire respondents said there had been questions they did not ask during outpatient consultations. In terms of doctor-patient communication, several women felt that effective decision-making was compromised by the abrupt or uncaring attitude of doctors or by feeling pressured to make up their minds quickly. They also mentioned feeling inhibited by conditions in the consultation room, e.g. feeling disempowered when presented with a major decision whilst lying on the examination couch or the presence of medical students. Doctors who did take the opportunity to explain things clearly and gave the women time to reflect on their decision were valued and appreciated.

Entwistle and Watt (2002) video-recorded consultations and interviewed the health professionals and patients involved within the context of five areas of clinical practice, chosen for their variation in terms of traditional practice cultures. In a case study element of the research focussing on 13 'core cases', participants identified a variety of contextual factors relating to the organization/delivery of services and to the specific characteristics of individual patients and health professionals that might affect the ease and sense in which patients can be involved in their health care. They found that giving information to patients in advance (e.g. preparing them for a likely diagnosis or telling them about decision points likely to arise in the future) could enable patients to engage more effectively in decision-making but that this was greatly dependent on the context and individuals involved. The authors also identified a potential source of mismatch between health professionals' and patients' understanding of a problem through non-disclosure of information by either party and identified examples of patients exhibiting behaviour the authors termed 'playing for what they want' i.e., strategically managing the information they give in order to achieve a particular end and therefore working 'around' rather than 'with' the health professional. From their post-consultation interviews with health professionals, the authors established that doctors see varying scope for patient participation in decisions. The participants felt they may be less likely to facilitate patients' taking a shared role in the decision process if they: perceive there to be only one good or feasible option; think the decisions are about 'technical details' and are dominated by practical considerations; or if they are unwilling to compromise to accommodate the patient's views.

The four causes of communication breakdown identified by McKenzie in her work on pregnant women have been considered in Section 3.3.2, i.e. failure to ask questions; disclosure barriers (source unable/unwilling to disclose an answer), lack of realization or comprehension and connection failures during the communication process. McKenzie (2002) moves on to discuss counter-strategies employed by the pregnant women to limit communication breakdowns and ensure that they gained as much as possible from the information encounter. She links these strategies to two established modes of information practices: active seeking and active scanning. Regarding active seeking, the women

explained how they planned their question-asking strategies by making lists, actively asking questions, being persistent and by using techniques to ‘keep the process on track’ (i.e. using active information seeking to ensure that an expected next step occurred even if the health professional did not initiate it). Examples of active scanning included opportune questioning, observation/listening, and monitoring the situation to clarify procedures and find out what was happening. McKenzie’s participants revealed themselves to be ‘watchful, attentive information seekers, seizing opportunities to clarify situations or elicit disclosure’ (p. 43) and showed that to participate fully in the decision-making process patients must be vigilant and willing to take the initiative even if the internal and external contexts of the encounter appear to disadvantage them.

#### **3.4.2.3 How can shared decision-making be encouraged?**

Salkovskis et al. (2004) consider the question of shared decision-making in the context of the menopause and found it of particular relevance, by giving the patient the opportunity to engage in taking some responsibility for their own treatment. The authors claim that it also permits the identification of and discussion about distortions in the perceived balance of evidence for and against any specific treatment (in a clinical field which sees frequent debate about these issues in the professional and popular press), that it may improve levels of adherence to prescribed treatments such as HRT, and that fears that it would result in doctors’ expertise being compromised by the demands of ill-informed patients are unfounded. This article appears in the *Journal of the British Menopause Society*, an organisation that is regularly seen to defend the use of HRT and is very active in the debate about the risks and benefits of the treatment hence, it could be argued, the use of emotive words such as ‘distortion’ in the paper. However, the authors do stress the importance ‘in the present climate of opinion’ of giving patients access to information about changes in lifestyle and complementary treatments and suggest that the very fact of openly discussing these ideas with patients will increase confidence in the consultation process.

The women who had undergone hysterectomy interviewed by Skea et al. (2004) made their own suggestions for ways in which information provision and communication could be improved, including the provision of basic information prior to attendance at a clinic

with explanations about possible investigations and the kinds of treatments that might be suggested or checklists for doctors outlining the relevant information topics. They also requested the opportunity to talk to other women who have undergone hysterectomy reflecting the wishes of women facing other health problems such as those with Polycystic Ovary Syndrome in Avery and Braunack-Mayer's (2007) study.

In their review of patient-focussed interventions, Coulter and Ellins (2006) found that true shared decision-making is not widely practised, that doctors often fail to explore patients' views and values and that risk communication is often poorly expressed by doctors and not well understood by patients. They recommend that communication skills should be emphasized during doctors' training, that communication skills coaching for patients might have a beneficial effect on knowledge and information recall, and that well-planned strategies should be developed to support fully informed and shared decision-making and risk communication. The importance of successful communication during the consultation is not a new phenomenon. Early consultation models such those developed by Balint (in 1957) Byrne and Long (in 1976) and Stott and Davis (in 1979) stressed the need for empathy with patients and consideration of patients' ideas about the consultation process resulting in a more 'patient-centred' approach to medicine (Ridsdale, 1995). More recently authors have questioned the quantity and quality of communication-skills training provided in medical schools. As Arnold (2003) points out, telling someone to try to be empathic does not necessarily make it happen. Arnold bemoans the fact that although most medical schools in the USA – 65% according to Travaline et al. (2005) – offer a communication skills course in the first two years such courses are usually short and are frequently not taken seriously by students. As the student progresses through medical training the opportunities for communication-skills training decrease just as the need for communication with real patients increases. Towle and Godolphin (1999) suggest that successful involvement of patients in decisions requires communication skills at a higher level than those typically taught in medical schools (in the late 1990s) which focussed on obtaining information from patients, breaking bad news and health promotion. They propose a framework of competencies for the practice of shared decision-making by both physicians and patients but point out that if finding

opportunities to educate professionals in the required skills is difficult, then finding ways to refine and teach patient competences is an even greater challenge. As part of their continuing professional development programme, the NHS includes Communication in Healthcare in a suite of interactive online learning materials freely available to NHS staff and the public (The London Deanery, 2003). The course is divided into four modules (understanding differences, developing trust, sharing information with patients, and reaching shared decisions) and includes guidance on the importance of careful attention to non-verbal forms of communication such as body language and eye contact. Authors stress the importance of careful listening and of attention to body language, tone of voice, use of silence etc. in the consultation, both in terms of how the physician presents to the patient and of sensitivity to the patients' emotions and reactions (Arnold, 2003; Thistlethwaite and Morris, 2006; Travaline et al., 2005).

Thistlethwaite and Morris's book *The Patient–Doctor Consultation in Primary Care* (2006) provides a more contemporary look at communications skills and relates specifically to general practitioners (GPs) practising in the UK. The book covers shared decision-making, the communication of risk and the sharing of information between doctor and patient but goes beyond this to consider the role of the patient in the 21<sup>st</sup> century. The 21<sup>st</sup>-century patient is seen as resourceful and autonomous and the core of the GP's personal and professional task is 'learning to link their medical contribution to a patient's healing with the personal work of patients, their families, friends and communities, and the professional work of nurses, therapists and other colleagues' (p. 127). The authors also consider the active contribution made by patients, carers and the community in the process of educating doctors. Examples of successful 'learning with patients' initiatives from English-speaking countries include:

- Patients contributing experiential knowledge in teaching students how to perform more accurate and gentle physical examination and help them understand the impact of illness and disability;
- Local people serving as simulated or standardized patients to help students learn communication and other clinical skills within a philosophy of collaboration;

- Patients participate as equal partners in research projects, not just as subjects, but also in determining the research questions;
- Patients sit on advisory groups or core committees, helping define the curricula of professional schools and training;
- Patients work in partnership with providers of community services, to make them more accessible and appropriate;
- Patients help improve health outcomes by developing self-help groups and sharing expertise.

Following their observations of video-recorded consultations and the subsequent interviewing of the patients and health professionals involved, Entwistle and Watt (2002) (*see* Section 3.4.2.2) developed three sets of implications: for policy-makers, for health professionals, and for patients. For **policy-makers** they advise caution in making assumptions about what constitutes ‘good’ patient participation in decision-making since the experience of individual patients will be affected by a variety of contextual factors. They point out that health professionals see different scope for patient involvement depending on the characteristics of the decision to be taken and that they are unlikely to spontaneously engage patients in some types of decision. Like Coulter and Ellins they advocate training for both health professionals and patients, and they stress that any initiatives should be flexible enough to respond to the ranges of decisions to be made and to contextual factors since the issue is complex and patient participation in decision-making cannot *per se* be equated with good decision-making. For **health professionals**, they advocate an awareness of the characteristics of different approaches to decision-making and a willingness to develop their own ability to employ more bilateral approaches. They recommend providing patients with information in advance of situations (as requested by the women in Skea et al.’s study) and suggest that in taking care to explain their reasons for recommending/rejecting certain healthcare options health professionals should be sensitive to that fact that both the content and the form of their reasoning within the explanations can affect the extent to which they facilitate patient participation. Finally, for **patients** they stress the need to raise public awareness of the feasibility and benefits of shared decision-making, to encourage patients to develop the



skills needed to participate fully in the process, to ensure that patients who do opt to play a greater role in the process receive support from their health professionals, and to prevent patients feeling pressured about their healthcare in ways that make them uncomfortable.

In summary, Salkovskis et al. (2004) conclude their thoughts about shared-decision making in the context of the menopause by suggesting that health professionals must develop ways of helping patients make difficult decisions about their healthcare options according to the values and beliefs they hold whilst monitoring and improving adherence to whatever treatment is chosen and ensuring that patients are not pressured to be responsible for decisions that they neither understand nor wish to participate in.

### *3.4.3 Provision of consumer health information*

‘Everyone should have the opportunity to access generic health information through ways that are personally acceptable. The way information is written, presented and made available should take into account diversity in ethnicity, culture, religion, language, gender, age, disability, socio-economic status and literacy levels.’

(Department of Health, 2004a)

The White Paper *Better information, better choices, better health* from which this quote is taken (p. 9) is subtitled: ‘Putting information at the centre of health’. Informed choice is a cornerstone of successful shared decision-making which is itself at the heart of public health policy (Department of Health, 2004b). It is essential therefore that members of the public, or ‘consumers’, should have access to information that is both reliable and easy to understand.

Providing information that meets the needs of such a diverse population is a huge challenge and researchers have tackled the problem from a variety of angles including: information-needs studies for different groups of health-information consumers, health literacy studies (or how to make information easily-digestible), accessibility issues (including hard-to-reach groups), and quality-control. Information needs studies will not be included here since they have been discussed in earlier sections, but this section will

focus on later stages in the process: once information-providers have decided what information they need to present to their target audience, how do they ensure that the audience is able to access it effectively? Furthermore, how can the users be certain that what they are accessing is trustworthy?

#### **3.4.3.1 Access**

Studies have shown that health-information consumers access a whole range of sources beyond a traditional reliance on health professionals including: the Internet, leaflets, books, newspapers/magazines, television/radio, family and friends, public libraries and NHS Direct (Childs, 2004; Coulter et al., 2006). In theory, the development of new technologies and new approaches to providing health information, for example via the Internet or through call centres, touchscreen kiosks, walk-in centres, or by using digital interactive television (Grier, 2000; Jenkins and Gann, 2002), should support health information providers in reaching a wider and more disparate audience. Indeed, some studies (Coulter et al., 2006; Jackson and Peters, 2003) have looked at new delivery methods and have suggested that audio-visual and interactive media (e.g. touchscreens) can deliver health information effectively to low health-literacy groups including ethnic minority groups. Graham et al. (2000), however, compared the effectiveness of a touchscreen system with a traditional information leaflet for providing women with information on prenatal tests. They concluded that the touchscreen conferred no additional benefit (except perhaps by reducing levels of anxiety) albeit whilst acknowledging that their choice of user group – well-educated women whose baseline levels of knowledge and ‘compliance’ with prenatal testing were already high – might have influenced this result.

Getting information physically in front of the consumer is only part of the challenge however; the next step is to ensure that users are able to assimilate and understand the message. In a US-based review of the literature on health literacy, McCray (2005) established that ‘the literacy levels of patients in the health care setting is inadequate. The measured literacy level of an individual is often several years below what would be predicted by the number of years of schooling completed.’ (p. 154). What is more, McCray explains that the traditional definition of literacy has been expanded in recent

years to include ‘the skills that are necessary to function in modern society’ (p. 157). We now have the concept of ‘information literacy’ which goes beyond the skill of being able to read the written word to encompass, according to the Chartered Institute of Library and Information Professionals (2007), ‘knowing when and why you need information, where to find it, and how to evaluate, use and communicate it in an ethical manner’ (n.p.). This expanded definition reveals our vulnerability and the importance of context. As McCray points out, irrespective of one’s literacy level, a stressful setting such as a hospital emergency room can have a negative impact on comprehension of complex health information.

Information providers strive to find ways of making their material available in a format that will assist ease of comprehension. McCray lists a variety of techniques that have been suggested for improving the accessibility of materials including: readability guidelines, guidelines relating to the content of materials and to presentation and page-layout whilst warning that over-simplification of text in the pursuit of readability can lead to even greater problems. Although the importance of clear presentation and readability in facilitating comprehension has long been recognized by researchers (Durbin et al., 2003; Hartigan, 2004; Newton et al., 1998) quality-assurance has emerged as a key theme in the literature, especially given the substantial rise in Internet access and the popularity of Web-based materials experienced in recent years.

#### **3.4.3.2 Quality issues**

As consumers are encouraged to bear more responsibility for decisions about their health and lifestyle, so their need for health-related information grows. At the same time, opportunities to access such information are continually expanding, especially through the Internet. In 2007 almost 61% of households in Great Britain had Internet access (Office for National Statistics, 2007) and a 2005 US study showed that 80% of American Internet users had looked for health information (Pew Internet and American Life Project, 2005). Researchers do acknowledge that there are advantages to Web-based information resources which are there all the time and can be accessed at the user’s leisure. The information is flexible and can be adapted to the individual’s patterns of thinking and

personal knowledge. Furthermore users can tailor their search to their own needs and can increase the tailoring and support through discussion groups and message boards and through direct communication with professionals and peers (Ginman, 2000; Wilson, 2005). However, concerns are expressed (e.g. by Childs, 2004; Ellins and Coulter, 2005; McCray, 2005; Woloshin et al., 2003) that many consumers of online health information do not have the skills to access online information or to judge the relevance and the quality of Internet resources in the same way that they would be able to judge information provided through traditional media (i.e. by assessing the nature of the outlet, the look and feel of the publication and by knowing who to contact for further information) (Wilson, 2002).

In a series of focus groups held for consumers of health information, Childs (2004) found that users tended to struggle with judging the quality of Websites and attempting to validate the medical information presented on them. Concerns identified during the sessions included:

- Do sites contain unbiased information – who is writing or sponsoring them?
- Users can sometimes be unaware that they are accessing non-British sites.
- Interactive features such as email lists and chat rooms can be misused.
- It can be difficult to put the information into context - information can disempower people if not clearly explained/discussed.

The participants also felt they would benefit from guidance to cover searching skills, judging information quality, and managing information in partnership with health professionals. Of course some of the concerns listed above are not exclusive to online sources. Hardcopy resources such as can also be disempowering if they are not easily comprehensible and may be seen as value-laden – written with the intention to persuade and influence the reader (Payne, 2002). This is of particular relevance to menopause information since the patient information leaflets supplied in GP surgeries and pharmacies are frequently sponsored by pharmaceutical companies and can be interpreted as having their own agenda (Coupland and Williams, 2002; Rogers, 1997).

In an attempt to address the problems faced by health-information consumers, the Department of Health White Paper *Better information, better choices, better health* (2004a) proposes an information accreditation scheme to help people ‘find information that they feel is trustworthy’ and to provide ‘an easy way to recognise levels or aspects of quality and differentiate between sources of information’ (p.14). In a scoping study for this scheme Coulter et al. (2006) carried out a review of the research evidence on patients’ information needs and the effectiveness of providing health information, a survey to estimate the number of organisations providing health information, detailed assessment of 40 information materials, and a telephone survey of information providers to explore the development process.

Not surprisingly, they found that patients and the public require information that is timely, relevant, reliable and easy to understand. They also found evidence to suggest that the benefits resulting from providing of good-quality information could include: impact on patients’ knowledge and recall, improvements in their experiences of healthcare and in involvement in decision-making. In their assessment of information materials they found wide variations in quality. Providers tended to score well in terms of the clarity and the structure of layout etc. but they often faltered in the provision of accurate, reliable and sufficiently detailed clinical information to assist patients in decision-making. Although the providers interviewed claimed a commitment to ideals of user involvement in producing and evaluating materials and in ensuring information was evidence-based, the review found that this was achieved with varying levels of success.

The Coulter et al. review focussed on four specific health topics, covered a range of providers from the public, voluntary and commercial sectors, and the materials assessed included both simple resources such as leaflets/Websites and more complex packages such as interactive computerised systems. Other researchers have concentrated on Websites, which are frequently identified as popular sources of health information (e.g. by Ankem, 2007; Childs, 2004; Coulter et al., 2006; Ellins and Coulter, 2005; Pew Internet and American Life Project, 2005; Warner and Procaccino, 2004), although Harbour and Chowdhury (2007) have pointed out that high levels of Internet use for

health information are not necessarily consistent throughout the UK. Juhl Jørgensen and Gøtzsche (2004) used a checklist to investigate whether 27 Websites in Scandinavia and English-speaking countries presented balanced, current and independent information on mammographic screening. They contend that the material provided by professional advocacy groups and governmental organizations was information-poor and biased in favour of screening compared to the information provided by consumer organizations. The results of this study should be considered in the context of one author having worked on a systematic review that questioned the value of breast screening. Pandolfini and Bonati (2002) repeated a 1997 study on the reliability of information for managing fever in children at home which had found that the quality of information was poor. After re-evaluating those Web pages that still existed from the original sample along with 40 new pages, they concluded that the standard of information had improved over the intervening years but that the need for continued monitoring for accuracy, completeness and consistency remained fundamental. Eysenbach and Kohler (2002) used several methods including focus groups, interviews and observation to explore consumers' techniques of retrieving and appraising health information from the Internet. Participants cited criteria for judging the credibility of Websites including: official sources, professional layout, comprehensible text, and scientific references. Interestingly, some participants expressed a preference for seeing a picture of the site owner: if the site owner/author looked trustworthy then the site content was perceived to be credible. Some participants mentioned that a controlling authority or an endorsement by a third party would be helpful which lends support to the concept of quality assurance/accreditation schemes.

#### **3.4.3.3 Quality assurance**

There appears to be widespread acceptance of the need for quality assurance schemes and agreement on the criteria that can be used to evaluate sites, listed by Childs (2004) as: authoritativeness (e.g. authorship, attribution), trustworthiness (e.g. disclosure), message characteristics (e.g. currency, accuracy), audience characteristics, and design features. The debate centres more around the best way of devising and implementing such schemes and grapples with the concept that 'quality' is in itself 'an inherently subjective assessment which depends on the type of information needed, the type of information

searched for, and the particular qualities and prejudices of the consumer' (Wilson, 2002, p.600).

There have been various attempts to develop rating, or assessment, schemes but many have been short-lived (Childs, 2004; Gagliardi and Jadad, 2002) Each type of scheme has its own set of advantages and disadvantages that further fuel the debate and raise the question of whether a new approach is needed. Childs groups the different types of established rating/assessment schemes as follows:

- Lists of principles and quality criteria, e.g.
  - European Union *Quality Criteria for Health Related Websites*  
[http://ec.europa.eu/information\\_society/europe/ehealth/quality/draft\\_guidelines/index\\_en.htm](http://ec.europa.eu/information_society/europe/ehealth/quality/draft_guidelines/index_en.htm))
- Guidance on assessing the presence of these criteria, e.g.
  - The Quality Information Checklist (QUICK)  
<http://www.quick.org.uk/menu.htm>
- Kite-marking schemes, e.g.
  - Discern <http://www.discern.org.uk/>
  - Health on the Net <http://www.hon.ch/HONcode/Conduct.html>
- Technical mechanisms, e.g.
  - MedCIRCLE <http://www.medcircle.org/> (p.15)

As deliverables for her project, Childs produced two sets of guidelines, one to help consumers make informed choices about Websites and one to assist support groups to produce good-quality sites.

When Coulter et al.(2006) asked the information providers in their scoping study about the accreditation scheme proposed by the Department of Health, the interviewees identified possible advantages of such a scheme. These included: improved quality, increased revenue, enhanced trust in information from health professionals, increased use of materials by consumers, improved public image for providers, and wider recognition of best practice. Concerns included the likely time and costs required, a fear that the

scheme would fail if not adequately publicized, and worries about the possible impact on small providers and on independence and branding. In her focus groups with consumers, Childs also found mixed reactions to rating schemes. Participants expressed interest in kitemarking but were concerned about who would make the quality judgments and about the implications for support-group Websites. Wilson (2002) considered the merits and limitations of different types of rating schemes. The article is a few years old and her taxonomy is slightly different to Childs but the discussion is still relevant several years on. Wilson points out that although tools such as quality labels/kitemarks and user guidance systems have the potential to draw consumers' attention to the importance of the principles inherent in the label and allow them to check whether a site complies with certain standards, they place the onus of use solely on the consumer. Users are required to understand the nature of the label and to care about its aims and objectives, a burden which Wilson feels may limit usage and hence effectiveness.

#### *3.4.4 Communicating risk*

It has been shown that that provision of accurate and understandable information is a key element of current trends towards increased patient empowerment and participation in decision-making. A particular challenge for health professionals lies in the communication of information relating to the risks and benefits of different treatment options. According to Berry (2004), 'Effectively communicating even the simplest and most unthreatening of messages to a diverse audience is difficult enough, but the problems of communicating complex medical information, involving risk and uncertainty, are immense' (p. 5). Not only do patients struggle with interpreting probabilistic information, they are also prone to cognitive biases and can be influenced both by the way in which risk information is presented to them and by a range of emotional and affective factors. The individual healthcare professional's approach to presenting risk information is important, but effectiveness also depends on the environmental and social issues in play such as the interaction between the health professional and patient, personality and personal aspirations (Berry, 2004, p. 27; Julian-Reynier et al., 2003). Much of this of course relates back to discussions about the medical model, about barriers to effective shared decision-making, and about the doctor-patient



relationship covered in earlier sections but the sheer complexity of risk information and the way in which it reveals the levels of uncertainty that still exist in medical practice make it a relevant topic in its own right. Furthermore, it is a topic of particular importance in decisions about the treatment of menopausal symptoms where concerns about drug safety, especially in response to media reports, are endemic (McPherson and Hemminki, 2004; Salkovskis et al., 2004). Burkell (2004) explains that much consumer health information addresses questions such as ‘How effective is the treatment?’ or ‘What is the likelihood that this test will give a false positive result?’ and that consequently it is quantitative information (typically fractions and proportions), addressing outcome likelihood, which consumers struggle to digest. Researchers have mainly focussed on identifying the most effective approaches to presenting risk, both in terms of the data (i.e. the differences between absolute risk and relative risk or between ‘loss’ framing and ‘gain’ framing) and in terms of the format (i.e. oral explanations or visual explanations, etc.).

Berry (2004) defines absolute risk reduction as ‘... the difference between risk of an event in a control group and risk of an event in a treatment group’ whereas relative risk is ‘the ratio of risks of the treatment group and control group’ (p.38). She explains that there is evidence that giving people information about relative risk reductions can have more influence on their behaviour than information about absolute risk reductions. An example of this would be that ‘if the chance of having a disease is 10 percent and this reduces to 5 percent when a person takes a certain drug, then this can be thought of as an absolute risk reduction of 5 percent or as a relative risk reduction of 50 percent’. Berry claims that it is not surprising that people are often influenced by relative risk descriptions when they see figures like this (p. 38).

Julian-Reynier et al. (2003) differentiate between the probability-based approach to risk presentation and the contextualized approach. The former focusses on numerical information and the second on informing patients about the antecedents and consequences of a health problem. In an article considering risk communication strategies in the context of cancer genetics services, they suggest that the difficulties associated

with effectively presenting information using the probability-based approach necessitates an alternative, contextual approach. Such an approach should help people place the risk within the context of their own lives and to understand, for example, the link between a health problem and their own family history. Similar to the way in which people's decisions can be affected by presentation of risk in absolute or relative terms, Julian Reynier et al. point out that in a contextualized approach 'message framing' can influence the decision to adopt or reject a particular healthcare behaviour. 'Gain-framed' messages present the benefits of adopting the behaviour (e.g. of undergoing a procedure) whereas 'loss-framed' messages convey the costs of not adopting it. For example, Jasper et al. (2001) studied women's perceptions of foetal risk from using a drug during pregnancy. Half the participants were given negatively-framed, or loss-framed, information (1–3% chance of having a malformed child) and the other half were given positive-, or gain-framed, information (97–99% chance of having a normal child). Women in the negative group had a significantly higher perception of risk than those in the positive group and were less likely to want to take the drug.

To further complicate the issue, attempts to articulate the concept of likelihood in a less intimidating way must face the challenge of subjectivity. Verbal labels (such as 'low'/'high' risk) are generally viewed as 'easier to use and more natural, perhaps because they consist of common words that seem easily understood' (Burkell, 2004, p. 202). However, there is no consensus about the particular numerical value that best represents the verbal label and this may vary depending on the individual's interpretation (is 'low' risk 5% or 15%?) and context (a 1% risk of death might be considered high but a high risk of minor injury might be 20%). If numerical representations are selected for their precision over verbal labels then they can be presented in different ways to facilitate interpretation, for example using probability (0.05), percentages (5%) or frequency (5 in 100). Visual, or graphical, formats are also considered and include groups of circles with some blocked out, stick figures or facial expressions. Researchers conclude that certain methods for presenting risk are well suited to particular situations and that individual patients will have their own preferences (Burkell, 2004; Lipkus and Hollands, 1999; Thomson et al., 2005).

Some studies have specifically looked at risk in the context of the menopause and HRT. Edwards et al. (2004) included menopause patients in a study to evaluate the effects of training GPs in shared decision-making and the use of risk communication aids. Although the study found no change in patient outcomes following skills training received by GPs, the authors did note improvements in patients' confidence in decisions and expectation to adhere to treatment after exposure to a 'protected' environment (i.e. without interruptions etc.) and increased time for the consultation.

Walter and Britten (2002) used interviews and focus groups to explore women's understanding of the risks associated with the menopause and HRT. They found that the supportive atmosphere generated in the focus groups facilitated the exchange and development of ideas. Study participants tended to view risk as a danger requiring an assessment to enable an informed decision about how to cope with it. Personal interpretation of the meaning of a risk involved using 'knowledge, the presentation and context of that risk, together with [participants'] unique belief system particularly relating to representations of womanhood, lay beliefs and fatalism, control and choice. Experience, age and emotions often modified the meaning of a risk, and participants then used this meaning to weigh up the risks and benefits of a particular threat' (n.p.). Walter and Britten suggest that, since the study shows experiences of womanhood to be central to understanding risks around the menopause and HRT, risk information could be communicated more effectively by the addition of contextual information about other familiar risks (e.g. those related to pregnancy or to the use of oral contraception).

Ballard (2002) focussed on women's attitudes to the use of HRT for disease prevention. Through semi-structured interviews she explored participants' awareness of diseases associated with the menopause and their perceptions of the risk of their own health being affected. Of the 32 participants only one referred to coronary heart disease although almost all mentioned an increased risk of osteoporosis. Despite the general awareness of menopause-related disease (albeit mainly osteoporosis), Ballard found that most participants did not consider themselves to be at personal risk. Ballard infers that there is

a 'dual consciousness' with women interpreting the risk of menopause-related disease on both a collective and an individual level. At the collective level assessments are primarily formed from statistically based medical evidence which shows that menopausal women are at an increased risk of disease. At the individual level, however, women assess their own level of risk based on lifestyle and family history. The implications for HRT use are that study participants saw little value in taking it primarily for disease prevention since they considered their own risk to be low or, if they did acknowledge a potential risk of disease, they were put off by the perceived risks of taking the HRT itself. Only those women who had been medically 'diagnosed' as being at risk of disease were in favour of using HRT preventively on a long-term basis.

Harrabin et al. (2003) looked at media reporting of health-related stories and explored whether television and newspaper stories distort perceptions of risk by focussing on 'scare' stories to the detriment of serious public health issues such as obesity and smoking. Although most public health professionals and policy-makers interviewed for the study were concerned about the lack of media coverage of serious public health risks, most journalists and editors felt that their role was to prioritize new or revelatory facts rather than to concentrate on 'old' news. In the selection of stories, novelty, drama and, especially for television, strong visual content were seen to be important, and reporting conventions such as having two opposing 'experts' to discuss a story were identified as giving an appearance of balance that did not necessarily reflect the weight of evidence. The reporting of risks in an accessible way was seen as particularly challenging, with journalists unable to predict how their audiences would respond. The authors conclude that the public must learn to live with uncertainty without expecting governments or experts to always have ready answers and that for this to happen there needs to be debate about how to negotiate health risks and how to achieve a closer match between proven health risks and news coverage.

Perception of risk can play as important a role in the decision-making process as actual probability. Decisions are not always made by the rational weighing up of the benefits and risks of the various options and can be influenced by anxiety, motivations and

heuristics (rules of thumb). Ultimately, no matter how well risk messages are presented, understood and made meaningful to consumers, people will only take account of them if they trust the information in the message and the source of the information (Berry, 2004; Salkovskis et al., 2004).

### 3.5 Summary

This chapter has focussed on topics that defined themselves as central to the core concepts in the study. The topics fell into three broad categories: information behaviour theory; women's information behaviour; and the empowered patient. Section 3.2 explored how studies of everyday life information-seeking have emerged as a valid strand of information behaviour research and considered the role of models within that research. Section 3.3 established that, although it would be difficult to make generalizations about the information-seeking behaviour of such a large and diverse group of individuals as 'women' *per se*, researchers have considered groups of women in different contexts and from this body of literature it has been possible to identify some common threads in women's preferences and approaches to information-seeking. Researchers have noted a preference for interpersonal and informal sources of information. Despite some reluctance to engage with structured support groups, women have been found to enjoy networking and sharing experiences. The virtual environment provided by the Internet extends the boundaries of networking and enables women to extend their social networks but women's relationship with technology is acknowledged to be ambivalent and tempered with scepticism.

When women are obliged to come into contact with professionals there can be mismatch between the assumptions and attitudes of the professional and popular sectors, and the constraints experienced by professionals and their reliance on traditional models of care can be interpreted by female service-users as uncaring and dismissive. Women look at their information needs in the context of their whole lives but frequently struggle to find professional help that will do the same. The relationship between patients, particularly female patients, and professional healthcare providers was discussed in Section 3.4.

Chapter Four will explain the methodological approach taken and the specific methods selected.

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# Chapter Four: Methodology

## 4.1 Methodological approach

Since a key objective of this study was to consider the findings in relation to the work carried out by McKenzie (2001) and to test her model of information behaviour, it was essential that the data collection methods and approach should complement those adopted by McKenzie in her original study. McKenzie chose a naturalistic framework (Lincoln and Guba, 1985) and therefore selected a methodology that facilitated this approach: she collected data in natural settings (e.g. in women's homes); she herself as the researcher was the major research instrument; data analysis was inductive and the research design emergent with questions, analytical coding categories and frameworks evolving as the analysis progressed. She recognized her findings to be both 'context-dependent' and 'applied tentatively' (McKenzie, 2001, p. 38).

A naturalistic approach has also been taken here though not simply in order to provide data complementary to that collected by McKenzie. Such an approach is consistent with the research question and aims of the study. A naturalistic, or constructivist, approach accepts that human beings do not find or discover knowledge so much as 'construct' it; inventing concepts, models and schemes to make sense of experience and to continually test and modify these constructions in the light of new experience (Schwandt, 1994). Individuals are seen as attributing meaning to behaviour and are authors of their social world rather than simply passive objects in it (Bryman, 2001). Taking a qualitative approach allows the researcher to explore a problem from the perspective of the study participant and to accommodate the fact that individuals may have multiple realities and multiple levels of understanding (Glazier, 1992). Lincoln and Guba (1985) developed a framework of naturalistic inquiry 'the naturalistic paradigm' that links the practical implications for carrying out a naturalistic study to axioms about:

- The nature of reality (that realities are multiple, constructed and holistic);
- The relationship of knower to the known (that both are interactive and inseparable);

- The possibility of generalization (that only time- and context-bound working hypotheses are possible);
- The possibility of causal links (that all entities are in a state of mutual simultaneous shaping so that it is impossible to distinguish causes from effects); and
- The role of values (that inquiry is value-bound) (Lincoln and Guba, 1985, p.36; McKenzie, 2001, p.38).

For Lincoln and Guba, naturalistic inquiry should be carried out in a natural setting (since context is heavily implicated in meaning). It demands a human instrument that can adapt to the indeterminate situation that will be encountered and that can use tacit knowledge as well as propositional knowledge and can apply methods such as interviews, observations or document analysis. In the Lincoln and Guba framework, the inquiry is formed from successive iterations of four elements: purposive sampling (to maximize information until information redundancy is reached); inductive analysis (moving from raw units of information to subsuming categories of information); grounded theory (theory follows from data rather than preceding them); and emergent design (the very nature of a naturalistic inquiry study – the value it places on context, multiple realities and the interaction between researcher and context – dictates that study design cannot be predetermined, but must unfold as the study progresses).

This current study was guided, within the practical constraints, by the precepts of naturalistic inquiry. In-depth interviews allowed participants to explore their ‘lived experience’ of the menopause transition (although postal questionnaires were also used to increase the validity of the findings and support the community menopause clinic evaluation). Each woman places her own interpretation on her menopause transition, which encompasses the sum of her previous life experiences. All of this contributes to attitudes to midlife (as a time) and menopause (as an experience) that may range from the positive to the extremely negative (Daly, 1997). A sole researcher responsible for the interviewing and data analysis has a duty to remain sensitive to these interpretations and to be aware of how their own world-view and interpretation might impact on the process.

The setting for interviews was as natural as practical constraints would allow. Some interviews were carried out in the participants' workplace but the majority was by telephone call to the participant's home and at the participant's convenience. The interview schedule was adapted over the course of the study to respond to issues emerging from participants' responses and the adoption of a narrative approach, with the interview schedule used as a guide to ensure that topics were not overlooked, facilitated a more natural and conversational tone during the interviews (Gorman and Clayton, 1997). Without adhering strictly to the tenets of 'grounded theory' which has its own methodology (Strauss and Corbin, 1994), the analysis process allowed theory to emerge from the data through an inductive process of coding and interpretation.

In seeking to design a study that would support the testing of McKenzie's model precedents were sought in the literature. Despite the plethora of information behaviour models developed and the acknowledgement of authors that their models should be tested and refined across a range of contexts (Johnson, 2003; Wilson, 1999), there is little evidence of rigorous testing. Järvelin and Wilson (2003) point out the difficulty of assessing conceptual models empirically since they form the basis of formulating empirically testable research questions and hypotheses. According to Järvelin and Wilson, such models can only be assessed in terms of their instrumental and heuristic value by assessing the research strategies and programmes (and results) they create.

Research by Beverley et al. (2007), published too late to inform the design of the menopause transition study, tested Wilson's (1999) revised model of information behaviour and that of Moore (2002) – developed in response to a literature review of the information needs of visually impaired people – in the context of the information behaviour of two groups of visually impaired people seeking health and social care information. This study was also conducted within a constructivist (or naturalistic) paradigm with semi-structured face-to-face or telephone interviews structured around a topic guide. During the thematic-coding stage results relating to Wilson's and Moore's models were identified and the authors concluded that both models provided a useful basis for examining the information behaviour of visually-impaired people seeking health

and social care information but suggested that the addition of an ‘intervening variables’ category relating to an individual’s health characteristics would be appropriate for the study population.

As in Beverley et al.’s work, the aim of the menopause transition study was not to replicate methods exactly but to find a complementary approach that would be appropriate for my subject and yet permit analysis in the context of McKenzie’s findings. The data collection methods employed by McKenzie (2001, p.34) were face-to-face interviews and periodic check-in telephone interviews which formed the basis of a research diary. The diary in turn was used to structure a face-to-face follow-up interview. Whilst interviews were also a preferred method for the menopause study, logistical challenges meant that they could not all be face-to-face. Periodic check-ins and follow-up interviews were not considered appropriate given that the menopause has a different time-line to pregnancy: some interviewees had been coping with the menopause transition for many years and their information behaviour spanned this period. A follow-up interview after a short interval would have been unlikely to have produced any new instances of relevant information behaviour and may have been considered intrusive by participants many of whom had already given their time to complete one interview and a questionnaire. The scope of the study did not permit the more longitudinal approach that would have been necessary to chart information behaviour during the whole of a woman’s menopause transition and so one-off in-depth interviews were identified as the most appropriate method.

The commitment to produce a user-satisfaction evaluation for the community menopause clinic directed the use of postal questionnaires as the method of choice in anticipation that it would maximize coverage and response rates (Booth, 2003). Questionnaires were not a method employed by McKenzie who had a much smaller pool of potential participants (women pregnant with twins at a specific time in a specific location). It is accepted that the use of two different research methods combining qualitative (interviews) and quantitative (questionnaires) approaches permits the cross-checking of results thereby increasing confidence in the findings. It also allows the researcher to use one method to

explore areas of interest or confusion identified by the first (Bryman, 2001). Silverman (1993), however, cautions against too great a reliance on the validating effect of triangulation since in seeking to compare two different sets of results the researcher can lose sight of the different contexts by which the two sources of data are bound.

This chapter will provide details of the data collection and analysis processes, relating them to McKenzie's methodology and to broader ethical and practical issues.

## 4.2. Study participants

### *4.2.1 Recruiting participants*

Participants were recruited through a range of strategies which drew on a variety of contacts and opportunities:

1. A previous research project provided a contact at an NHS community menopause clinic in a market town in eastern England. Further discussion with this contact resulted in an invitation to carry out a service audit.
2. Through a further professional contact, it was possible to interview a midlife woman who lived in the town where the NHS menopause clinic was based but who had not attended the clinic.
3. A personal friend facilitated access to seven midlife women working in a care home for the elderly in south-east England.
4. Finally, contact was made with a woman who had read about the research on the Internet and who asked for advice about finding menopause services whilst at the same time volunteering to be interviewed for the study herself.

The community menopause clinic element of the study provided the largest number of study participants and requires brief further explanation. This element of the study had two aims. The first was to provide meaningful feedback for the clinic that would help inform decisions about how to develop services and work effectively with local GPs to ensure good-quality care and support for women during the menopause transition. The second aim was to provide results that would contribute to meeting the aims of the PhD analysis. To achieve these ends, the service evaluation sought to canvass the views of

women registered as patients at the clinic and of GPs from the geographical area covered by the clinic.

Throughout the service evaluation, planning decisions were taken jointly with the Lead Clinician at the clinic. After discussion it was agreed that all registered patients should be given the opportunity to participate in the study but that careful planning would be needed to optimize response rates and ensure the level of confidentiality desired by ourselves and required by the local Research Ethics Committee (REC).

By October 2004 ethics approval had been received and in December 2004 all 519 women registered with the clinic were contacted by letter (on Primary Care Trust headed-paper) and asked whether they would be prepared to participate in the study. To ensure confidentiality these letters were sent out directly by clinic staff. The letter included a reply slip and a copy of an information sheet giving details about the evaluation and the broader aims of the PhD. Copies of the letter and information sheet can be found in Appendices 4 and 5. Potential participants were asked to indicate whether they would be willing to receive a postal questionnaire for the evaluation and whether they would be prepared to take part in a follow-up interview to contribute to the overarching PhD study.

A sample of 20 GPs was selected randomly (using a random-number generator) from a list of all GPs in the 22 primary care practices covered by the community menopause clinic. To ensure a spread of views the sample was purposive in that if more than three doctors were randomly selected from the same surgery one of these was re-sampled. Some names were re-sampled because doctors had moved practice but the final sample contained 14 male and 6 female GPs. The sampled GPs were sent a letter from the community menopause clinic along with a copy of the tailored information sheet (Appendices 6 and 7) and a reply slip to indicate whether they would be willing to be interviewed.



## *4.2.2 Response rates*

### **4.2.2.1 Questionnaires**

The response to requests for participation in the clinic evaluation element of the study exceeded expectations. Of the 519 women contacted, 216 (41.6%) agreed to receive a questionnaire and 147 (28.3%) volunteered to take part in a follow-up interview. The 216 questionnaires were posted in January 2005 with a response deadline of 11 March 2005. Again these questionnaires were sent directly from the clinic to ensure confidentiality of patient details. At this point, however, contact details of any women who had volunteered to be interviewed were passed on. The response rate for the return of completed postal questionnaires was very high: of the 216 questionnaires sent out 199 were returned giving a response rate of 92.1%.

The high response rates and number of women volunteering to take part in a follow-up interview could have been due to the fact that initial contact was made directly from the community menopause clinic with a letter signed by the Lead Clinician. Great care was also taken to reassure potential participants that their comments would be treated confidentially and would in no way influence the care they received from the clinic. However, high response rates may also have been due to a genuine wish to provide feedback about the service or it is possible that the topic of the study appealed to women and prompted them to take part. Women were not specifically asked about their motivations for participating in the study so this cannot be substantiated.

### **4.2.2.2 Interviews**

Of the 147 clinic patients who volunteered to be interviewed only 140 were actually included in the sampling process. The remaining seven were excluded for a variety of reasons including: an offer to participate only if there were insufficient volunteers and offers to participate without contact details being supplied. Again a random-number generator was used to produce a sample of 40 women to be contacted. This was the maximum number of volunteers it was possible to approach given the timescale of the project. The honorary contract from the PCT received following granting of ethics approval had a duration of six months which was a tight schedule for the process of

contacting potential participants, waiting for responses, sending out questionnaires, again waiting for responses, sampling the interview volunteers and contacting those selected to arrange interviews.

From the sample of 40 women, 26 interviews were completed (65%) and one woman responded by letter. Two potential interviewees had moved away and several attempts were made to contact the remaining 11 without success. Of the 20 GPs contacted, six volunteered to be interviewed. Of these three were male and three female, and between them they represented five different primary care practices. All women who had volunteered to be interviewed but were not selected for the final sample were sent a letter thanking them for their offer (Appendix 8). Similarly all women who formed part of the final sample but whom it had not been possible to contact were sent a letter thanking them and explaining that their views would be welcome if they wished to contribute (see Appendix 9).

As explained in Section 4.2.1, access was also given to staff members in a care home for the elderly and seven face-to-face interviews were carried out at the home in March 2004. Two further telephone interviews took place in 2006: one with a woman who lived in the same town as the community menopause clinic but had not attended it and one with a woman who made direct contact having seen information about the project on the Internet. Figure 4.1 shows the sampling process with response rates for the different elements of the research.

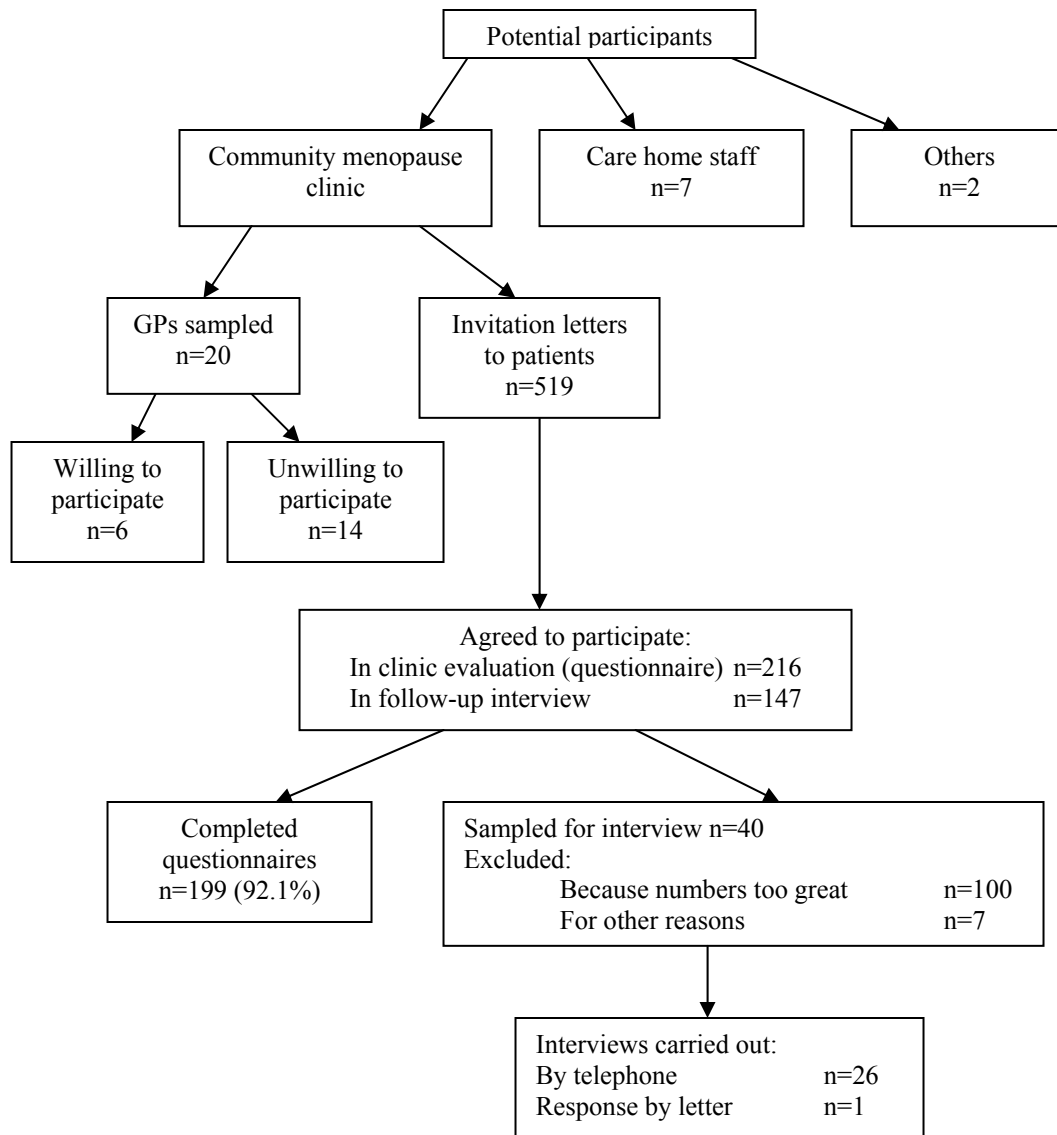


Figure 4.1 Sampling and response rates. After Schonberg et al.(2005) p.188.

## 4.3 Developing the survey instruments and analyzing the data

### 4.3.1 Community menopause clinic evaluation: questionnaire and GP interview schedule

After discussion with the Lead Clinician at the community menopause clinic it was apparent that a combined approach of questionnaires (for patients) and interviews (for

GPs) would best meet the requirements of the service evaluation element of the study.

The objectives of the evaluation were to establish:

- Why women looked for information/advice about the menopause;
- What sources they used;
- The issues they most needed advice about;
- Whether they had had problems locating information/advice;
- How they first heard about the community menopause clinic;
- Whether they were satisfied with the pre-appointment contact they had with the clinic;
- Their opinions on the experience of visiting the clinic;
- How GPs from the area served by the community menopause clinic managed patients with menopause-related queries;
- How GPs viewed the services provided by the community menopause clinic.

Copies of the questionnaire and GP interview schedule can be found in Appendices 10 and 11. Both instruments were developed in close consultation with the clinic Lead Clinician and the questionnaire was piloted with a member of clinic staff. For practical reasons there was no opportunity to pilot the GP interview schedule but both instruments were further scrutinized as part of the REC ethics approval procedure. Consistent with the naturalistic approach to the study, the GP interview schedule was refined over the course of the interviews to reflect emerging topics of interest (e.g. later interviewees were asked more specifically about their attitude towards complementary and alternative approaches to menopause treatment). However, any such refinements were limited in scope since the REC procedure stipulates that all survey instruments should be prepared in advance and be open to scrutiny by the Committee. This procedure restricted the emergent nature of the research at this site.

Postal questionnaires were identified as the most effective way of reaching a large number of participants since there was only one researcher for the project. A prepaid envelope was included for return of the completed questionnaire since avoiding the need

to pay postage has been shown to increase chances of receiving a response by 26% (Booth, 2003).

The clinic evaluation was a prerequisite of gaining access to women registered there in order to carry out the in-depth interviews that were to form the main focus of the PhD research. The questionnaire was therefore developed to be the primary method for gathering feedback about the clinic. The questions were compiled in collaboration with the Lead Clinician at the clinic and were designed to elicit responses about satisfaction with the clinic's performance. Although the content was therefore very much directed by the requirements of the clinic evaluation, the Lead Clinician was willing to include a limited number of questions that would provide information about participants' information behaviour beyond that directly relating to attending the clinic. The questionnaire was therefore divided into three sections: Finding Advice about the Menopause (which asked why women first began to look for information and advice; what sources they have used; what they have needed advice about; and whether they have encountered any problems), Your Experience at the Community Menopause Clinic (which asked how they first heard about the clinic; whether they were happy with the appointment letter from the clinic; whether they were happy with the time they had to wait for an appointment; and asked for their comments about the clinic) and finally a section asking a few demographic questions (age; whether their periods had stopped; whether they were currently taking HRT; and whether they had been taking it before their periods finished). The questions in section two were identified by the Lead Clinician as pertinent to aspects of service to be evaluated. The questionnaire contained a mixture of closed questions that would provide quantifiable results and open questions that gave participants the opportunity to expand on their views in the hope that the responses to open questions would not only provide greater detail for the clinic evaluation report but might also feed into the PhD discussion. The follow-up interviews facilitated exploration of women's information behaviour and their attitudes to the menopause more deeply and contributed more directly to the testing of McKenzie's model.

The GP interview schedule also comprised a mixture of questions directly relevant to the clinic evaluation (e.g. how participants felt about the clinic being a self-referral service and whether information supplied by the clinic had ever helped in the management of a patient) and of questions that would feed into the wider aims of the study (e.g. GPs' own information behaviour and the extent to which patients tended to have informed themselves about the menopause before visiting a GP).

#### *4.3.2 Menopause story interviews: interview schedule*

The interview schedule was designed prior to receipt of confirmation that the community menopause clinic would be willing to participate in the study. The initial group of interviews (with care home staff) took place in early 2004, before ethics approval was granted for the clinic evaluation. This interview schedule was more generic than the questionnaire and the GP interview schedule, and focussed on women's experience of the menopause transition and the information behaviour associated with that experience. The interview schedule was designed to be semi-structured, more a guide of topics to be covered than a definitive list of questions. It was piloted with a peer group (i.e. midlife women approaching or experiencing the menopause) and adjustments were made to reflect their comments. Since this interview schedule was also used for the follow-up interviews with clinic patients it was submitted for REC scrutiny along with the questionnaire and GP interview schedule. As it had already been piloted and used in the care home it had been possible to respond to emerging themes from early interviews and the schedule had already been amended to reflect this.

The interview schedule opened with a question inviting participants to tell their 'menopause story'. The remaining topics were used as prompts when interviewees had not already covered an issue during their menopause story and were intended to help interviewees focus on their information behaviour in a way that would allow comparison with the results from McKenzie's study. McKenzie used the principles of discourse analysis to explore:

- The interpretative repertoires used in women's talk (from the interview transcripts) and published pregnancy literature;

- Women's representations of cognitive authority in various sources of information;
- The ways pregnant women represent information as helpful; and
- Women's representations of themselves as information seekers and of their information seeking process (McKenzie, 2001, p.106).

The interview schedule (Appendix 12) was informed by McKenzie's and the initial open question was succeeded by a checklist of topics to be covered if they had not spontaneously occurred during the menopause story. The term 'schedule' perhaps implies a greater level of structure than was actually the case. The document was used more as a 'guide' to topics and as a reminder than as a structured list to be followed. McKenzie also referred to her document as an 'interview guide'. With the aim of ensuring that the menopause participants were given the same opportunities as McKenzie's interviewees to comment on their concerns and information behaviours, similar topics to those raised by McKenzie were included (e.g. whether participants had ever found information that conflicted with something they knew or thought and whether there was anything they worried about but hadn't asked anyone about). Topics identified from the piloting process as being relevant to the menopause were also included, for example at what point women decided they needed to look for advice/information about the menopause, and where they would be most likely to turn for support. Despite accepting that there was a need to be guided by McKenzie's interview schedule to ensure a level of comparability between findings, it was important not to actively direct interviewees towards giving similar answers to her respondents. For this reason participants were given the opportunity to express themselves freely as they told their menopause stories and a flexible approach was taken to asking additional questions. Appendix 13 contains a comparison of the two interview schedules. As hoped, interviewees tended to be forthcoming and gave a lot of information about their own experiences and circumstances which frequently covered topics on the list without the necessity to raise them.

The storytelling approach complemented the aim of capturing the 'lived experience' of women during the menopause transition (Im et al., 2008). The use of narrative interviewing in everyday information behaviour allows the interviewee to relate their

experiences and to include whatever they consider to be relevant. The interviewer probes as necessary to guide the interviewee through the research topics. Narrative studies are sited within a person-centred approach to information behaviour research as researchers hope to reconstruct events from the perspective of the interviewee (Bates, 2004). Storytelling is an approach well-suited to studying the menopause transition since each interviewee's personal construction of the menopause impacts strongly on her experiences and behaviour. It has been acknowledged to be a rich method which can infuse facts with meaning and can be emotionally and symbolically charged (Gabriel, 1998). There are, however, potential disadvantages to the narrative interview since meaning and symbolism can come at the expense of accuracy. Stories are subjective. Although this subjectivity gives the researcher the desired outcome of seeing events from the interviewee's perspective, the storyteller begins to hear their life anew through the process of relating it and can exaggerate, minimize, keep silent and otherwise shape the narrative. This can be a cathartic experience for the teller but the researcher must be sensitive to the limitations of the method and must equally be aware that he or she risks imposing his or her own definitions of what is important on the story. Ryan (2006), from the field of life-history research, uses the terms 'narrator' and 'interpreter' rather than 'interviewee' and 'researcher'. He points out that although the interpreter may take measures to ensure that the research process is collaborative (e.g. by giving narrators the opportunity to review their transcripts) the ultimate power of representation of the story rests with the interpreter.

If considerable time has passed since the events the interviewee is being asked to recount there is also the possibility of bias introduced by memory lapses, this is a possibility in the case of the menopause stories since some interviewees had been experiencing the menopause transition for several years and had difficulty recalling certain events and feelings (Aranda and Street, 2001; Charmaz, 1999; Gabriel, 1998). It is therefore possible that, not only are stories interpreted by 'interpreters' who cannot ever totally excise their personal (and for Ryan political) pasts, they are also interpreted by the narrators' themselves who may, perhaps unintentionally, be providing selective versions of accounts. Techniques such as explicitation (Urquhart et al., 2003) attempt to improve



recall of a specific event by asking participants to ‘relive’ a particular event and then prompting them with a stream of detailed questions about the event. Such a method was not appropriate for this current study since the aim was to consider everyday information behaviour over the period of the menopause transition rather than focussing on an individual incident. However it was important to remain aware of the potential limitations of the storytelling method. The inclusion of stories from non-clinic women which reflected many of the experiences of clinic attendees gave greater confidence in the stories from this second group who could potentially have simply related instances that were prominent in their minds given the acknowledged severity of their symptoms.

### 4.3.3 Data analysis

#### 4.3.3.1 Questionnaires

The questionnaire data were analyzed using an Excel spreadsheet and were used descriptively in the production of a report for the clinic. Interview responses were also included in the report if they were directly relevant to the clinic evaluation (e.g. comments about services received at the clinic). As had been hoped, the open questions provided greater insight into respondents’ views and have contributed to the PhD findings as presented in Chapters Five, Six and Seven. Table 4.1 demonstrates how the responses to individual questions from Sections One and Two in the questionnaire have been incorporated into the thesis and provides the data collected from responses to Section Three.

SECTION 1: FINDING ADVICE ABOUT THE MENOPAUSE	
Questionnaire Question	Presentation of Results in Thesis
1. Why did you first start to look for information and advice about the menopause?	Results displayed as Figure 5.1 in thesis.
2. Since you have been looking for advice about the menopause, what sources have you used?	Results displayed as Figure 5.2 in thesis and included in Table 7.1. Also included in discussion (e.g. Section 5.3; Section 6.3.2; Section 6.4.3.2).
3. What have been the issues you have most needed advice about?	Results displayed as Figure 5.3 in thesis.

4. Have you ever had problems finding the menopause advice you needed?	Results displayed as Table 5.1 in thesis. Also included in text (e.g. Section 5.3.2; Section 5.3.3; Section 6.4.2; Section 6.4.3.1; Section 7.2.3.2 and in Table 7.2).
SECTION 2: YOUR EXPERIENCE AT THE [COMMUNITY MENOPAUSE CLINIC]	
<b>Questionnaire Question</b>	<b>Presentation of Results in Thesis</b>
5. How did you first hear about the [clinic]?	Responses incorporated into discussion (e.g. Table 5.1; Section 7.2.1.3; Section 7.2.1.4 and in Table 7.1.)
6. Were you happy with the appointment letter you received from the clinic?	Results relevant to evaluation of Community Menopause Clinic but not to thesis.
7. Were you happy with the time you had to wait to get an appointment at the clinic?	Responses incorporated into discussion (e.g. Section 5.3.2; Section 7.2.3.1 and in Table 7.2).
8. Is there anything you would like to say about your visit to the clinic?	Responses incorporated into discussion (e.g. Section 5.3; Section 5.3.3; Section 6.4.1; Section 6.4.2; )
SECTION 3: ABOUT YOU	
<b>Questionnaire Question</b>	<b>Presentation of Results in Thesis</b>
9. Are you taking HRT at the moment?	85 respondents (42.7%) indicated that they were currently taking HRT at the time of responding to the questionnaire. 105 (52.8%) indicated that they were not taking HRT at the time of responding and 9 respondents (4.5%) did not answer this question.
10. If you are/have been taking HRT did you start before your periods actually finished?	93 respondents (46.7%) indicated that they had started taking HRT before their periods finished. 62 respondents (31.1%) indicated that they did not begin taking HRT before their periods ceased and 44 (22.1%) did not respond or said they were unsure.
11. If your periods have stopped, did this happen naturally?	100 women (50.3%) indicated that they had had a natural menopause. 38 (19.1%) confirmed that they had not had a natural

	menopause and the rest did not respond to this question (30.7%).
12. Please indicate your age.	3 were aged under 40 8 were aged 40-44 20 were aged 45-49 59 were aged 50-54 67 were aged 55-60 33 were aged over 60 and 9 did not supply their age

*Table 4.1 Mapping of questionnaire responses to thesis findings.*

#### **4.3.3.2 Interviews**

In accordance with naturalistic methodology, an inductive approach was used to analyze the findings from the interviews. McKenzie chose to use discourse analysis in her study of women pregnant with twins, drawing on the work of constructionist social psychologists which focussed on the everyday conversation of ordinary people (Bryman, 2001; Potter and Wetherell, 1987). The foundation for McKenzie’s analysis was Potter and Weatherell’s interpretation of discourse analysis in which discourse is seen as not simply reflecting a realistic account of an individual’s version of reality, but has a meaning contingent upon the function the discourse is meant to perform. In this interpretation, discourse is constructed out of ‘interpretative repertoires’, which are recurrently-used systems of terms used for characterizing and evaluating actions, events and other phenomena. A repertoire is constituted through a limited range of terms used in particular stylistic and grammatical constructions and may be organized around specific metaphors and figures of speech. As individuals go through life facing ‘an ever-changing kaleidoscope of situations’ they draw upon different repertoires to suit needs as they occur (Potter and Weatherell, 1987, p.156). The specific analytic practices associated with discourse analysis include:

- Paying close attention to the details of language use by examining transcripts or written texts rather than numerical summaries or remembered notes of interactions;

- Focussing on the discourse itself as the primary object of research rather than as a transparent medium revealing the true nature of an individual's attitudes and beliefs, or the true nature of events;
- Making a close study of variations in the ways discourse is constructed, both within and across accounts, in order to derive some understanding of the functions that discourse might be serving and the interpretative repertoires used to construct the versions. (McKenzie, 2001, pp.103-105; Potter and Weatherell, 1987).

McKenzie postulated that the Potter and Weatherell interpretation of discourse analysis could be used within LIS research to study information use as discursive action thereby elaborating on LIS concepts such as 'cognitive authority' and 'helpfulness' and providing new insights into individuals' representations of themselves as information seekers and of the barriers they encounter during the information-seeking process (McKenzie, 2001).

Whilst acknowledging the importance of the interplay between women's interpretations of their menopause experience and the constructions of menopause presented in various forms of textual information and whilst remaining sensitive to the nuances of storytelling as a research medium (i.e. that it is likely to impart meaning rather than accuracy and may not reveal the true nature of the events), a full discourse analytic approach was not adopted. Instead a process of thematic coding was selected as the most appropriate method of inductive data analysis. According to Lincoln and Guba, inductive data analysis is in essence a process of 'making sense' of the field data. During this process (akin to content analysis), two subprocesses are involved: 'unitizing' and 'categorizing'. Unitizing is a process of coding data into defined information-bearing units which can be understood as single pieces of information that stand by themselves and are interpretable in the absence of any additional information. During the categorization process, units are organized into categories that provide descriptive or inferential information about the context or setting from which the units were derived. As the number of units within each category expands, the analyst attempts to define the category by writing a 'rule' or propositional statement to serve as the basis for eligibility for inclusion in the category. The rule may be amended as further units emerge and shape the analysis process. What

distinguishes the rules in a naturalistic inquiry from those in a conventional inquiry is that the naturalistic rules emerge from and are defined by the data rather than data units being made to fit into predetermined categories (Lincoln and Guba, 1985).

Once all the data have been coded, the process of analysis reveals a framework of patterns and contrasts from which theory can potentially be developed. As a sole researcher it is imperative to document decisions about categorization rules and record the emergence of theory from the data since opportunities to ensure the integrity of the analysis are more limited than in a multi-researcher situation in which reliability can be checked by, for example, having two researchers code the same document (Westbrook, 1994). To enhance the validity of the study, a colleague coded one of the interview transcripts to permit comparison of decisions taken (*see* Appendix 14).

As the data are written up, the categories, or themes, are interconnected to tell the story of the social group being investigated (Rice-Lively, 1997). King (1998) chooses the term ‘template analysis’ to describe the process of thematic coding and suggests that it might be more appropriate for constructionist researchers than true grounded theory since grounded theory has come to be associated with the uncovering of the ‘real’ beliefs and values of participants which is not compatible with a constructionist approach.

Furthermore template analysis allows more flexibility in procedures for data gathering and analysis than grounded theory and allows the researcher to develop and apply an initial template which can then be modified in the light of ongoing analysis. Although an initial template of codes/categories was not produced (with codes and themes being allowed to emerge from the text), an element of King’s approach must be acknowledged since interviewees were prompted from the interview guide to ensure that topics were covered (rather than leaving them to simply tell their story entirely in their own words). The result of this was that on starting the coding process there was already an idea of some of the themes that were likely to emerge. This has the effect of imposing a certain structure on a researcher’s internal conceptualization of the findings. However this is likely to be the case with data collected using an interview schedule that is in any way structured.

All interviews were tape-recorded (with the permission of the participants) and then transcribed before being loaded onto NVIVO (version 1.3) software for analysis. Using a software package like NVIVO can be an advantage for organizational aspects of the data analysis process. For example, documents (e.g. interview transcripts) can have 'attributes' (i.e. variables) attached to them as a record of the characteristics of that individual encounter. For this study, attributes included whether or not a women had had a hysterectomy, which sample the interviewee came from (i.e. clinic attendee, care home employee, GP etc.) and the gender of GP interviewees. The attributes facility was also used to manage stages of the analysis process (e.g. keep a record of which documents had been transcribed and coded). A copy of the Attributes table can be found in Appendix 15. NVIVO can also be used to support a reflexive analysis through, for example, the creation of a research journal (Appendix 16). Payne (2004) stresses the importance of working and writing in an explicitly self-aware and self-critical way since this feeds into discussion of the validity of qualitative research studies. Researchers are encouraged to question their own practice constantly, reflecting both on what they are trying to do and on the progress of their work so that they remain conscious of their work as a creative process and communicate their ideas effectively to their audience. Using NVIVO tools to keep a record of decisions and thought processes helps the researcher retain continuity throughout what may be a prolonged period of emersion in the data and allows decisions to be revisited and questioned as new themes emerge and feed into the process.

The approach taken with the coding was to use NVIVO to code the interview transcripts by broad themes whilst documenting reasoning. The themes were then revisited and reasoning reconsidered to confirm that earlier decisions still seemed appropriate. The material was then recoded into smaller, more precise categories. Progress was documented in the research journal as were impressions of the coding process. In naturalistic studies, the analysis should feed back into the interviewing process as new ideas emerge. Here opportunities for this were limited. After the care home interviews the interview guide was amended to reflect issues that came out of these early interviews but once the guide had been approved by the REC for the community menopause study there

was no option to alter it further. Scope for adhering fully to the guidelines of naturalistic inquiry was further inhibited by the fact that changes in personal circumstances meant there was not enough time to ensure that each interview was transcribed and coded before starting the next. It was, however, possible to respond to topics that emerged during interviews by ensuring that later participants were probed more deeply about these topics.

As text units were coded to more precise categories (*see* Appendix 17 for an example of a coded transcript) the process of constructing a ‘node tree’ began (*see* Appendix 18). The broader codes had all been open codes or, as NVIVO terms them, ‘free nodes’ with no structure and with equal weighting. By creating a ‘node tree’ an index structure was introduced thereby beginning the process of identifying patterns and relationships between different codes. By moving through the stages of creating broad categories, reassessing and refining these categories and then coding more specifically to a structure, the work reflected the three types of coding associated with content analysis. Here open coding provides the initial, provisional work carried out on an unrestricted basis to produce broad concepts that seem to fit the data, as major categories emerge from the data the researcher moves into a phase of axial coding where he or she focusses on one category and develops a cumulative knowledge about that category and those related to it. The final stage is selective coding which takes place as soon as the open and axial coding has begun to establish the ‘core categories’ which gradually begin to dominate the whole process and would form the main branches of the node tree (Westbrook, 1994). A final stage in the menopause study analysis was to review the interview transcripts, coding specifically for categories relating to McKenzie’s Model of Information Practices in Everyday Life Information Seeking (e.g. for examples of active seeking, active scanning etc.).

The process of coding facilitates the organization of data and enables the researcher to identify patterns and relationships but the analysis process leading through to writing involves an iterative reflexive practice of validating the patterns, allowing theories to emerge from them, and applying these theories in the context of the ethical considerations which provide the foundation for the study.

## 4.4 Ethical considerations

### *4.4.1 Gaining Research Ethics approval*

As part of this study took place in an NHS environment – the community menopause clinic – it was necessary to submit details of the project for scrutiny and approval. This was a lengthy and, understandably, thorough process. The procedure is administered by the National Research Ethics Service (National Patient Safety Agency, 2008) through local Research Ethics Committees which have a remit of safeguarding the rights, dignity and welfare of people participating in research within the NHS. Potential research participants come under the protection of a REC which is entirely independent of the researcher and of the organizations funding and hosting the research.

At the time of making the application to the local REC (2004), the procedure involved the completion of an extensive electronic form providing full details about the intended research. The form sought to establish a whole range of information about the project including: the type of research intended (e.g. whether there would be direct contact with patients, whether the aim of the study was to test a medicinal product etc.); the research question and justification of the research; the proposed research methods; the sampling criteria; and whether similar research had already been carried out on the topic of choice. A key concern of the process is to ensure confidentiality and protect the wellbeing of study participants. The form therefore contained many very specific questions relating, for example, to whether participants might be asked about potentially sensitive or upsetting subjects, whether there would be possible discomfort or lifestyle changes for participants, what the potential benefits might be for participants, and whether participants from vulnerable groups might be included. Applicants were required to provide details of measures that would be taken to obtain informed consent from research participants, of the time they would be given to reflect on whether they wished to take part in the study, of how confidentiality would be ensured, and of how data would be managed and securely stored. Given that the form was generic and that much of the research carried out within the NHS is of a clinical nature, it proved a challenge to complete. Many of the questions were difficult to answer in the context of the menopause study.



After sustained correspondence with both the local REC and staff at the local Research and Development (R&D) office, who also needed to approve the research, the forms were posted in June 2004. The process of preparing the forms for submission had taken six months and had involved a variety of related tasks including seeking clarification from the relevant committees, contacting senior NHS staff who needed to sign the application (e.g. the PCT Clinical Director), and discussing issues with the Trust Data Protection Officer. The Data Protection Officer was able to offer criticisms of the study design which, although they initiated more work and indeed at times appeared insurmountable, did ease the progression of the application through the eventual committee scrutiny. When the application was considered by the Ethics Committee at the end of June they requested some minor revisions (e.g. clarification of who would provide counseling to participants if needed) which were quickly resolved. The R&D panel also requested clarification of certain points but the application was finally accepted and in the October of 2004 an honorary contract from the PCT was received to officially allow the project to proceed.

#### *4.4.2 Confidentiality and security*

The REC and R&D committees robustly examined the project in relation to guarantees of patient confidentiality and security of data. The following measures were taken to ensure that the study was fully compliant with their requirements:

- The initial letters asking for volunteers contained an information sheet (*see* Appendix 5) giving full details about the study and included a reply slip for women to indicate whether they would be prepared to receive a questionnaire and/or take part in an interview. All participants were assured that taking part in the study would in no way impact on the care they received.
- These letters (*see* Appendix 4) were sent out by menopause clinic staff.
- Questionnaires were also sent out directly from the menopause clinic but were returned anonymously to the researcher (so that clinic staff did not see the completed questionnaires).

- Only women volunteering to be interviewed were asked to supply their contact details.
- The information sheet sent out with the initial letter explained that interviews would be tape-recorded from preference but that notes could be taken if preferred. Before each interview participants were asked whether they were happy to be recorded.
- If all the interviews had been carried out on a face-to-face basis as originally intended, interviewees would have been asked to sign an informed-consent form (Appendix 19) at the start of the interview. In the event, for telephone interviews forms were posted and the signed form returned in a stamped addressed envelope.
- At transcription stage, the interview data were anonymized (through the use of pseudonyms) and all tapes and hardcopy data were stored safely. All electronic data were stored on a password-protected home computer.
- Interviewees were given the opportunity to review a printout of their transcribed interview and to request that some or all of it be removed from the study if preferred (Appendix 20).

Whilst satisfying the REC and R&D committees was obviously a key dependency of the community menopause clinic element of the study, the need to ensure confidentiality for participants and to secure research data is good practice in any investigation. Participant information sheets and informed-consent forms were supplied with the ethics and R&D committee applications but they had already been used for the earlier interviews at the care home. Although not recruited for their status as NHS patients, these interviewees, and indeed the other two participants interviewed towards the end of the study, were equally entitled to know that they and the information they provided would be treated with respect and discretion. All interviewees were given the participant information sheet before commencing the interview and were asked whether they had any questions and whether they were willing to be tape-recorded. They were also given informed-consent forms to sign. Due to personal circumstances it was necessary to recruit help with the transcribing from an experienced transcriber. The transcriptions were quality-controlled by running spot-checks against the tape-recordings to confirm reliability.

All interviewees were given the opportunity to review and comment on their transcribed interviews prior to analysis and some did request that sections of text be omitted, for example if they regretted a comment or felt it might be misinterpreted. All interviewees from the clinic-evaluation strand of the study were sent copies of the Executive Summary of the report (*see* Appendix 2). One interviewee also asked to see a copy of the completed thesis.

#### *4.4.3 The ethical challenges of interviewing women*

An early preconception about the study had been that the menopause would be a taboo subject and that many women would be reticent in talking about it, especially with a stranger. In fact a surprising number of women offered to be interviewed for the study and were willing to talk about their menopause experiences and the impact these had on their wider lives. Van Wersch and Uniken Venema (1994) conducted interviews with Moroccan women living in The Netherlands and found that many women ‘visibly appreciated’ the researcher’s interest in their stories. Many of their interviewees were very talkative and elaborated on all questions and subjects. Other interviewees were less ready to talk and the authors found a flexible approach to interviewing was required with a more structured approach for women needing encouragement. Experience from the menopause study reflects this with some interviewees being very forthcoming in response to the invitation to tell their menopause story but others (particularly some interviewees from the care home environment) needing more structured probing to ensure that they were given ample opportunity to express themselves.

Feminist writers have specifically considered the particular ethical issues faced by female researchers interviewing women. A feminist approach to interviewing is seen as an opportunity to redefine the researcher–participant relationship and challenge the traditional methodology. Traditional approaches are seen as turning the interview into a one-way process in which the interviewer elicits and receives information but does not provide any. Furthermore, traditional approaches are perceived to reduce the interviewee herself to an objectified role as ‘data’ and to have no meaning in terms of social

interaction (Oakley, 1981). Oakley suggests that the primary orientation of feminist researchers is the validation of women's subjective experiences as women and as people and that traditional methodology does not fit well with this. The paradigm of the traditional social research interview is therefore perceived as having the following shortcomings from a feminist point of view:

- That it is in essence a mechanical instrument of data collection;
- Its function is as a specialized form of conversation in which one person asks the questions and another gives the answers;
- Its characterization of interviewees as essentially passive individuals;
- Its reduction of the interviewer to a question and answer rapport-building role (Oakley, 1981, p.36).

Through her own experience of interviewing, Oakley struggled with this traditional culture and found that it limited the success of the interview. She found that an attitude of refusing to answer questions or give any personal feedback was counterproductive, inhibiting the development of rapport, and she advocated a different approach labelled 'no intimacy without reciprocity'. Oakley was working with in-depth longitudinal interviews and realized that interviewees needed some level of personal satisfaction from the interview process in order to invest in it. Duelli Klein (1983) also called for a new approach to methodology, one that would allow women studying women to take part in an interactive process without the artificial object/subject split and would stress the obligation to try to maintain honesty between researcher and participants.

In her research focussing on clergymen's wives and on working-class playgroup attendees/organizers, Finch (1993) also preferred less-structured strategies that avoid the objectification of the interviewee and promote a more equal relationship between researcher and participant. Finch claims that not only is this approach more ethically and politically sound for a feminist researcher, it is also successful. She discusses the enthusiasm women have for talking to a female researcher (even if they may have some initial concerns about the purpose of the research or their own performance during the interview) and the effectiveness of the in-depth interview. For Finch, women are

receptive to the in-depth interview because, through their experiences of motherhood and as those with prime responsibility for running the household, they are used to intrusions and questioning about the private aspects of their lives (e.g. from health visitors, social workers, housing officers etc.). They are therefore more accepting than men of questions about their lives and more willing to disclose information. Furthermore, if the interview takes place in the woman's home and is conducted in an informal way it can easily take on the character of an intimate conversation. In her own research Finch found that women often welcomed a sympathetic listener as a way of attempting to make sense of the contradictions in their lives.

Finch suggests that the very fact of having their gender in common provides the basis for an assumed intimacy that allows women to feel they can talk about areas of their lives and that the researcher will understand by virtue of being a woman herself. Finch felt that during the interviews, women were seeking to 'place' her as a woman in terms of possible experiences (e.g. of marriage and motherhood) and that until this had been achieved there remained some unease in the relationship. If the researcher has another point of commonality with the interviewee this may further facilitate connections. In Finch's case she herself was the wife of a clergyman. McKenzie has reflected on the extent to which her own status as a mother of twins whose experience of having 'been through it' helped in providing a comfortable and trusting environment for respondents to disclose their feelings and experiences (Carey et al., 2001).

Although the willingness of women to disclose information about their lives can contribute to a rewarding interview experience for both researcher and participant, Finch cautions that there is 'a real exploitative potential in the easily established trust between women, which makes women especially vulnerable as subjects of research' (p. 174). For Finch, the 'techniques' for research can become divorced from the moral basis of feminism, and information can be used to the detriment of the women who gave it willingly to a woman they found easy to connect with. There is little evidence in the LIS literature of studies that engage with male participants in such a way. One exception may be a study by Minion looking at the information world of HIV-positive gay men from the

perspective of their personal histories and their home environments. In a paper giving an overview of his work (following a doctoral workshop), Minion explains that he held meetings (lasting on average 2.45 hours) with 24 men in their own homes. During the meetings the researcher:

- Asked participants to complete a self-administered health questionnaire;
- Asked them to draw a sketch of their home's floor-plan identifying anything that was in the home solely because of their HIV-status;
- Carried out an unstructured interview covering experiences such as disclosure of sexual orientation to family members, the experience of testing positive for HIV, and information needs and uses post-diagnosis;
- Took photographs of items identified by participants on their home maps; and
- Made fieldnotes (n.p.) (Minion, 2008).

Minion does not reflect on his approach and had not completed his analysis at the time of writing the paper. However, the fact that he met with participants in their own homes and that they were willing to disclose information about their health and personal situations and to allow him to photograph their belongs suggests that the study was carried out with an orientation towards the feminist perspective of openness between participant and researcher and validation of the subjective experiences of the interviewee. In a sociology context Ryan (2006) reflected on his choice of a narrative technique for interviewing eight gay men about their recollections of coming to terms with their sexuality during the 1970s. He confirms that the use of storytelling has been a feature of feminist research given its supposed ability to 'uncover a hidden history of women's lives while acknowledging concepts of power within the research process' (p. 152) and points out that men have also been encouraged to conduct research using feminist epistemology to explore male subjectivities. According to Ryan, some researchers have taken up this challenge, mainly to explore concepts of masculinity (e.g. Connell, 1995; Lohan, 2000), but 'the extension of feminist research methodologies, particularly using personal narrative to study men's lives has been limited' (p. 153). Reflecting on his own study, Ryan explores the nature of his relationship with his participants and, in an echo of Finch's work, the extent to which he was considered 'outsider' (as a researcher) or 'one

of their own' (i.e. as a gay man himself) by the narrators. If few studies of men have used feminist principles to direct engagement between researcher and participant(s) this is particularly so within the field of LIS research where Minion's study was the only example located during the literature review. When preparing the literature review only limited studies were found to focuss specifically on men. There were examples of studies that used gender as a variable in an exploration of information behaviour (Hargittai and Shafer, 2006; Huber and Cruz, 2000; Lorence and Park, 2007; Steinerová and Šušol, 2007) or that considered information behaviour relating to male health topics such as prostate cancer (Feldman-Stewart et al., 2000) but few that used in-depth interviews to explore participants' lived experience of a topic, their feelings about it and the impact it has had on their lives. For example, the Feldman-Stewart et al. study of men with early-stage prostate cancer used a postal survey to determine the questions that patients thought should be addressed. It is possible that male participants would be less willing to discuss personal topics in such depth (Finch suggests that women are more accustomed, and hence more accepting, than men to questioning about private aspects of their lives through involvement with running a home and childcare) or that female researchers tend to be more attracted by such an approach than male and gravitate towards female-related topics which they may perceive to be easier to negotiate access to. However, it could be suggested that until there is a greater research base that takes account of emotions and personal values in men's information behaviour in the same way that women's emotions and personal values are considered in studies such as McKenzie's study of pregnant women and this current study, it is difficult to draw conclusions about the information behaviour of women. This raises questions about the validity of taking 'women' as a special case. Unless men are given the same voice as women, i.e. are given the same opportunity to express themselves through feminist-inspired techniques that allow them to speak without the imposition of traditional power-relations it is not possible to gauge the extent to which information behaviour is directed by gender as opposed to by sets of circumstances or other variable factors (e.g., if taking a sense-making approach, by the type of gap that needs to be bridged).

## 4.5 Reflections on the methodology

### *4.5.1 Interaction with participants*

In an article by Carey, McKechnie and McKenzie, the authors reflect on their experiences of gaining access to participants in LIS studies among three different populations: a self-support group for people with a chronic auto-immune illness (Carey), preschool children visiting their local library (McKechnie) and McKenzie's group of women pregnant with twins. From their combined experience, the authors conclude that gaining and maintaining access to research participants is an emergent process, dependent on the characteristics of the researcher, the participants, and the research context. They propose a list of factors that LIS researchers might consider when preparing and conducting naturalistic studies:

- Respect for participants (Gaining access and trust depends absolutely on feeling and demonstrating respect for participants and their points of view.);
- Respect for and sensitivity to the participants' life worlds (Participants do not live in a vacuum. Gaining access often means gaining the trust of their families or colleagues. Maintaining access requires working around the needs and schedules of work and family.);
- Flexibility (The research requires creative approaches to gaining access. When an initial idea does not work, investigators are most successful when they manage to 'think on their feet' and change strategies as needed.);
- Time for developing trust (Gaining trust takes time. Participants first need to consider whether to participate, and then need time to feel comfortable with the research process. When participants recognize the researcher as an insider, initial trust may come quickly. When the researcher is an outsider, participants may need time to assign the researcher a role with which they are comfortable before being ready to disclose.);
- Recognition of trust (Although established in different ways with different participants, a trusting relationship needs to be achieved.);
- Maintaining trust (Gaining trust is not a one-time affair, but an ongoing process that begins before the participant makes the initial overture to the researcher, and



- continues to the present, as investigators recruit additional participants, report their findings, and conduct follow-up studies.);
- Role negotiation (The negotiation and revision of shared roles are also part of a continuing process. Although a researcher may begin as an outsider, prolonged engagement affords an opportunity to negotiate new and often unexpected roles.);
  - Reciprocity (The researcher–participant relationship determines what kinds of reciprocity are most appropriate. As the relationship evolves, reciprocity must be renegotiated.). (Carey et al., 2001, p.331)

Though this current study was neither approached from a feminist ideology nor with an overtly feminist methodology, an appreciation of some of the principles of feminist research seemed appropriate. Reflection on the recruitment of and interaction with the participants in the context of Carey, McKechnie and McKenzie’s recommendations of good practice suggests that within the practical constraints of this study it was possible to demonstrate:

**Respect for participants and for their life worlds** through sensitive interviewing (e.g. by attempting to ensure that my responses could not be interpreted as judgemental about decisions the interviewee had taken and by allowing the interviewee time to express herself) and by giving participants flexibility to arrange the interviews at a time that suited their personal life (e.g. most of the telephone interviews took place in the evening when women were home from work and after they had finished home-related tasks).

**Flexibility.** Participants for piloting and interviewing were recruited through a variety of strategies – mainly through personal or work-related contacts but one woman volunteered having seen information about the study on the Internet. The approach had to be flexible, for example it was initially planned to recruit participants through their contact with a Wellwomen Information centre but this was cancelled due to a change of staff at the centre and a personal contact was used to recruit midlife members of staff in a care home instead. Flexibility within the interview situation itself was also important since each

individual responded to different levels of interaction: some were very talkative but others required gentle probing and reassurance.

**Time for developing trust.** All participants (potential interviewees and potential questionnaire respondents) were given time to decide whether they wished to participate in the study and were provided with information about the research.

**Recognizing and maintaining trust.** Developing a trusting relationship was a challenge in the context of this study because it was not a longitudinal project with several points of contact with the same individuals. For participants in the menopause clinic element of the study the fact that contact was originally made via the Lead Clinician at the clinic and that ethical approval had been given by the local REC helped establish a level of authority and reassurance that it was a bona fide study and that due consideration had been given to issues of confidentiality etc. All interviewees were contacted by telephone to discuss willingness to participate in the study and to arrange a convenient time for the interview. This gave an opportunity for introductions and ‘ice-breaking’ with participants and for participants to ask questions before the actual interview. Since discussion about when to carry out the interview tended to revolve around work and/or family commitments, a certain level of empathy and/or commonality of situation was often established at this point. Hobson (1978) suspected that the fact she had to arrange interviews around her own son’s school-run meant that although her housewife interviewees may have perceived her life as more ‘exciting’ than their own, they were unlikely to have perceived it as ‘ideal’ and were therefore less likely to see her as far removed from their own experiences. Given that interviews in the menopause study were conducted by telephone rather than face-to-face as originally intended, it was important to remain aware of the potential shortcomings of this method (see below) and to be sensitive to the challenge of establishing rapport when unable to make visual contact.

For the care home staff interviews the issue of establishing trust is perhaps more complicated. These interviewees were approached in advance by their colleague who had given them details about the study before asking whether they would be willing to

participate. The interviews took place in the care home setting and the interviewees appeared relaxed in this environment. Participants were given the opportunity to read the participant information sheet and ask questions before confirming that they were willing to take part and were asked to sign a consent form. Despite being in the workplace the interview room was made as informal as possible and every attempt was made to keep the atmosphere relaxed.

Some of these participants were less forthcoming than many of the menopause clinic interviewees and often required a more structured approach to the interview. Although their interviews were face-to-face rather than by telephone they tended to be much shorter which is perhaps not to be expected. It could be suggested there were two main reasons for this. Firstly the care home staff were having a mixture of experiences of the menopause transition and had not necessarily felt they needed to look for specific information or advice. The menopause clinic interviewees, on the other hand, had experienced enough problems during their menopause transition to warrant active seeking of advice either by a trip to the GP (and subsequent referral) or by self-referral directly to the clinic. They therefore tended to want to elaborate on their experiences and, if anything, needed reassurance that they were not talking too much:

‘Am I babbling on?’ [IMOGEN]

Secondly, the menopause clinic interviewees had taken a more active role in the decision to participate. By not returning the original response slip they would have indicated a wish not to participate at any level. By agreeing to receive a questionnaire and then by actively offering to be interviewed they were volunteering themselves as a group who felt they had information to give. The care home staff had been given opportunities to refuse to participate but may have felt an obligation to take part since they were being asked in their workplace by a senior colleague.

**Role negotiation and reciprocity.** Carey, McKechnie and McKenzie discuss the role of the researcher as ‘insider’ and/or ‘outsider’ in their relationship with participants. For

example, McKenzie found herself granted ‘insider status’ with gatekeepers at potential recruiting sites through her membership of the twin-parenting organization. McKechnie identified herself as ‘a children’s librarian, a mother, and a doctoral student’ when seeking families to participate in her study of preschool girls. She believes that mothers perceived her as both an expert (researcher) and as an insider (mother and library user) and that this contributed to their decision to allow their daughters to take part.

In the menopause study the researcher’s role was also a mixture of insider and outsider with an element of ambiguity about it. The ‘outsider’ element was emphasized by the fact that it was not possible to visit women in their own homes and that they were only interviewed once, thus limiting opportunities for integration (e.g. Oakley was offered meals by some of her participants and helped out with household chores or childcare). On the other hand the researcher was not a member of the medical profession, and was a woman which helped establish some commonality with several women expressing curiosity about personal circumstances, for example:

‘ALISON: Have you got any idea whether they are getting any better, the hot flushes?

EVE: Well sometimes I think they are, some days are better than others, but you find it at night mainly when you sit down, perhaps in the daytime because I’m more active and doing other things, thinking of other things, but when you are sat at night, or in bed, you get a bit hot, it’s a nuisance. You are not at that stage?

ALISON: No.

EVE: Too young.

ALISON: I’ll be 40 this year.

EVE: How do you think you’ll deal with it?’

The fact that the menopause transition inevitably becomes part of most women’s lives at some point promoted empathy and further similarities of experience with individual interviewees established the researcher as a fellow woman with points of common experience.. This process of ‘placing’ the researcher (Finch, 1993) often happened in conversation after the interview had been completed and the tape recorder switched off

and so it is difficult to know whether an interviewee's perceptions (right or wrong) impacted on the content of the interview itself. Hobson (1978) reported the value of such conversations that happen at the end of the official interview which her interviewees took the opportunity to question her about her own personal circumstances.

Although the information sheet and introduction to interviewees explained that the research was being conducted from an LIS perspective, several interviewees asked about specific medical issues. Other interviewees asked about particular alternative treatments or sources of information:

'ALISON: Is there anything else you'd like to tell me about it, or ask me?

DEBORAH: No it was the amazing properties of Sea Buckthorn, have you heard of this?

ALISON: I haven't heard of that actually no.

DEBORAH: That's supposed to be marvelous, its got omega 7 in it, I just quickly read it through and thought oh I ought to find out some more.'

It was sometimes possible to pass on information about potentially useful information sources (e.g. the National Osteoporosis Society and the EarlyMenopauseUK Website) and some interviewees said that thinking about issues through involvement in the study would prompt them to go to their GP or the menopause clinic for further advice, e.g.:

'I talked to the nurse, and my GP and procrastinated for a while, and eventually went back to the [clinic]. In actual fact I was reminded by your letter.' [MAUREEN]

#### *4.5.2 Validation with flexibility*

Whilst research should of course rigorously ensure that standards of validity are maintained to permit useful conclusions to be drawn from it, a study such as this one also calls for flexibility to respond to the needs of individual participants thereby meeting both the ethic's committees' aims of safeguarding dignity and wellbeing and the feminist-influenced aims of treating each participant with honesty and as a partner in the research process. The internal validity of a research design ensures that a study can sustain the

conclusions drawn from it (de Vaus, 2001). In this study, a triangulated approach using both questionnaires and interviews was taken to support confirmation of the validity of findings, the viewing of issues from different perspectives, and to reduce the impact of limitations of individual methods (Hart and Bond, 1995). Smith (1997) points out that it is difficult to have different kinds of qualitative data that line up exactly but since in this study similar themes emerged from both the interviews and the free-text questionnaire responses, the findings can be considered with greater confidence.

Further validation was sought through a process of member checking. This process is related to Lincoln and Guba's concept of 'negotiated outcomes' in which facts and interpretations are subjected to scrutiny by the respondents who earlier acted as sources of information. Member checking, or respondent validation, requires that the researcher provide the study participants with an account of the findings. According to Bryman (2001, p. 273) there are several different forms of respondent validation:

- The researcher can provide each participant with an account of what was said in the interview.
- The researcher can feed back to a group of people or organization the impression of his/her findings e.g. to gauge a response to a draft report.
- The researcher can ask a group of people or organization to comment on draft writings (e.g. articles or book chapters).

Bryman points out that although respondent validation has the laudable aim of ensuring that there is good correspondence between the researcher's findings and the perspectives and experiences of participants, it is not without problems since it may induce defensive reactions from participants, there may be a reluctance on the part of participants to criticize the researcher, or participants may struggle to understand the researcher's analysis that was intended for an audience of peers.

In a process of respondent validation, each interviewee was asked whether they would like to see a hardcopy version of their interview transcript for comment (*see* Appendix

20) or receive information about the results following analysis. Twelve of the 35 interviewees asked to see a printout of their transcription and of these four requested that some comments be either removed or altered. Interviewees were sent a copy of the Executive Summary of the clinic evaluation report (Appendix 21, *see also* Appendix 2). GP interviewees were also given the opportunity to review their transcribed interviews and were sent a copy of the Executive Summary. A draft version of the full community menopause clinic evaluation report was sent to the Lead Clinician at the clinic for comment. She was also given the opportunity review and comment on the Executive Summary.

Flexibility of approach was achieved through the use of a semi-structured, flexible, interview schedule which was intended to allow women the freedom to tell their own stories whilst providing a checklist of topics to provide a structure for women who required some support and to make sure important topics that would allow comparison with McKenzie's results were not overlooked. Making a decision on the extent to which the interview schedule should or should not reflect the questions in McKenzie's schedule was challenging since there is little precedent of researchers testing other researchers' models. In their work testing two models of information behaviour in the context of visually-impaired people, Beverley et al., (2007) drew on the results of a systematic review of the literature to inform their research design (Beverley et al., 2004). They also used a topic guide to structure the interviews which was piloted with two of the visually-impaired advisors to the study and amended to reflect their comments. This study was different in that the authors tested their findings against two models one of which (Wilson's 1999 model) is a very well-established model that is itself a revised version of an earlier model and the second (Moore's model of social information need) is specific to the needs of visually-impaired people and had been used by the Royal National Institute for the Blind as part of a review of information needs and provision.

A key criticism of taking a naturalistic approach, and indeed of qualitative research in general, is that such studies lack objectivity and generalizability which impact on validity since they tend to be drawn from small samples in specific contexts (Myers, 2000;

Bryman, 2001). Lincoln and Guba (1985) suggest that different criteria should be used for assessing qualitative research to those used for quantitative studies. They propose that concepts from quantitative research could be translated into elements that would help establish the ‘trustworthiness’ of qualitative studies and recommend the use of:

- Credibility (to be established through the process of member-checking);
- Transferability (whether the findings from one context can be transferred to another which can be established through the use of ‘thick description’ to provide other researchers with sufficient information to make judgements about transferability);
- Dependability (which requires the researcher to include process notes and provide an accessible account of the research process);
- Confirmability (which requires an understanding of the fact that complete objectivity is not possible in qualitative research and that the researcher should provide a reflective account of the study to demonstrate that she has been conscious not to allow personal values to influence the process).

Cho and Trent (2006) call for a holistic approach to validating qualitative research that includes elements of thick description, member-checking, and other elements of ‘trustworthiness’ but which is also flexible and accepts that validity strategies in qualitative research cannot be defined to the extent that they are equal to those of conventional research methods. It is with this in mind that this thesis has been written from a reflective viewpoint and has sought to establish the level of transferability of results between the twin-pregnancy and menopause studies.

#### *4.5.3 Limitations of the study*

In common with many other studies of the information-behaviour of homogeneous groups, this study is small-scale (Case, 2007). This was not due to problems recruiting participants but to the logistics of there being only one researcher. Many women volunteered to be interviewed but the time constraints imposed by the granting of ethical approval for a defined period limited the number of women that could realistically be



selected. A far greater number of participants, however, were able to take part in the questionnaire element of the community menopause evaluation. Although many of the questions were specific to the service provided by the clinic, many responses (particularly to free text questions) also fed into the broader discussion of women's experiences of the menopause transition. Interview responses from GPs again contributed not only to the menopause clinic evaluation but to wider discussions such attitudes to CAMs and keeping up-to-date with the evidence.

The majority of the interviews (26 of the 35 midlife women and all of the GPs) were associated with the community menopause clinic strand of the study. This has several implications. These interviewees all came from the same geographical area and this sample of midlife women had all found the menopause transition impacting on their lives enough to prompt them to actively seek advice or information. Attempts were made to balance this cohort of interviewees with women from a different geographical area and whose experiences of the menopause transition had not necessarily resulted in them seeking advice or information from health professionals. One further interviewee was identified from the town in which the clinic was based but who had not visited it and a further interviewee self-selected herself by making direct contact and asking to participate in the study. By coincidence she also lived in the geographical area served by the clinic but she did not know of it prior to the interview.

Although the study participants were not strictly self-selecting they were voluntary participants which has potential to affect the internal validity of the research. It is possible that only clinic attendees who had experienced the greatest problems with their menopause transition and with seeking information about it volunteered to take part in the study and that their opinions were therefore not representative of the majority. As strict confidentiality rules were conditions of the granting of ethics approval it was not possible to establish this. No access was permitted to records at the community menopause clinic and it was not possible to match interviewees to completed questionnaires. If a point was raised both in a questionnaire and by an interviewee there was no way of establishing whether both comments originated from the same participant. The inclusion of

interviewees from the non-clinic settings therefore added greater validity to the study since their responses could be checked against those of clinic attendees. Although not taking a true grounded-theory approach, it was possible to establish that ‘theoretical saturation’ in the sampling had been reached: no new coding categories emerged from the analysis of the non-clinic participants beyond themes relating to the fact that some had not sought medical advice in managing their menopause transition. This was by definition different to the clinic-attendees but these themes were themselves confirmed by several non-clinic participants.

It had been hoped that the provision of demographic data in Section Three of the questionnaire would permit more in-depth analysis of the questionnaire findings. However this was not possible. During discussions with the Lead Clinician at the time of preparing the questionnaire the questions chosen for this section had appeared relevant. However, when returning to the data after completion of the study it was apparent that a different set of data would have yielded more useful results. For example, given that women who had experienced an early menopause (whether surgical or natural) identified themselves as experiencing particular problems in finding information it would have been useful to investigate whether questionnaire responses from women who had experienced an early menopause differed from those who had not. This however is not achievable with the demographic data supplied. Only the women who had a surgical menopause can be identified not those with a natural yet early menopause. Furthermore, in comparison to the two earlier sections of the questionnaire, response rates in Section 3 were low with 22.1% of women failing to respond to question 10 and 30.7% to question 11.

Although the stated aim was to be flexible about the interviewing process, some women were less talkative than others and required a more structured approach. This may have influenced the results in that it directed discussion towards topics on the interview guide rather than allowing interviewees to themselves define the relevancy of topics. The care home interviews were more structured than many of the community menopause clinic interviews. It is possible that some of these interviewees were inhibited by the fact that they were in their place of work or by the fact that their manager had asked them to

participate. Every attempt was made however to ensure that participants knew they could change their minds and decide not to participate and to make the environment as informal as possible. The care home staff worked together as a team and had strong interpersonal relationships which helped to make the atmosphere less intimidating than it might have been in a different work environment.

Ideally all interviews would have been conducted on a face-to-face basis and this was the original intention. There are acknowledged disadvantages to telephone interviewing, especially for in-depth qualitative interviews, since it clearly limits opportunities for the researcher to observe the interviewee and pick up non-verbal clues that might help interpretation or alert the researcher to the interviewee's feelings about their responses or about the interview itself (Bryman, 2001; Frankfort-Nachmias and David, 1996; Payne, 2004). Furthermore, it is possible that interviewees may be more reticent on the telephone, not wishing to impart sensitive information to a stranger they can't even see. Gorman and Clayton (1997) give advice on telephone interviewing and suggest using open questions and ensuring that the interviewee is given plenty of time to reply fully without the interviewer jumping in at every pause. Payne (2004), on the other hand, suggests that a lack of physical presence may be an advantage in that respondents are less likely to react to an interviewer's appearance and may feel safer in an anonymous 'relationship'. However, feminist researchers have stressed the value of face-to-face encounters with participants that foster relationship-building and where the process 'placing' of the researcher by weighing her up and assigning the attributes of wife/mother etc. is an important step towards consolidating a relationship and finding points of commonality of experience (Finch, 1993; Oakley, 1981).

Comparison of the experiences of face-to-face interviews and telephone interviews suggests that in this case the quality of the experience and of the information provided was not greatly influenced by the method of interviewing. There was no attempt to make notes during the interviews but a tape recorder was used (apart from one telephone interview when the tape recorder did not function correctly) and it was therefore possible to give full attention to the interviewee throughout. Every attempt was made to remain

sensitive to the need to give telephone interviewees time to think through their replies and any points of uncertainty were clarified since there were no visual clues to aid interpretation. On the whole interviewees responded well to the menopause-story approach adopted and talked openly about their experiences and personal situations including about issues that could be considered sensitive. Since this was not a longitudinal study permitting the building of a relationship over several visits it is hoped that the potential inhibiting factors associated with telephone interviews had only a slight effect on this particular study. However it is not possible to confirm this definitively since none of the menopause clinic women were interviewed face-to-face for comparison and, indeed, each interview was very much flavoured by the personality of the interviewee and the dynamics of the interaction between interviewee and researcher.

A further limitation is the fact that it was not possible to transcribe all of the interviews personally. Ideally transcription should be carried out by the interviewer and as soon as possible after the interview so that the event itself is fresh in the researcher's mind. In this case that was not possible due to personal circumstances (transcribing is extremely time-consuming and can be expected to take around six times as long as the original interview (Bryman, 2001)). An experienced transcriber was employed and her work was both spot-checked against the interview recordings and compared against the transcriptions completed by the researcher (12% of the recordings).

Identification of the limitations of a study is essential for validation of the findings and for understanding how far the results can be interpreted within the wider context of the literature. It is also an important element of the process of reflexive analysis. The researcher must be aware of how things could have been done differently and how far the results obtained may have been influenced by the way they were obtained. Since there is little precedent for this type of study (testing another researcher's model) many decisions about research design were taken without the benefit of other researcher's experiences to provide guidance. It is hoped that this discussion of the limitations of this project would help inform the decisions of other researchers hoping to carry out a similar type of study.

## 4.6 Summary

The aim of this chapter was to describe the process of developing and carrying out the study, and to ground it in a methodological approach with sensitivity to the challenges of using the data to test another researcher's model. Chapter Five will present the findings under the themes of: how the menopause impacts on women's lives; how study participants were managing their menopause transitions; their experiences of encountering information and support; and the challenges experienced by providers of information and support.

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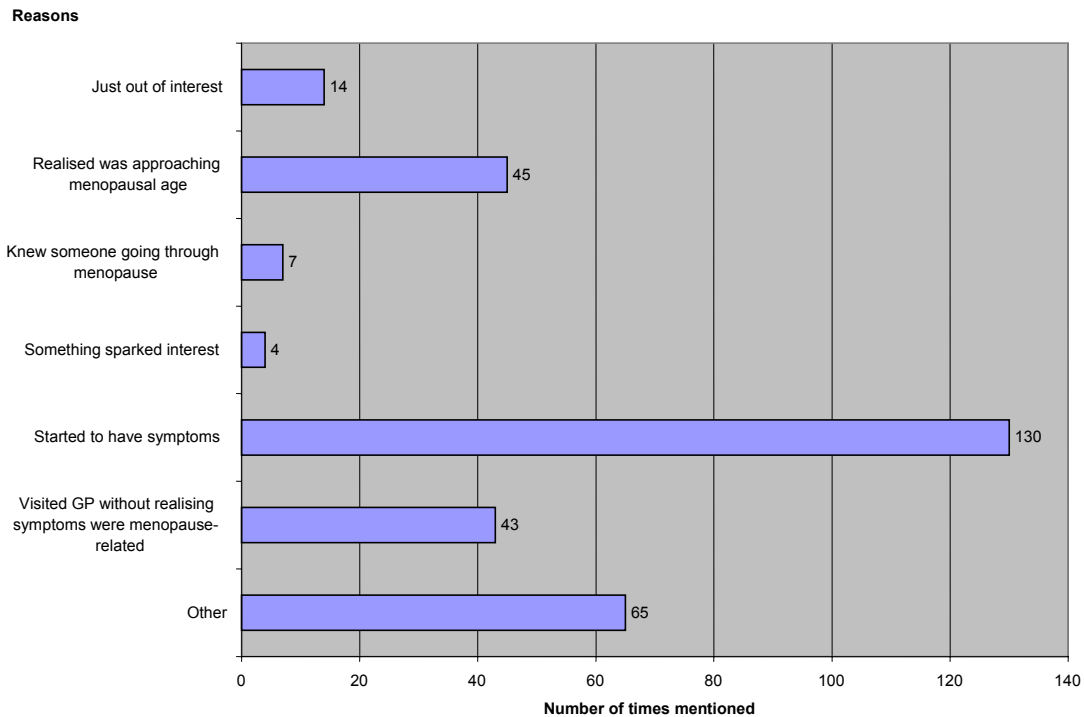


# Chapter Five: Accounts of the Menopause Transition

## 5.1 Impact of the menopause on women's lives

As explained in the Methodology chapter, most interviewees responded to the request for their 'menopause stories' with what seem to be very frank accounts of their menopause transition and the way it impacted on their lives. Although most of the interviewees came from the community menopause clinic sample and therefore tended to have experienced sufficient discomfort with or anxiety about the menopause to prompt a visit to the clinic, their individual experiences and attitudes towards what was happening to them were varied. The inclusion of participants from the care home and of the two women recruited after the community menopause clinic interviews had taken place provided insights into experiences of women who had either not sought or not had access to the services of the clinic, and participants' stories provided a rich seam of information about the menopause transition and its meaning for individual women. The number of interviews (35 with one response by letter) makes it impractical to provide in-depth profiles of each individual participant but Appendix 22 briefly summarizes whether each interviewee had experienced/was experiencing a natural or surgical menopause, her HRT-status at the time of the interview, and any relevant research notes including details of which sample each participant was drawn from (i.e. clinic/care-home/other).

Questionnaire respondents (from the community menopause clinic sample) were asked what had first triggered their search for information and/or advice about the menopause. The results are shown in Figure 5.1.



*Figure 5.1 Reasons why questionnaire respondents first started to look for information/advice about the menopause.*

By far the greatest number of women cited experience of menopause-related symptoms as a reason for their desire to locate information/advice about the menopause. The need to understand and manage symptoms was also widely cited by interviewees as a dominant theme of their menopause transition. They reported a range of symptoms including:

- Depression (e.g. Hannah, Janice)
- Dizziness (e.g. Louise)
- Excessive tiredness (e.g. Imogen)
- Feeling constantly hot (e.g. Grace)
- Feelings of ‘lowness’ and ‘dread’ (e.g. Imogen, Sylvia)
- Forgetfulness and lack of concentration (e.g. Angela, Hannah, Viv)
- Heavy periods (e.g. Helen)
- Hot flushes (e.g. Belinda, Fiona, Jane, Kathleen, Nicola)
- Insomnia (e.g. Viv)

- Irritability (e.g. Isobel)
- Lack of energy and ‘buzz’ (e.g. Olivia)
- Migraines and severe headaches (e.g. Denise, Kate, Sally)
- Mood swings (e.g. Imogen, Jane)
- Night sweats (e.g. Kathleen, Olivia, Sylvia)
- Painful intercourse (e.g. Sylvia)
- Panic attacks (e.g. Viv)
- Weak bladder (e.g. Deborah)

Menopausal symptoms impacted significantly on interviewees’ quality of life and could persist for many years. Belinda thought her menopause transition had been going on for ten or twelve years and was still experiencing hot flushes in her early sixties. One GP interviewed as part of the community menopause clinic evaluation confirmed that up to ten percent of women can continue to experience hot flushes for the rest of their lives. Fiona had been experiencing hot flushes for over twenty years and still suffered several a day:

‘And I’m nearly boiled alive. And I get them through the night. I sleep, well I haven’t slept in a nightdress for ages. I can’t sort of bear one on. The duvet goes on and off and often it’s just the sheet and the duvet over me feet so that me feet don’t go cold.’

[FIONA]

Sylvia would have to take towels to bed, so severe were her night sweats. She would wake up in the morning with three nightdresses strewn across the floor from changing during the night. She also talked about waking in the morning with feelings of dread:

‘And also one of the other things is you wake up in the morning getting these feelings of dread. If you wake up in the night or in the morning, real horrible dread and I read that as well somewhere recently, you get this feeling and you have to tell yourself “for goodness sake you’ll feel alright at ten o’clock” at six in the morning. It comes over you like you are going to die next week or something.’ [SYLVIA]

Hannah also experienced feelings of sadness and anxiety that something horrible was going to happen to her. It was as though ‘a black cloud’ had descended on her and, despite the fact that she considered herself to be a normally happy-go-lucky person, she ended up sitting in her GPs’ surgery in tears without knowing why. Hannah also found that she had problems making decisions and remembering things at certain points of her menstrual cycle and was even thinking that she would have to change her job:

‘[...] that’s what was absolutely frightening to be honest with you. I was turning into something, for forty-odd years I’d been this person then all of a sudden I’m turning into somebody else.’ [HANNAH]

Hannah said that she had read a newspaper article about a woman going through ‘the change’ who felt that there was somebody else inhabiting her life. Hannah could equate to the feeling of looking in the mirror and finding somebody else there ‘you think you’ve done something and then all of a sudden you haven’t and that was really weird [...] there’s definitely another person there, it’s just very peculiar’.

For many women the menopause was having a destabilizing effect on their lives. Belinda also struggled with feelings of no longer knowing herself. She talked of being afraid of losing her brain, of her body being ‘out of control’ and of not knowing whether what was happening to her was part of a normal menopause experience. Denise described negative feelings sweeping over her unexpectedly so that she would want to sit down and cry for no apparent reason in the middle of a really lovely day. She found that these feelings would impact on her life and working environment (the care home) where she was expected to appear cheerful when carrying out her duties. She described it as ‘an awful feeling’ but said the hardest thing to deal with was lack of support, even from doctors. Rowena had also found contending with the menopause at work to be a challenge. She had been working in a male-dominated environment and knew she would have to cope with ‘the sexism one gets if they sort of get a hint of anything like that’. She described her menopause experience as being ‘a bit isolating’, partly because of working in ‘a

man's world' but also because she didn't really know anybody else who was going through it at the same time as her. Like Rowena, Jane had experienced a natural early menopause. Jane was in her early forties when test results confirmed that she was menopausal and she was finding it hard to adjust to her new status.

'It is really a shock, it's been like a year now and I still can't take it in, I feel like it's a dream really, you know when things happen and you just think oh god that isn't really happening.' [JANE]

Interviewees appeared to reflect on the menopause transition in the context of their whole lives. They saw it as a natural stage on the continuum of their own individual life and at the same time as enmeshed with the experiences of their mothers, sisters, friends and other women. They drew on the experiences of women they knew or had heard about to situate their own menopause and to help validate their own experiences. Hence feelings of isolation, of being different from the majority of other women, were particularly hard to deal with:

'I feel that I'm some kind of freak or something and it shouldn't be happening this early.'  
[JANE]

At the end of the interview, when I asked Jane whether she had anything else she wished to discuss, her question was: 'I'm not the only one at this age am I?'. Olivia had a close circle of friends that met up a couple of times a year. They had known each other since childhood and had offered each other support throughout the various stages of their lives. For Olivia this continuity of support reinforced her view of the menopause as just another stage, a natural life event:

'[...] but with the school friend group that's really quite funny because we've laughed at ourselves [...] you know, when your periods start, that age, and then here we are again discussing the other end of the process together. So it's quite funny [...] It's super really, yes I think it's best to laugh about it more and maybe it's made it feel more like a normal

process and less traumatic in some ways by the fact that we could, you know, share it with the same people.’ [OLIVIA]

Rowena and Angela (both in their sixties) also reflected on the process of ageing. Angela had words of encouragement for other women going through the menopause:

‘When you are actually going through menopause, when you are having a really bad time it just feels as though it’s all downhill but it isn’t and if you have got a family and you’ve got grandchildren and you retire you’ve got the time and you can focus your life in a different way. I myself write poetry that I wouldn’t have been keen on doing and now I can. I’ve got a more relaxed mind where I can sit and do it you know and you do come through it and no matter how bad it feels at the time it’s not bad being in your sixties.’ [ANGELA]

Rowena commented on the fact that perceptions of ageing have changed for current generations. She remarked that a woman aged over 60 in her grandmother’s day would have been ‘the chubby lady with the overall and the big bosoms’ and would have been consigned to the background. For today’s older women things can be different. Rowena found that it was not until she looked properly at herself in the mirror that she remembered what age she was. She knew that she did not want to be Peter Pan but neither did she want to be ‘old’. Being older could have advantages as families grow up leaving women with more time to devote to their partners, yet Rowena felt that unless women get the support they need with the menopause then it can impact on life at a time when things should be good – ‘it’s important that you are well in yourself’.

Women who had been through an early menopause faced particular challenges. According to the British Menopause Society (2008), the age of 40 is frequently used as an arbitrary indicator of premature menopause but many gynaecologists prefer to consider menopause earlier than age 45 as early. In this study the term ‘early menopause’ is used for participants who began their menopause transition before the age of 45 years since interviewees whose menopause transitions started in their early forties considered

this to have been earlier than anticipated. These women found themselves dealing with the consequences of the menopause, often unexpectedly, at a time when most of their peers had not given it any thought.

Six interviewees had experienced a natural (i.e. not induced) early menopause. Helen said that she worked in a healthcare environment and had suspected that her symptoms (heavy bleeding and weight loss) might be related to the menopause. Eileen on the other hand, who also worked in a healthcare role, did not initially suspect the menopause until she attended a talk from the Lead Clinician at the community menopause clinic organized by the Occupational Health Department at the hospital. Eileen had a young baby and assumed that her hormones were still unsettled from the birth. She felt like ‘a hopeless, inadequate female who just couldn’t get it together’ especially being an older mother surrounded by much younger women:

‘I can’t believe I was so ignorant about something that happens to half the world’s population. [...] I just never thought about it, never talked to anyone about it. I’ve really put up with a lot of symptoms for a long time before it dawned on me what it was.’

[EILEEN]

Nine interviewees had undergone hysterectomies. If a woman’s ovaries are also removed (oophrectomy) doctors recommend that HRT should be taken until at least the age of 50. This is also the case for women who have experienced a natural early menopause since both groups are considered to be at increased risk of osteoporosis and/or heart disease. HRT for an early menopause (whether natural or surgically-induced) is perceived to be merely replacing hormones that would normally be present. For these women evidence suggests that taking HRT until the age of 50 (i.e. average age of menopause in the population) does not pose any higher risk of breast cancer, heart disease or strokes beyond that found in menstruating women with a normally-timed natural menopause. Women who undergo hysterectomies but retain their ovaries may reach menopause a few years earlier than they would otherwise have done (MacGregor, 2006).

Jane was not alone in facing challenges dealing with an early menopause. Although Vicky's hysterectomy was not an emergency she felt that there was no time to 'grasp the whole situation' and that she was unprepared for the decisions involved and for taking HRT. Erica was in her thirties when her ovaries were removed, one following an ectopic pregnancy and one during a hysterectomy:

'I mean for three or four days after I had my ectopic pregnancy I still thought I'd had my appendix out, eventually they did tell me but they didn't tell me anything about how it can affect conceiving and that sort of thing. Eventually they sort of told me and then because I'd only got the one child, eventually I went to a gynaecologist who then explained to me that because I was only working on one cylinder basically it would be a little bit more difficult and after an examination he decided I'd got cysts or something on my ovary and I should have a hysterectomy, but no discussion about the HRT until afterwards and then very little, we've popped this in to make up for what you haven't got.' [ERICA]

Nicola acknowledged that going through a sudden menopause (her ovaries were removed) changes a woman's life and 'sets you apart in a way'. It alters a woman's self-image and is like 'losing a part of yourself'. Even if a woman does not want any more children it is still a shock to the system to have the end of the reproductive phase of life happen instantly. Nicola's personal coping strategy was to try and be open about things: she would happily sit at work with a cool pint of milk on her chest when having a hot flush and reacted strongly to glib comments. Men have asked her 'what's wrong with having your ovaries removed?' and Nicola would riposte with a comment like 'would you like me to chop your bollocks off?'. She suggested that ovaries are perceived differently because they are hidden away inside a woman's body. She had also received comments about having her 'womany bits' removed but would counter with 'are you saying I'm no longer a woman?'. Nicola responded to her situation by joining an online support group to offer support to other women.



As with those women experiencing natural menapauses, each individual had her own set of circumstances and interpretations of her situation. Ann was content to have her hysterectomy. She knew someone suffering menopause-related depression and felt that she was lucky to have avoided the potential disadvantages of a natural menopause. She felt that her family was complete and was philosophical about possible implications:

‘[...] I would recommend it to anybody. But they said “oh, your bones will go and you’ll get older quicker”. I don’t care if I do or not. I mean I haven’t had any problems.’ [ANN]

Like Ann, Barbara and Marion expressed relief to have found a solution to their problems. Barbara had suffered from pain and from heavy bleeding that restricted her social activities. Marion had known for a couple of years that she would need the operation and was glad to be rid of the pain she had been suffering. Although Ann was satisfied with her own status she showed sensitivity to the fact that not all women might feel the same:

‘ANN: [...] but I was just happy to have it done. I’d got two children, I didn’t have, I was 51 anyway so you wouldn’t want any then would you anyway, so no, I know some women have bad feelings about it don’t they.

ALISON: Yes

ANN: If you were young, yes I suppose you would wouldn’t you, because when I was in the hospital there was a few young ones in there having it done, I suppose because they had to.’

When Nicola was in hospital having her hysterectomy, her daughter started to menstruate for the first time. She didn’t like to tell her mother because she thought it might be ‘rubbing salt into the wounds’. She told somebody else who later told Nicola. Women’s menopause experiences are woven into the fabric of their lives and touch the people around them. They can last for several years and can provoke a woman to question who she is and undermine her self-confidence (like Hannah who felt she was losing her sense of self and began to doubt her ability to do her job) and can shape women’s interactions

with family, friends and colleagues. All interviewees offered glimpses of their personal circumstances, and indeed many were very frank in relating how the menopause was entwined with other elements of their lives. For some women there were issues of self-image and of accepting the ageing process. Rowena commented that there is a common perception that middle-aged women are seeking attention and struggling to accept the fact that they are no longer attractive. Belinda, Deborah and Denise all mentioned that they were concerned about putting on weight:

‘I just hate getting old, I have a much thicker waistline than I used to, I would love someone to tell me how to create a smaller waist because that seems to go part and parcel with this kind of early menopause I think, but I’d love a magic wand.’ [DEBORAH]

Life with the menopause takes place within the context of all the other things that are going on in a woman’s life. Several women were contending with complicated personal situations at the same time as dealing with their menopause. My contact at the Wellwomen Information centre, where counselling sessions were offered, explained that for many women the menopause occurs at a time when they may already be coping with other issues:

‘Trying to link it to menopause again, I was thinking when I was speaking on the phone to that woman just then how it’s so often an element in what people bring, but sometimes it is the thing, other people just want information, but so often with the work that we do anyway, it’s an element in something wider. About somebody who’s got anxieties about her house, she’s had bereavements, the responsibility for a young child, menopause might be part of it, so it’s part of the whole mixed bag...’ [WELLWOMEN INFORMATION]

In midlife, family responsibilities often come to the fore and relationships must adapt to take account of a woman’s changing perspective. At the time of Belinda’s menopause her mother-in-law was very ill and Belinda described the situation as ‘unbearable’. As Belinda suffered from thrombosis she was unable to take oestrogen but was so desperate to take something that would help her keep on top of her personal circumstances that she

asked to be prescribed oestrogen despite the danger to her health ('[...] it was the only thing that made me sensible because somebody in the family had to be sensible'). Denise had been through a broken marriage but felt this experience had given her a different perspective on her menopause. She reflected that a lot of people think it's a simple process from A to B but that actually it isn't. She had heard of people whose marriages had broken up because the wife no longer wanted to engage in sex as often as the husband. Denise felt that if she had still been in her first marriage this would have worried her but now she knew that if her current husband left her for somebody else because she didn't want sex as regularly she would be able to cope with the situation.

Not only did women seek to situate their menopause transition within the context of their life-course and of the environment around them, they also took account of other women's experiences of the menopause transition as a way of making sense of their own. There is evidence that a woman's age at natural menopause can be influenced by genetic factors thus reflecting her mother's age at menopause (Ashrafi et al., 2008; Murabito et al., 2005). Interviewees looked to their own close relatives' experiences of the menopause and related it to what they themselves were going through. Janice's mother had several major breakdowns which were attributed to her menopause and spent several years in private clinics. When Janice herself began to feel a bit depressed she assumed it was the start of 'the change' and went to see her GP. She was frightened that she would find herself in the same situation as her mother and was not reassured by the GP's response:

JANICE: At that time I, I was so desperate for an answer to how I felt and I was so worried about being, my doctor also told me that I, he didn't know my mother's history and he said "Most probably it'll be along the same lines as your mother".

ALISON: Oh right.

JANICE: And I thought "Oh my God!"

Imogen suffered from a feeling of lowness that took away her pleasure in things she used to enjoy, such as riding her horse, yet her mother told her that she had experienced no problems at all when she went through the menopause. Women described using their

close relatives' experiences to inform their decisions about management of the menopause. Tracy 'sailed through the menopause' after deciding to take HRT. Her decision was based on evaluating the experiences of both her mother and her sister:

'I started off I think at about 50 having hot flushes and night sweats, intermittently, nothing too bad and after a bit I just thought well my mother had horrible experiences of the menopause which have haunted me thinking about how terrible it was and she had in fact right to the end of her life, which was a long life she died at the age of 93, she continued to have sweats, these used to sweep over her and she'd be absolutely drenched in perspiration and I have a sister who's nine years older than me and she has always had the same thing unless she was taking HRT and so she told me she'd found it very good.'

[TRACY]

Charlotte struggled to weigh up the risks and benefits of taking HRT given that her mother suffered from osteoporosis yet her grandmother had breast cancer. Barbara elected to have her ovaries removed during her hysterectomy because there was a history of ovarian cancer in the family. However she was concerned by media reports about the breast-cancer risks associated with HRT because both her half-sister and her cousin had developed breast cancer and was finding it difficult to equate the level of risk to the type of HRT she was taking.

Extending their comparisons, interviewees regularly referred to friends, colleagues or other women they knew/had heard of anecdotally to provide a gauge by which to measure their own symptoms and feelings. Frances would listen to other women talking about 'what they had and this, that and the other' and then go home and think 'oh, I didn't have that'. Women with symptoms expressed envy for those whose menopause transition appeared to be passing by uneventfully.

'I've learnt that everybody, there's no, you know, such and such a time this is what you are going to go through, everybody is so different aren't they? So different, some get it

worse than others and I've heard some people say "it didn't affect me at all". I think "you lucky devil".' [DENISE]

Others felt themselves to be the lucky ones, either because they had been through hysterectomies and therefore avoided some of the issues of a menopause (e.g. Ann) or because they had simply experienced fewer symptoms than other women they knew:

'I've been very lucky according to what other people have said they've had, just had at night the odd flushes and that, and that's about it. I'm not on HRT or anything like that. I haven't bothered with that.' [EMMA]

Kate also felt she had been lucky to have relatively few symptoms and suggested that women tend to 'put things down to the menopause' but sometimes wonder whether their problems are menopause-related or not. Eleanor had a friend who had started her menopause early. The friend suffered from a range of symptoms including emotional disturbances but nobody believed that she was going through the menopause, including her GP. Eleanor sympathized with her friend and acknowledged that 'you can sometimes feel like a bit of a failure because you are feeling like this, which she did, which is a shame'.

Looking at the experiences of women around them provided a frame of reference to help women make sense of their own menopause transition. They empathized with other women and saw the menopause as a common experience that only another woman could truly understand. Several interviewees mentioned that men, whether partners or health professionals, failed to appreciate what they were going through, although Sylvia described her husband as 'a rock' and Eve said that she talked to her husband about the menopause 'not that he can help much'. Denise said that her husband was not very supportive and was 'kind of in horror' at the idea that she might be going through the menopause. Belinda and Janice both talked about communication barriers with their GPs which they attributed to a lack of understanding because men do not go through the menopause themselves. Despite the commonality of experience there was also acceptance

that each woman's experience of the menopause would be different, that each woman faces her own individual challenge and that this can at times be isolating. Nicola, who suffered from severe hot flushes following her hysterectomy, found that women who had not experienced a hot flush were embarrassed by her plight – they knew that one day it might be them in that situation and so did not want to 'take the mickey' but Nicola felt they were thinking 'thank God that's not me'.

## 5.2 How were women managing their menopause transition?

In striving to put the menopause into perspective in their lives women used a number of coping mechanisms. As well as using the experiences of others as a frame of reference for their own situation, they turned to a range of formal and informal sources for advice and support (*see* Section 5.3) and attempted to maintain a positive and healthy attitude. Exercise and a sensible diet were seen as ways of promoting health during the menopause and several interviewees mentioned that they thought their own outlook on life would help them through. Angela, Denise and Olivia all felt that being able to laugh about what was happening to them helped them feel better. Kate saw herself as an outgoing person and found it easy to talk to other women and exchange useful information. Marion had her hysterectomy in her early thirties and at the time of the interview most of her peers had still not reached their menopause. Although she had few people with whom she could share experiences Marion said that she was the kind of person 'that just gets on with things' and didn't find her situation a problem.

Several interviewees stressed that they saw the menopause as a natural stage or, as expressed by Angela, as 'part and parcel of life' and some expressed a preference for taking a 'natural' approach to managing their menopause transition. Whilst acknowledging that her view was perhaps a bit stoical, Olivia said that she felt that the menopause was a natural process and that there should therefore be natural ways of banishing it. Emma tended to avoid visiting her GP unless she was 'really poorly'. She didn't like the idea of HRT and didn't 'believe in taking a lot of this and that for things'. She thought that, if anything, she would prefer to visit a 'health shop' Imogen also felt that the menopause was natural and should not require medical intervention:

‘[...] I didn’t agree with the fact that I was taking something that would put off what was a natural process of my body... that’s what I think I was against more than anything, it didn’t worry me about the sort of cancer side of it as such and all that bit it, it was just the fact that I felt that if this is a natural thing, and you get all other people’s opinions don’t you.’ [IMOGEN]

Beyond her feeling that the menopause was a natural part of ageing, Imogen was further deterred from taking HRT by her strong feelings about the way some hormone replacement products are produced. Some preparations are made from conjugated equine oestrogens which are derived from the urine of pregnant mares (MacGregor, 2006; Murray, 2001). Imogen and also Kathleen were concerned about the ethics of producing this type of HRT. Kathleen asked to be taken off a conjugated equine oestrogen product because she wasn’t happy with the way horses were treated. Although her GP sought to reassure her that the mares were well-treated, Kathleen said she had heard otherwise from her sister and from something she had read. Kathleen changed to an alternative product.

A wide range of CAM approaches had been tried by participants including:

- Acupuncture (Sally)
- A mixture of seeds that can be made into bread/cake intended to help calm menopausal symptoms (Angela, Gwen)
- Black cohosh (Fiona)
- Calcium (Fiona)
- Dong quai (Belinda)
- Evening primrose oil (Frances, Olivia)
- Hypnosis tapes (Viv)
- Increased intake of soya (Belinda, Fiona, Viv)
- Olive oil (Sylvia)

- Proprietary preparations (mixes of supplements, vitamins and minerals aimed specifically at perimenopausal women, e.g. Confidence and Flash Fighters) (Gwen, Isobel, Rowena)
- Reducing wheat in the diet (Viv)
- Vitamin supplements (Belinda, Gwen, Olivia)

Feelings about the effectiveness of the treatments were mixed. Angela found that the seed-based loaf of bread which she had read about in a magazine and seen on television made her feel sick so she only tried it once. Frances and Olivia had both tried evening primrose oil but neither found it effective:

‘Yes I tried evening primrose oil and that was no use whatsoever. B vitamins and of course in fact most of what’s recommended seems to be what was always recommended for PMT, and they didn’t work for that either!’ [OLIVIA]

On the other hand, Isobel had a very positive experience of using a CAM product to control her frequent hot flushes (she could have as many as twenty hot flushes in one hour). She had been to a health food shop and the assistant had advised her to try a product called Flash Fighters which she thought were ‘terrific’. Gwen was trying a combination of Vitamin B6, a different CAM product, and a mixture of seeds similar to those found in the menopause bread/cake. She also confirmed that she was feeling better after starting the products.

Gwen and Sylvia both mentioned reluctance to take a product after they came across negative reports about safety. Sylvia was wary of trying St John’s Wort because she ‘had a horrible feeling’ she had read something about it and Gwen had stopped taking black cohosh after reading that ‘they found it done something in your body’. Other reasons cited for not using CAM products included the prohibitive cost (Grace referred to products costing £20 or £30 for a seven-day supply), lack of time and inclination (Isobel’s sister had made the herbal cake tried by Angela in its alternative loaf form but



Isobel herself ‘couldn’t be bothered’ to cook it), and a dislike of ‘ferreting around for information’:

‘I like the one-stop-shop idea, go in, state the problem, get the answer and it doesn’t strike me that [i.e. using CAMs] would be a quick and easy solution, so no I haven’t pursued that. [...] I’ve gone straight to the GP and expected him to come up with the answers.’ [LOUISE]

GPs themselves expressed caution about CAM approaches. Although they acknowledged that patients were interested in products like black cohosh and red clover, they felt unsure of the evidence base and didn’t necessarily feel they could give advice about these products. They were concerned about the lack of controlled trials of CAM products and about the lack of controls in the market:

‘[...] and there’s no standardization as to what’s actually in a preparation because of the fact that it’s regulated as a food supplement and not as a medication. So in a way patients aren’t very well protected when they take these sort of things.’ [GP3]

This GP also expressed concern that patients tend to believe that ‘things that are natural are good for them and that’s not always the case’. Having said that, she reflected that patients do seem to get better through taking red clover and by increasing Soya and chickpea intake in their diet and commented that although the results may not be as dramatic as those achieved by the use of HRT the side-effects, as far as health professionals are aware, are less unpleasant. She said that she was not surprised that patients tried different remedies when seeking symptomatic relief and that she tried to keep an open mind. This GP had a particular interest in the menopause and said that she had only once referred a patient to the community menopause clinic because she liked to work with these patients herself. GP 4 was willing to pass on anecdotal information about the effectiveness of alternative/complementary remedies to patients but always stipulated that it was not his advice but simply what other patients had told him. Echoing Grace’s concerns about the cost of these remedies, he pointed out that some women may end up

spending a lot of money on something that isn't necessarily proven. GP4 and GP5 both said they would like more research on and information about CAMs but both acknowledged that it was probably 'wishful thinking'. GP5 had been told that there is little financial incentive for these trials to be conducted. She felt 'very much at a loss' when women came to ask for advice about alternative ways of controlling menopausal symptoms because she herself had not been through the menopause and therefore didn't know what it felt like.

Of the 36 interviewees (including one letter response), 30 (83%) had at some point used hormonal replacement treatments of some sort although 12 had stopped taking HRT altogether and several others were either considering stopping or were in the process of 'weaning' themselves off. The high level of HRT-use among the interviewees is not surprising given that the majority were recruited through the community menopause clinic and had therefore suffered symptoms severe enough to require medical consultation. To put this into some context, it has been estimated that in 2003 less than 26% of British women aged 57 years were taking HRT (Mishra et al., 2006).

Experiences of HRT-use were mixed. For many women HRT provided relief from intolerable symptoms. A mild dose of HRT 'made a hell of a difference' to Eve's night sweats and Frances, who's periods were so heavy they made her feel ill, found complete relief from her symptoms. Despite Imogen's initial reluctance to take HRT she felt so unwell that she reconsidered her decision:

'In the end I spoke to one of the consultants [...] I said "I don't want to go on HRT and yet I just feel so bad, I feel all worried about it and everything" and she said "Go on it. I guarantee you within three to four days you'll feel a different person" and I thought "I've got to do it, I can't live like this". I just felt so awful in myself, so I went on it [...] and I haven't looked back.' [IMOGEN]

For others the quest to find the right product and dosage was long and arduous. Isobel's story illustrates how long the journey can be for some women:

‘ISOBEL: I went along [to community menopause clinic] and had a chat to them yes, it was [Lead Clinician] herself.

ALISON: What was the outcome of that?

ISOBEL: Well the outcome was that they said they would try and find an oral contraceptive that would suit me so they put me on one for about 3 months, I did have a history of fibroids as well, they thought I had fibroids because of the heavy periods, and I kept having more abdominal pain in between and spotting in between, so they changed the pill, gave me another one, that wasn't suitable, I felt a bit of a pest but they said it doesn't matter this is what happens, I tried a couple more pills and I also tried the patches. The patches I was allergic to the patches. In the end I asked if I could have a m-coil fitted because I know that there is a hormone implant in the m-coil, isn't there, and it's also very good for heavy bleeding, so I started using the m-coil for a couple of years along with HRT supplements. I had to go along to my doctor, to my own GP once, I can't remember what for but we got talking about the HRT and my own GP decided to lower the dose because she said as seen I was having the m-coil I was still on quite a high dosage so my own GP cut the dosage in half.

ALISON: Did you notice any difference?

ISOBEL: Well the thing was even though I've still got a m-coil the periods did reduce themselves considerably but I was hoping that they would eventually stop, as often they can do using the m-coil, they never actually stopped and I would often bleed in between periods and if it wasn't fresh blood I would have a heavy old blood discharge. This lasted until I was about 54 or 55 and I asked could I then go onto a no-bleed pill because I was still having bleeding all that time. I went through a period of four years, I only ever went through one three-month period without having a period. So when I came of age for them to change the pill because I was still bleeding I actually asked for the m-coil to be removed and could I go onto a no-bleed pill, which they did do and I still continued to bleed. In the end they decided to send me for a hysteroscopy and I had that performed last year and on the advice of the gynaecologist they advised that I stop taking the HRT because it was due to hormone imbalance totally. I stopped taking the HRT, I had one

massive period when I did stop taking it which was last September and I've had nothing else since, until last week I started another period.'

Like other women who had been through hysterectomies, Erica was initially given implants. In Erica's case these were paid for through private health insurance from her husband's job. Then she moved and her GP said she would no longer be able to get the implants. Erica therefore tried various tablets and jelly but found them inferior to the implants. Eventually she was able to try implants again, this time paid for by the NHS, but her body rejected them and they 'popped out all the time' leaving her looking 'like a battle zone'. Vicky was hoping that the community menopause clinic would provide implants since she found the process of going through the system every six months 'a lot of hassle'. She tried oestrogen gel as an alternative but knew that she would struggle with it because she had never been any good at doing something on a daily basis. Ann had tried implants and patches but the patches didn't make her feel any different and they would fall off in bed or get stuck on her husband's foot. Marion found the delivery-methods difficult for a younger woman. She said 'I didn't want to have a HRT patch stuck on my bum' and didn't want people to know that she needed HRT. Looking back she acknowledges that she probably had more of a problem with the concept of taking HRT than with the physical taking of it 'which now sounds a bit stupid really but at the time it was a fairly big deal I think for me'.

Several women who were considering stopping/reducing HRT, whether on the advice of health professionals or because they chose to, expressed uncertainty and concern about the possible recurrence of symptoms. Eileen said this was something she would need to ask about and Barbara was hoping to avoid her sister-in-law's experience of feeling 'quite awful' within a few days of reducing her HRT dose. Fiona had ceased HRT only to enter what her GP called 'mini menopause' which was likely to last three months. So far it had lasted two years and Fiona was concerned that if she ever started taking HRT again she would have the same problems again at some point in the future:

‘What’s going to happen if I go on again. Am I still going to have to go through that again? That I suppose is the question I haven’t asked. Uhm, because nobody tells you that.’ [FIONA]

Not surprisingly, concerns about the risks of taking HRT exercised many of the interviewees and were a key factor in their decisions about managing their symptoms. Denise, Eleanor and Olivia all mentioned that their decisions not to take HRT were influenced to some extent by concerns about the risks, although they were careful to weigh up their options and Olivia noted that she did not necessarily want to ‘buy into’ the scaremongering that followed reports in the press. Eve chose to stop taking HRT because she was anxious about a bleed but she was also conscious of press reports about safety issues:

‘[...] but there is always the risk you know you read about reports don’t you in the paper, they keep coming up about heart or breast cancer and I examine myself and do all that.’ [EVE]

Weighing up the advantages and disadvantages of taking HRT can be challenging. Grace said that she had received confusing advice from a breast surgeon. She had been for a biopsy following a mammography and had been told there was granular tissue in her breast. The surgeon said that it was probably due to HRT but could not say whether the tissue would turn malignant if she stayed on HRT. Grace had done some research on the Internet and had found information claiming that ‘HRT is good for granular tissue in the breast’. Unfortunately it wasn’t on her own computer so she couldn’t print a copy to show to her doctor. She felt that ‘you sort of run round in circles’. Tracy also found the situation confusing:

‘Well yes I read woman’s magazines from time to time and whenever there’s an article I read it with interest. Obviously I listen to things on the media and sometimes I’m quite concerned by the adverse publicity for HRT, it stops you in your tracks and makes you think am I doing the right thing, you know is this a silly thing I’m doing, am I going to

finish up with breast cancer or something else, is it worse than having hot sweats and night flushes? So yes that's all quite confusing [...]'. [TRACY]

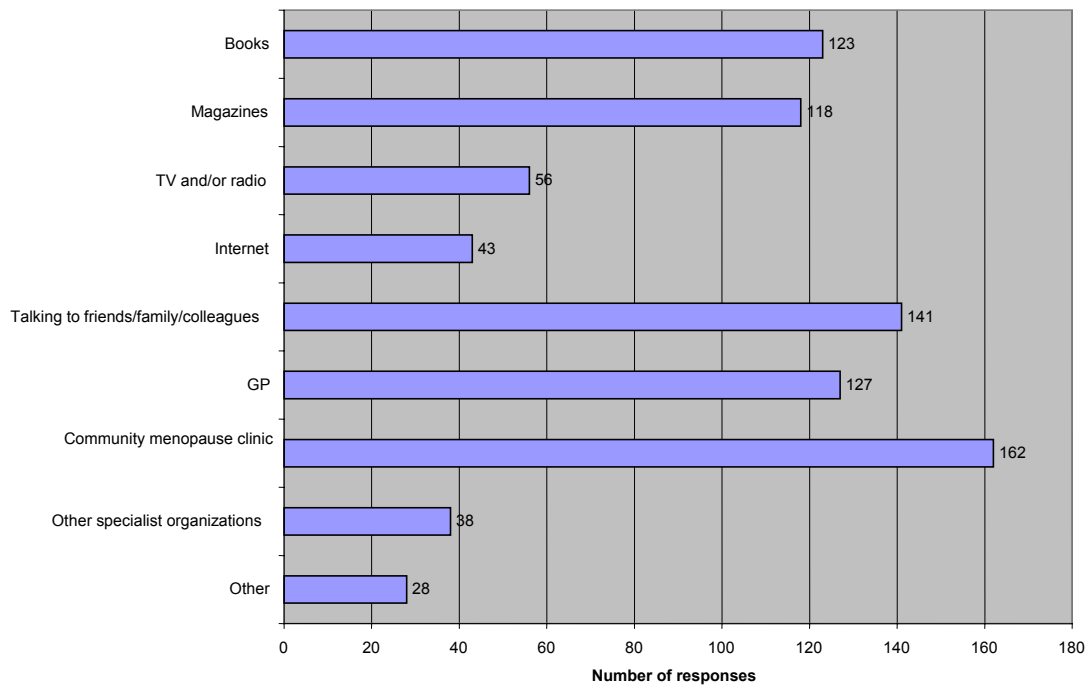
Some interviewees had come to terms with the risks or had tried to adopt a philosophical outlook. Angela pointed out that when she was younger tomatoes were thought to pose a health hazard but that now people are advised to eat as many tomatoes as they can. Her own attitude was that, unless something was 'absolutely positive and proved', you have to go along with the advice you are given 'because they wouldn't advise you to do anything that was dangerous anyway, not knowingly'. Charlotte decided to keep taking HRT because her mother suffered badly from osteoporosis. Hannah had a history of breast cancer in her family and discussed the pros and cons of HRT with the staff at the community menopause clinic. On balance she felt that her menopause symptoms were so unpleasant that she was not 'living life' and that she would prefer to take HRT and accept the risk:

'I'd rather have the tablets and have both breasts removed than feel the way I did, it sounds silly really but it's a horrible feeling.' [HANNAH]

### 5.3 Encountering information and support

To guide and support their journey through the menopause participants had turned to a range of resources. Questionnaire respondents indicated that they had referred to both formal and informal resources in their search for advice and information (Figure 5.2).

#### Sources



*Figure 5.2 Resources used by questionnaire respondents when looking for information and advice about the menopause.*

Respondents were given the opportunity to provide further details about the resources they had accessed. For example, respondent Q119 commented that she had found a particular book by Dr Miriam Stoppard very useful, and respondent Q121 had asked her mother and sisters about their age during the ‘change’. Respondents did not appear to differentiate between ‘other specialist organizations’ and ‘other’ sources of information, and mentioned the following resources in the combined results of these categories:

- The Menopause Amarant Trust
- Marie Stopes
- The Women’s Nutritional Advisory Service
- MIND
- The Daisy Network (previously Daisy Chain)
- Women’s Health Concern
- The Menopause Exchange

- An unspecified menopause helpline
- NHS Direct
- Health professionals (occupational health nurse, nutritionist, practice nurse, medical specialists e.g. gynaecologist)
- Family Planning
- Education sessions/talks/study days
- Well Woman Clinic
- Health food shops
- Alternative therapies (acupuncture, Bach Rescue Remedy, homeopathy, reflexology, aromatherapy)
- Leaflets (from GP, Well Woman Clinic, the community menopause clinic, Boots)
- Own knowledge-base as health professional (including access to medical journals)
- Websites from Royal College of Obstetricians and Gynaecologist and university department

From this list of resources it can be inferred that participants' interests reflected many of the same issues as those explored later in the interviews including: CAMs, mental health, early menopause, and nutrition. This is not surprising given that the majority of interviewees had also contributed to the questionnaire survey. Questionnaire recipients were specifically asked which issues they had needed advice/information about and their responses can be found in Figure 5.3.



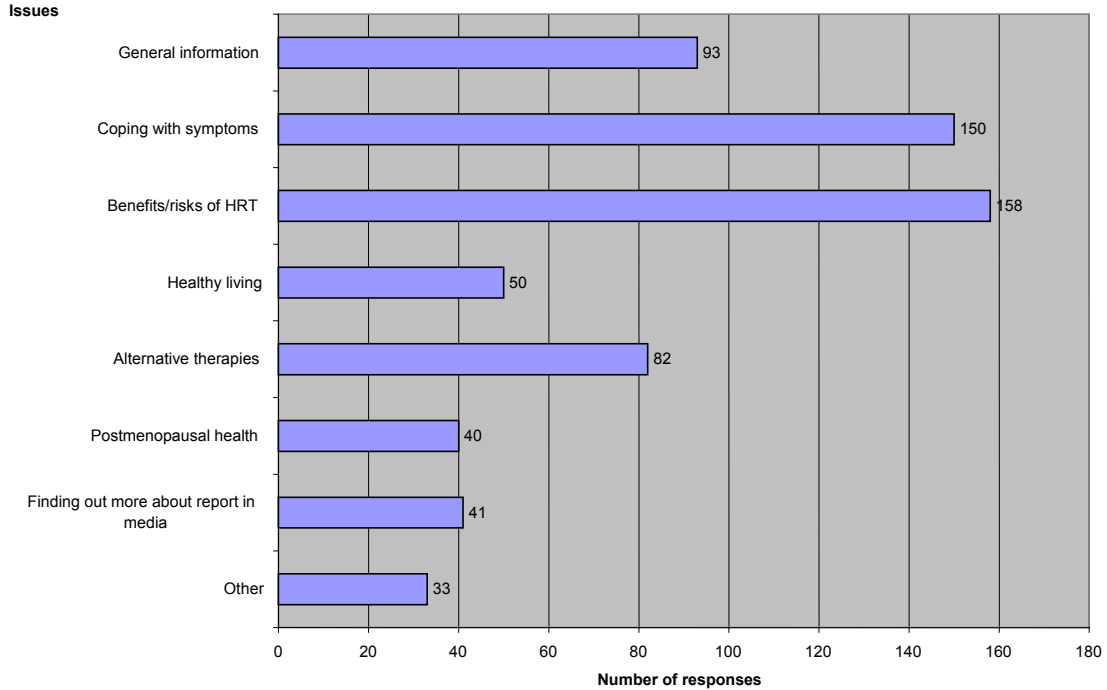


Figure 5.3 Issues about which questionnaire respondents sought advice/information.

The women that selected the ‘other’ option stated that they had needed advice/information about the following issues:

- Queries about their own menopausal symptoms n=11
- Concerns about the safety of HRT n=5
- Other HRT-related issues n=5
- Osteoporosis n=4
- Alternatives to HRT n=3
- What is happening to me? n=1
- The emotional implications of menopause n=1
- General health queries not specifically related to the menopause n=1
- What is the best option for me? n=1
- Early menopause n=1

In seeking answers to their questions and advice to help them navigate their menopause transitions, women demonstrated a range of information behaviours both active and passive. The menopause transition can extend over several, sometimes many, years and as circumstances and symptoms changed women often tried various approaches to locating and interacting with information sources. By far the majority of questionnaire respondents (over 90%) indicated that they used more than one information resource, and deeper exploration through the interviews revealed a mesh of interwoven encounters. The representative from Women's Health Concern was aware that women often use their advice helpline as just one of several sources in a process of comparing information:

'So that sort of thing, again, that happens in hospital, you know, the patient'll stop one nurse walking down the ward and say, you know, 'Can you tell me what...' um, you know, she'll tell you, and then five minutes later a different one'll walk by and they'll ask the same one again and see if the story, if it, if it, tallies with what you've been told previously. [...] often I know that women actually ring several helplines and then they'll say to one or other of us, "Oh, well that's what Bloggs said".' [WHC]

The use of multiple resources occurred in the context of a general monitoring of the environment for useful information and of more active forays into the world of experts and organized providers of support when the answer to a specific question was required. Questionnaire respondent Q13 noted that 'My ears pricked up whenever I heard/read menopause. I felt so confused and muddled'. Interviewees spoke of spotting relevant articles in newspapers, books or magazines – Gwen read everything she could about the menopause and if she found an interesting item she would cut it out and put it on the fridge until she had time to read it. Janice would keep an eye out in the local papers to see if any meetings about the menopause were coming up. Others mentioned information gleaned from the media: Angela heard about the menopause loaf from the television, Deborah had heard a radio programme with a guest talking about HRT, and Ann commented that a lot of the soaps cover medical issues in their storylines although she had not seen anything about the menopause. Barbara, who had had a hysterectomy as a result of fibroids, said that she sometimes spotted things she could relate to, for example

‘Holby City once had a thing about a woman with fibroids and when you’ve been there you know what they’re on about you know’. Eleanor summed up the process of environmental monitoring:

‘Only again through things like Women’s Hour maybe or magazines, that kind of thing, just happening to be listening to a programme or watching something on television or reading an article, that way I might come across something without actually practically looking.’ [ELEANOR]

Sources of information that provided an insight into other women’s experiences were particularly valued. Denise reflected on how husbands can support their wives through the menopause based on stories she had read in the heart-to-heart sections of magazines. Kate had found magazine articles more useful than patient information leaflets because they were easier to relate to:

‘I do read, you know letters in books and mag’s a lot you know, with people’s symptoms I’m a bit of a, about them sort of things I think you find a lot of information about what people say they’ve got and how to treat things and I really do think an awful lot of women do read up about that more in a magazine than on a leaflet. I do anyway I can’t say I’ve really picked up many leaflets concerning anything like that or any other things. I don’t think they’re self explanatory enough, I don’t think so, I think if you read a mag’ and they tell you, you know a letter somebody’s written in or something, sometimes you can relate to something and you feel a bit more peace of mind.’ [KATE]

Denise wished that someone would produce a book about ‘women who’ve had a horrendous time and they could put their feelings down and how they coped. If you could get one like that and read that, that would probably be a big help, because there’s light at the end of the tunnel isn’t there’. She had been lent some books by a colleague and had found them ‘nice books but full of what you could eat and all sorts of things’ without any reference to real women’s experiences. The value of sharing experience and the need for empathy whether by reading/hearing about other women’s menopause journeys through

the media or by talking to friends, colleagues and family emerged as a strong theme throughout the interviews. The fact that the Lead Clinician at the community menopause clinic was female and herself a 'mature lady' (Q52) was seen as an advantage by several of the questionnaire respondents because they felt that she was more able to appreciate what they were going through. Questionnaire respondent Q28 thought it was 'fantastic to speak to a female professional of my age who had experienced the menopause – was willing to listen – and not brush me aside as a “moron”'. On the other hand, questionnaire respondent Q19 was disappointed by her visit to the clinic because she was seen by younger women who she felt did not have enough knowledge about the menopause and were not able to 'sympathise' with her.

Many women were facing a time in their lives when they were being forced to redefine their concept of 'self', when they frequently felt isolated and doubted that anyone else could understand what was happening to them. They valued sources of support and exchanges of advice and information. Angela acknowledged that she would be feeling 'really scared' if she didn't have the support of her friends from church who were a similar age and could talk and laugh about things with her. Sally had found out about the community menopause clinic through a work colleague. Indeed one criticism of the clinic identified from the questionnaire responses (and from interviews with GPs) was that it was not sufficiently well-publicized. Several participants had only found out about the clinic through networking with friends or colleagues or had encountered it by chance when passing the premises.

Although, as can be seen from Figure 5.2, questionnaire respondents had accessed a range of support and advice services including: charities (e.g. MIND and The Daisy Network), specialist women's health/menopause organizations (e.g. Women's Health Concern and The Menopause Amarant Trust), NHS-based resources (e.g. NHS Direct and the Royal College of Obstetricians and Gynaecologists Website), as well as health professionals and CAM practitioners, few interviewees confirmed that they had contacted specialist support/advice services beyond visits to their GP, to the community menopause clinic, and using the library or Internet to locate information. It is interesting that uptake

of specialist advice services (e.g. telephone helplines) was low amongst interviewees given the value placed on one-to-one communication and support. It is possible that the small sample size is not fully representative of women's use of such services. It is also possible that women encounter barriers such as lack of awareness (e.g. Deborah was concerned about bone density but was not aware of the Osteoporosis Society helpline), inhibition (e.g. Helen thought that some women might be embarrassed to ask for information about the menopause in a public library), or difficulty negotiating access (e.g. Rowena previously lived in London and had sought privately-funded help at the Menopause Amarant Clinic, she now lived outside London and was put off further visits by the logistics of reaching the clinic). Nicola had become involved in the EarlyMenopauseUK Website (<http://www.earlymenopauseuk.co.uk>) following her hysterectomy. This Website had been set up by a woman (who had a hysterectomy at the age of 29) in response to a perceived lack of opportunities for younger women to offer each other support and exchange menopause stories. Nicola explained that the Website is an offshoot of the US-based Hystersisters Website (<http://www.hystersisters.com/>). The founder of EarlyMenopauseUK had realized that information on the US site was not always relevant to British women and that attitudes towards early menopause differed between the two cultures with British women being chastised for introducing humour into their exchanges. Nicola was one of a 'hardcore' group of contributors who had become friends and offered each other support in all aspects of life. They had met each other socially and Nicola felt that the menopause had become incidental to their relationship. These women had posted their own menopause stories on the Website for other women to read and offered a discussion forum so that new members could express their concerns and receive support. At the time of the interview, the Website had just launched a chat room for men since the group acknowledged that an emergency hysterectomy can also be a shock for male partners who suddenly find themselves with a partner whose skin is different and who has concerns about her bones – 'They take in a young wife and take out an old one'.

As Deborah had been through an early menopause she suspected that she would find herself using her own experiences to offer support and information to her peers. Eileen

was already viewed as a source of support by other women ('I'm the one that's giving the support I think because I'm further on'). Imogen had helped other women by passing on some of the information she had been given and by informing them about the community menopause clinic, as had Rowena. Seven of the questionnaire respondents indicated that they had looked for information about the menopause on behalf of someone else (Figure 5.1) and the Women's Health Concern contact spoke of the barriers faced by women from different cultures who may not have the language skills necessary for locating and interpreting the information they need. Women from the Asian community will telephone the WHC helpline on behalf of their mothers to ask for advice.

Study participants also identified challenges and barriers that had impacted on their experiences of finding and interacting with information and advice. Questionnaire recipients were asked whether they had encountered any problems finding the menopause advice they needed. Sixty-six (33%) indicated that they had experienced problems and in fact 71 questionnaire respondents provided examples of challenges they had faced. Their responses can be grouped loosely into three main themes that emerged from the analysis: making sense of the situation; identifying and interacting with sources of relevant advice, information and support; and interaction with health professionals. Examples of comments to illustrate each of these themes appear in Table 5.1.

<b>Making sense of the situation</b>	<b>Identifying/interacting with sources of advice/information/support</b>	<b>Interacting with health professionals</b>
Wanted advice on how to cope and if I was in the menopause, had it etc. And could not get an answer from GP. Felt very isolated even though I could read facts on internet etc. [Q9]	If a friend of mine hadn't been a doctor's wife I would never have heard of [community menopause clinic]. [Q28]	Most people wishing to force HRT. Not giving other advice. [Q5]
My GP does not agree with long term HRT (2yrs). Find contradictory reports in the media very unsettling. [Q52]	Only in as much as symptoms vary from woman to woman so not all advice and information applies to oneself. [Q38]	Following a visit to a surgeon since the promised information didn't arrive. I followed this up with phone calls and a visit but to no avail. [Q10]
No, but matching advice to what was happening to me varied. I moved house. My current GP would not give me HRT but [community menopause clinic] did. [Q57]	There is a lot of advice but not necessarily correct for me. [Q54]	I have a lovely GP, but with the menopause he brushes it under the carpet and with HRT he always says it is up to me what to do. The nurses also have told me it is up to me. They are very good with other things, but I found the menopause is a no go area. [Q26]
Very many unanswered worries and questions [Q61]	Finding information about premature menopause such as mine. [Q62]	It is not possible to see the same GP at the surgery and they all have their different (sic) views and advice, which is confusing. [Q35]
But often the information is very general and I would prefer more detailed explanations. [Q82]	Did not know who to contact for advice/understanding. [Q95]	Different ideas from GP on coping with menopause. [Q48]

<b>Making sense of the situation</b>	<b>Identifying/interacting with sources of advice/information/support</b>	<b>Interacting with health professionals</b>
No one seemed prepared to admit just how many ways it can affect you and what to do about all the symptoms. [103]	Most information/advice seemed to be aimed at older ladies. [Q111]	Lack of knowledge by GP – also seemed to feel threatened by the fact that I had done my own research. [Q63]
I didn't feel the reasons for going on HRT were really clear or concise; it seemed to be a 'wonderful' thing to do rather than giving clear medical reasons for using it. [Q110]	My doctor and the [community menopause clinic] did not seem to know much about alternative therapies - I was only advised about HRT. [Q123]	Have had to do a lot of research myself. My GPs do not seem to be very informative although one of them is a woman. Does not seem to be a central place where you can find it all out. [Q77]
As you get older you don't realise why or what you are suffering from necessarily. There is a need for more education. [Q135]	My doctor did not suggest [community menopause clinic]. I [had] to find out about it myself. [Q176]	Doctors don't seem to want to help. [Q127]
Although sharing issues with friends, no two people seem to have quite the same symptoms, or know fully about different HRT treatments. [Q137]	Doctors only provide limited help – [community menopause clinic] mainly HRT advice. Difficulty finding advice on alternative therapies etc. [Q185]	The advice is very limited/not individualized basically – these are the options - you choose. [Q163]

*Table 5.1 Questionnaire respondents' examples of challenges to successful information-seeking.*

Interviewees echoed and elaborated on some of these challenges, and their comments also fit under the three headings identified above:

### *5.3.1 Making sense of the situation*

As seen from earlier sections, the menopause transition can be a destabilizing time filled with uncertainty and confusion. Reflecting the questionnaire responses, interviewees also



spoke of struggling to understand what was happening to them, of being confused by conflicting reports about treatment options and of feeling that the information and advice available did not really move them forward in their attempts to make sense of things and resolve their problems. Several mentioned that they had unanswered questions or worries that they had yet to quell. Most of these uncertainties related to how long symptoms were likely to persist, to whether they would return if HRT was discontinued, and to the long-term effects of taking medication.

Understanding the implications of reports about the risks and benefits of HRT use was identified as a key cause of anxiety, not least because women felt themselves to be subjected to a barrage of different opinions from the lay and medical communities and from within the medical community itself. Kathleen pointed out that discussion of HRT in books and magazines is frequently based on anecdotal evidence and presented in terms that are ‘black and white’ with authors being either very pro- or very anti-HRT. Erica equated the problem to deciding whether to take a baby for the measles, mumps, rubella (MMR) triple vaccination. Eileen was also wary of media reports that are often wrong or angled to make ‘a jazzy story’. Guidance from health professionals was seen as inconsistent and dependent on the individual’s personal views on HRT. Grace had been informed that the male GPs at her practice tended to take an anti-HRT stance and was confused by conflicting advice she had been given:

‘...apart from being told that you are at risk of breast cancer which my GP told me, if I took it, which is contradictory to the [community menopause clinic] who sort of say “well, you have the same risk with or without”, so I mean I’d like to stay on it actually but I don’t know if it’s safe after the amount of years I have been on it, so it’s difficult.’  
[GRACE]

Deborah was also left confused by differing advice from two professional sources:

‘I’m not sure really quite what to do, what I’ve done is cut it down and I thought I might write a letter to [Lead Clinician at community menopause clinic] and ask her whether it

would be fine for another year or two. I mean she doesn't seem to be that alarmed by it. The GPs you know go ooh ooh ooh and whether it's because, I don't know which is the one that's out of date, it can't be [Lead Clinician] can it because that's her field.'

[DEBORAH]

Although family and friends were often welcomed as sources of advice some interviewees found that they were not always supportive (e.g. Grace's friends refused to talk about HRT and claimed to be just living through it all) or that they had strong views which added to the pressure (e.g. Imogen's daughter urged her not to take HRT since she perceived it to be 'so unnatural').

For women seeking help to navigate their way through the menopause transition the problem is not so much 'lack of information' as 'lack of trusted and pertinent information'. The challenge is to pick through the plethora of media reports, books, and magazine articles and through the views of individuals from the professional and lay communities to make sense of their situation and of the options available to them. This issue was highlighted by several interviewees who noted that much of what is written is about 'the average woman and there isn't an average woman' (Denise) or that information sources dwell on unusual symptoms rather than explaining what could be considered 'usual' in the context of the menopause (Eileen). Each woman's menopause experience, medical history, and set of personal circumstances are so unique that it is hard to extract information that is appropriate and useful for the individual. Belinda asserted that locating 'written literature that actually made any sense to what I was going through I found nearly impossible... I am quite well-educated and I do read an awful lot, I do know how to look for things but nothing seemed to get me anywhere.' Sylvia told of reading in a book that taking progesterone can counter the negative effects of oestrogen and wondered why her GP hadn't mentioned this: 'What's behind all of that then? I just want to ask someone who knows.'

### *5.3.2 Identifying and interacting with sources of relevant advice, information and support*

Again, interviewees recounted similar concerns to those expressed by questionnaire respondents. For some, barriers were linked to their own personal situations, for example one interviewee stated that she didn't even know how to turn on a computer, another was dyslexic and had problems reading written information, and two referred to lack of time available to resolve an information gap. Like Sylvia, Viv wished for someone to sit down and talk her through the implications of her situation. She felt that her GP was not particularly helpful and that it was just a case of 'oh that pill didn't work we'll try another pill'. She would have liked advice about non-medical alternatives and didn't want to keep trying different pills because they just upset her. Eve also hoped for advice about a self-help approach to the menopause and asked her GP about using Soya milk and different types of beans. Eve felt that her GP gave no encouragement in that direction and decided to go to the library and see what she could find out for herself. Eleanor also identified herself as a proactive information-seeker. She had visited the library and the community menopause clinic and had accessed the Internet as well as talking to friends and colleagues. She had also selected HRT and the menopause as a project topic for her university access course.

'Well I'm interested because I'm sure its going to affect me personally in some way, or probably is affecting me in some way. I needed to find out before it actually attacked me, it's quite an interesting subject I think and I want to be positive about it rather than worry about it.' [ELEANOR]

Eleanor had looked at a variety of Websites including: the BBC site after she heard about it on the Woman's Hour radio programme, the World Health Organization site, and a range of smaller sites although she acknowledged that some of these were American-based and were probably attempting to sell products. Deborah and Sylvia also demonstrated awareness of the reliability issues associated with looking for information on the Internet. Both were wary of information originating in the USA with Deborah admitting that she didn't trust American Websites and Sylvia commenting that she had

ordered four books from the USA through the Internet but that she didn't know what she was reading and 'it might be just American garbage for all I know'. The Lead Consultant at the community menopause clinic also expressed concerns about information originating on the Internet, although she admitted to being a technophobe and suggested this might influence her opinions:

'So I'm not terribly thrilled with the thing anyway but what does make me nervous about it is that anybody can put stuff on the Internet and it doesn't have to be validated and so people can be bombarded with information that's inappropriate and not very scientific. I worry about people, I mean we all know how difficult critical reading is even when you are taught how to do it, how can Mrs Smith sitting at her home computer know what's valid and what's not...' [LEAD CONSULTANT]

Issues of trust and authority were also commented on by other interviewees. Whereas Belinda and Isobel had both appreciated the advice they had received from staff in a well-known health food shop (in fact Isobel was referred to a member of staff identified by colleagues as particularly knowledgeable about the Flash Fighters product), Eve, on the other hand, was wary of advice from staff in health food shops and felt that they were often young girls who might simply be reading off the label. She didn't know what knowledge they had. The Women's Health Concern informant also expressed concern about some of the advice given in this context:

'But again, when you hear the people there actually giving out information, and I think, again, it's a bit of a... a bit of, not wanting to be precious 'cos I think that only nurses can give out information, but you know, what do people like me do in situations when you know that people are perhaps not giving out the right stuff?' [WHC]

This interviewee also explained that women would contact the WHC helpline stating that they phoned because they knew the helpline had no allegiance to any pharmaceutical company. Louise and Tracy both expressed a preference for seeking professional medical advice and Jane said that although the reports about negative effects of HRT did frighten

her and although she didn't really understand why she was taking HRT she was putting her trust in 'the people that know really'. Tracy acknowledged that talking to friends would be interesting in terms of hearing their stories but said that for 'real advice' she would go to the GP or menopause clinic. Denise pointed out that 'you can read all the books in the world but if you haven't got the support you might as well put them in the bin'. The Lead Clinician from the community menopause clinic explained that there was a real need for the advice and support offered by specialist menopause services. Although some women attended her clinic simply looking for information to support them in making an informed choice, others came because they had been given something they didn't understand by their GP:

'...and nine times out of ten they have been given the right thing it just hasn't been, they haven't been informed enough about it, about why that choice was made, why they are taking that particular thing, why they have those particular side effects or whatever. So they simply come and talk it through and go away feeling more comfortable with what they've got, and therefore more likely to continue taking it.' [LEAD CLINICIAN]

Access to specialized services can, however, be dependent on geographic location. When I explained to interviewees from the care home that I would also be talking to women about a community menopause clinic they said that they were unaware of anything like that in their local area. Nicola had advised one of the correspondents from the Early Menopause chat room to go to a specialist clinic but her correspondent lived on the Isle of Wight and there was nowhere for her to go. The Women's Health Concern informant pointed out that, like Rowena who visited the Menopause Amarant Clinic in London, some women pay to access private advice and care during the menopause. However this is not an option for everyone and she felt that some areas of the country were particularly disadvantaged in this respect. The Lead Consultant from the community menopause clinic acknowledged that there are limited opportunities for women to access dedicated menopause services. She explained that survival for many years beyond the menopause is a relatively recent phenomenon and that every woman should be considering 'what difference it will mean to her being without her oestrogen in a third of her life, and every

woman should be having the conversation with somebody about what it means to them, what the facts are, so that they can make an informed choice about whether or not to use HRT. So it's an awful lot of people, half the population need access to somebody to talk to and there aren't that many people providing it, it's getting better but it isn't universally available'. This clinician had started the community menopause clinic because so many women were turning up at her normal contraceptive clinics asking for menopause advice that they were blocking the clinics for the patients requiring contraceptive advice. So popular was the menopause clinic that the waiting list for new patients at times reached six months. Several questionnaire respondents commented on the length of time they had had to wait for an initial appointment and others disliked the limited opening times which precluded evening visits. Questionnaire respondent Q9 noted that she felt there was a stigma attached to asking for time off work to attend a menopause clinic.

### *5.3.3 Interaction with health professionals*

Many reasons for the popularity of the community menopause clinic were given by both questionnaire respondents and interviewees. Questionnaire respondents were mainly complimentary about the clinic staff and stressed that this extended to all staff not just the doctors. Their comments indicated that the service was perceived as both professional and efficient but not at the expense of humanity. Respondents were appreciative of the friendly and caring atmosphere at the clinic and, above all, liked being listened to and taken seriously:

[Lead Clinician] was clear answering my questions. I am just glad she is there if she wasn't, where do you go! [Q34]

'Reception, nurses and Drs were all very friendly and helpful. Didn't make me feel old.'  
[Q46]

'The staff were very kind, sympathetic and understanding. It was amazing to talk to people who understood how desperate I felt and how the menopause was destroying my

life. No one I had spoken to prior to this visit had any idea. It is treated as something light and silly to laugh at.’ [Q142]

Several questionnaire respondents compared a visit to the clinic favourably with a visit to a general practice and for these women the amount of time allotted to each encounter was a key issue. Respondents valued the longer appointments at the clinic (the Lead Clinician confirmed that women were given at least 30 minutes at the initial appointment) and felt that this gave them the opportunity to explore their problems and led to a more truly informed choice, for example:

‘Having had several appointments with my GP who is very busy and I felt unable to discuss my problems with fully (due to time) I was so pleased that my 1<sup>st</sup> appointment at the Centre was unhurried, calm and one to one, I was able to ask questions and was answered, honestly and fully. I was followed up for a long time and was always given the opportunity to ask about anything I was worried about.’ [147]

Most questionnaire respondents indicated that they had high levels of confidence in the currency and accuracy of advice given by clinic staff. Again, some respondents contrasted this with visits to their GP and many expressed relief at finding a specialist service that could answer their questions. Not only were staff viewed as knowledgeable and informative, respondents also valued the practical and emotional support provided by the service and appreciated that fact that they had the option to contact the clinic at any time if they felt worried or had problems.

‘I felt very confident that I was in the right place to get sound advice. I was pleased to be given a health check including blood pressure – not done by GP. I was happy that someone was taking the time to listen to my anxieties and concerns, and was attempting to address them.’ [Q22]

‘All staff extremely helpful and very understanding, especially when I could not cope and landed myself with out [sic] an appointment in the waiting room.’ [Q73]

Some respondents were, however, dissatisfied with their contact with the community menopause clinic. As explained above, some had issues with accessibility and others were disappointed that they were not able to see the same doctor at each visit or felt that their examination was not as thorough as they would have liked or that the appointment was rushed. Another issue that provoked negative feedback was the perception that clinic staff focussed too much on HRT at the expense of advice about other treatment options:

‘...in all of this time I was getting distressed and upset. HRT seemed to be the main topic. I needed advice on my many problems, something I didn’t get. And left very dissatisfied [sic]’ [Q5]

‘Visit was relaxed and helpful if you were going down the HRT route – not much advice on other therapies.’ [Q185]

Interviewees’ reflected many of these issues with several commenting that they appreciated the service available at the clinic, for example Charlotte felt she had received very little help from her GP but found the clinic to be ‘absolutely wonderful’, and Maureen (who was included in the interview sample but responded by letter) stated:

‘I have no complaint about my doctors but I feel that the advice given by the [community menopause clinic], with the background of so much experience was to me, and my peace of mind, invaluable and made it possible for me to make an informed choice.’

[MAUREEN]

Isobel also thought that specialist advice conferred advantages over that offered by GPs:

‘I knew that I could go to my GP and ask about it but on the other had if you can go to a specialist why go to an odd-job-man, if you see what I’m saying. Your GP I’m sure is very good but on the other hand if you find someone who specializes in a subject...’

[ISOBEL]



Not only did interviewees elaborate on their feelings about the value of expertise in specialist environments they also reiterated that lack of time in traditional GP consultations can act as a barrier to effective information-seeking. Eileen, Rowena and Tracy all specifically mentioned that the brief amount of time accorded to a GP consultation inhibited their opportunities to find information. Rowena pointed out that effective communication with a GP is essential because ‘when, you know, you’ve only got ten minutes to talk to somebody when you go to your GP then you need that ten minutes to be ten minutes that’s well used’.

Interviewees had different experiences of GP consultations and different impressions of how effective communication with health professionals had been. Practice nurses were mentioned by several women since they often have a role in general health checkups or in HRT checks. Some nurses were perceived to be uninterested whereas others took an active role in passing on information about the menopause itself or by signposting participants to services such as the community menopause clinic. The representative from the Wellwomen Information centre noted that although people do want information, what they probably want even more than that, particularly at a time when information itself is relatively easy to come by, is help to think about what is going on for them. Interviewees had differing views of the extent to which their encounters with GPs had afforded them the opportunity to explore what was happening and make informed choices. Some, for example Fiona and Kathleen, were very content with the service they received from their primary care practices. Both highlighted that their GPs were approachable and that they had a good relationship with them. Kathleen’s GP had received a letter from the Lead Clinician at the menopause clinic which referred to Kathleen as ‘young-looking’. The GP joked about this and Kathleen said that the encounter made her feel good: ‘...that’s how he treats me, it gave me a real lift you know’. This GP had spent time with Kathleen making graphs to help her understand the potential risks of taking HRT and showing an awareness of quality-of-life issues. Kathleen and her GP had evaluated her situation together and taken a shared decision. Fiona also felt she had a good relationship with her GP and in fact preferred talking to him about her menopause rather than to the

community menopause clinic because she felt he had a better understanding of her complicated medical history. This GP was open to the idea of complementary medicine and Fiona felt that his approach to the menopause was in tune with her own.

Although interviewees clearly valued the expertise available through the community menopause clinic, poor communication rather than lack of confidence in GPs' knowledge appeared to make the greatest impact on their perceptions of the primary care consultation. Eileen had expected her GP to dismiss her concerns as those of a 'neurotic woman' and send her away with antidepressants but in fact she found him to be very good. Others were not so fortunate. Before her menopause Olivia had suffered from very painful periods but had received little support from her GP:

'...I really felt I needed help but I didn't really get it and I think actually I was very conscious I suppose that it wasn't something he particularly wanted to discuss. You know, it wasn't something that he was particularly comfortable with, or interested in.'  
[OLIVIA]

Olivia reflected that this experience had probably 'coloured' her view about going for help with her menopause. Janice felt disappointed that her GP who had known her for many years had not told her about the community menopause clinic. She had subsequently discovered that this particular GP was not in favour of the clinic. Frances disliked going to see doctors in general because they made her feel as though she was being 'a pest'. Although her doctor was pleasant she asked to see a female GP to talk about her menopause because she found talking to a male GP about it embarrassing. Several women said that they felt male GPs were less able to empathize with menopause-related issues than female doctors. Sylvia said she suspected that her GP didn't believe women and thought they were wont to exaggerate. Belinda and Ann both expressed overall satisfaction with their GPs but qualified this with comments like 'he's very good, but I suppose they don't know do they, not like a lady doctor' [ANN]. Even female GPs were not necessarily seen as able to empathize, Denise felt that her concerns were dismissed having specifically opted for an appointment with a female GP: '...basically

“life’s rough isn’t it when you’re a woman” and that was it, so that was a complete waste of time’. Eve also visited a female GP but felt that she was too young to understand what Eve was going through.

Imogen recounted a specific incident in which communication with her GP had been on the verge of complete failure. The receptionist had given Imogen an emergency appointment slot by mistake. When Imogen then began to talk to the GP about her hot flushes and about generally feeling unwell he reacted abruptly and told her that it was inappropriate for her to be there:

‘...he said “you were late” and I said “no I wasn’t”, he said “I’m here trying to do my jobs waiting for you” and that was it. I thought I don’t need this. I said “I’ve come here because I don’t feel well and now my heart is palpating[sic]” I said. “I feel iller now than what I did when I came in the door...and then as I got up to leave, [I] told him all this and I just said “right that’s it I’ll go then if you haven’t got the time” and then he sort of took notice...’. [IMOGEN]

The doctor asked whether Imogen would prefer to see a different GP but she remained with him and returned the following week to find him very apologetic and now considers that they get on well. In telling this story Imogen twice mentioned that she was surprised by her own assertive reaction with comments like ‘I don’t know where that came from’. She had been feeling ‘a bit weak and wimpy with the menopause’ but was so mortified and beside herself that she had summoned the self-confidence to stand her ground. Nicola and Rowena also commented that sometimes women need to be ‘pushy’ or ‘bolshy’ to get what they need. Erica looked back to the time of her hysterectomy and reflected that she had received very little explanation of what was going to happen to her. She wondered whether, at the age of 30, she would have been confident enough to question the clinicians rather than just accepting what they were doing.

Although some participants provided examples of good communication leading to effective shared-decision making (e.g. Fiona and Kathleen cited above) and many clearly

welcomed the opportunities for discussion afforded by the community menopause clinic, some felt that they would have liked more guidance. Grace felt that she had been given too much responsibility for the decision:

‘No, no information whatsoever from the GP, it was just entirely up to you, you can have HRT not what type or what would happen, how I took it, nothing. So I thought I know it’s up to me but on the other hand a little bit of advice would have been good, for confidence reasons really, not that I’m incapable of looking it up myself, to know that the medical field are confident in that as well, so that’s what took me off to the [community menopause clinic].’ [GRACE]

Nicola said that one GP had simply taken out a book, pointed to all the different HRT preparations, showed her the side-effects and said ‘which do you fancy?’. The representative from Women’s Health Concern acknowledged that although the principle of shared decision-making was laudable, the reality did not always meet patients’ needs:

‘...the consultant might say to them “Well, right. You need a hysterectomy, but it’s, you can either have it done abdominally or you can have it done vaginally. Now what would you like dear?”... And I think that this idea about working in partnership with people is fine, but, you know, how does the person make that choice? .... It’s a bit like if I take my car to the garage and the mechanic says to me “Well, what sort of oil change would you like?” I mean, you’ve got to have the information haven’t you?’ [WHC]

#### 5.4 Challenges for providers of information and advice

Although six GPs volunteered to be interviewed, none had had extensive contact with the community menopause clinic. They had all been aware of the clinic but only three had referred a patient there and one knew that some of her patients had referred themselves. The three GPs that had referred patients had all received positive feedback about the clinic and the others all confirmed that they would be happy to send a patient there if they ever had the need. For all six interviewees, initial management of a menopause patient would be in-house, drawing on their own clinical experience, with only the more difficult

cases ('...where no HRT or menopause treatment seems to be working' [GP4]) or those requiring treatment not provided by the practice, being referred on to either the clinic or to a consultant at the hospital. Three interviewees identified themselves as having a particular interest in women's health or as being perceived as the doctor most appropriate to deal with menopause issues. For example, GP5 was the only female partner in her practice and felt that she therefore tended to see more menopause patients and GP1 explained that she was 'the doctor that wears the menopause hat in this practice'.

The Lead Consultant at the community menopause clinic felt that interest in the menopause amongst primary care practitioners was increasing. Membership of the British Menopause Society (BMS) was growing and she suspected that most new members were coming from the primary care environment (since specialists were likely to be members already). She commented that it was one of the few societies she belonged to where membership was probably equally divided between men and women although most of the acknowledged experts in the field were men. The Lead Clinician also remarked on the level of interest taken by many practice nurses who were now members of the BMS or were able to access specialist postgraduate courses. She was encouraged that the number of nurses taking an interest in the menopause was increasing since she thought that they were well-placed to give basic advice and that patients were frequently more willing to sit down and talk to a nurse due to the (often unfounded) perception that they are less busy than GPs. The Women's Health Concern informant also discussed the role of practice nurses and felt that it could be expanded to include a remit to provide education about the menopause. She did however acknowledge that nurses' time was already limited due to their responsibility for providing other services such as asthma and diabetes care. Furthermore, she noted that whereas doctors receive funding for any training they undertake nurses are not entitled to the same incentives – '...so if you go as a nurse, you've either got to get your employer to pay, or you pay out of your own pocket'. Besides providing advice and information services to the lay community, Women's Health Concern saw education for health professionals as one of its key objectives. The organization had received lottery and Department of Health funding to host conferences and menopause-awareness events.

The GPs interviewed confirmed that there was a need for education and support in dealing with some aspects of managing menopause patients. Examples of some of the areas they found challenging included:

- The see-sawing debate about the risk–benefit ratio of HRT and how to present these risks to the patient;
- The need for more research into non-hormonal alternatives to help patients who can't, or don't want to, take HRT;
- The danger of patients thinking that things that are natural are, by definition, good for them, which is not always the case – the lack of regulation in this area;
- The importance of keeping a balanced view and listening to the opinions of other professionals objectively;
- Coping with the overwhelming amount of choice in different treatments.

GPs cited a range of information sources they had accessed in their attempts to keep up-to-date with developments in the field. These included specialist study days, guest speakers invited to primary care practices and journal subscriptions. For the Lead Clinician at the community menopause clinic the 'bedrock of information' was the BMS. She attended their meetings and liked the fact that members 'whose judgement you trust' will write reviews and will critically appraise and interpret the available evidence. She commented that the press do not critically evaluate in the same way and that health professionals then end up sitting in clinics having to sort out patients' misconceptions. The staff from the Wellwomen Information centre also subscribed to journals, located up-to-date leaflets, and used the Internet and media sources to keep themselves informed. They relied on specialist organizations to provide authoritative information. In contrast to many of the comments from other sources, the representative from this organization said that she felt that fundamentally 'quite a big chunk of the work is the same stuff actually, you know the reasons for the menopause don't change, OK treatments might although not very much, people's anxieties don't change that much... I think you can get drawn into thinking that updating and information is more significant than perhaps it is'.

GPs were asked for their views on how well-informed patients themselves tended to be about menopause-related issues. GP1 believed that many women who actually visit their doctor tend to be better-informed since they have been able to see past the publicity surrounding HRT and recognize that they need actively to seek help. She elaborated that some of these patients may not necessarily be in possession of accurate information and that it is likely to have come from a range of sources including from the Internet or anecdotal stories from friends. GP2 found that most of his patients were very well-informed and that they were all aware of the debate about HRT and of some of the key studies. GP5 agreed that women tended to be more informed now than in the past and thought that women going through the menopause transition were motivated information-seekers compared to some other patient groups but commented that although she would suggest patients looked at the Internet she worried about this and generally recommended they stick to UK-based Websites. By contrast GP4 thought that the majority of patients were not well-informed before an initial visit to the practice:

‘I’m actually a lot of the time, particularly if I have a shot across the bows sort of question, I often ask them to go to the library because I am aware that the modern feeling is that it ought to be a mutual decision between patients, as indeed all treatment should be, but never more so than with HRT which very much should be their decision as to what they do and so they need some knowledge or forethought. Even though they are coming for advice it’s important to look into it, so often I say “come back and see me in a month or two” if the problem or their symptoms aren’t screamingly awful, and say “lets discuss it further when you know more about it”.’ [GP4]

This GP said that he was willing to ‘wade through’ all the different types of medication but that there was more to the decision than having information ‘it’s actually thinking what they want...sometimes it’s better done away from the surgery to be discussed in more detail when we’ve got that onboard’. GP1 also pondered the process of shared decision-making. She felt that patients had to take the responsibility for decisions about managing their menopause ‘...because you know there isn’t a right or wrong answer to it,

it's not as if it's going to save their lives or anything like that, you know it's going to save them possibly a few years of misery but I think...in the end you just have to say to them "listen what we are saying for example is there's a slightly increased risk of breast cancer if you've been on it for five years so the risk is continuing to increase and we are not sure about heart disease but that's probably also a risk, are your symptoms so miserable that you would rather have the risk?" and decide. And if they won't decide then they have to go away and think about it really, we can't tell them what to do, and I suppose there aren't many who haven't got the sort of understanding eventually to at least realize what they are deciding about.'

GP3 reflected on the fact that the menopause is more than a biochemical process and can be a very significant emotional time in a woman's life requiring time and attention. She felt that it was too much for patients to be faced with 'this sort of great outpouring of information about the Million Women Study and this sort of thing and actually, while patients need to know that information, it's not why they're there. They're there to be told "well this could happen or that could happen or the other could happen if you take these tablets", they actually want to know how to feel better... which is where I think it all gets a bit unstuck.'. She felt that a key benefit of the community menopause clinic was the time it was able to devote to individual women. For her, the actual factual information and treatment was consistent between the two settings but 'the real difference is that the patients have half an hour initial consultation with the nurse whereas we have ten minutes... and for that reason the patients come away understanding and feeling satisfied which is never going to happen when you're under time pressure.' These views were echoed by GP5:

'I mean some people want to be given drugs and practical stuff but other people just want to understand... So probably time is the greatest commodity that anybody can offer people.' [GP5]



## 5.5 Summary

This chapter has explored women's accounts of their menopause transitions and has identified some of the factors that impact on the way they perceive and manage this life-change. Many of their experiences can be summed up in this quote from Denise:

'Yes and it's frightening you know because you think to yourself well where's it going to go from here? What if I do feel really ill and it's menopausal and the doctors aren't prepared to give you HRT and if they did offer HRT would I really want it because of the cancer scares? But do you go through the rest of your life feeling miserable until it finishes, which could take years according to them, and the pre-menopausal thing could take up to ten years before you actually go menopausal. So it's quite frightening and worrying to have to go through. How women coped years ago I don't know, I really don't know. I think the most help that you get is a load of women sat together and discussing their feelings, that's the best so far.'

The next two chapters contain analysis of the findings, relating them firstly to other research about midlife women and the menopause transition (Chapter Six), and secondly to McKenzie's Model of Information Practices in Everyday Life Information Seeking (Chapter Seven).

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# Chapter Six: Information Behaviour during the Menopause Transition

The participants in this study reflected the views of other midlife women surveyed in the literature. Like those interviewed by Price et al. for their study of rurally-based Canadian women, my interviewees had mixed feelings about the process of ageing and about their menopause transitions (Price et al., 2008). In Im et al.'s feminist-inspired study of the lived-in experience of menopausal white women in the USA, the authors found that participants' experiences could be grouped under four themes: redefining self, laughing at suffering, differences within sameness, and talking to the wall (Im et al., 2008). The themes that emerged from my study can be integrated with those of Im et al.. They are presented here in a slightly different order from that used by the original authors as presented in Chapter Two (*see* Section 2.3.2). Using Im et al.'s themes as a framework provides a springboard for the discussion and for comparison with the findings of other researchers – in particular from Price et al.'s study.

## 6.1 'Redefining self' (making sense of the situation)

The midlife women in Im et al.'s study found that, although they may not have given any thought to the menopause prior to experiencing symptoms, it spurred them to think about their lives and about ageing. They saw it as an inevitable and natural stage of life and, whilst acknowledging that it could be a struggle, accepted that it had the advantage of freeing them from pressure to meet society's expectations and felt that they could deal with it and move onto a new phase of life. The women interviewed for my study also tended to see the menopause as a natural stage of life ('part and parcel of life' as expressed by Angela) and saw it within the context of their whole life. For several this interpretation influenced their decisions on managing the menopause as they sought out 'natural' ways of controlling their symptoms. Despite this underlying acceptance of the menopause transition as natural and inevitable, it could still be an uncomfortable and unsettling period which in some cases could last for many years. Since the majority of the interviewees (and all questionnaire recipients) were recruited from the community

menopause clinic sample, many participants had experienced symptoms that necessitated professional advice or intervention. Participants frequently found that they had more to contend with than the purely physical symptoms of the menopause. Several mentioned depression or feelings of dread and lowness that took away their enjoyment of life (e.g. Imogen) or made them feel they no longer recognized themselves (e.g. Hannah). Belinda talked of her body being ‘out of control’ which reflects the traditional medical-establishment view of women at the mercy of ‘uncontrollable’ bodies as decried by feminist writers (Oakley, 2007).

As with their Canadian counterparts from Price et al.’s study, my interviewees often found themselves coping with the symptoms of their menopause alongside a range of emotional and practical challenges in their personal lives. Belinda was dealing with her mother-in-law’s illness and Eileen began experiencing menopausal symptoms as she was adapting to her new role as an older mother. For some it was a time for reflection on ageing and for learning to come to terms with a new self-image. Feminist writers reject the negative portrayal of midlife women as unpredictable and redundant in society, and urge women to interpret the menopause as a rite of passage, as a watershed – a time to leave behind demands made of younger women and move towards an older, stronger self (Campioni, 1997; Coupland and Williams, 2002; Gullette, 1997; Sybylla, 1997). Yet this is a challenging time for women, and renegotiating a self-image is not necessarily easy. Deborah hated ‘getting old’ and Rowena strove to find a balance between not wanting to stay permanently young as a ‘Peter Pan’ figure yet not wishing to be ‘old’. Like Angela, Rowena did however acknowledge the positive aspects of ageing as women find themselves released from work commitments with more time for themselves and their partners. These women were able to focus on their own personal development and enjoyment, thereby reflecting Greer’s image of the post-menopausal woman emerging from a chrysalis free at last from her need to conform to other people’s expectations (Greer, 1991).

Although Im et al.’s participants did find the menopause to be a liberating experience, freeing them from the pressure of society’s expectations, some of the women interviewed

by Price et al. still felt the weight of society's expectations and believed there was a perception that menopausal women should not 'dwell' on any problems they were experiencing during their menopause. Some of my interviewees echoed this with comments like:

'You can sometimes feel like a bit of a failure because you are feeling like this...'  
[ELEANOR]

and with Grace's description of her friends' refusal to support her by discussing HRT amidst claims that they were 'just living through it'. Rowena also suspected that there is a common perception that middle-aged women who want to acknowledge their problems are simply seeking attention and struggling to accept the loss of their attractiveness. In fact, descriptions from participants in my study illustrated that some women suffer severe symptoms during this life-change and meeting the ideals of feminism which call for the menopause to be spoken of as a more 'joyous experience' (Mackie, 1997) may not be easily achievable for all.

## 6.2 Differences within sameness (interpretative repertoires of the menopause)

In her study of women pregnant with twins, McKenzie identified two interpretative repertoires that described the characteristics of such a pregnancy. The first emphasized the commonality of the experience – the fact that women in this situation are likely to share certain experiences and feelings. The second draws on the fact that each woman is an individual with experiences of pregnancy, birth and motherhood that will be unique for her (McKenzie, 2001). These two interpretative repertoires are equally valid for the menopause transition. Women in my study saw their own experiences as enmeshed with those of other women and actively sought out information about other women's menopause stories to provide context and validation for their own. They referred to the experiences of family members, of friends and to anecdotal stories gleaned from media reports or unspecified sources. Hannah recognized her feelings of no longer knowing herself in a newspaper account of a woman who felt someone else was inhabiting her life,

and Denise had heard of women whose marriages had floundered due to their reduced interest in sex. Interviewees frequently revealed that they had drawn on the experiences of friends or relatives to help them make sense of what was happening or to inform their decisions. They looked to their mothers' experiences to try and evaluate how their own menopause transition might progress (e.g. Janice who feared that her feelings of depression would escalate as her mother's had done) and, like Tracy and Charlotte, used information from close relatives to weigh up the benefits and risks of taking HRT. Interviewees empathized with other women and felt that only another woman of menopausal age herself could really appreciate what they were going through.

Whilst acknowledging that the menopause is an essential experience of womanhood, interviewees were aware that each woman's menopause transition was entirely her own and was influenced by a mix of factors including medical history, diet, work patterns and personal circumstances (Coope, 1979; Greer, 1991; World Health Organization, 1996). Women who experienced few or relatively mild symptoms considered themselves lucky and were perceived as such by their less fortunate peers who could suffer any combination of a whole range of symptoms. Some women who had undergone hysterectomies also considered themselves lucky to be avoiding many of the unpleasant effects of the menopause and were relieved to be free of the problems that had necessitated their surgery. Interviewees sought reassurance from the experiences of others, using the comparison to gauge their own progress through the menopause whilst accepting the uniqueness of their own situation since 'everybody is so different' (Denise). Im et al.'s participants noted the duality of the experience, suggesting that commonalities would be balanced by ethnic and cultural differences (a point not raised by my cohort of participants) and by generational differences as women were now able to talk more openly about the menopause. The concept of freedom from past taboos was also mentioned by Price et al.'s interviewees and both Rowena and Denise pointed out that opportunities are very different for the current generation of older women who are not consigned to the background and have more options for managing their menopause. Sylvia felt that she belonged to the first generation of women to be able to openly discuss and question their menopause experiences:

‘We go to older people for advice and they go ‘Oh we just put up with it dear, you know I didn’t really notice mine’. How can you not notice something like this, or whatever your symptom is? So I think our generation are a bit more questioning and open and up to now we are like the first wave of modern women I think.’ [SYLVIA]

In common with participants from Price et al.’s study and with those from Suter et al.’s work with Canadian women (Suter et al., 2007), some of my interviewees expressed a desire for reassurance that their experiences were not unusual. Belinda spoke of the concern of not knowing whether what was happening to her was ‘normal’ and Olivia’s contact with her friends helped her feel that the experience was more ‘normal’ and less traumatic. Participants who had gone through/were going through an early menopause whether natural or surgically-induced were particularly at risk of feeling different and isolated. Jane felt like ‘some kind of a freak’ and sought reassurance that other women were in the same position as her. Marion had also been through an early menopause (having had a hysterectomy at the age of 31) and had struggled to find relevant information. At the time of the interview most of her friends were in their early forties and were ‘nowhere near’ going through the menopause themselves. Marion felt that she had no-one to talk to, no-one in the same situation as her. Having been informed about the EarlyMenopauseUK Website by Nicola, it was possible to suggest this site to Marion as a potential source of support.

The decision of how to manage menopause-related symptoms provides another example of ‘differences within sameness’. Those women who felt the need to control their symptoms sought out approaches that took account of their individual medical histories, their tolerances of different treatments, and that were tailored to their individual beliefs. Selecting a course of action that does not compromise their values is a way for women to assert some control over the management of their symptoms and retain some authority in the interaction with health professionals. Coupland and Williams (2002) suggest that a decision to turn to CAM treatments may reflect a woman’s rejection of the influence of the patriarchal medical system. In their study of Australian women’s views of CAM

approaches to managing the menopause, Gollschewski et al. found that participants preferred to adopt a healthy lifestyle and use CAM products/therapies as a way of retaining control over treatment and ownership of their bodies (Gollschewski et al., 2008).

Several participants talked about the way in which their personal values had impacted on their decisions. Some rejected HRT (e.g. Emma and Olivia) on the basis that it conflicted with their view of the menopause as a natural process that should be dealt with in a natural way or because they preferred not to take medication. Imogen and Kathleen had both used HRT but had declined conjugated equine oestrogen products because of concerns about the way mares were treated. Other interviewees (e.g. Eve and Frances) had welcomed HRT as a way of controlling unacceptable symptoms and discomfort. Imogen was forced to re-evaluate her original belief that the menopause was a natural life event that shouldn't require medical intervention as she began to feel increasingly unwell. She decided to try HRT despite her reluctance to take medication, her concerns about the ethical production of HRT products, and against the advice of her daughter. A woman's decision about taking HRT is very personal – 'everyone has their own ideas what they want to do' (Isobel) – and based on a range of perceptions. Schapira et al. (2004) found that different groups of women place different value on factors that contribute to decisions about HRT such as the risk of heart disease or osteoporosis depending on whether they were current- or never-users of HRT. The decision is also influenced by a woman's interaction with sources of advice and information, on her values and beliefs, and to a large extent on the severity of her symptoms. Several participants, whilst acknowledging the risks of taking HRT or their reservations about it for ethical reasons, decided to take it simply because their lives were too unbearable without it as illustrated by Hannah's comment that 'I'd rather have the tablets and have both breasts removed than feel the way I did.'



## 6.3 Laughing at suffering (receiving and providing advice, information and support)

### *6.3.1 Valuing other women as sources of advice, information and support*

Evidence from the literature consistently shows that women value informal, interpersonal sources of information and advice (Ankem, 2007; Avery and Braunack-Mayer, 2007; Davies and Bath, 2002; Dunne, 2002; Meadows et al., 2001; Raupach and Hiller, 2002; Schapira et al., 2004; Warner and Procaccino, 2004). As in Im et al. and Price et al.'s studies, my participants reported using humour to help them through difficult times (e.g. Angela, Denise, Olivia). Nicola noted that British women had been criticized by their American counterparts for making humorous comments on the Hystersisters Website. Laughing with friends was seen as a way of putting the menopause into perspective and reassured women that others could understand what they were going through and, above all, that they were not alone. Validation from others that they are experiencing similar symptoms and that a woman is not 'going crazy' is seen as central to a woman's sense of health and wellbeing (Price et al., 2008). Rowena recognized that although life can be good for older women it is essential to receive the right support during the menopause for a woman to feel well in herself and Angela would have been 'really scared' if she had not had the support of her friends. This validation could come from interpersonal encounters but interviewees also found it through hearing/reading accounts of other women's experiences.

The exchange of advice and support could be reciprocal. Women actively sought out the menopause stories of others and would use the experiences of family and friends to inform their own decisions but they also recognized that they had a role in providing support to others. Olivia's group of friends had met regularly since they were at school and continued to support each other through the various stages of life. Nicola's involvement with EarlyMenopauseUK had introduced her to a new group of friends to provide mutual support but had also given her with the opportunity to reach out to other women through the Website, telling her own story and offering support to a wider audience. Other interviewees recognized that they were likely to have a role in disseminating their knowledge to others as friends began to approach the menopause, or

had already passed on information (e.g. about the existence of the community menopause clinic). Rowena had been telephoned by acquaintances to ask ‘Oh you know, have you been through the menopause? Are you on HRT? Etc., etc.’.

Nicola and the members of EarlyMenopauseUK had identified a need for establishing a peer-support network for women experiencing an early menopause. This may be a specific subset of menopausal women who have their own particular needs for information and support but Denise also remarked on the value of opportunities to tap into the experiences of other women:

‘I think the most help that you get is a load of women sat together and discussing their feelings, that’s the best so far.’ [DENISE]

Denise would also have welcomed a book containing a collection of menopause stories from real women who had had ‘a horrendous time’ expressing their feelings and explaining how they coped. She felt that this would inspire other women by showing them that there was ‘light at the end of the tunnel’. Interestingly no interviewee (apart from Nicola) specifically mentioned having been in contact with a peer-support group although Marion expressed an interest in contacting EarlyMenopauseUK after hearing about the Website during her interview (‘I’ll go and have a look at that then, it’d be nice to speak to other people that have been in the same sort of situation to myself’). In the questionnaire responses one ‘menopause helpline’ was listed as a source of information but no further details were supplied. Raupach and Hiller (2002) found that use of support groups and peer support programmes by breast cancer sufferers was low with less than ten percent of respondents indicating that they had used such services. Luker et al. who also studied women with breast cancer found that participants were reluctant to join support networks. Interviewees felt that they wanted to put the experience of breast cancer behind them and not to listen to other people’s stories of ‘doom and gloom’ (Luker et al., 1996). Breast cancer is, however, a different context to the menopause which is not in itself a ‘disease’ but a phase of life and one for which women often welcome other people’s stories. Avery and Braunack-Mayer (2007) conducted a small-

scale study of women with Polycystic Ovarian Syndrome. The majority of these women had taken part in a clinical trial which had provided them with a support network in the form of contact with other trial participants. These women had found the contact to be positive because it gave them a frame of reference and validation for their own experiences. This reflects the views of women from my own study and from other research (e.g. Price et al., 2008; Suter et al., 2007).

For Price et al.'s participants, the most highly-valued sources of information about the menopause were women of menopausal age with medical experience. My participants endorsed this preference (both in interviewees and in questionnaire responses) through their positive reactions to the fact that the Lead Clinician of the community menopause was herself a woman who had personal experience of the menopause. Partners, along with male health professionals and female health professionals of pre-menopausal age, were often judged unable to truly appreciate what a woman was going through, however empathic they might be. Eve felt able to talk to her husband about her menopause but qualified this by saying 'not that he can help much'. Denise found that her husband (who was a bit younger than her) was struggling to come to terms with the fact that she was going through the menopause. She also found that her children were dismissive of her problems:

'And my children, well the eldest is 30 and they don't want to talk menopause because that's old, they don't want to know.' [DENISE]

In their study of the social support husbands provide to their perimenopausal wives, Mansfield et al. found that men were often facing their own midlife challenges which could either encourage or inhibit the levels of empathy and support they felt able to provide (Mansfield et al., 2003).

### 6.3.2 *The information mix*

In Ankem's (2007) five-stage information-behaviour model grounded in her study of women who had received treatment for symptomatic uterine fibroids, the author established that women relied on different sources during different stages of the decision-making process. During the first stage (Awareness) participants expressed a preference for interpersonal information sources such as friends and for sources from the media (e.g. television and magazines). Participants moved through the different stages of the model (Awareness → Conscious exploration of options → Self-education → Probing, discussion, and decision → Procedure) with their choice of information-source changing to reflect key concerns at each stage. As they entered the stage of exploring options they sought advice from gynaecologists, returning to search the Internet and monitor the media during the self-education stage. When shaping their thoughts into a decision they once more sought professional guidance and to a lesser extent advice from friends. In the final, Procedure, stage they relied heavily on information from radiologists. Such a defined model does not translate too well to discussion of the menopause transition because a woman's experience of the menopause may meander through different stages as symptoms come and go and as she tries various approaches, perhaps (like Imogen) reassessing and trying something different or finding that one treatment is no longer effective or indeed causes its own set of problems. Isobel's account of her efforts to find a suitable hormone-replacement product (Section 5.2) illustrates how protracted and complex this process can be. However, other studies from a range of contexts relating to women's health have also reflected the fact that information needs can change over time (Baker, 1997; Huston et al., 2009; Luker et al., 1996; Rees and Bath, 2000; Suter et al., 2007).

In their investigation into women's trust in and use of information sources in the treatment of menopause symptoms, Huston et al. (2009) confirmed that women use a variety of information sources according to their HRT-use status and their self-assessed stage of the menopause transition. Sources cited by Huston et al.'s questionnaire respondents included physicians (the most important sources for all groups of respondents), media broadcasts, and friends and family. Suter et al. (2007) explored

Canadian women's information behaviour relating to CAMs for the management of the menopause and also found that participants used a combination of sources including CAM and traditional medical practitioners, staff in health food shops, and interpersonal sources. As with many other studies, including my own, Suter et al.'s participants particularly valued first-hand accounts from friends and family. They continued researching until they felt satisfied that they had enough trustworthy information from across their sources to validate their experiences and make an informed decision. Like Huston et al. and Suter et al.'s participants, interviewees and questionnaire respondents in my study also indicated that they had used a range of sources of information, support and advice. These are detailed in Chapter 5 (Section 5.3) and included health professionals, interpersonal contacts, books, magazines, media broadcasts, the Internet, and specialist organizations (including charities, helplines and health food shops).

Interviewees revealed a mesh of interwoven encounters which could take place over many years as women's symptoms and personal situations changed and as they sought to compare and confirm information, especially in the light of frequent and widely-reported developments in the HRT debate. They displayed both active and passive information-seeking techniques as they monitored the environment for relevant information (e.g. keeping an eye out for useful information in the local newspapers or spotting things on the television) and then ventured into the world of health or CAM professionals for specific advice as needed. Meadows et al. drew on Kleinman's model of the popular and professional healthcare sectors (Kleinman, 1980) as part of a project looking at midlife women's health in rural Canada. In Kleinman's model, laypeople move in and out of the popular sector which is the anchor from which they evaluate services from the professional sector and make decisions about whether to continue accessing professional support. Meadows et al. (2001) confirmed that women moved literally and figuratively back and forth between the two sectors and had to take decisions about whether a specific health need was important enough to warrant accessing the professional sector. They also had to second-guess the perception of the professionals sector as to the legitimacy and potential urgency of the problem. The authors found that both the popular and professional sectors have their own fundamental assumptions about health and illness and

their own language through which knowledge is expressed. The transfer of knowledge between the two sectors was often inhibited by a clash of messages and women often found themselves ‘silenced’ by dismissive statements as they tried to bring their knowledge from the popular sector into the professional encounter. Participants in my study also had to negotiate both the popular and the professional sectors. The next section will explore the challenges they faced in interacting with both these sectors and in attempting to make sense of what they found.

## 6.4 Talking to the wall (challenges in encounters with information and support)

‘When is somebody actually going to help me with this?’

Denise’s plea illustrates the frustration felt by many women as they strive to chart their way through their menopause transition. Information and advice is needed to support both the practical resolution of problems and the management of the emotional aspects of this life-change which challenges women to reconsider their self-image, their views on ageing, and their relationships with their existing social and professional support structures. Marmoreo et al., in their study of decision-taking about HRT, note that women undertake ‘an intricate process of networking’ in order to further their knowledge, understanding and management of the menopause (Marmoreo et al., 1998). This networking draws on resources from both the popular and professional communities and women must negotiate their way through and between both sectors if they are to feel in control of decisions about managing their menopause. Although most evidence points to the fact that support from informal sources is highly valued, it adds to the swell of competing, and often conflicting, voices that can assail a woman and must be evaluated for trustworthiness and relevance. Women can be left feeling that they are running ‘round in circles’ (Grace).

#### *6.4.1 Taking account of personal values*

Looking for information about the menopause takes place in the context of the competing constructions of the menopause identified by Coupland and Williams (2002). Here, the first discourse (represented by leaflets available in primary care practices) constructs the menopause as a disease which can be treated by HRT. The second discourse (represented in many popular publications) turns away from the idea of medical intervention and advocates that women should take personal control through lifestyle changes and by taking a ‘natural’ approach to management of symptoms with the use of CAM remedies. Finally, the feminist interpretation focusses on rejection of the gendered experience of ageing and urges women to move towards ‘new realizations and releasings’ (Mackie, 1997; Oakley, 2007). Several study participants indicated a reluctance to subscribe to the first view of the menopause and actively sought out ‘natural’ ways to manage their menopause experience. In keeping with Coupland and Williams’s view and with that of the women in Gollschewski et al.’s study (2008), my participants saw this as a way of managing the menopause on their own terms: of adhering to their values (e.g. rejecting what they believed to be unethical practices in the production of HRT), of attempting to keep the menopause in perspective as a natural part of their lives, and of avoiding contact with the medical profession.

The choice to take a ‘natural’ approach was not without challenges however.

Interviewees gave examples of products that either did not work for them or exacerbated their problems (e.g. Frances and Olivia both found evening primrose oil ineffective and the ‘menopause loaf’ made Angela feel sick). Some expressed concerns about the safety of products, for example Gwen had stopped taking black cohosh after reading that it could be harmful – it has been linked to hepatotoxicity (MHRA, 2006). Others were deterred by the cost or were unsure where to turn for trustworthy advice about CAM products. Eve was wary of advice from assistants in health food shops, unlike some of Suter et al.’s interviewees who assumed that staff in long-established shops would be trustworthy sources. Sylvia’s herbalist had recommended St John’s Wort but she had read negative reports about it and wasn’t sure whether it was safe to take:

‘There’s all this not knowing who to believe business that gets you down really.’

[SYLVIA]

Interviewees who had broached the subject of CAMs with their GPs had met with mixed reactions. Fiona felt her GP was receptive to the idea of CAMs and was willing for her to try alternative approaches as long as she discussed them with him. She welcomed this openness and felt that ‘you can’t sort of say fairer than that’. Other participants had met with less positive responses from their GPs. Viv and Eve were both disappointed that their GPs offered little advice about CAMs (Eve had specifically asked about Soya milk and beans) and several questionnaire respondents noted that they had been frustrated in their attempts to find out about alternative remedies. This was one criticism in which the community menopause clinic was included – several respondents felt that the balance of advice was weighted in favour of HRT at the expense of CAM treatments:

My doctor and the [clinic] did not seem to know much about alternative therapies - I was only advised about HRT [Q123]

Doctors only provide limited help – [clinic] mainly HRT advice. Difficulty finding advice on alternative therapies etc. [Q185]

Gollsechewski et al.’s participants also perceived the negative attitudes of doctors and the lack of reliable information as barriers to their adoption of CAM treatments.

The issue of CAMs is challenging for healthcare professionals. None of the GPs interviewed for my study was overtly negative about alternative remedies. They generally showed understanding of the fact that women might be tempted to try them and a cautious willingness to discuss this with patients. They did however express concerns about the lack of reliable evidence on the effectiveness and safety of CAMs and explained that it was not an area they felt particularly confident about. Concerns at the popular perception that anything labelled ‘natural’ must be ‘safe’ are echoed in the literature (Gokhale et al., 2003; Greenhalgh, 2004; Rees, 2009). To justify their



reservations about CAM products health professionals point to the lack of good quality research evidence and also to the lack of standards and controls in the alternative medicines industry (Huntley and Ernst, 2004; Nedrow et al., 2006; Palacio et al., 2009; Rees, 2009). Dew et al. analysed the content of 105 patient–doctor encounters in primary care practices in New Zealand to explore how patients and GPs responded to CAM issues during the consultation. They concluded that finely-tuned interactional work took place during the encounters with patients being tentative in their approaches to introducing the topic of CAMs and GPs seeking out non-threatening ways to present countermands or contrast proposals if they do not concur with a patient’s suggestions (Dew et al., 2008). Suter et al. investigated Canadian women’s approaches to evaluating CAM therapies for the treatment of the menopause. They found that whereas some women relied on healthcare professionals’ advice and approval others believed that conventional medical practitioners were less willing to consider CAM approaches as viable alternatives to HRT and that these practitioners would simply put forward their own perspective during the consultation. The authors expressed concerns that if women perceived their doctors to be unable or unwilling to provide advice about CAMs they might be less likely to discuss the topic during visits and might therefore miss out on an information resource highly relevant to their decision-making.

#### *6.4.2 Participating in shared decision-making*

In their definition of shared decision-making, Towle and Godolphin stress that it is a process that should be informed by best evidence, not only about risks and benefits but also taking into account patient-specific characteristics and values (Towle and Godolphin, 1999). In an article about shared-decision making in the menopause, Salkovskis et al. (2004) conclude that health professionals must take account of patients’ values and beliefs as an integral part of the decision-making process. Huston et al. (2009) suggest that failure on the part of healthcare professionals to make clear their readiness to discuss CAM therapies may result in women perceiving them to be biased and therefore reduce the levels of trust necessary for successful shared decision-making.

Women do have preconceptions about the attitude of healthcare professionals towards the management of the menopause and may interpret the legitimate concerns of GPs as unwillingness to take account of their values and preferences. Eileen had expected her GP to dismiss her anxieties as those of a 'neurotic woman' (being pleasantly surprised when he was very supportive) and from her experience of visiting a GP about other health matters Sylvia had inferred that 'he doesn't really believe women, they're exaggerating'. Some participants in Im et al.'s study had not contacted medical practitioners because they assumed that the doctor would not care about their symptoms. Denise dismissed the idea of HRT because she doubted that it would be prescribed for her ('I don't think that's an option because I don't think doctors are very keen to give it').

Sylvia's confidence was further undermined by the fact that she had read about using progesterone to counter the risks associated with oestrogen-only therapy but that her GP hadn't informed her of this. Sylvia was immediately suspicious – 'I thought well, why doesn't the doctor say that? What's behind all of that then?'. Concerns that male GPs, and indeed younger female GPs, may not be able to relate to a woman's situation because they have not experienced the menopause themselves can also influence perceptions of the effectiveness of the consultation. Questionnaire respondent Q19 was seen by younger women at the community menopause clinic and felt that they were neither sufficiently knowledgeable nor able to empathize. GP5 herself admitted that she sometimes felt at a loss because she had not yet been through the menopause herself.

The fact of acknowledging a patient's values and preferences and of being perceived as open to discussion of these values and preferences is a key element of effective shared decision-making as defined by Towle and Godolphin and has been identified as a factor likely to increase confidence in the consultation process (Salkovskis et al., 2004). A further element of effective shared decision-making is appreciation of patient-specific characteristics. In the case of the menopause transition this is a complex issue. During this phase of life many women are grappling with a whole range of physical symptoms and emotional challenges. They are seeking to establish whether what is happening to them is 'normal', whether their experiences are comparable with those of their peers, and

whether their existing support networks will be sufficient to help them through this life-change. They are having to redefine themselves as women beyond their reproductive years and adapt to a new rhythm of life exploring their attitudes towards ageing and their self-image. Some women are feeling isolated or have to cope with negative reactions from their partners. Some women are suffering from severe and potentially persistent symptoms and are facing decisions about how to manage those symptoms in accordance with their own beliefs and taking account of their own and their family's medical history.

The concept of 'differences within sameness' (or 'commonality and individuality') is central to discussion about the menopause transition. Each woman's story is different and combines a unique mix of genetic, physical and emotional components that, along with differences in life history and current situation (level of education, whether they have children etc.), impacts on their attitude towards and way of coping with the menopause. To gain a full and balanced picture of a woman's state of health and mind and to take a genuinely informed decision about the optimal way of managing her menopause all of these different elements would need to be explored. Each of the organizations offering advice and support contacted for this study expressed an awareness of the need to consider the menopause from a holistic point of view. The representative from the Wellwomen Information centre explained that the needs of the women who visited her centre extended beyond a simple information-gap. She felt that what the women really needed was help to think about what was going on for them, putting the menopause into the context of their lives. The community healthy-living centre offered women the opportunity to discuss ways of improving their lifestyle through healthy eating and provided them with the chance to meet other women and share experiences as a way of reducing feelings of isolation. Women's Health Concern provide a telephone helpline staffed by nurses and try to offer women the time they need to talk through their problems ('...you might have somebody really distressed that's on the phone for an hour and a half or something, in, in a dreadful state').

Not taking time to explore a patient's situation and worldview, to explain things clearly and to allow women to reflect on their decision has been shown to inhibit effective shared

decision-making (Salkovskis et al., 2004). Several participants indicated that lack of time had impacted negatively on their encounters with health professionals (e.g. ‘The feeling I often have in my doctor's surgery, and I have only been twice in four years, is that my problem must fit in with the 5 minute allocation’ [Q28]). Vicky felt that, although her hysterectomy was not an emergency, she had not had time to understand what was happening and was unprepared for the decisions involved. Rowena pointed out that it’s important to get the maximum benefit out of the ten minutes a patient is able to spend with their GP and when Eileen expressed a wish for more information about what is ‘normal’ during the menopause I asked her whether that was something she had asked her GP about:

‘I don’t know whether I’ve asked or not to be quite honest, a lot of the time, I mean they only have so much time to see each person and much of that time is spent dealing with you know the symptoms you are currently experiencing.’ [EILEEN]

GPs themselves acknowledged that the brief nature of the average consultation was not conducive to spending the time necessary for ensuring that patients fully understood what was happening to them and what their options were. GP5 commented that ‘time is the greatest commodity that anybody can offer people’ and GP4 asked patients to go away and find out as much as they could from other sources then come back when they had had a chance to digest the information and were ready to talk through their options. GP3 explained that the advantage of attending the community menopause clinic over a primary care appointment was that the clinic staff were able to devote half an hour to the consultation. The fact that community menopause clinic staff were able to take time to explore each woman’s situation, discuss her options fully and answer any questions was highly valued by study participants and was seen as confirmation of the fact that their problems were being taken seriously and that they were being listened to. Lack of time for full discussion was also identified as a barrier by Im et al.’s participants who felt that they were not listened to and that their doctors, bound by tight schedules, rushed into decisions about treatment.

The literature relating to factors that support/inhibit shared decision-making and that impact on effective communication between doctors and patients draws attention to the power balance in the encounter. Helman suggests that the internal context of the consultation (setting and social influences) determines where the power lies and can influence the types of communication possible (Helman, 1994) and feminist authors have portrayed women as battling against the weight of the medical profession in a network of power relations (Gardner, 1981; Sybylla, 1997). None of the participants in this study made a direct comment about power relations with their healthcare providers, however it can be inferred from their responses that at times they felt themselves at times to have less than equal authority in the decision-making process. Several mentioned that they had been refused access to HRT because of their GP's opinions about it (e.g. 'My current GP would not give me HRT' [Q57]) and others made comments which indicated that they had low self-confidence during encounters with health professionals or felt inhibited (e.g. Isobel felt 'a bit of a pest' for having problems settling on HRT and Frances found that 'Talking about women's problems to a man is embarrassing really.'). Some found that their GPs discouraged contact with the community menopause clinic either actively (e.g. 'I would have liked to go back for advice later but my GP did not think this was appropriate.' [Q35]) or by omitting to inform patients that the clinic existed. Criticism was not limited to contact with GPs however and some respondents reported that they had felt at a disadvantage during contact with the community menopause clinic:

'On my last visit consultant short and sharp. I have been struggling (sic) for over 2 years with no results. This is not my fault and she made me feel bad. And that she did not believe me.' [Q61]

'Most appointments went well until I decided, by encouragement from my daughters, to stop HRT. As far as I could tell, there was no other help offered and it seemed I caused an annoyance by rejecting HRT treatment.' [Q54]

The Women's Health Concern informant explained that although their policy is to encourage women to work in cooperation with their GPs, they would offer advice about

the best way of approaching a consultation and about how to phrase questions to increase the chances of eliciting the desired response (e.g. to secure access to a second opinion).

From their literature review of patient-focussed interventions, Coulter and Ellins found that, although patients do expect to be given information about their problems and associated treatment options and do want health professionals to take account of their preferences, not all are keen to play a full role in the decision-taking process (Coulter and Ellins, 2006). Daly considered attitudes towards decision-taking in an Australian menopause clinic. Staff at the clinic tended to explain the risks and benefits of HRT and then offer women 'a choice'. Some women did not respond well to this as they felt they had come to the clinic for specialist advice and guidance and felt burdened with a 'choice' that was giving them too much responsibility in the decision (Daly, 1997). Some of my participants also struggled with the responsibility of decision-making given that there is an overwhelming amount of information available from a whole range of sources and that it can be challenging to make sense of it in the context of an individual's life. Grace and Nicola both gave examples of situations in which they felt they had been given the responsibility for a decision without sufficient guidance and the Women's Health Concern contact supported this with her analogy of taking a car to the garage and being asked which kind of oil change she would like without being provided with appropriate information on which to base the choice. GP1 on the other hand believed that patients had to assume the responsibility for decisions about managing the menopause since it was a question of balancing the risks associated with HRT against quality of life issues that only the patient could evaluate for herself.

### *6.4.3 Trust and authority*

#### **6.4.3.1 Trust in interpersonal encounters**

For many women the process of weighing the risks and benefits of taking HRT is a key challenge and indeed GPs interviewed for my study confirmed that for them also it is a particularly demanding area. Barbara and Charlotte both gave examples of struggling to evaluate the potential benefits of HRT against the risks inherent in their own medical backgrounds (i.e. family histories of breast and ovarian cancer). Several interviewees

mentioned concerns about how long it was safe to continue taking hormone therapy (e.g. Grace and Tracy) or about the process of ceasing treatment and had unanswered questions about whether symptoms would reappear (Eileen and Fiona).

‘I don’t think anybody wants to give you a definite yes or no, like everything else it’s up to you. But I think it’s when the percentages, which quite often you can’t find, are put in front of you it’s a little bit easier to weigh up the pros and cons. The amount of people that get breast cancer with it is just the same as without virtually, the only question that can’t be answered is really how long can you be taking HRT? No one will answer that question.’ [GRACE]

Again this relates back to the concept of ‘differences within sameness’ as women try to extract information that is relevant to them amidst the plethora of sources that deal with ‘the average woman’ or as they attempt to locate a source of support that can tailor advice to their own individual mix of circumstances.

It is for this reason that resources such as the community menopause clinic are particularly valued – women felt that the clinic offered an environment in which they were treated as individuals, were taken seriously and were given the time to explore all the factors that were impacting on their menopause experiences and, as a result, could come to an informed decision about treatment with the help of someone they recognized as an expert in the field. As GP3 pointed out, women can be overwhelmed by the volume of information about various studies and research findings, what they need is for someone to interpret that for them and help make sense of their situation. Jane and Tracy both indicated that they would place their trust in healthcare professionals for ‘real advice’ over that available through the popular sector and other interviewees were wary of information received from non-professional sources. Eve distrusted the advice from staff in health food shops, and in trying to reach a decision about taking HRT Imogen found herself bombarded by ‘all other people’s opinions’.

In her comment about preferring a specialist to an ‘odd-job man’, Isobel voiced the opinion of many participants that they placed high levels of trust in the contact with the community menopause clinic at the expense of that with their GPs. The GPs however felt that they provided a good service to menopause patients and had rarely felt the need to refer a woman on to the community clinic. These findings may have been influenced by the fact that the GPs who were willing to participate in the study tended to be those with an interest in the menopause. Furthermore, the majority of women surveyed were registered at the clinic and many had therefore been through previously unsuccessful attempts to manage their symptoms which may have involved what they considered to be unsatisfactory encounters with their GP. On the other hand, some respondents expressed confidence in their primary care practices and felt that their GP had the advantage of a longstanding relationship and a detailed knowledge of their individual medical history. Even Imogen who had a difficult consultation with her GP after confusion over the appointment slot chose to stay with him although he offered her the opportunity to change to a colleague.

Negative comments about encounters with GPs tended to relate a perception that they ‘didn’t seem to want to help’ [Q127] or that patients are at the mercy of the policy adhered to by an individual doctor or practice. Questionnaire respondent Q35 found that she was unable to ensure that her appointments were always with the same GP and that each one she saw had different views and advice which she found very confusing. Deborah and Grace were both unsettled by conflicting opinions between GPs and the staff at the community menopause clinic. In an environment in which women are regularly exposed to opposing views through the media and other contacts in the popular sector, lack of consensus between medical practitioners adds to uncertainty that can erode trust.

In their study of women’s trust in and use of information sources during the menopause, Huston et al. (2009) found that physicians were the most important source of information for all groups of participants although women who had never used HRT rated physicians, pharmacists and other healthcare providers as significantly less trustworthy than did



current HRT-users. The authors suggest that this may be because current users had developed a relationship with their doctors over time or that some never-users had made up their minds about HRT without visiting a healthcare professional and had therefore not opened themselves up to developing a trusting relationship. As explained above (Section 6.4.2) a perception of bias on the part of healthcare professionals can greatly influence levels of trust. Huston et al. found that presenting balanced information and acknowledging the validity of alternative viewpoints may be helpful in reducing perceptions of bias.

In attempting to present balanced information doctors must be sensitive to the fact that patients' decisions can be influenced by the way in which information about risk is presented (Berry, 2004). This is particularly salient in the case of the menopause where a fundamental decision for many women involves judging the risks associated with HRT-use, and indeed of non-use for some women (e.g. those with an increased risk of osteoporosis). Walter and Britten explored women's understanding of risk in the context of the menopause and found that participants' interpretations of the meaning of 'risk' tended to involve using knowledge, the presentation and context of that risk, together with a woman's unique belief system particularly relating to representations of womanhood, lay beliefs and fatalism, control and choice (Walter and Britten, 2002). Ballard found a 'dual consciousness' in which women interpret the risk of menopause-related disease at a collective level (in which they consider statistically-based medical evidence to the effect that menopausal women are at increased risk of some diseases) but also at an individual level (in which they take account of lifestyle and family history to assess their own level of risk). In this study only women who had been medically diagnosed as being at risk of disease were in favour of using HRT as a preventive measure on a long-term basis. The other participants were less willing to take HRT preventatively because they either perceived their own risk as very low or thought the risks of taking HRT outweighed the benefits (Ballard, 2002). As with many aspects of the menopause transition, Ballard's participants appeared to be striking a balance between the collective ('sameness'/'commonality') level and the individual ('different') level to negotiate their own niche in which their unique circumstances were brought in to inform

their decision. Some studies have investigated the use of decision aids as a way of helping women to play a more active role in the decision-making process and to make sense of the variables and risks but, not surprisingly, they have concluded that different methods of delivery work best for different people. Walter and Britten suggest that risk information relating to the menopause may be best communicated through the use of contextual information about other risks familiar to women such as those associated with childbirth or oral contraception.

The consultation between a health professional and a woman seeking advice about the menopause can be a complex encounter. Since women may have preconceived ideas about doctors' attitudes towards the menopause, effective communication that presents information in an accessible way, without implications of bias and that shows a willingness to consider the patient's viewpoint can play an important part in ensuring the success of the encounter. As explained above (Section 6.3.2), the incompatibility between the popular and professional sectors and the clash that sometimes results from efforts to transfer knowledge between the two communities can result in women feeling that their values are being dismissed and that they are not true participants in the decision-making process which can in turn impact negatively on the trust they place in health professionals' advice.

#### **6.4.3.2 Trust in published resources**

Women may bring information gleaned from a wide range of popular-sector sources to the medical consultation. Questionnaire responses revealed that women who had attended the community menopause clinic had also read books and magazine articles about the menopause, seen/listened to media reports, talked to friends and/or family members and accessed a range of other advice and information resources including leaflets, CAM professionals, staff in health food shops, Websites, and charities. Some interviewees revealed themselves to be proactive information-seekers, for example Eleanor had accessed a range of sources including her local library, friends, health professionals and the Internet. Belinda felt herself to be an experienced and 'quite well-educated' reader who knew 'how to look for things' but admitted that she had struggled to find literature that made any sense of what she was going through. She found a friend, who was

medically qualified, and staff in a health food shop to be the most informative sources of information. Denise was also willing to search for information independently but commented that all the books in the world were useless without support. Like the women with symptomatic uterine fibroids (Ankem, 2007), my interviewees were open to many different interpersonal and published sources of information but would often turn to health professionals for discussion and exploration of options at moments of decision-making.

The support women like Denise need is in interpreting and evaluating information and in understanding what is applicable to their individual set of circumstances, particularly in the case of HRT. This was acknowledged by health professionals and other support-providers interviewed for the study. GP3 felt that women visiting their GP do not need to be overwhelmed by an ‘outpouring’ of information about trial outcomes; they simply want to find a way to feel better. The highly-publicized results of the HRT studies have been criticized for several reasons including the fact that types of HRT used, dosages and types of study participants were not necessarily representative of the majority of UK users (MacGregor, 2006; Rees and Stevenson, 2006; Women's Health Concern, 2007) and reporting of the results by the media or on the Internet does not necessarily provide a clear and balanced view. Eileen had reservations about interpretations of the HRT debate in the popular press pointing out that media reports are often incorrect or selective to provide a ‘jazzy story’. The Lead Clinician at the community menopause clinic explained that attendance levels at the clinic could be sensitive to media reporting about HRT risks:

‘There is definitely a, I mean until very recently I had a waiting list for new patient appointments of six months, that has definitely dropped off lately and it hadn’t occurred to me that it was probably this adverse publicity that we’ve had, but that’s probably what it is, is that women aren’t actively seeking at the moment. All of our existing patients I think without exception rode the storm quite comfortably, because we had already had the discussions about the pros and cons. Some of them came in saying what about it and we just revised if you like, I don’t think anybody gave it up.’ [LEAD CLINICIAN]

She also pointed out that health professionals can be left to sort out patients' misconceptions following media reports by journalists who do not critically appraise results in the same way that health specialists would do. In their study of media reporting of health-related stories, Harrabin et al. (2003) found that reporting conventions such as having the views of two opposing 'experts' gave an appearance of balance to a discussion that did not necessarily provide a true reflection of the weight of evidence. In the face of such reporting techniques it can be difficult for the layperson to judge authority and to evaluate the evidence as presented. The Lead Clinician further expressed concerns about women's ability to appraise information available on the Internet and worried about 'the plethora of information amongst which there might be some useful stuff but how do you know what it is if you haven't been taught how to look?' These concerns are documented in the literature by authors who suggest that many consumers of online health information are ill-prepared to judge the relevance and quality of Internet resources or do not have the skills required to access them (Childs, 2004; Ellins and Coulter, 2005; McCray, 2005; Wilson, 2002; Woloshin et al., 2003).

Forty-three questionnaire respondents indicated that they had used the Internet to look for information about the menopause. Although interviewees were not specifically asked about their experiences of using the Internet several did mention it and their views were mixed. For Nicola it had been a source of information and, above all, support as she found and became a proactive member of the online EarlyMenopauseUK group. Eleanor, Deborah, Sylvia and GP5 all expressed doubts about the reliability of information available on the Internet, especially Websites from the outside the UK. Research into women's use of the Internet suggests that, although they are known to be more regular searchers of online health information than men (Lorence and Park, 2007), their overall relationship with new technologies is somewhat ambivalent. Like Nicola, the women with polycystic ovarian syndrome in Avery and Braunack-Mayer's study (2007) appreciated online chat groups as a source of support. They liked the fact that they could interact with other women whilst remaining anonymous. They particularly valued the anonymity of the Internet as a source of support and information since aspects of their condition could be potentially embarrassing but they also valued the fact that they could

control the type and timing of information received and that it allowed them to access information about a complex condition which is poorly served by traditional information mechanisms. The women in this study tended to have a high level of education and were aware of the need to assess critically the information available via the Internet but the authors point out that this would not be the case for every woman.

Simon considered women's 'lived relationship with technologies' and suggests that the very ambivalence of women's attitudes towards ICT can be seen as an active and critical approach to change – women do have doubts about some areas of computer-use but enjoy the feeling of being in control that comes with taking opportunities to access information independently and make contacts (Simon, 2006). Dholakia (2006) and Wyatt et al. (2005) identified aspects of the home environment that might inhibit women's use of the Internet such as lack of time due to the division of household tasks or of opportunity due to male family members dominating access to the computer. These factors were not specifically mentioned by my interviewees whose doubts focussed mainly on the reliability of information. One interviewee (Ann) did explain that although she knew there probably was information available on the Internet she was unable to access it because she had no computer skills.

Huston et al. (2009) investigated use of and trust in information sources about the menopause. As discussed above (Section 6.3.2), they found that women's opinions varied according to their self-assessed menopause status and their history of HRT-use. They found that women who had discontinued HRT used the Internet more frequently than either current users or women who had never taken HRT. The authors suggest that this may be because they were stimulated to look for information following the publicity surrounding HRT trial results or that they may have been looking for information about CAMs since confidence in doctor's ability to provide information about CAMs has been shown to be low (e.g. Suter et al., 2007). The authors recommend that healthcare providers should consider discussing the reliability and validity of Internet and media sources of information with their patients. They also suggest that doctors may wish to provide patients with examples of reliable Internet resources or that patients should be

taught how to evaluate Websites for reliable medical information. In a UK-based study Childs (2004) found that users do struggle with judging the quality of consumer health Websites and of evaluating the information they contain. Participants in Childs' focus groups concurred that they would benefit from information skills training to improve their search and appraisal techniques. Along with other authors (e.g. Coulter et al., 2006; Gagliardi and Jadad, 2002), Childs also considers the potential benefits and practical challenges of developing quality-assurance schemes to validate the provision of online health information.

Issues of trust and authority are not, however, restricted to online information sources. Hardcopy resources may also be perceived as value-laden, trying to influence the reader towards the author's own persuasions, (Payne, 2002) or as of limited use. Kathleen commented that she had looked at various books and magazine articles but found that authors tend to 'come down either one side or the other' and are 'either very pro or very anti' HRT/CAMs and that it is difficult to negotiate these opinions and find the right advice. Deborah concurred:

'Every time you read something it depends which side they're on as to whether you should take it or not, it's very difficult.' [DEBORAH]

Fiona was sceptical about the HRT 'scares' reported in the media and suspected that it was 'a money-saving exercise' on the part of the NHS. Her comment to her GP was 'well, yes, the NHS are going to save money on this now and then they'll have, you know, an extra crop of hip replacement operations in ten or fifteen years' time!' Kate had rejected patient information leaflets in favour of magazine articles having found that leaflets were not 'self-explanatory enough' and that it was easier to relate to another woman's story published in a magazine. Another issue with patient information leaflets lies in the fact that many are produced by pharmaceutical companies. Coupland and Williams (2002) explain that such leaflets construct the menopause as a disease caused by failure of the reproductive system and tend to advocate treatment with HRT. They can therefore be little more than adverts for the pharmaceutical company's products and some

consumers are wary of the relationship between advice and commercial interests. The Women's Health Concern representative interviewed for my study confirmed that women would sometimes explain that they had contacted the WHC helpline specifically because they knew it had no allegiance to pharmaceutical companies. Coulter et al. (2006) carried out a survey of organizations providing consumer health information and an assessment of information materials as part of a scoping study for a proposed Department of Health information accreditation scheme. Thirty percent of the information providers they surveyed were commercial organizations (including pharmaceutical companies). They concluded, however, that the category of provider (e.g. commercial organization/public sector/voluntary sector) did not impact on the quality of the information produced with the range of quality scores wide in all categories. Although caution is needed when assessing information materials supplied by commercial organizations since they may well have their own agenda (Coupland and Williams, 2002; Rogers, 1997), involvement of pharmaceutical companies is sometimes an unavoidable element of the provision of support. The Lead Clinician of the community menopause clinic explained that she had no funding to supply medication to patients. The clinic relied on the pharmaceutical industry to provide free samples of HRT drugs. The arrangement benefited individual patients because they were able to try a number of different products to find the most appropriate without paying prescription charges. Since many women require two different hormones there can be two prescription charges to pay each time a new combination of products is tried. The pharmaceutical industry was willing to subsidize this because once a woman settled on a prescription she would be likely to continue with it on her discharge from the clinic back to the primary care practice.

## 6.5 Summary

Having explored the findings from this study in the context of the literature about women's experiences of the menopause and their interaction with sources of information, support and advice, the findings will now be related to McKenzie's Model of Information Practices in Everyday Life Information Seeking for discussion of the extent to which the menopause has been a valid testing-ground for the model.

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# Chapter Seven: Analysis of the Findings in Relation to the Model of Information Practices in Everyday Life Information Seeking

## 7.1 The context of McKenzie's model

McKenzie's model of everyday information practices evolved from a naturalistic approach to the study of information behaviour in which individuals are perceived to be the authors of their social world, attributing meaning to behaviour and to be constantly redefining and shaping knowledge in response to new experiences. Naturalistic approaches to information-behaviour research lie within the social approaches to metatheory and focus on the meanings and values associated with the sociocultural aspects of information behaviour (Bryman, 2001; Lincoln and Guba, 1985; Pettigrew et al., 2001; Schwandt, 1994). McKenzie's work forms part of a movement away from the original concept of 'information seeking' as an intentional and directed process towards an acceptance that individuals experience a rich variety of information encounters which can be better described by the term 'information behaviour'. Along with instances of directed, purposive, information seeking, researchers identified a whole range of other 'conceptual and physical contacts with information' (Erdelez, 1996) including information encountering, browsing, serendipitous discovery and incidental information acquisition (Erdelez, 1996; Toms, 1999; Toms, 2000; Williamson, 1998). Furthermore, researchers began to appreciate that the concept of 'information' encompasses the whole process of communication and creation of meaning for different social groups and should include consideration of how people use information and pass it on to others within the context of their past and future information needs and of their own personality traits (Heinström, 2005; Rice et al., 2001; Rioux, 2005).

The fact that McKenzie's model is grounded in experiences of everyday life information behaviour reflects a further departure from the traditional base of information-seeking research which tended to focus on the workplace (Ellis, 1993; Leckie et al., 1996; Mick et al., 1980; Palmer, 1991). As researchers became more aware of informal exchanges of

information they began to explore people's wider social worlds and to take account of the influence that surroundings can have on behaviour (Hargittai and Hinnant, 2006).

McKenzie's interest in everyday life information behaviour further explains her choice of a naturalistic approach to research. There are precedents in the work of other researchers (e.g. Chatman, 1991; Pettigrew, 1998; Williamson, 1998) and such an approach allows the researcher to explore participants' worlds through the use of qualitative research methods with sensitivity towards the fact that findings can only be context-bound.

McKenzie (2001) set out to explore the information behaviour of Canadian women pregnant with twins as they negotiated their way through a life transition. She recognized that previously-existing support networks may be insufficient to help women cope with the transition due in part to a mismatch between individual and society's assumptions about the meanings and experiences relating to twin pregnancy. McKenzie recognized the journey to negotiate other people's understandings and to find help that fitted a woman's own experience as a potentially fertile ground for the study of information behaviour and expanded her original goal of exploring 'active' and 'incidental' information seeking to take account of the rich data she had collected. The final version of her model (Figure 7.1, *see* Section 7.2) describes four modes of information behaviour reported by her participants: active seeking; active scanning; non-directed monitoring; and by proxy. She then identifies two phases of the information process during which these activities may take place – Connecting and Interacting – and considers how the activities relate to each phase and the barriers that may inhibit successful connection and interaction with potential sources of information. McKenzie further identifies counter-strategies that may be employed in an attempt to circumvent some of the barriers to successful information-seeking. In keeping with her naturalistic approach to the study, McKenzie acknowledges that her findings are context-bound, relating to the physical characteristics and social meaning of multiple pregnancy for participants and those around them. She suggests that further testing in a different context would help establish the transferability of the interrelations between mode of information practice and stage of the information process (McKenzie, 2003).

As a relatively new field, Library and Information Science (LIS) has sought to establish itself as a discipline through the generation of theory. In their attempts to construct a theoretical base for the discipline, many researchers have developed models as a way of communicating their emergent ideas through the, often diagrammatic, representation of information behaviour in a particular context. Models can be seen as a stage in the development of full theory. If treated with caution, a model can provide a succinct and, hopefully, easily interpretable way of expressing ideas so that they can be tested for validity in an iterative process that, over time, will generate true theory (Bates, 2005; Case, 2007). Models can also provide indications of how ideas within LIS research have developed over time, with early examples (e.g. Krikelas, 1983) adhering more to traditional approaches which focussed on linear information-seeking patterns with little acceptance of the information-seeker as an individual or of unconscious information needs. Gradually models began to portray the search process as more holistic with an acknowledgement that people experience emotions such as uncertainty, confusion and optimism that are unique to each individual encounter (Kuhlthau, 1991). Later models, including McKenzie's, stress the importance of context and of a non-linear, flexible, process that takes account of experience and beliefs, and preserves individuality and 'fluidity' (Foster, 2004; Johnson, 2003).

Caution is necessary when considering models as their very simplicity can encourage a tendency to draw conclusions that may be overgeneralized or an inference that information seekers follow ideal optimized routes (Case, 2007; Godbold, 2006). Along with the creation of new models, the rigorous testing of existing models to assess their validity beyond the original context is necessary for the consolidation of the LIS research base. Although authors, including McKenzie, recognize the need for their models to be tested and refined (e.g. Johnson, 2003; Wilson, 1999) there is little evidence to suggest that this is routinely done. Possibly the idea of generating a new model is more appealing to researchers than that of working with an existing framework. For whatever reason, there are a plethora of models with relatively few examples of testing. The literature review for this study did identify recent work by Beverley et al. (2007) who tested two models (Wilson's revised general model of information behaviour and Moore's model

relating to the needs of visually-impaired people) in the context of visually-impaired people seeking information about health and social care (Moore, 2002). The authors found that both models provided a useful basis for examining the information behaviour of their chosen study group. They built upon Moore's concept of 'clusters' of information need (Moore described social information as having six different dimensions: function; form; clusters; agents; users; and mechanisms) to develop an ordered hierarchy to better reflect the perspective of the visually-impaired people in their own study but found that Moore's model did not take account of all the 'intervening variables' that are depicted in Wilson's model and that the authors thought were important in determining information behaviour among people with a visual impairment.

Beverley et al. chose to compare two models: one taking a general view of information-seeking situations and the other focussed on the same group of individuals as their own study (i.e. people with a visual impairment). My own approach to testing McKenzie's model was to select a related yet contrasting topic: a different experience from a woman's journey through her reproductive life. As discussed in Section 2.2, some authors have noted parallels between the states of pregnancy and menopause. Rothfield (1997) points out that both are experienced by women, are culturally and biomedically defined in relation to notions about reproductive femininity, and are medically managed in industrialized societies. Brown et al. (2002) further comment that the medicalization of both pregnancy and menopause can leave women feeling ill-equipped to participate actively in decisions about interventions impacting on their health and well-being. Both experiences thrust a woman into a new phase of life in which she must reassess her own self-image and becomes vulnerable to society's interpretations of her reproductive status. She must also test the social and professional support systems available to her and attempt to negotiate a way through her contact with these systems that takes account of her own beliefs and values. Furthermore, both experiences reflect the concept of 'differences within sameness' or, to use McKenzie's terms 'commonality of experience' and 'uniqueness and individuality'.

Despite these similarities, there are some significant differences between the two conditions. Whereas pregnancy (and maybe particularly twin pregnancy) becomes increasingly visible to others the menopause is not necessarily visible and the majority of women do not welcome outward signs of their menopause should they at times become visible (e.g. through a woman noticeably having a hot flush or bleeding heavily). Although some authors (often with a feminist viewpoint) note the ambiguity of society's response to pregnancy and the feelings of unease that it can cause in the pregnant woman herself and those who come into contact with her (e.g. Oakley, 2007; Wolf, 2001), general perceptions of pregnancy are that it is a positive event that celebrates fertility. The menopause, on the other hand, is frequently associated with more negative perceptions of ageing and loss of fertility. The duration of the experience is another significant difference that can impact directly on information behaviour. A woman's life changes dramatically from the moment she conceives her first child but the actual state of pregnancy has a finite duration. According to McKenzie (2001), in the absence of complications it involves fairly extensive contact with the healthcare system for a relatively short period of time, after which contact returns to its former level. Symptoms relating to the menopause may continue for many years, sometimes stretching from well before until well after the final monthly period itself. Interaction with health professionals and other providers of information and advice may fluctuate over this period as symptoms change and as women assess and reassess their choices in the light of their own personal values and preferences and of the advice and guidance they receive.

## 7.2 Relating the findings to McKenzie's model

Although participants in this current study provided many examples of their experiences of encountering information and advice about the menopause, analyzing these experiences in the context of McKenzie's model proved more challenging than originally anticipated. As explained in the methodology chapter, the intention was not to replicate McKenzie's study exactly. McKenzie conducted initial semi-structured interviews in which she asked participants about significant incidents of information/advice seeking or encountering. She then carried out two telephone 'check-ins' in which she asked about incidents arising over the course of the week following the initial interviews. Finally, she



used follow-up interviews to expand on some of the incidents described during the ‘check-ins’. Such an approach was neither practical nor necessarily appropriate for this study. Having negotiated access to patients at the community menopause clinic there was a commitment to the provision of a user-satisfaction evaluation for the clinic and a postal questionnaire was identified as the method most appropriate to survey the 519 women registered at the clinic. As in McKenzie’s study, semi-structured interviews were selected as the method best suited to explore women’s experiences in more depth but, given the different timescale of the menopause as compared to pregnancy, it was not thought that additional interviews or weekly ‘check-ins’ would necessarily add many new examples of information behaviour (McKenzie uses the term ‘information practices’). Furthermore, extra interviews may not have been welcomed by participants from the clinic sample who had already completed the postal questionnaire and were unlikely to have been approved by the Research Ethics Committee who were anxious to limit intrusion.

The development of the interview schedule was guided by McKenzie’s schedule with the intention of eliciting data that could be discussed in relation to the Model of Information Practices in Everyday Life Information Seeking. It did not, however, mirror McKenzie’s schedule exactly (see Appendix 13). Little precedent was found in the literature to inform decisions about design of an interview schedule that would allow participants to speak in their own words but that would provide data to be used in testing an existing model (as explained in the Methodology chapter, Section 4.1, the Beverly et al. (2007) study was published too late to inform the design of my survey instruments). A decision was therefore made to open each interview with an invitation for the participant to tell her ‘menopause story’. The schedule then contained a list of topics that equated to some of the topics from McKenzie’s interviews and could be used as prompts to encourage interviewees to focus on their information behaviour.

Each interview transcript was coded three times. Firstly to identify broad themes, secondly to confirm these earlier decisions and to code the broad themes into more specific units and, thirdly, to recode the transcripts specifically for the themes identified

by McKenzie. It is the process of recoding according to the themes in McKenzie's model that was most challenging. There were three main reasons for this:

1. **Understanding another researcher's thought process** is not always easy unless the second researcher is able to question the first and explore their reasons for taking a particular decision or has access to a record of the decision-making process. For example, an incident in which a pregnant woman noticed a father pushing twins in a pushchair appears under both 'non-directed monitoring' during the Connection phase and 'non-directed monitoring' during the Interaction phase. To facilitate the process a table showing the categories from McKenzie's model with supporting examples of each type of information practice from the text in her thesis was produced (Appendix 23). Using the table to retain a clear picture of McKenzie's concept of how activities related to the categories of information practice, attempts were made to fit examples from the menopause transition study into her framework.
2. **Deciding how my examples could fit into the model** was another challenge. Although many of the examples of locating and interacting with sources of information/advice provided by participants slotted comfortably into the model there were instances of behaviour that did not have an obvious fit. An example of this would be the role played by several of participants in actively passing on information and/or advice to other women.
3. Finally, **the different contexts of pregnancy and menopause** sometimes made comparison of results with those of McKenzie difficult. McKenzie's interviewees provided very detailed accounts of significant encounters with sources of information and advice. They could often remember the exact words in a conversation, the tone of voice of a health professional, or the expression on someone's face:

‘...So I was going “Well, there’s probably twins in there or something.” And then just the way she looked at me I was going, “No way!” And I go, “No way!” and, she’s going, “Well I didn’t know what to say or if I should

say anything or if I should wait or,” And I’m going [exaggerated voice] “Get outta here! You’re lying to me, you’re full of shit! You’re B.S.in’ me.” I just broke out in hysteria, like a laughter, kind of a nervous, like, and I was cracking up....” [Holly on discovering she was pregnant with twins during a sonography appointment]

Many of the encounters described by interviewees in the menopause transition study had taken place over a long period of time, sometimes several years prior to the interview, and interviewees often had difficulty recalling them:

‘The one I went and bought I went through the bookshop, I was fed up one day and I thought right I’ll go and have a look at that, and picked up a small book, I can’t remember what it’s called now and I gave it to someone.’ [DENISE]

‘ALISON: Do you remember where you found that out in the first place?

TRACY: That was at the menopause clinic.

ALISON: Sorry I mean what made you think it did help?

TRACY: Oh gosh, no I can’t remember where I heard that.’

Because of this, their responses were often more general than those provided by McKenzie’s interviewees which sometimes made it difficult to identify the subtleties of context that would allow correct positioning within the parameters of the model. For example, McKenzie differentiates between calling a friend to ask for advice (Active Seeking in Connecting) and finding something out by hearing a friend talk about her own experiences (By Proxy in Interaction). By contrast, my interviewees would remember that they had been informed of something by a friend without providing specific details of the actual event because it had happened years previously.

As with McKenzie’s participants, analysis of my questionnaire responses and interview transcripts provided rich data about women’s experiences of encountering information and advice about a reproductive health topic. Although the different context of the studies provided some challenges in relating findings to McKenzie’s model and brought its own quality to the discussion, most of my participants’ experiences could be positioned within the model. The extent to which findings from the menopause transition study fit with the Model of Information Practices in Everyday Life Information Seeking (Figure 7.1) will be demonstrated by taking each element of the model in turn and discussing how certain themes were not reflected in McKenzie’s categories.

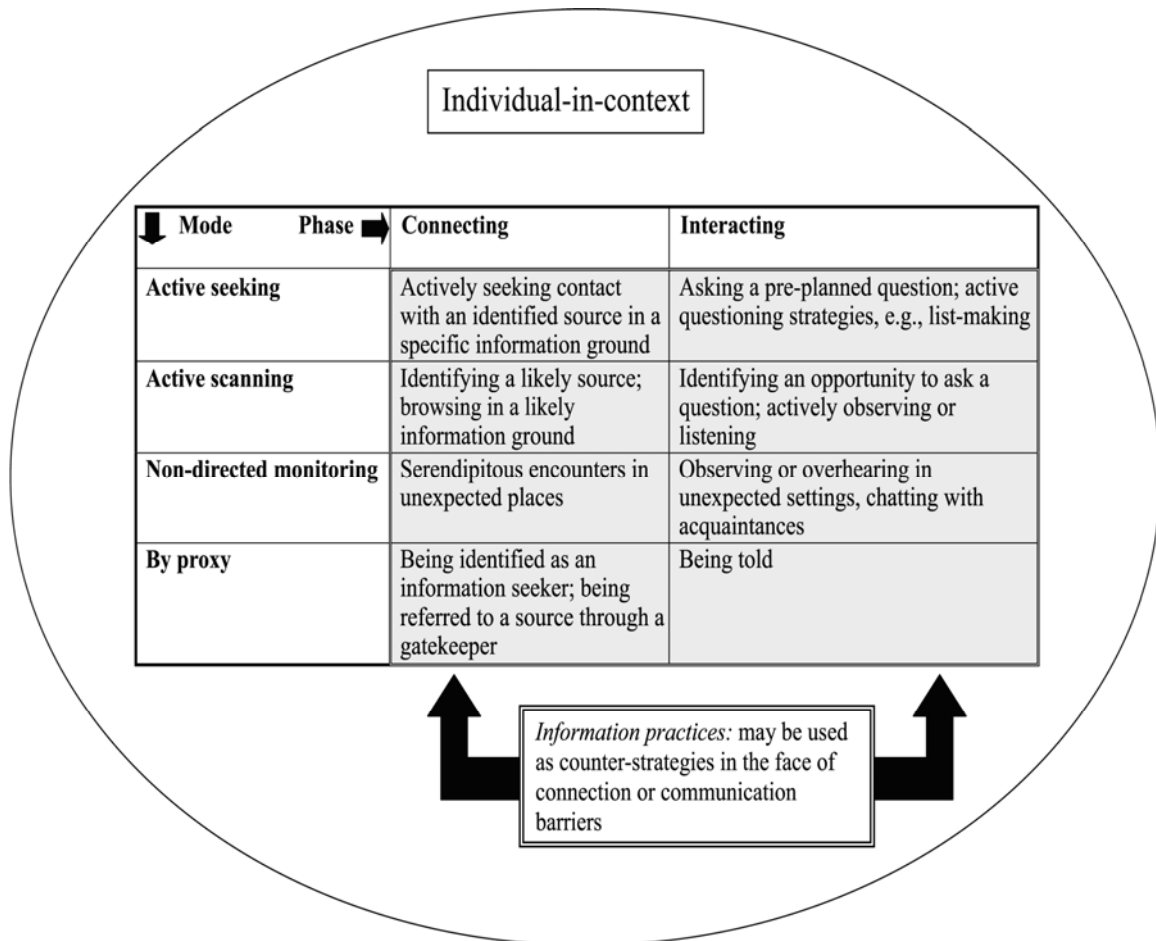


Figure 7.1 McKenzie’s Model of Information Practices in Everyday Life Information Seeking (Reproduced from McKenzie, 2003, p.26).

### *7.2.1 Connecting with sources of information and advice*

McKenzie uses the phase of 'Connecting' for examples of the barriers and practices involved in identifying (or being identified by) and making contact with (or being contacted by) information sources or potential sources whether directly or through a referral. Within this phase of the information process she provides examples of the four modes of information behaviour or practices that emerged from her analysis.

#### **7.2.1.1 Making connections through active seeking**

For McKenzie, active seeking is the most directed form of information practice. It involves pre-emptive methods of making or seeking contact with likely information sources. Examples from her research included making contact with a source to meet an acute need (calling the doctor's office between appointments or looking for a book about gestational diabetes after receiving an abnormal test result); re-connecting with a previously-known source (such as a former neighbour with twins) to meet a new need; and activating an ongoing informal relationship for a specific need (calling a friend for advice). In this category McKenzie also includes examples of women actively pursuing relationships with potential sources of information/advice in anticipation of future needs (e.g. joining a multiple birth association). On finding she was pregnant with twins one interviewee immediately contacted a magazine that offered a pen-pal service whereby mothers sent in descriptions of their circumstances and invited letters from others in a similar situation. McKenzie found that active seeking happened in making connections with all kinds of information sources including with healthcare professionals, personal contacts, other parents of twins and with published literature. She defined it as a response to a specific and premeditated question or goal, as requiring systematic attention to the connection process and as occurring in specific places where women sought out information sources (e.g. in doctors' offices, homes, bookshops or libraries). McKenzie equates these environments to the 'information grounds' described by Pettigrew (1999).

In the menopause transition study, the most frequently-cited example of connection-making through active seeking was the initial visit to a health professional once a woman realized that she needed advice. This is not surprising given that the majority of participants were patients of the community menopause clinic and had therefore actively

sought help from health professionals. Some women spoke about their first visit to a GP when they began to suspect that they were approaching the menopause or because they had symptoms they did not understand or of returning to seek clarification, particularly following news reports about HRT. In these cases they often had specific issues to discuss:

‘Well what started me off wondering if I had problems was feeling dizzy, light headed and I found myself walking from the office to the office car park sort of meandering and that concerned me seeing as I was driving three quarters of an hour each way to work, so when it persisted I thought well something’s altered in my life, quite what I don’t know and that was when I went to the doctors and it was suggested that the menopause might be the problem.’ [LOUISE]

‘...I was having splitting headaches like every month, they would come on every month. So I went back to the GP and I said you know “look I’m nearly 50 years old could it be menopausal?”’ [DENISE]

‘...about two years ago I decided that I’d like to come off [HRT], simply because of what you read in the press really and hear on the TV, so I went to see the doctor and the doctor just took me off it.’ [CHARLOTTE]

Some, like Deborah, had made appointments directly at the community menopause clinic without contacting their GP. The fact that the clinic allowed self-referral and that it welcomed active seeking on the part of patients by encouraging them to make contact whenever they felt they needed advice was highly valued by study participants. Deborah had decided to self-refer to the clinic because she was worried about osteoporosis but only after living with her symptoms for a year. Deborah’s story provides an example of how the timescale of the menopause contrasts with that of pregnancy. On positive confirmation of conception, the pregnant woman enters a relatively short period of finite duration and usually finds herself slotting into a medical system that guides, and according to some feminist writers dictates, her journey through pregnancy:

‘I soon lost the quiet confidence I had briefly felt when newly pregnant on a bench in the Italian sun. Being home meant that I was inducted into a medical system that had very clear expectations of me – but little room for me to negotiate my expectations of it.’ (p.13)  
(Wolf, 2001)

Women experiencing their menopause transition have more flexibility as to whether and when they make contact with health professionals. They do not have the wellbeing of their foetus(es) to consider and can weigh up the severity and impact of their symptoms against their own preferences and views on medical intervention.

Like McKenzie’s participants, interviewees gave examples of connecting through active seeking that did not involve making formal contact with health professionals including:

- Asking a medically-qualified friend (Belinda);
- Looking at a specific book (Erica);
- Asking for advice in health food shops (Eve, although she was wary of the advice given);
- Accessing a specific Website (Grace looked at the Menopause Amarant Trust Website; Nicola contacted EarlyMenopauseUK and emailed questions to a menopause expert via his Website);
- Writing to The Menopause Amarant Trust for information (Helen); and
- Contacting a CAM practitioner (Sylvia).

### **7.2.1.2 Making connections through active scanning**

In McKenzie’s study women described scanning for information when they found, or deliberately placed themselves in, resource-rich environments such as doctors’ offices or bookshops. The process of active scanning involves seeking and recognizing appropriate information sources by ‘having feelers out’. Examples from McKenzie’s interviews included finding a relevant telephone number on a bulletin board in the obstetrician’s office or finding pamphlets in a ‘community room’ at the doctor’s office. In libraries or bookshops participants would spend time ‘going through the pregnancy books’ and on the Internet they would use search terms such as ‘TWINS,’ ‘MULTIPLE,’ to look for

relevant information without having a specific Website in mind. According to McKenzie, a key element of active scanning is the ability to recognize a relevant source when it is encountered.

For several of the menopause study participants work provided the kind of resource-rich environment identified by McKenzie as a location likely to promote active scanning. One of the criticisms of the community menopause clinic that emerged from the user-satisfaction survey was that it did not publicize itself widely enough. Many women had only discovered it by chance or through recommendations from friends or colleagues. Some interviewees (e.g. Charlotte, Eileen and Isobel), however, were employed by the local hospital and had heard about the clinic through talks given by clinic staff to hospital employees. Interviewees working in healthcare environments reported other instances of recognizing useful sources of information through their work contacts. Questionnaire respondent Q81 identified opportunities to question representatives from pharmaceutical companies when they came to the primary care practice where she worked. Olivia (who did not seek medical intervention for the management of her menopause) had worked as a healthcare practitioner and found that her experiences of working in a women's health environment had helped her to absorb useful information:

‘...being a midwife, that part of it too because it does mean even if you don't directly talk about it you have had access to, in a sense I've had access to consultant advice without asking for it, you know I haven't asked for it myself but over time...I have worked in clinics and things were women have come and presented problems.’ [OLIVIA]

Other information-rich environments identified by participants included GP practice and community clinic waiting rooms – questionnaire respondent Q37 spotted a notice about the menopause clinic on the wall when she came to the community clinic for a chiropody appointment and Imogen and Barbara had picked up ‘lots of bits of information’ from doctors’ surgeries.



Denise had browsed in a bookshop and had located a book she then passed onto someone else. Some interviewees mentioned looking in the library (e.g. Eileen, Fiona and Kathleen) or carrying out a general Internet search (e.g. Hannah 'went in under MENOPAUSE and then just picked different ones'). Gwen would 'read everything about the menopause' and would cut useful information out of the newspaper and stick it on the fridge until she had time to read it. Viv also commented that 'whenever there's an article in a magazine I always read it'. This implies more active behaviour than simply coming across things serendipitously but the borders between 'active scanning' of newspapers, magazines and media broadcasts and simply finding something serendipitously through a process of non-directed monitoring were sometimes hard to distinguish.

### **7.2.1.3 Making connections through non-directed monitoring**

In her original thesis (2001) McKenzie refers to 'Everyday monitoring' although by the time the model appears in later papers (e.g. McKenzie 2003) she has changed the term to 'Non-directed monitoring'. The concept of 'everyday monitoring' captures the idea of people carrying out activities simply to 'get along in the world' without seeking information actively. For McKenzie this includes such activities as reading the newspaper or watching the news on television as well as serendipitous encounters such as bumping into other parents of twins in public places. McKenzie found that many women did not provide accounts of non-directed monitoring during their interviews and often had difficulty recalling examples if they were specifically asked about encountering information 'out of the blue'. Characteristics of non-directed monitoring were that the practice required no specific information-seeking goal; that the information-seeker was not particularly paying attention to the environment in an attempt to locate information; and that accounts were situated in any kind of environment where pregnant women were likely to go. McKenzie notes that the visibility of twins facilitated their connections with potential sources of information (e.g. noticing a woman with several children including a set of twins in a shop).

Participants in the menopause study provided a range of examples of making connections through non-directed monitoring. Most examples came from spotting articles in

newspapers or magazines or in hearing/seeing useful information during media broadcasts, a process summed up by this comment from Eleanor:

‘...through things like Woman’s Hour maybe or magazines, that kind of thing, just happening to be listening to a programme or watching something on television or reading an article, that way I might come across something without actually practically looking’  
[ELEANOR]

Other examples included finding things in books that the interviewee ‘just happened to be reading’ (e.g. Ann) or unexpectedly meeting someone who could provide assistance (e.g. Belinda met the Lead Clinician from the menopause clinic because she was a customer of Belinda’s dressmaking business). Barbara had spotted a storyline about fibroids while watching a hospital drama on television, Gwen had found out about dietary supplements from a magazine article, and questionnaire respondent Q24 had read about the community menopause clinic in the local newspaper.

With the exception of Belinda’s encounter with the Lead Clinician, participants provided fewer examples of interpersonal connections than those of McKenzie’s interviewees. This may be context-driven: McKenzie identifies the visibility of twins and of twin-pregnancy as a factor in promoting connections with potential sources (either because a pregnant woman notices a parent with twins or because she is herself recognized as a likely information-seeker). For menopausal women the situation is different, there are few outward signs of the menopause and society’s negative perceptions of this life transition make it less likely that a woman would be approached by someone offering advice ‘out of the blue’.

#### **7.2.1.4 Making connections by proxy**

As with non-directed monitoring, the visibility of twinship played a role in facilitating the making of connections by proxy. In this case, the fact that a woman could be seen to be pregnant with twins allowed her to be identified as a potential information-seeker by a potential source. Proxy connections occurred when someone other than the woman herself engaged in active seeking or active scanning on the woman’s behalf or identified

the woman as an information-seeker through the process of non-directed scanning. Participants in McKenzie's study described three types of proxy connections: being identified as a potential information-seeker; specific occasions on which people referred them on to other sources; and family members or friends who acted as gatekeepers providing regular information and referrals. Examples of these three types of connection included a woman at church suggesting to the interviewee that she might be having twins, hearing about a local multiple birth organization from the nurses in the hospital, and having a sister who was a garage-sale fan and was always on the lookout for things to buy for the pregnant woman.

As explained above, the contextual differences between pregnancy and the menopause limited examples of women in my study being spontaneously identified as potential information-seekers (one possible example of this type of behaviour was given by Barbara who mentioned that a work colleague used to say to her 'I'm sure you've got fibroids' and would then offer support). Neither did participants provide examples of family members/friends acting as gatekeepers which may also be due to differences in the two life transitions: compared to the menopause which can last for several years, pregnancy provides a short and focussed period of information-seeking in which other people may be highly motivated to look for information on a woman's behalf.

On the other hand, some interviewees did identify themselves as passing on information and providing support to other women or as being likely to do so (e.g. Deborah, Eileen, Nicola, Kate), usually because they were further advanced in their menopause transition:

'ALISON: So now you say you have come across other women who are going through it as well?

EILEEN: Yes.

ALISON: Do you find it easy to talk, do you turn to them for support?

EILEEN: I'm the one that's giving the support, I think because I'm further on.'

In some cases healthcare professionals could be identified as acting as gatekeepers. Fiona explained that one of the nurses at her primary care practice had an interest in CAM approaches to management of menopause symptoms and would inform Fiona if she found anything useful. Jane's practice would send out information about changes in HRT advice, keeping her updated about developments.

Most of the examples of making connections by proxy from the menopause study related to being referred on to sources. In many instances this was through a process of signposting or formal referral (often to the community menopause clinic) by health professionals. Questionnaire respondents Q79 and Q112 were both told about the clinic by practice nurses and respondent Q1 was informed about it through the Family Planning service. Several interviewees were referred by their GP (e.g. Angela, Erica and Louise) but a surprising number found out about the clinic by other means even if they had consulted their GPs about management of their menopause symptoms. Eleanor and Janice were both told about the clinic by friends, as was Tracy:

‘...the night sweats and hot flushes and not feeling generally very good, under par, and again through talking with some friends of mine, this friend said she was on HRT and then another friend said that there was a clinic that was very good, [Lead Clinician] was in charge and she'd been most helpful, and she suggested that I should contact her.’

[TRACY]

Work colleagues also proved rich sources of by proxy connections with Charlotte, Sally and Maureen all finding out about the clinic through colleagues. Questionnaire respondent Q155 had looked in the telephone directory after her sister told her ‘there must be a menopause clinic in the area’. Two interviewees provided examples of by-proxy connections to sources other than the community menopause clinic. Olivia and her friends, in a mutual exchange of connections, would swap books, and Viv's sister-in-law referred her to a mail-order source of progesterone cream.

### *7.2.2 Interacting with sources of information and advice*

McKenzie's examples of interacting with sources describe what happened to her interviewees once they had connected with information sources. She considers the ways in which the four modes of information behaviour figure in women's accounts of overcoming communication barriers in interactions with sources of information and advice: the nature of information-seeking interactions, the strategies for getting answers and the ways in which information was either disclosed to or withheld from participants.

#### **7.2.2.1 Active seeking in interactions with sources**

In this mode of information behaviour, McKenzie's participants focussed on their attempts to get people to answer their questions. They used a range of techniques to elicit responses: list-making (in which women would, for example, note down things they wanted to ask about and then take a list of questions to an appointment or would make notes during a multiple birth association meeting); actively asking questions (in which women would plan not only what questions to ask during an encounter but also who to ask them or would devise strategies such as the use of humour to elicit the desired responses); keeping the process 'on track' (in which women would find that an information source was not providing the anticipated 'next step' and would use active seeking techniques to ensure that the next step happened, for example by telephoning the doctor's office); and being persistent (repeatedly asking questions over time and of several sources to try and find an answer, for example asking sonographer, GP and obstetrician about the sex of the foetuses).

Although the participants in the menopause study were not able to provide such detailed accounts of their actual interactions because many of their encounters took place well in the past, they did give examples of some of the types of behaviour exhibited by McKenzie's interviewees including the asking of planned questions and the devising of strategies to achieve a desired goal. Many participants had made appointments with health professionals to discuss specific issues of concern and had gone armed with questions they planned to ask. Belinda knew that she would need to negotiate with her GP to secure access to oestrogen since she suffered from thrombosis which precluded the use of oestrogen therapy. She went to her GP and asked whether he would prescribe

oestrogen in spite of her health status since she was coping both with her menopause symptoms and with family issues and found that oestrogen was ‘the only thing that made me sensible because somebody in the family had to be sensible’. In the end she was prescribed oestrogen but took Warfarin to counteract the undesired effects. Kathleen returned to her GP because she had concerns about taking HRT derived from mares’ urine. Her GP attempted to assure her that the horses were well-treated but Kathleen countered this by saying she had read otherwise and persuaded her doctor to change her prescription. Questionnaire respondent Q78 was interested in CAM therapies. She researched on the Internet before attending the community menopause clinic and took the information she had found with her to the appointment. Nicola gave an example of keeping the process ‘on track’ after attending a community menopause clinic open-day. When the clinic didn’t contact her as anticipated she went to her GP and asked him to refer her. At this point the clinic lost the referral letter but Nicola persisted and was very happy with her experience of the clinic once she actually managed to secure an appointment. Persistence was also required by Tracy, both through asking more than one person about the same issue and through pressing for an answer:

‘I was fine and feeling good and I’d had a check-up at the clinic and everything and then a year last January I started to bleed for about six weeks...so I consulted the doctor again and she said she thought I ought to go to the hospital and have some investigation...she said “it’s up to you whether you keep taking HRT whilst you’re waiting for your appointment or stop it” and I decided to stop it.... The follow-up was that I went to the hospital and had an ultrasound...and after that I talked to the gynaecologist and said “What do you think about HRT? Do you think in my case it would be a bad thing to take it?” and she said... after a bit of pressure from me she said “If I were you I wouldn’t take it unless you feel that you really need to.” So I haven’t taken it since but to be honest I am now getting the hot flushes and the night sweats again and I would really be happier taking it.’ [TRACY]

#### **7.2.2.2 Active scanning in interactions with sources**

Active scanning took place during encounters with information providers when women were not seeking to address particular concerns but were open to opportunities for asking

questions or for observing others around them. In environments such as prenatal classes, multiple birth association meetings or during medical diagnostic procedures women would watch parents interacting with children, 'listen in' to relevant conversations, or use their observations of other pregnant women to validate their own experiences. They would try to spot opportune moments to ask questions, particularly in situations where women were spending a long time with another individual (e.g. during a prenatal scan) and would use these opportunities to monitor what was happening in instances of nondisclosure by information sources and to attempt to clarify what was happening. Examples of active scanning were not limited to interpersonal encounters and McKenzie's interviewees gave examples of scanning print materials (such as newsletters from the Multiple Birth Association to find birth announcements giving details of gestation length) or skimming through books without reading sections about negative issues such as risk factors for twin pregnancy.

Several participants in the menopause study gave accounts of active scanning during encounters with information sources. Their recollections tended to be of listening to other people or of identifying opportunities to acquire information rather than of observing people which again, may due to the relative lack of visibility of the menopause compared to pregnancy. Emma had listened to colleagues talking about HRT and hysterectomies in the staff room at work. Isobel heard about the clinic through a promotional talk at the hospital but used her work reading medical notes to glean useful information about issues such as the use of the Mirena Coil for delivering progestogens. Barbara had had a hysterectomy and spoke of meeting other women in hospital:

'Because you obviously talk to women when you're in the hospital, actually it's quite nice because you realize all the things, well I had this, oh yes I had that, you know...'  
[BARBARA]

Belinda had gone into a health-food shop to look for something unconnected with her menopause but took the opportunity to ask a member of staff how she could stop her brain feeling like 'scrambled egg'. Kathleen would talk to the practice nurse 'about

everything' while she was attending a diabetes session. This nurse was able to signpost her to the community menopause clinic. Deborah found out about the clinic by listening to colleagues at work and, although she herself was not experiencing the menopause at the time, had stored up the information for future reference:

'ALISON: How did you find out about the menopause clinic in the first place?

DEBORAH: Well that was from some of the ladies at work who are like a generation older than me they were talking about it years ago and when my periods started to go funny and then I had none for a year I thought right I think I'm a candidate for the menopause clinic.'

Hannah and Denise both noted the information-rich environment that is produced when a group of women in a similar stage of life are brought together:

'...I actually work in residential care for older people so a lot of the people I work with, its quite strange actually, we are all reaching the same age at the same time, we've got a lot of menopausal women, it's quite good actually, quite interesting.' [HANNAH]

'...I suppose recently because you're sat down with a bunch of girls you overcome the embarrassment by saying well what happens, when menopause is mentioned you think "great I can start asking a few questions" and you can talk to them and some of them have been through it.' [DENISE]

Like some of McKenzie's interviewees who spoke of scanning printed materials to identify parts they did not want to read as well as parts they thought would be interesting, Olivia had browsed through bookshops 'reading bits I want to and putting the book back on the shelf'. She had also shared books with friends but found that she needed to be selective about the bits she felt would be useful:

'And then there's books, we've sort of swapped books, you know the kind of self-help things, because there are quite a lot of those about aren't there? ...And you kind of dip in



and out of them and things that you think might be useful or helpful, but I don't think anyone takes them, well not any of my friends would take them terribly seriously. ...They are a source of amusement really as much as anything else and you pick the bits you fancy and sort of leave the rest don't you?' [OLIVIA]

### **7.2.2.3 Non-directed monitoring in interactions with sources**

A few of McKenzie's participants gave accounts of 'out of the blue' encounters in situations where they were not expecting to find information, of observing behaviour or physical characteristics in unexpected settings, of overhearing conversations or of chatting with acquaintances. Specific examples of this type of behaviour would be watching a father manoeuvre a double pushchair in a shop or telephoning a colleague about a work matter and then taking the opportunity to ask a question of his wife when she answered the phone. Again, women found that the visibility of twins and of pregnancy facilitated such encounters with the common understanding that pregnant women will be information-seekers promoting ease of contact between strangers.

Examples of non-directed monitoring during interactions with information sources were notably sparse in the accounts of menopause study participants. Once more the fact that the menopause is not as visible to the outside world as pregnancy may inhibit contact and opportunities for observing others. Another factor may be that the menopause, although less of a taboo subject than it used to be, is still something many women wish to be discreet about. A woman is therefore less likely to have opportunities for 'overhearing' conversations about the menopause 'out of the blue' (unless she is in an environment where she would expect to find menopausal women which would then constitute an example of active scanning in McKenzie's model); she is also less likely to chat about her menopause to 'acquaintances' such as, to use the example from McKenzie's study, a colleague's wife (although my research confirms that friends are a valued source of information and support during this time). McKenzie however also found that many of her interviewees were less forthcoming with examples of non-directed monitoring practices. In my study Eleanor provided one example of exploring a useful Website having heard about it by chance whilst listening to a radio programme but it was not possible to identify any further instances of this behaviour.

#### **7.2.2.4 By-proxy interactions with sources**

Instances of McKenzie's participants being told information without enquiring were described in three ways: informing through story or experience (in which people would pass on information through their own or anecdotal stories); by providing diagnostic information (during encounters with health professionals); and through the provision of advice in the guise of information (e.g. advice from a colleague on the fact that a woman pregnant with twins will need to visit her doctor more frequently). Such exchanges also occurred when a woman identified herself to a potential interpersonal source of information who then provided advice relating to the pregnancy. An example of this is a participant who explained to her pharmacist that she felt ill because she was pregnant with twins, the pharmacist then explained that she had also given birth to twins and went on to describe her own experiences.

From the menopause study, examples of by-proxy interactions were significantly more abundant than examples of non-directed monitoring in interactions. This is because McKenzie's definition of such encounters includes informing through story/experience and providing diagnostic information, both of which feature strongly in women's accounts of finding information and advice about the menopause. McKenzie's third category of by-proxy encounters, providing advice in the guise of information was not represented in my study, possibly because participants did not always remember exactly how advice was presented to them, simply that they had received it from a particular source.

The role of other women as providers of advice, information and support and the value that menopausal women place on these encounters has been discussed in Chapter Six (Section 6.3.1). Participants welcomed the menopause stories of friends, colleagues and family members as well as anecdotal stories passed on through other women. They used these stories to inform their own decisions about the management of their menopause but also used them to contextualize their own experiences and to find solidarity – making them feel 'normal' and less isolated. Belinda gave an example of an informal support network establishing itself naturally through women of a similar age coming together

regularly in the same environment – creating their own information ground (Pettigrew, 1998):

‘Yes because running the kind of business I ran, clothes you know it’s all women, and the girls that worked for me they were, we were all about the same age, so we used to chat. I suppose that was our support group. ...we had quite a big network in a lot of our customers were our age as well and it’s surprising what people talk about in a dress shop.’ [BELINDA]

Eleanor commented on the value of having friends to compare with and validate her own experiences:

‘It’s a very interesting thing to go through and it’s lovely when, I do have some friends who have been through it or who are going through it, and they say “that’s happened to me” and it’s just really nice to know that it’s OK to feel like this or be like this.’ [ELEANOR]

and Imogen told of a friend encouraging her to try HRT when she realized how ill Imogen was feeling:

‘...and a very good friend of mine had started on it about two months prior to me and she kept really nagging me to go on it, she said “just try it” and I kept saying “oh I don’t know” and she said “oh well I’m not going to tell you any more” sort of thing “you ought to just try it”.’ [IMOGEN]

McKenzie’s category of ‘providing diagnostic information’ included examples of health professionals or social contacts giving advice about what physical symptoms meant or what they could expect to happen physically as the pregnancy progressed. There are many examples of interactions with health professionals running through my interviewees’ accounts and their relationship with health professionals as providers of information and advice has also been discussed in Chapter Six (Section 6.4). Examples of

behaviour that illustrates McKenzie's concept of 'being told' include Eve being advised to cease HRT treatment because she was experiencing a bleed and had been taking the drugs for ten years, and Jane's GP carrying out test to confirm that she was experiencing an early menopause:

'ALISON: Would you mind telling m a bit about your experience of the menopause so far, like when you started to think about it?

JANE: Well I hadn't really thought about it at all it was just the fact that I was getting sort of like symptoms and I was feeling pretty rough so I went to the doctors and they did some blood tests.

ALISON: What sort of symptoms were you getting?

JANE: Hot flushes, mood swings, I wasn't having any periods.

ALISON: Had you suspected it was the menopause before you went to the doctor?

JANE: Well I thought hot flushes and then I ruled it out because of my age I thought it can't be that because I was too young, even the doctor said it's highly unlikely. I had two or three tests and they all came back.'

McKenzie notes the difficulty of discerning the agency-balance between information-seeker and the potential source of information and notes that the fluidity of the exchanges women described frequently made it difficult to isolate the individual elements of an encounter. As explained above, attempting to apply the model in a different context, to understand McKenzie's original thought processes and to interpret my data using her framework brought its own set of challenges. Before considering how data from this current study relate to the barriers and counter-strategies identified by McKenzie, Table 7.1 provides a summary of McKenzie's categories expanded from Appendix 23 to illustrate how the menopause examples fit within the phases and modes of the Model of Information Practices in Everyday Life Information Seeking.

	<b>CONNECTING WITH SOURCES</b>	<b>EXAMPLES FROM MENOPAUSE STUDY</b>	<b>INTERACTING WITH SOURCES</b>	<b>EXAMPLES FROM MENOPAUSE STUDY</b>
<b>Active seeking</b>	<ul style="list-style-type: none"> <li>• Systematic known-item search</li> <li>• Seeking out known source</li> <li>• Asking pre-planned question</li> <li>• Planning question strategy</li> </ul> <p>(e.g. calling doctor between appointments; shopping for specific books; calling a friend for advice; contacting local community information service; contacting magazine support group)</p>	<ul style="list-style-type: none"> <li>• Making contact with NHS Direct for advice after hearing/reading about a study. [Q99]</li> <li>• Making appointment with community menopause clinic to ask about symptoms. [Deborah]</li> <li>• Writing to The Amarant Menopause Trust. [Helen]</li> </ul>	<ul style="list-style-type: none"> <li>• Asking a pre-planned question</li> <li>• Active strategies: list-making or questioning techniques; counter-strategies to barriers</li> </ul> <p>(e.g. asking questions in consultation: finding ways of remembering things to ask; calling the doctor if an expected phone call didn't happen; using different sources to try and locate the same information)</p>	<ul style="list-style-type: none"> <li>• Negotiating with healthcare professionals to achieve desired outcome. [Belinda, Kathleen]</li> <li>• Taking information to encounter. [Q78]</li> <li>• Taking the initiative if anticipated contact is not made. [Nicola, Q163]</li> <li>• Asking different people about the same issue. [Tracy]</li> </ul>

	<b>CONNECTING WITH SOURCES</b>	<b>EXAMPLES FROM MENOPAUSE STUDY</b>	<b>INTERACTING WITH SOURCES</b>	<b>EXAMPLES FROM MENOPAUSE STUDY</b>
<b>Active scanning</b>	<ul style="list-style-type: none"> <li>• Semi-directed browsing in likely locations</li> <li>• Systematic observation of behaviour</li> <li>• Identifying opportunities to ask spontaneous questions</li> <li>• Active listening to conversations in likely locations</li> </ul> <p>(e.g. keeping feelers out; browsing in likely information grounds; scanning bookshops or libraries; general Internet searches; watching a TV programme about pregnancy that referred to twins)</p>	<ul style="list-style-type: none"> <li>• Spotting a notice about the community menopause clinic on the wall when attending a chiropody appointment. [Q37]</li> <li>• Asking medical reps at work. [Q81]</li> <li>• Browsing in a bookshop. [Denise]</li> <li>• Browsing in the library. [Eileen, Fiona, Kathleen]</li> <li>• Carrying out a general Internet search. [Hannah]</li> </ul>	<ul style="list-style-type: none"> <li>• Identifying an opportunity to ask a question</li> <li>• Actively observing people or behaviour, or listening to conversations in likely locations</li> </ul> <p>(e.g. during routine medical encounters; scanning print materials; observation and listening e.g. at multiple birth association meeting; opportunistic questioning; looking at other mothers to see whether they had slimmed down)</p>	<ul style="list-style-type: none"> <li>• Listening to colleagues talking about the menopause. [Deborah, Emma]</li> <li>• Taking the opportunity to talk to other women in hospital. [Barbara]</li> <li>• Asking staff in a health-food shop whilst shopping for something unconnected with menopause. [Belinda]</li> </ul> <p>Chatting to practice nurse whilst attending for a different health issue. [Kathleen]</p>

	<b>CONNECTING WITH SOURCES</b>	<b>EXAMPLES FROM MENOPAUSE STUDY</b>	<b>INTERACTING WITH SOURCES</b>	<b>EXAMPLES FROM MENOPAUSE STUDY</b>
<b>Non-directed monitoring</b>	<ul style="list-style-type: none"> <li>• Serendipitous encountering of a source</li> <li>• Accidentally overhearing a conversation</li> <li>• Unexpected encounters e.g. with friends</li> <li>• Regular activities to stay informed without actively seeking twin pregnancy information</li> <li>• Often facilitated by high visibility of infant twins or pregnancy</li> </ul> <p>(e.g. recognizing a source: seeing a father with a pushchair; finding book sale; reading the newspaper)</p>	<ul style="list-style-type: none"> <li>• Saw community menopause clinic whilst walking by. [Q24]</li> <li>• Read about clinic in local newspaper. [Q77]</li> <li>• Spotting useful information in books or magazines. [Ann, Gwen]</li> <li>• Meeting an information source through a dress-making business. [Belinda]</li> <li>• Spotting a relevant storyline on television. [Barbara]</li> </ul>	<ul style="list-style-type: none"> <li>• Observing behaviour or physical characteristics in unexpected settings</li> <li>• Overhearing conversations</li> <li>• Chatting with acquaintances</li> </ul> <p>(e.g. seeing/hearing things ‘out of the blue’; watching a father with a pushchair)</p>	<ul style="list-style-type: none"> <li>• Finding a useful Website after hearing about it by chance on the radio. [Eleanor]</li> </ul>

	<b>CONNECTING WITH SOURCES</b>	<b>EXAMPLES FROM MENOPAUSE STUDY</b>	<b>INTERACTING WITH SOURCES</b>	<b>EXAMPLES FROM MENOPAUSE STUDY</b>
<b>By proxy</b>	<ul style="list-style-type: none"> <li>• Making contact through initiative of another agent</li> <li>• Being identified as a potential information seeker by a potential source</li> <li>• Being referred to sources by other people</li> <li>• Making connections through intermediaries or gatekeepers</li> </ul> <p>(e.g. being identified as an information seeker; someone in the family looking for information on their behalf)</p>	<ul style="list-style-type: none"> <li>• Being referred to clinic by Family Planning staff. [Q1]</li> <li>• Being told about the clinic by a friend or colleague. [Q188, Eleanor, Hannah, Janice, Tracy]</li> <li>• Swapping books with friends. [Olivia]</li> <li>• Having a friend recognize problem and offer support. [Barbara]</li> </ul>	<ul style="list-style-type: none"> <li>• Being told (e.g. through stories of their own or others' experiences; diagnostic information from health professionals; other people's advice or opinions; offering of unsolicited advice)</li> </ul>	<ul style="list-style-type: none"> <li>• Hearing information during sessions held at primary care practice. [Q144]</li> <li>• Being advised to try HRT by a friend. [Imogen]</li> <li>• Exchanging menopause stories [Belinda, Eleanor]</li> <li>• Receiving diagnostic information from professionals. [Jane]</li> <li>• Using CAMs that family or friends use [Gwen]</li> </ul>

*Table 7.1 McKenzie's categories of phases and modes populated with examples from the menopause transition study.*



### *7.2.3 Barriers to connecting and interacting with sources of information and advice*

The Model of Information Practices in Everyday Life Information Seeking suggests that information practices may be used as counter-strategies in the face of barriers to successful connection or interaction with sources of information and advice.

#### **7.2.3.1 Connection failures**

For McKenzie, ‘connection failures’ prevent a woman from either (i) identifying an appropriate source or (ii) connecting with an identified source. McKenzie’s interviewees gave accounts in which the relative rarity of multiple-pregnancy acted as a barrier to information-seeking, making it difficult for them to identify relevant sources of information. The women described a lack of resources for parents of twins (e.g. difficulty finding books about twins in the library) and uncertainty as to whether resources would be appropriate for their needs (e.g. whether a family member’s experience as a mother of singleton children would qualify her to give helpful advice about twins). Once a source had been identified, McKenzie’s interviewees sometimes struggled to make contact with it. The multiple birth association proved particularly difficult to reach, with several interviewees being frustrated in their efforts. Other participants described delays scheduling medical appointments or whilst awaiting test results. Informal contacts were also difficult to connect with as other mothers of twins were often busy. Examples of failure to connect with identified print resources included a book being out-of-print and forms being unavailable. Some of McKenzie’s interviewees were constrained by physical barriers such as having insufficient funds to pay the bus fare to travel to an antenatal class or being afraid that speed bumps in the road might induce a miscarriage.

Issues of identification of relevant sources of information and/or advice for both twin-pregnancy and the menopause transition relate back to the dichotomy of ‘commonality’ and ‘uniqueness’ of experience. The menopause is a natural phase of a woman’s reproductive life and is therefore common to the great majority of women. However, each woman’s menopause transition is unique to her and her experience of it is contingent on a set of circumstances including symptoms, attitudes towards medical intervention, attitudes towards ageing, and personal situation. Women in this study drew attention to

the fact that many sources of information about the menopause were generalized and did not necessarily reflect individual concerns:

‘I talked to my surgery, I looked in the library, I looked in magazines... but to find written literature that actually made sense of what I was going through I found nearly impossible.’ [BELINDA]

‘Oh the self-help book, books on menopause, the ones where more or less they are looking on everybody as the average woman and there isn’t an average woman is there, we’re all totally different. So I think you’ve just got to face each day as it comes and put up with it.’ [DENISE]

Women who had undergone hysterectomies or who had experienced early natural menopauses felt themselves to be particularly disadvantaged, both in terms of identifying physical sources of information and of knowing where to turn for support from interpersonal connections:

‘...but there wasn’t a lot of information for people like me, if you were going through the menopause there was a lot of information but I found there wasn’t a lot of information for people like myself who were going through a hysterectomy and needed to go on HRT...’ [MARION]

‘...I mean I didn’t really know of anybody else who was going, I mean I had friends who were in their fifties and who hadn’t even started the menopause so it was a bit sort of, I suppose isolating is too strong a word but it was a bit isolating in the fact that it was just me you know... well of course now it gets talked about quite regularly you know, but for me there wasn’t anyone no, and I think perhaps now looking back with hindsight...it would have been quite nice to have had someone who perhaps had experienced some of the similar things, that would have perhaps helped.’ [ROWENA]

For Janice it was the fact that her work colleagues were all younger than her that inhibited her identification of a suitable source of support in that environment. She didn't tell anyone at work about her feelings of depression. Eve also hesitated to talk to colleague since most were younger than her and she thought 'perhaps they don't know'. These experiences reflect the 'uncertainty of appropriateness' barriers of McKenzie's interviewees. Other interviewees (e.g. Ann and Belinda) mentioned that they had been too busy to pursue all potential routes of identifying information and support or explained that, at the time when they were looking for information, there were fewer resources available:

'I remember you know quite early on when the information wasn't as abundant as it is nowadays but there was certainly stuff out there, I can't remember that actual sites, the names.' [VICKY]

For my participants, many of the challenges of actually connecting with sources focussed on securing appointments with GPs and at the community menopause clinic:

'I just felt to be truthful everybody was very helpful to me, it was just the waiting. "Come back in six months and we'll look at you" and when you're suffering it's a long time.' [BARBARA]

Jane thought it was 'disgusting' to have to wait two weeks to see her GP and many respondents indicated their disappointment that the community menopause clinic was only open for one afternoon a week resulting in long waiting-times for initial appointments and in logistical challenges for women who could not easily attend on the right day.

One interviewee was dyslexic which limited her ability to access print-based resources and for others changes in personal circumstances impacted on their opportunities for connecting with information sources. Moving house could pose problems in terms of accessing healthcare and could separate a woman from established sources of

interpersonal support. Erica moved house and found that policy at her new GP practice impacted on her treatment, and when Denise remarried and moved house she was unable to see her friends as regularly.

### **7.2.3.2 Barriers and the use of counter-strategies during interaction with sources**

McKenzie identified four themes implicated in failures during the phase of interaction with sources:

- Failure to ask questions;
- Disclosure barriers;
- Lack of realization or comprehension;
- Connection failures during the communication process

For the women pregnant with twins, **failure to ask questions** could be the result of perceptions of doctors' being busy. Some found that clinics were oversubscribed or that doctors' body language (e.g. moving away in an attempt to end an appointment) discouraged further communication. At times women simply forgot to ask questions or were concerned that their question might seem inappropriate or disruptive (e.g. in an antenatal class), particularly because their status as women pregnant with twins marked them out from other pregnant women. Women from the menopause study were able to provide examples of questions they felt had remained unanswered (notably relating to what happens on ceasing HRT treatment) but often these were questions that lingered in their minds and might be asked at some future point rather than instances of questions not being asked during a specific encounter. Once again this may be due to the different timescales and patterns of interaction with health professionals of pregnancy and the menopause. A few interviewees did, however, describe instances where they felt they could have been more proactive in their interactions with health professionals. Following an appointment with her GP, Deborah was unclear about his advice to stop taking HRT since she had concerns about bone density. When asked whether she felt able to challenge her GP and ask for further information in cases such as this, Deborah explained that she perhaps should have asked for clarification but that at the time she had been 'taken aback

really'. Eileen wanted information about what could be considered 'normal' experiences during the menopause but couldn't remember whether she had asked her GP about this because she felt constrained by the time allotted for each appointment. Erica had not asked questions about her hysterectomy and admitted that her younger self had been less assertive:

'I mean me now I'd be asking questions, but then I suppose I was a little bit naïve really.'  
[ERICA]

Hannah echoed this by explaining that she felt inhibited during her contact with health professionals and did not feel strong enough to press for answers at the time:

'...I don't really know what it is about doctors and all the rest of it but when I'm not well myself I can't cope with it, so really speaking I suppose if I'd gone into the, maybe thinking about it logically maybe I should have gone in and said "right this has happened to me and I want to know"... I can say that now because I'm feeling stronger but at the time you're not able to do it.' [HANNAH]

In McKenzie's study, **disclosure barriers** occurred when women asked questions for which the source was unable or unwilling to disclose an answer or for which the source used evasive forms of disclosure. For the pregnant women, the greatest number of examples of this behaviour centred on nondisclosure relating to divulging the sex of the foetuses to the mother. Other examples included caregivers not disclosing the reason for recalling a woman for further assessment, inability to perform a procedure (e.g. due to technical failure), or the use of coyness or evasive language (e.g. when providing confirmation that a woman was pregnant with twins). In the context of the menopause there are still many issues, particularly relating to the risks and benefits of HRT, for which the medical profession cannot provide definitive answers. Women recounted instances in which they perceived that health professionals were not sufficiently informed, were unwilling to provide advice and answers, or were placing a lot of the responsibility for a decision on the woman's shoulders:

‘I feel my GP doesn’t really know much about it, that’s why he referred me on to the clinic and it was a doctor from [elsewhere] and she was lovely, but there was no real facts.’ [ERICA]

‘...I just don’t think I was given the information... I just thought there wasn’t enough information, not that I didn’t trust what I was given, I just wasn’t given anything that seemed to do anything.’ [BELINDA]

‘And the GP don’t really want to know, I think they want you to be bad with it before they help you and then it’s straight on the HRT.’ [DENISE]

‘I mean how long can you stay on it? No one will give me an answer. I’m just getting “it’s up to you really”.’ [GRACE]

Other examples of disclosure failure related to perceptions that health professionals were motivated by their own personal opinions. Janice felt that her GP had withheld information about the existence of the community menopause clinic because he personally didn’t agree with it and Eve had asked her GP about non-medical ways of managing her symptoms but felt that her enquiry had been dismissed with out any scope for further discussion.

The final two categories of failure during interaction comprise ‘**lack of realization or comprehension**’ and ‘**connection failures during the communication process**’. Menopause study interviewees did not provide many examples of these types of barriers. McKenzie’s interviewees talked of failure to comprehend the initial diagnosis of twin pregnancy due to factors such as missing the doctor’s hint about twins due to excitement at hearing the baby’s heartbeat, or wondering whether the diagnosis was a joke. Although some of my interviewees did talk of not initially realizing that they were experiencing symptoms of the menopause (especially women like Jane who at first ruled out the menopause because she thought she was too young) this was not necessarily in the

context of an actual information encounter. One exception to this was Fiona who gave an account of not initially believing her GP's diagnosis of the menopause, partly because the explanation was not explicit but also because she considered herself too young to be starting the menopause:

'I had a male GP but I normally got on with him quite well and he sort of "uh, yeah, uh, well things are winding down you know". And I said "What?" and he said "yeah, they're winding down". And I thought "Well he can't..." so I started reading some books and thought "Oh yeah, he's right, I've got all these symptoms" you know.' [FIONA]

Those interviewees that did refer to lack of comprehension during an encounter with a health professional tended to imply that the health professional had been unable to understand them rather than that they themselves had lacked comprehension. This was evident in comments relating to perceived dismissiveness or lack of empathy on the part of a health professional:

'One of my main problems, and its still not been addressed by my doctor, is that fact I have tremendous insomnia.... My doctor just doesn't seem to think it's a problem but it is.... But my own doctor doesn't seem to take it seriously at all.' [VIV]

'Yes and I think as well what got me was I never ever go to a GP...and yet I went up there and I sat in there in tears, maybe I thought she should have realized there was something else, do you know what I mean?' [HANNAH]

Like some of the participants in McKenzie's study, Hannah assumed partial responsibility for the lack of communication by suggesting that '...maybe I didn't explain properly, I honestly don't know, but I got the feeling from her it was a kind of well it happens kind of get on with it.'

McKenzie uses the example of a doctor leaving a consultation before the woman had had a chance to digest information and ask questions to illustrate her interpretation of

connection failures during the communication process. Again because of the timescale of their menopause journeys participants in this study tended not to provide enough detail to identify many examples of this type of behaviour. For these interviewees, remembered instances of connection failures during the communication process were less physical (i.e. less about someone walking out of the room) than emotional, linked to the feeling that their concerns were being rebuffed and that they were being cut off from help. These concerns are discussed more fully in Chapter Six (Section 6.4.2). Denise talked about GPs simply saying ‘go back, go back’ leaving her to think ‘well how ill have I got to feel before somebody says we are going to start giving you some treatment’. For Frances a look from a GP could be sufficient to make a woman feel she is being a pest. On the other hand, Grace felt unable to continue her contact with the community menopause clinic because she had decided to take herself off HRT against the clinic’s advice and so no longer felt confident going back there in case she would be ‘in the way’. Some respondents did, however, provide examples of ‘system failures’ where referral letters were lost or not sent (e.g. questionnaire respondent Q163, Nicola).

McKenzie goes on to describe instances of information practices across all modes of behaviour being used as counter-strategies used by women to negotiate their way around barriers encountered whilst interacting with sources. In later publications she develops the theme of communication barriers in accounts of practitioner-patient encounters in greater detail and suggests that barriers can be grouped into those originating with the provider, with the information seeker, and with both participants (McKenzie 2002). McKenzie’s interviewees demonstrated the use of information practices as counter-strategies in three main ways:

- Through persistent and often lengthy interactions with information sources in pursuit of an answer;
- By devising questioning strategies to help them ask questions and maximize the chance of a response; and
- Through monitoring sources to stay aware of what was happening and keep the process on-track.



Examples of individual counter-strategies included list-making, approaching a question obliquely to avoid jeopardizing chances of receiving an answer, calling a doctor's office when an expected call didn't happen, and contacting different sources to find an answer to the same question. Counter-strategies also featured in the accounts from the menopause study although, again, the types of example reflected the different contexts of the two life transitions. Menopause study participants did not mention list-making although questionnaire respondent Q9 did indicate that she wished she had made audit of her symptoms to act as memory jogger. It is possible that interviewees had in fact resorted to techniques like list-making but did not remember them as they were not specifically asked about counter-strategies during the interviews. A key concern for these interviewees was the problem of judging the trustworthiness of sources and of the information they provided, especially relating to the debate about HRT. Women would compare the answers they received from different sources:

'The GPs you know go ooh ooh ooh and whether it's because, I don't know which is the one that's out of date, it can't be [Lead Clinician] can it because that's her field.'  
[DEBORAH]

and Isobel and Janice both dealt with the uncertainty about reliability by treating information with caution:

'I think you can get carried away sometimes on media and publicity that you read about it, it's like coffee, on minute coffee's bad for you and another time it's good for you, there's so much that you read in the press about it I think you've got to take an awful lot on it with a pinch of salt depending on how you feel yourself.' [ISOBEL]

'And my doctor, when I told him I was coming off it, he said "Well it is generally accepted that if you take HRT it can put weight on." So, how true this all is I don't know, I take it all with a pinch of salt.' [JANICE]

Some interviewees had tried a range of sources to find answers to their questions, either actively seeking out different types of resource (e.g. Belinda who asked in her primary care practice, talked to a medically-qualified friend, and looked both in the library and in magazines) or by approaching more than one health professional. The majority of women who had attended the community menopause clinic had also consulted their GPs about menopause-related symptoms. Several women had spoken to more than one GP to try and identify the one with whom they felt they could communicate most effectively (e.g. Sylvia and Denise). Denise specifically chose to see a female GP and was disappointed to find her less sympathetic than she had hoped:

‘DENISE: I even went to talk to a lady doctor.

ALISON: At the same practice?

DENISE: Yes and basically “Life’s rough isn’t it when you are a woman” and that was it, so that was a complete waste of time.’

Interviewees told of using strategies to support them in their interaction with health professionals. Erica took information with her to a consultation with her GP:

‘I kept finding, the against HRTs and you could get as many, I even took them to my doctor’s, the ones that were saying you mustn’t it’s bad for you, you are going to get cancer, and he said “Yes interesting” but insisted the benefits outweighed.’ [ERICA]

Hannah and Rowena used techniques of negotiation and compromise. Hannah agreed to stay off HRT for three months but said ‘I made her promise me that if I got the symptoms back she’d put me straight back on them again, but it would be my decision.’ Rowena resented the control that health professionals exerted over decisions about managing her menopause but agreed to follow her doctor’s advice with the caveat that she might return to a private clinic to request the treatment she wanted:

‘I quite understand them telling me that I’m running a bigger risk and everything else but I really do feel that for an adult woman who’s been sort of through the menopause for

twenty years and knows just about every pitfall there is I don't feel that somebody should dictate to me to that level, to tell me that I can't have something that I know will make me feel better and you know I conceded last time, I said "Alright I will give it one more try" but I had made the decision that if this one doesn't work...I will sort of go and talk to my doctor and say "Well look you know I, you'll probably now be hearing from the Amarant again" because I really do feel that that's what I want to do, but I'm hoping that it doesn't come to that quite honestly.' [ROWENA]

Several women spoke of the need for assertiveness. Imogen recounted her bad experience during a GP consultation in which only her outburst of indignation had prevented the encounter from failing completely and both Rowena and Nicola commented that women need to be 'pushy' or 'bolshy' to secure successful outcomes.

The need for assertiveness and, above all, persistence in combating barriers (often over several years) was summed up by Vicky's complaint that:

'It's just been such hard work to get what I want that I just haven't got the time to keep pursuing it.' [VICKY]

McKenzie's descriptions of barriers in connecting with and interacting with information sources and the counter-strategies that can be used to negotiate a way through them are summarized in Table 7.2 illustrated with examples from the menopause study.

	<b>CONNECTING WITH SOURCES</b>	<b>EXAMPLES FROM MENOPAUSE STUDY</b>	<b>INTERACTING WITH SOURCES</b>	<b>EXAMPLES FROM MENOPAUSE STUDY</b>
<b>Potential barriers</b>	<ul style="list-style-type: none"> <li>• Barriers identifying potential sources (e.g. lack of relevant information)</li> <li>• Uncertainty of appropriateness</li> <li>• Difficulty actually making connections (e.g. getting hold of a support group)</li> </ul>	<ul style="list-style-type: none"> <li>• Long waiting time for appointments with health professionals. [Q1, Q22, Jane]</li> <li>• Limited opening times of clinic. [Q9, Q78]</li> <li>• Difficulty finding advice from local sources [Q53]</li> <li>• Information too generalized. [Belinda, Denise]</li> <li>• Difficulty finding advice about early menopause or hysterectomy. [Q62, Marion]</li> <li>• Not knowing who to contact [Q95]</li> </ul>	<ul style="list-style-type: none"> <li>• Failure to ask questions</li> <li>• Disclosure barriers</li> <li>• Lack of realization or comprehension</li> <li>• Connection failures during communication (e.g. doctor leaves room)</li> </ul>	<ul style="list-style-type: none"> <li>• Promised information didn't arrive. [Q10]</li> <li>• Feeling GPs not interested. [Q20, Denise, Eve]</li> <li>• Feeling menopause is no-go area. [Q27]</li> <li>• Different advice from different GPs [Q151]</li> <li>• Feeling inhibited [Hannah]</li> <li>• GPs 'seem about 2 pages ahead in book'. [Q135, Q183]</li> <li>• System problems [Q163, Nicola]</li> </ul>

	<b>CONNECTING WITH SOURCES</b>	<b>EXAMPLES FROM MENOPAUSE STUDY</b>	<b>INTERACTING WITH SOURCES</b>	<b>EXAMPLES FROM MENOPAUSE STUDY</b>
<b>Counter-strategies</b>			<ul style="list-style-type: none"> <li>• Persistence</li> <li>• Devising questioning strategies</li> <li>• Monitoring sources to keep process on track</li> </ul>	<ul style="list-style-type: none"> <li>• Checking information from different sources. [Belinda, Deborah]</li> <li>• Scepticism [Isobel, Janice]</li> <li>• Selecting likely sources [Denise, Sylvia]</li> <li>• Taking information to encounter [Erica]</li> <li>• Using negotiation skills. [Hannah, Rowena]</li> <li>• Being assertive. [Imogen, Rowena, Nicola]</li> </ul>

*Table 7.2 Barriers to successful connecting and interacting with information sources experienced by women in the menopause transition and the counter-strategies they employ to overcome them.*

### 7.3 Reflections

Choosing to test a model in a different yet related context proved an interesting challenge and one for which there are few precedents and guidance in the literature. Most of the examples of information practices that emerged from the menopause study could be positioned within McKenzie's model although at times the decision about exactly where to place them was not straightforward. As explained above, there were three main reasons for the challenges encountered when attempting to apply data to the model. Firstly, it was necessary to consider carefully McKenzie's original decision-making process and her justification for placing examples of information practices within the modes and phases of her model. Secondly, the different context meant that women's recollection of events was not necessarily as sharp as that of McKenzie's interviewees whose accounts related to relatively recent encounters. Although the decision was taken not to adopt the same research methods as McKenzie (i.e. to include follow-up telephone calls), it is possible that more persistent probing during the interview would have reminded participants of practices they had employed but had initially forgotten about (e.g. asking them directly whether they had ever made lists might have resulted in greater recall). On the other hand, the intention was for women to be allowed space to recount their own stories and to see what emerged from the telling rather than to shape the interview so that women were directed into producing data that would clearly reflect McKenzie's findings. The third challenge also grew out of the context and centred on examples that did not seem to 'fit' neatly within McKenzie's model.

Some of these differences were quite subtle and related mainly to the challenges that women face in connecting and interacting with sources of information. In identifying the differences as 'subtle' there is no implication that they are barriers missing from the accounts in McKenzie's study but rather that they place a slightly different interpretation on some of these barriers. A woman going through her menopause transition is coming to terms with a frequently unsettling and sometimes disturbing experience that can undermine the foundations of her self-image and of the way she is perceived by others. McKenzie and other writers (e.g. Oakley, 2007; Wolf, 2001) have shown that the experience of pregnancy is also fraught with uncertainties and with the pressures of

facing society's preconceptions, yet in Western societies the menopause is seen, especially by feminist writers, to be particularly imbued with negative imagery and associated with undesirable constructions of ageing that place women at a disadvantage (e.g. Campioni, 1997; Greer, 1991; Gullette, 1997; Kaplan, 1997; Sybylla, 1997). The women in my study, and in other studies of mid-life women (e.g. Im et al., 2008; Price et al., 2008), were seeking reassurance that what they were experiencing was 'normal'. Unlike the women pregnant with twins, whose state is highly visible and attracts contact even from strangers, many menopausal women can be left feeling isolated. There is a perception that their concerns are not taken seriously by health professionals and that even members of established support networks (e.g. family members and friends) are not able to appreciate what they are going through. Such impressions tended to skew some of the categories of barriers so that whereas McKenzie's interviewees spoke of not understanding that they were being informed that they were pregnant with twins, mine spoke of doctors not being able to comprehend how they were suffering. Similarly, McKenzie's concept of connection failures during interaction with sources focussed on the physical breaking-off of a communication process (e.g. by a doctor leaving the room) whereas my interpretation of this category was more in terms of an emotional response: a doctor being dismissive of a woman's story or friends brushing off efforts to open a discussion about HRT.

A fundamental issue for women seeking information and advice about the menopause is the HRT debate. Women seeking relief from menopausal symptoms find themselves on shifting sand as guidance on the risks and benefits of taking HRT constantly changes. In the discussion of barriers the HRT debate has been placed within McKenzie's category of 'Disclosure failures' since women often perceive that health professionals are unable or unwilling to give them advice about the best way of controlling their symptoms. This is a much wider issue however that touches on questions of trust in both interpersonal and print/media-based sources and on women's own ability to interpret information and to extrapolate what is relevant to their individual set of circumstances. 'Making sense of information' (in this case about HRT) was a major challenge for the women surveyed in this study and cuts across all of the different types of barrier identified by McKenzie. It is

not neatly encapsulated by the existing categories of barrier and would perhaps warrant one of its own.

McKenzie's aim was to create a model that preserved the fluidity of women's interactions with sources of information and support. The concept of fluidity was particularly strong in the accounts of menopausal women. The great value placed on by-proxy interactions for this group of women extended beyond 'being told' things by other people into an active exchange of information and support. Unlike McKenzie's participants who were clearly, and easily, identified as 'information seekers' menopause study participants moved in a more complex environment in which they engaged in exchanges of mutual support. Such exchanges could be informal, through friends, colleagues or family members, or could occur in a more structured way as with Nicola's involvement with the EarlyMenopauseUK Website. As women's journey through the menopause progressed they themselves became acknowledged sources of information for others. The fact that the pregnant women in McKenzie's study turned to other women for advice indicates that they in turn could have a potential role as sources of information. However this did not appear to emerge as a theme from the study as it did in my own research. This may be because of the relative rarity of twin-pregnancy which limited opportunities for exchange of information with other pregnant women or to the fact that pregnancy is a relatively short period of high information-seeking activity and with a high level of involvement with professional healthcare providers. It is possible that the pregnant women would be more likely to be identified as authoritative sources of information after their babies were born when they would be perceived as women who had 'been through it', as was the case for McKenzie herself in her interaction with participants (Carey et al., 2001).

Applying the Model of Information Practices in Everyday Life Information Seeking in a different context has demonstrated that there is value in the testing of models. Although the model was sufficiently robust and flexible to permit adaptation to a different context there were elements of the new context that provided a richer and deeper interpretation of the categories within the model and suggested ways in which it could be developed further (i.e. by taking account of women's more complex relationship with information in



which they themselves may become sources of advice and by adding further depth to McKenzie's description of barriers and counter-strategies). Further testing in a different context again, perhaps one that was not related to women's health might provide further insights into how the model could be consolidated.

## 7.4 Summary

Considering the findings in relation to McKenzie's model revealed that, although many of the information practices exhibited by my participants could be positioned within the model, the change of context led to (often quite subtle) differences in interpretation that meant some findings could not be easily slotted into McKenzie's categories. Furthermore, the model did not allow sufficient scope for the fluidity of information practices in the context of the menopause since women in this situation move in a complex environment in which they engage in mutual exchanges of support and may themselves take on the role of 'experts'. The implications of this for the model and for the provision of advice and information for women during their menopause transition are discussed in the Conclusions (Chapter Eight).

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# Chapter Eight: Conclusions

## 8.1 Introduction

From an initial interest in the menopause transition as a context for information behaviour (following encounters with women experiencing the menopause/perimenopause and discussion with the Lead Clinician from the Community Menopause Clinic), this study developed into a desire to investigate not just how women seek information about the menopause but how they use this information to support their decisions about managing this life-change. The decision to test McKenzie's Model of Information Practices in Everyday Life Information Seeking grew out of frustration with the fact that information behaviour models are regularly produced yet frequently serve only as an outcome of an individual study, simply adding to the 'confusion' (Bates, 2005) of approaches that bedevil LIS research. The choice to incorporate a strategy of testing McKenzie's model into the study design was in response not only to an interest in the menopause and twin pregnancy as related yet contrasting experiences but also to a wish to contribute to the debate about the value of models and how they can support the development of LIS theory.

The research question was therefore: how does the information behaviour of women experiencing the menopause transition support their decisions about managing this life event? The aim was to use a qualitative approach to investigate everyday information behaviour in relation to the menopause, exploring the findings in the context of McKenzie's work conducted in a related topic. The objectives were to explore:

- What prompts women to start looking for information on the menopause;
- Whether they have preferences for different sources of information at different stages of the life transition;
- Whether they rely on different types of information source to meet different needs (e.g. emotional support, medical facts, lifestyle issues etc.);
- How women judge the authority and helpfulness of information sources;

- How they use information to inform decisions about managing their menopause transition (e.g. whether or not to take hormone replacement therapy);
- What happened during and after the information encounter;
- How the study's findings relate to the McKenzie Model of Information Practices in Everyday Life Information Seeking.

## 8.2 Methodological approach

The literature review presented in the thesis represents a narrative yet critical review of the literature in areas considered to be fundamental to the scope of the research. In collaboration with Dr Urquhart, a different approach was taking for the meta-analysis in the paper presented in Appendix 24. From the original intent of seeking information about a new subject area, it became clear that the literature, particularly the feminist studies of how researchers interact with participants, would guide and shape this study. As in McKenzie's study, a naturalistic approach was identified as the most appropriate way to explore the 'lived experience' of women during the menopause transition with sensitivity towards participants' own interpretations of what their menopause meant to them. Such an approach is supported by some of the precepts of feminist methodology as reflected in concern that participants should be treated with respect and engaged with as individuals and that they should be allowed to tell their own stories in their own words.

## 8.3 Everyday information behaviour relating to the menopause transition: key findings

- Participants used a range of resources to secure information and advice.
- They were frequently challenged by the fact that each woman has her own unique set of factors that impact on her experiences and choices whereas information resources often focus on 'the average woman'. Such information is therefore inadequate to meet individual needs.
- Participants saw their experiences both within the context of their own lives and also as enmeshed with the experiences of other women. They actively sought out other women's menopause stories and used them to provide validation and

context for their own, looking for reassurance that what they were experiencing was ‘normal’.

- Participants wished for greater opportunity to exchange menopause stories with other women since it is through these stories that they make sense of their own experiences. (The EarlyMenopauseUK Website referred to by Nicola does contain the personal stories of contributors to the site but of course they specifically relate to experiences of an early menopause. For women seeking more general accounts of the menopause, options currently available appear to be limited. The NHS Choices Website contains a brief video of two women talking about their menopause experiences and some outline ‘real stories’ but Healthtalkonline which replaced the Dipex database of individual patient experiences does not currently contain any accounts of the menopause transition.).
- Participants who had undergone an early menopause (either natural or surgical) were particularly at risk of feeling isolated and different.
- In their interactions with health professionals, participants valued contact that endorsed their wishes to manage their menopause according to their own set of circumstances and their own values. They wanted their concerns to be taken seriously and for health professionals to be seen to be listening to them and they appreciated services such as the Community Menopause Clinic that were perceived as providing a greater level of ‘individual’ care than could be attained through an appointment with a GP (due to restricted length of GP appointments or perceptions that GPs were dismissive of symptoms). Women valued advice tailored to their personal situation and belief system, delivered by someone they felt they could trust and in an environment that promoted discussion and exploration of their options.

## 8.4 Testing the McKenzie model of Information Practices in Everyday Life Information Seeking

To return to McKenzie’s Model of Information Practices in Everyday Life Information Seeking, the intention was to test the model in a related, yet different, context. Twin pregnancy and the menopause are both natural, yet medicalized, events; both reflect the

dichotomy of commonality of experience and uniqueness of the individual; both propel women into the unknown and can induce feelings of ambivalence and prompt renegotiation of a woman's self image. In both instances, women may feel ill-equipped to participate actively in decisions about their health and wellbeing. On the other hand, there are very apposite differences between the two conditions, with twin pregnancy being a highly visible state and one that is generally celebrated by society whereas the menopause frequently remains hidden and private and, in Western cultures, is often perceived as a time of loss and as a symbol of the negative effects of ageing.

Applying the findings to McKenzie's model demonstrated that the model is fundamentally robust and flexible enough to permit adaptation to a different context. However, there were challenges inherent in the process. Some were the natural result of attempting to use a researcher's model without access to her decision-making process and others stemmed from the particularities and subtleties of the change of context. Järvelin and Wilson (2003) developed a framework that can be used for judging the merits of a conceptual model or assessing the relative merits of two competing conceptual models. They suggest that desiderata for conceptual models should include:

- Simplicity (simpler is better, other things being equal);
- Accuracy (accuracy and explicitness in concepts is desirable);
- Scope (a broader scope is better because it subsumes narrower ones, other things being equal);
- Systematic power (the ability to organize concepts, relationships and data in meaningful systematic ways);
- Explanatory power (the ability to explain and predict phenomena);
- Reliability (the ability, within the range of the model, to provide valid representations across the full range of possible situations);
- Validity (the ability to provide valid representations and findings);
- Fruitfulness (the ability to suggest problems for solving and hypotheses for testing). (p. 3)



An issue for the development and testing of models is that interpretation of data is highly subjective. This can impact on the **simplicity** and **accuracy** of a model. McKenzie's model is simple in design but attempting to fit examples from a different context within it was more complex than had been anticipated.

In terms of the **scope** of McKenzie's model, 'connecting' with and 'interacting' with sources of advice and information are useful terms for a discussion about information encounters. The inclusion of 'interaction' is particularly welcome as it gives scope for discussions about the actual quality of the experience of dealing with sources of information; i.e. it moves the discussion beyond information 'seeking' and 'finding' (whether active or passive) which has long been a focus of LIS research into what happens once interaction with a source of information has been initiated. It could be argued, however, that the concept of 'interaction' does not completely meet the needs of the findings from the menopause study. McKenzie's accounts of women interacting with sources of information are couched very much in terms of women's attempts to overcome barriers or seeking out ways of informing themselves. There is little scope in the model for the idea of women exchanging information on an equal footing or of becoming themselves sources of information and advice which emerged from the menopause study. The model is therefore **reliable** and **valid** to a certain extent in that it can be reasonably successfully applied to results from a study in a similar context and undertaken from a similar standpoint, but it does not take account of the full range of possible situations when presented with a different set of data.

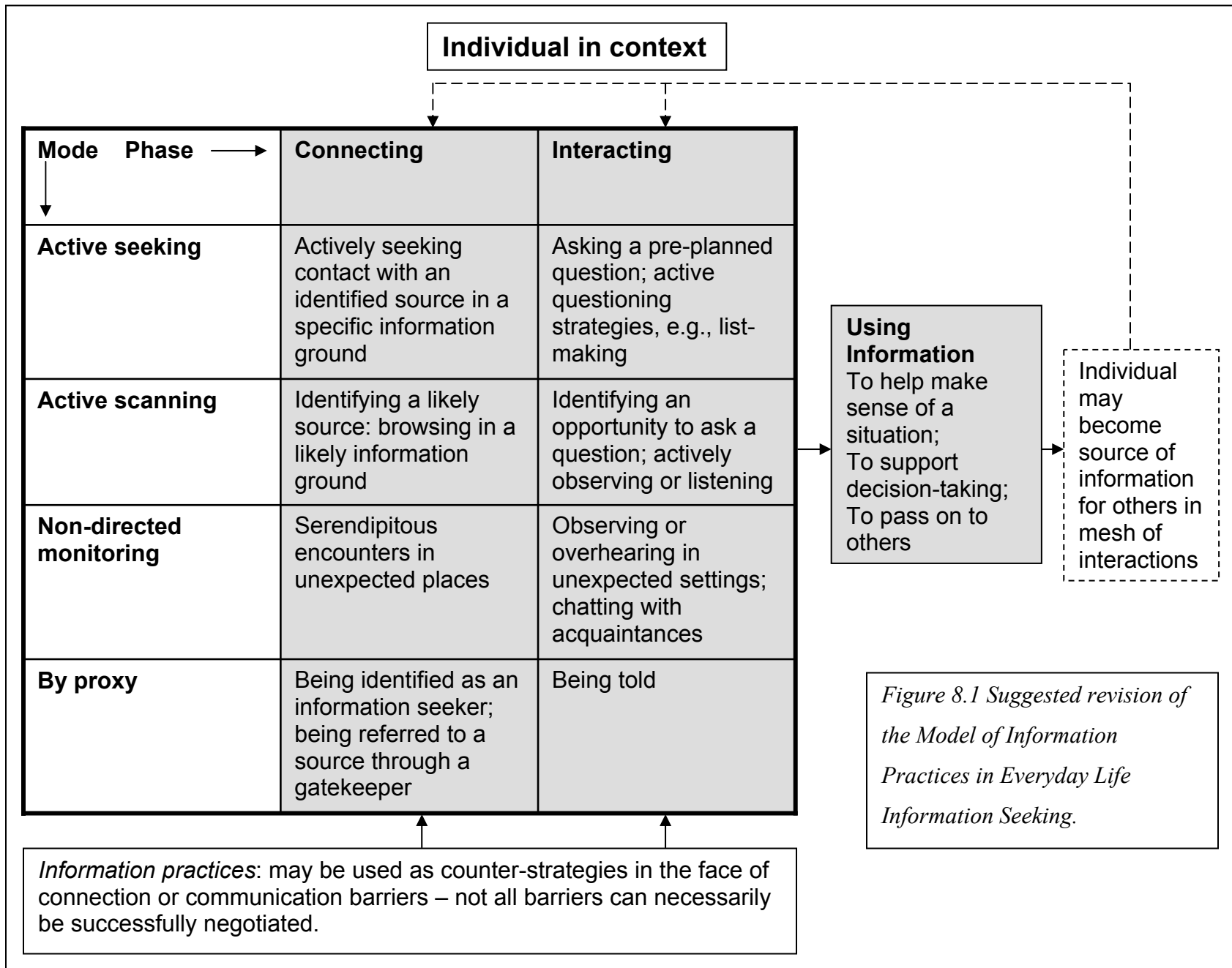
McKenzie deliberately avoided a linear representation of a systematic search process with the associated implications of a logical progression following optimized routes (Godbold, 2006). She sought to develop a flexible model that would preserve the fluidity of the information practices described but that would systematically describe the practices and the process. The model neatly encapsulates the findings from the twin pregnancy study. Superficially it is **systematic**, logical and easy to understand. Its simplicity enhances its **explanatory power** and, on the face of it, one would expect that it should be possible to predict how data from a different study would fit within it. It is only once a different

researcher begins to mine different data from a different context and attempts to insert them into the model that the situation becomes more complex. A paper co-authored with Dr Christine Urquhart (Appendix 24) identifies a move away from the ‘lone ranger’ model of the information seeker towards an acknowledgement of how the situation can affect the information seeker and how the information seeker in turn changes their situation. It presents information behaviour as a ‘mesh’ of interactions that is dynamic and changes in response to the interactions within it. The characteristics of such a mesh may be more appropriate to describe the behaviour of women in the menopause study whose experiences of encountering information and advice which helped inform their decisions and, in turn, allowed them to become potential sources of advice themselves, placed them within an interwoven and dynamic ‘information network’ (Marmoreo et al., 1998).

McKenzie identifies information practices used by her participants as counter-strategies in the face of connection or communication barriers (and in fact much of her discussion of the Interaction phase of the model focusses on the use of counter-strategies). In the context of the menopause, a different interpretation could be placed on some of McKenzie’s barriers – often challenges would be the result of perceptions of healthcare professionals’ indifference or that friends and family could not appreciate what a woman was going through. Some were more concrete, however, and were grounded in problems associated with the constantly-shifting HRT debate and the lack of evidence about the safety of CAM products. Although there are plans to regulate the CAM industry (MHRA, 2008), it is unlikely that a full consensus on the benefits and risks of HRT will be achieved in the near future. Despite counter-strategies such as persistence and asking direct questions etc. it is therefore equally unlikely that women will be in a position to resolve their outstanding questions and to fully counter the challenges they are facing. McKenzie’s model suggests that the resolution of barriers through the use of counter-strategies may be more effective than it actually is for women in the position of the menopause study participants.

Järvelin and Wilson's final requirement for a successful conceptual model is one of **fruitfulness**. They suggest that such a model should be able to suggest problems for solving and hypotheses for testing. In the context of the data from the menopause, it is the areas that did not fit so comfortably with the model that would best indicate problems to be investigated. See Section 8. 6 for suggestions for further research.

Given that this thesis queries the usefulness of the preponderance of models that have been generated by LIS research it is not the intention to formally propose yet another model as an outcome of this research. In the interests of clarity, however, a revised version of the McKenzie Model of Information Practices in Everyday Life Information Seeking is presented below (Figure 8.1) to take account of the findings from the menopause transition study. It is only with further testing of the model in different contexts that a true generic 'revised model' could be produced.



*Figure 8.1 Suggested revision of the Model of Information Practices in Everyday Life Information Seeking.*

#### *8.4.1 Limitations of the study*

The context of this study provided its own limitation in that participants' menopause stories frequently spanned events over several years. In some instances it was evident that this impacted on recall with interviewees making comments such as 'Oh gosh, no I can't remember where I heard that.' (Tracy). In allowing participants to tell their own stories and only then probing with topics from the interview guide it was hoped that a relaxed environment would encourage women to speak in their own words and allow their views to emerge as naturally as possible without unintentionally directing them towards giving similar answers to McKenzie's interviewees. It is however possible that more structured questioning might have resulted in better recall of events. Storytelling is a method well-suited to studies that explore the meanings interviewees construct for events but it is highly subjective and may be prone to bias introduced by memory lapses – a limitation which is particularly pertinent to the menopause stories. Section 4.5.3 details other potential limitations of the study which can be summarized as:

- Along with many other studies of information behaviour, it is relatively small-scale with only 35 interviews conducted (and one response by letter). However the fact that response to the questionnaire was high (199 completed questionnaires giving a response rate of 92.1%) added depth to the clinic evaluation element of the study and fed into the broader thesis discussion although the quality of data available from Section 3 of the questionnaire (demographic information) did not permit useful and reliable correlation of results.
- The majority of the interviews were with women registered at the community menopause clinic. These interviewees therefore all came from the same geographic area and had experienced symptoms severe enough to warrant a visit to a healthcare practitioner. Attempts were made to balance this with a cohort of women from non-clinic environments.
- Methodological limitations included the fact that the majority of interviews were carried out by telephone (potential implications of this are discussed in Section

4.5.3) and the fact that a transcriber was employed to assist with the interview transcriptions.

- A further constraint was the fact that the confidentiality requirements imposed by the ethics committees for the NHS community menopause clinic element of the study meant that it was not possible to match questionnaires to interviewees with the result that if a point was made both on a questionnaire and during an interview it was impossible to ascertain whether both comments originated from the same source.

## 8.5 Contribution to the research base

This study makes a contribution to the LIS research base in two main areas:

1. It looks at everyday life information behaviour beyond the simple location of information to consider how individuals interact with sources of information and use that information to support decision-making;
2. It tests a model of information behaviour in a different context thereby assessing its robustness and contributing to the development of a truly generic model that could be used to generate LIS theory.

## 8.6 Suggestions for further research

It is possible to identify three areas in which further research could contribute to improving the lot of menopausal women and/or to the advance and consolidation of the LIS research base:

- By investigating the potential for giving midlife women the opportunity to connect with other women and share stories. This could be achieved either by interpersonal means (e.g. through focus groups at primary care practices or supported by community projects) or by the publication of collections of ‘menopause stories’ since women feel that the experiences of ‘real women’ are frequently more relevant and useful than publications from official organizations. A mediated approach (i.e. rather than simply suggesting, for example, that women search for stories on social networking sites) would provide a level of quality-control.

- By testing the McKenzie Model of Information Practices in Everyday Life Information Seeking in a further context, possibly one which is not related to women's health or reproduction, to move towards the development of a more generic model.
- By exploring further whether it would be viable to conduct a study focussed on the information behaviour of men using the approaches more often associated with research by and about women. This would permit valid comparisons between the information behaviour of men and women and would contribute to a debate on whether gender should justifiably be considered as a variable in information behaviour.

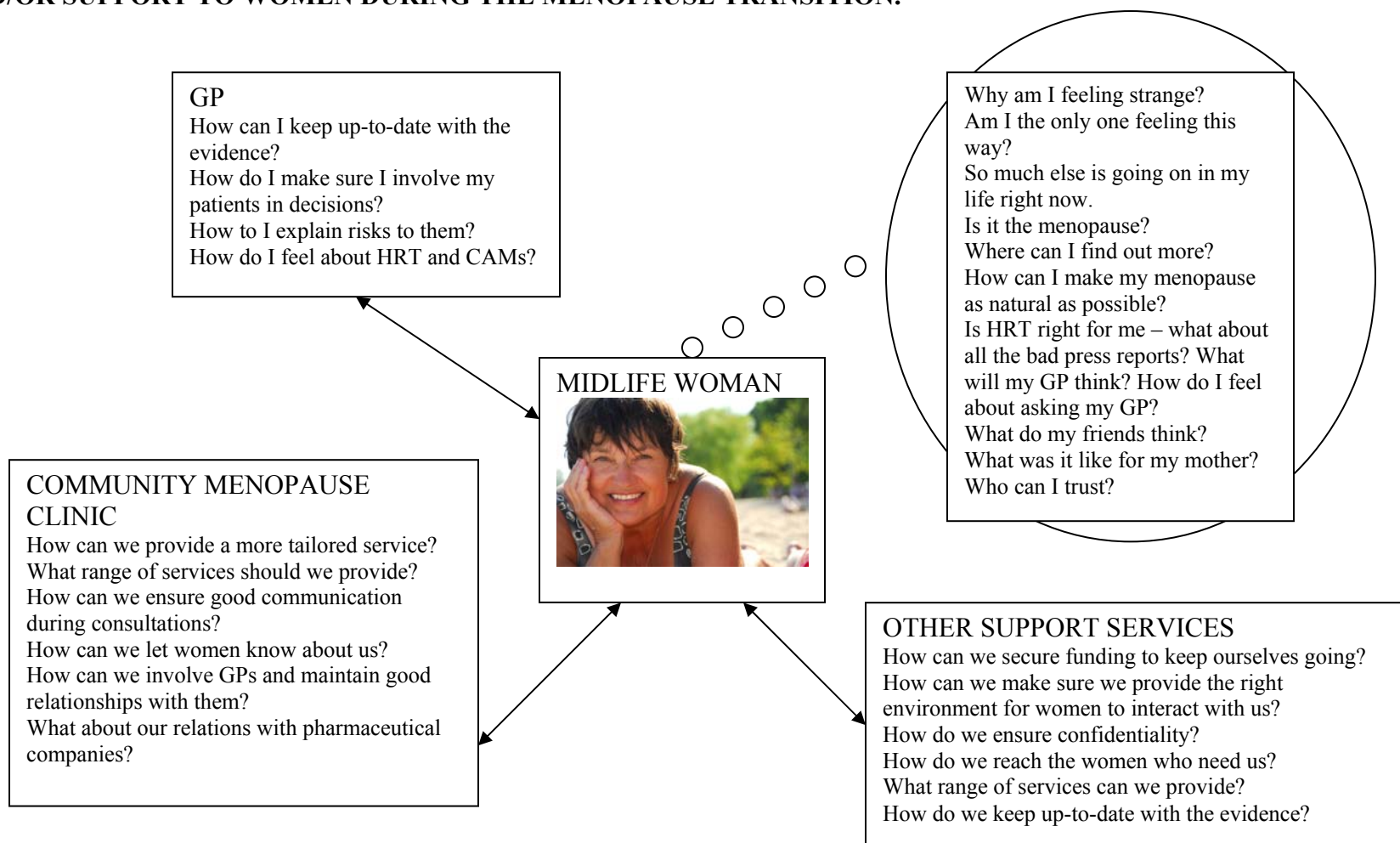
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# Appendices



**APPENDIX 1: RICH PICTURE REPRESENTATION OF CHALLENGES AND IMPLICATIONS (IDENTIFIED FROM THE LITERATURE REVIEW AND INTERVIEWS) FOR THOSE SEEKING TO PROVIDE SERVICES, INFORMATION, AND/OR SUPPORT TO WOMEN DURING THE MENOPAUSE TRANSITION.**



## **APPENDIX 2: EXECUTIVE SUMMARY OF REPORT TO COMMUNITY MENOPAUSE CLINIC**

### **FINDING ADVICE ABOUT THE MENOPAUSE**

#### **REPORT TO THE [COMMUNITY MENOPAUSE CLINIC] EXECUTIVE SUMMARY**

##### **Introduction**

This report covers an evaluation of the service provided by the [Community Menopause Clinic] and is a part of the researcher's PhD study exploring women's information behaviour relating to the menopause.

##### **Results**

###### ***Finding information about the menopause***

For the majority of study participants the search for information and advice about the menopause had been prompted by the onset of symptoms, by the realisation that they were approaching an age when the menopause transition might be expected to begin, or by issues relating to an early menopause. Responses revealed a wide range of sources used when looking for information with, unsurprisingly since all participants were registered patients, the [Clinic] mentioned by the greatest number of questionnaire respondents, followed by personal contacts, GPs and the media. Information was frequently required on:

- risks/benefits of HRT
- coping with symptoms
- general information about the menopause
- alternative therapies.

When asked about problems they had encountered when looking for information and advice, the main areas of concern included lack of confidence in the advice given in primary care settings and not knowing where to turn to find advice that is tailored for each woman's individual needs and experiences. This can lead to feelings of isolation and to worry that problems are not being taken seriously. Although respondents do want to be informed and to participate in decisions about their own health, they are often bewildered by the sheer amount of information available (particularly about HRT) and by the fact that it seems to be constantly changing and is frequently contradictory. They need someone to help pick through this information and advise them about the options most relevant to their own individual case.

Women are looking for health professionals who can give them time, the benefit of specialist knowledge, and above all, provide a sympathetic and understanding listening ear. Although several participants stressed that they had good relationships with their GPs and other health professionals who had in many cases tried hard to help and had willingly referred patients to the [Clinic], many felt that GP surgeries had not been able to provide the service they needed. This was often due to time constraints but sometimes to the perceived unhelpful attitude of individual GPs. The GPs interviewed for the study did not appear to fit this pattern. They were interested in menopause issues, positive about the [Clinic] and came from practices with a proactive approach to menopause management.

###### ***Visiting the [Clinic]***

Since study participants were drawn from the [Clinic] list of registered patients, they had all visited the [Clinic]. The most frequently cited ways of finding out about the clinic were by word of mouth or from a GP/other health professional. Women who were/had been employed by the health service had been to talks or knew about the clinic from their work and others had come across it whilst visiting the premises for other services. Some respondents felt that the [Clinic] could

advertise its presence more widely and GPs suggested that the clinic could promote its services through an annual update to primary care practices highlighting the advantages of its services: patients can self-refer and appointments are longer than would be possible with a GP.

Once contact had been established with the clinic the majority of participants were satisfied with their experience and many were enthusiastic in their comments. Positive comments about the clinic reflect the main areas of concern identified above. Participants who had previously felt isolated or overwhelmed by information they could not make sense of alone, who had not known where to turn for trustworthy and up-to-date advice, or who felt that their problems were not being taken seriously, expressed their appreciation of the service provided by the [Clinic]. They praised the knowledge, professionalism and caring attitude of all staff, and the time and patience devoted to finding the right solution for each patient.

Overall, the impression is of a clinic providing a much needed and much appreciated service to women in the local area. Apart from individual instances where participants were disappointed in advice/treatment from the [Clinic], most suggestions for improvement related to the accessibility of clinic services, for example knowing it is there in the first place, length of wait for an appointment, needing to take time off work to get there. These are all issues that could potentially be resolved through promotion and expansion of the service.

## **Conclusions**

The results of the project show overall satisfaction with the service provided by the clinic and indicate a real need for such a provision in the local area. In fact it appears that expansion and wider promotion of the clinic services would lead to even higher levels of satisfaction. Some participants did suggest improvements but it is likely that an expansion programme to include, ideally, a wider range of services and longer opening hours would remedy most of these. Several participants, both patients and GPs, advocated greater promotion of the clinic to reach more patients.

## **Survey methods**

The study comprised of a postal questionnaire sent out to 216 volunteers who are registered with the clinic and 26 follow-up telephone interviews. Response rates were extremely high with over 90% of questionnaires returned and a very generous response to the request for interviewees. The researcher only regrets that she was not able to speak to more of the interview volunteers. Interviews were also conducted with six local GPs.

## **Acknowledgements**

The researcher would like to give her very grateful thanks to the [Community Menopause Clinic] staff and to all the participants who generously gave up their time to complete questionnaires and be interviewed for the project.

## **For further information please contact:**

[Researcher's contact details]

**APPENDIX 3: CHARACTERISTICS OF STUDIES TABLE**

<b>Study</b>	<b>Methods</b>	<b>Sampling</b>	<b>Overview of main findings</b>	<b>Critical appraisal comments</b>
Ankem (2007)	Telephone interviews	Retrospective study tracking 28 women from the beginning of their illness (uterine fibroids). Recruited from patients who underwent uterine fibroid embolization procedure at Detroit Medical Center between January 2000 and March 2005.	<ul style="list-style-type: none"> <li>• Participants were active information seekers and wanted answers to many questions</li> <li>• Those with higher levels of education were more interested in knowing the reasons behind their doctors' suggested treatments</li> <li>• The Internet was heavily utilized for learning about treatment options</li> </ul>	A small-scale study, as are many of those looking at women with specific health problems, from which it would be difficult to generalize. The author notes that she was unable to conduct a pilot study and that the study applied only to women who had taken up UFE, those who chose not to or were unaware of it may have different opinions. The author further points out that participants' recall of events in a

				<p>retrospective study could be questioned but states that participants appeared clear in their recollections. She does not state the year of data collection but since the spread of dates of surgery ranged from 2000 to 2005 it is possible that recall would be difficult for some of those treated in the earlier years. This study is from the USA.</p>
Avery & Braunack-Mayer (2007)	In-depth qualitative interviews, face-to-face and often reflexive	A total of 10 interviews with women recruited from a previous Polycystic Ovarian Syndrome study (n=7) and from the Polycystic Ovarian	<ul style="list-style-type: none"> <li>Participants routinely used a range of information sources including pamphlets, the library and the POSAA.</li> </ul>	<p>An even smaller-scale study, this time from Australia. Other reasons that would make it difficult to generalise from the results (pointed out by</p>

		Syndrome Association of Australia support group (POSAA).	<ul style="list-style-type: none"> <li>• They valued the opportunity to network with other sufferers. <ul style="list-style-type: none"> <li>• They preferentially used the Internet as an information source since it was convenient, private, and accessible.</li> </ul> </li> </ul>	the author) are that all the women represented a narrow age group (deliberately since these women were at an age when fertility would be a primary concern) and that some of them had been involved in a clinical trial and might therefore be more confident and more assured information-seekers.
Baker (1997)	Postal questionnaires. Participants asked to indicate from whom they would like to receive information about 29 Multiple Sclerosis-related	Questionnaires sent to 260 randomly-selected women registered with an MS clinic. Response rate was 61.5% (n=160) and covered three time frames	<ul style="list-style-type: none"> <li>• More monitors than blunters preferred physicians as a source of information on all topics.</li> <li>• Both monitors and blunters expressed a</li> </ul>	This study is from Canada. It is relatively old but was included because it is widely cited in the literature and because it covered a range of time-frames which is useful

	<p>topics. Questionnaire also included the Miller Behavioral Style Scale.</p>	<p>covered by the study: newly diagnosed (n=36), 2-3 years post-diagnosis (n=67) and 5-7 years post-diagnosis (n=57).</p>	<p>desire to discuss non-medical topics with doctors</p> <ul style="list-style-type: none"> <li>Newly-diagnosed women expressed a greater desire to talk to their physician which may indicate that women who have had MS for longer had identified alternative sources of information for some topics.</li> </ul>	<p>in the context of the menopause.</p>
<p>Hargittai &amp; Shaffer (2006)</p>	<p>Collected data on web-use experiences using an orally-administered questionnaire. Participants were then asked to use a computer to perform a variety of online tasks by looking</p>	<p>A randomly selected group of Internet users. Researchers used a random sample of residential addresses for one county and sent letters requesting participation to 383 households using the next-birthday method</p>	<ul style="list-style-type: none"> <li>Overall men and women do not differ significantly in their actual abilities to find various types of online information.</li> <li>Women are more likely to underestimate</li> </ul>	<p>A US study but with in-depth information on 100 respondents. The respondents were required to attend a study session at a university but were compensated financially for their time and</p>

	<p>for a variety of content. Researcher observed participants as they searched. Skill was measured by seeing whether individuals could complete a task successfully given an unlimited time to look.</p>	<p>to sample randomly within the household. Letters were followed up by telephone calls. Final response rate was 58.5% with in-depth data presented from 100 respondents.</p>	<p>their skills.</p>	<p>costs which may have encouraged a wider range of participants. Following the background interview, respondents sat at a computer and worked through tasks under observation from a researcher. Although the researchers attempted to put participants at their ease by giving them the choice of a PC or Mac and by allowing them to move to another task if they became agitated, the very fact of being observed may have influenced participants' behaviour.</p>
Heimrath & Goulding	Questionnaire survey to	Questionnaire distributed to	<ul style="list-style-type: none"> <li>• Both sexes were generally</li> </ul>	This study was included because



(2001)	<p>explore gender-linked obstacles to women's use of the Internet and randomly-selected interviews</p>	<p>156 students in Information Studies department at Loughborough University and to 50 members of the public in a public library. Interviews with 14 students and 4 public library users.</p>	<p>positive about the Internet</p> <ul style="list-style-type: none"> <li>• Female interest and confidence in the Internet was generally high</li> <li>• Females had not taken to the Internet as rapidly as males</li> </ul>	<p>it was UK-based. This article lacks detailed information about the sampling process: how were the questionnaires distributed and had the interviewees also completed a questionnaire? The authors explain that recruiting interviewees was a challenge in the public library since many users approached were not Internet users or did not want to spend the time being interviewed. However this means that the disproportionate number of responses from</p>
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				students may have influenced the results. Also, in the public library, the majority of the questionnaire respondents were male (71%).
Lorence & Park (2007)	Quantitative analysis using binary logistic regression to investigate the extent to which health information seeking behaviours vary across genders or are differentially associated with access to computers, the Internet and online health information.	Used two datasets from the Pew Internet and American Life Project. Sample was stratified into i)computer user ii)Internet user and iii)online health information user. Identified 1509 people as online health information users.	<ul style="list-style-type: none"> <li>• Overall rates of computer use for both genders increased during the period 2000-2003, the period following the implementation of national programmes to provide Internet access across the USA.</li> <li>• Use of the Internet was dominated by males.</li> <li>• Use of online health information</li> </ul>	Since this US study used datasets from the Pew Internet and American Life Project it had the advantage of access to a large sample. However the analysis was purely quantitative and since the definition of 'health information user' was very broad (anyone who had ever explored any information on the Web relevant to his/her health)

			was dominated by females.	it can really only provide an overview.
Luker et al. (1996)	A follow-up study using structured interviews to investigate the specific information needs and sources of information of women with breast cancer. Interviews had been carried out at diagnosis with a second interview a mean of 21 months post-diagnosis.	105 women from one consultant's practice. The sample was a sub-sample of women from an earlier study of women newly-diagnosed with breast cancer.	<ul style="list-style-type: none"> <li>• At the newly-diagnosed stage the top three priorities were: information about the likelihood of cure, how advanced the disease was, and information about types of treatment.</li> <li>• At the follow-up stage the top priorities were: likelihood of cure and risk to family of developing breast cancer.</li> <li>• At the newly-diagnosed stage most useful sources of information were: consultants, breast care nurses, and</li> </ul>	This study, although relatively old, was included because it is UK-based and had a larger sample than many of the women's health-information behaviour studies. It also considered information needs over a longer timeframe which is useful for comparison with the menopause. Although interview schedules were structured (and obliged women to choose between two items of information they would prefer to

			<p>patient information leaflets.</p> <ul style="list-style-type: none"> <li>• At follow-up stage most useful sources of information were magazines, consultants, and TV/radio.</li> </ul>	<p>have information on over a range of topics) they did include some open questions giving women the opportunity to expand on their feelings.</p> <p>Initial interviews (prior to treatment) were carried out in hospital with follow-up interviews conducted in participants' homes. The difference in these settings (and stress related to approaching treatment) may have impacted on the results.</p>
McKenzie (2002)	In-depth semi-structured interviews. Uses a discourse analytic approach to explore	19 women pregnant with twins from Southern Ontario.	<ul style="list-style-type: none"> <li>• Participants described three major kinds of barriers to acquiring the information they needed:</li> </ul>	<p>This article gives some of the findings from a larger Canadian study. Although it provides a Study</p>

	women's accounts of practitioner-patient information-seeking encounters.		those originating with the information provider, those originating with the information seeker, and those that might originate with either. <ul style="list-style-type: none"> <li>Participants developed counterstrategies in their information encounters to try and overcome the barriers.</li> </ul>	Overview, it gives only scant details about sampling and methodology. Again the sample is small (19 women) and from the same geographic area (and older and better educated than the average for women giving birth in that area) so caution would be needed in generalizing the results to a wider population.
Meadows et al. (2001)	Interviews. Part of a larger study examining the interface between social characteristics, determinants of health, and health and wellbeing of midlife women. This element of the study	24 rural midlife women aged between 40 and 65 years. Participants were recruited through convenience and snowballing initiated by the community interviewers.	<ul style="list-style-type: none"> <li>All participants mentioned geographical, temporal or financial barriers to accessing healthcare from a rural residence.</li> <li>Women experience a</li> </ul>	Another Canadian study which focuses on midlife women in a rural context. This study is small (24 women were interviewed) and very specific and is therefore not easy to generalise to a

	<p>focussed on rural communities. The interview guide from the larger study was revised to capture rural issues.</p>		<p>clash of cultures between the professional and the popular (lay) sectors that can inhibit transfer of knowledge.</p> <ul style="list-style-type: none"> <li>• Women used knowledge of family history and risk of illness when making decisions about need to access professional healthcare.</li> <li>• Women are flexible in their pursuit of healthcare and refuse to limit their search to traditional sources. They are willing to consider nonallopathic (e.g. CAM) services.</li> </ul>	<p>wider context. However, it forms part of a large study which meant a research team large enough to allow for several interviewers and multiple team members developing codes and interpreting data which supported within-project validation.</p>
Raupach &	Postal	Questionnaire	<ul style="list-style-type: none"> <li>• Women</li> </ul>	Although this

<p>Hiller (2002)</p>	<p>questionnaire containing items about: the perceived importance of receiving information about specific breast cancer and quality of life issues and whether information had been received on these issues; current use of and satisfaction with a range of formal and informal information sources; and current use of and satisfaction with a range of formal and informal support services and the Internet.</p>	<p>sent to all 266 surviving women diagnosed with breast cancer at a public hospital in Adelaide during a 25-month period (1997-1999). The response rate was 82% (n=217).</p>	<p>reported a high level of need for information about a variety of issues following breast cancer treatment.</p> <ul style="list-style-type: none"> <li>• Few women reported receiving the information they needed.</li> <li>• The most frequently-used source of information was the surgeon, followed by television, newspapers and books.</li> <li>• The most frequently-used source of support was family, followed by friends and the surgeon.</li> <li>• Few women used formal</li> </ul>	<p>Australian article is dated 2002, the data are considerably older (the survey was carried out in 1999). It has been included here because it has a larger sample than many of the other studies and because it differentiates between sources of information and of support. The authors point out that the use of cross-sectional design limited the scope to examine changes over time and did not take into account cohort effects by year of birth. There are also limits to the generalizability of the study given that</p>
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			<p>support services or the Internet.</p> <ul style="list-style-type: none"> <li>• Women were very satisfied with information from health professionals but reported receiving less information and support over time.</li> </ul>	<p>women treated in the private sector were not included and that women from rural areas were under-represented as, potentially, were non-literate women since the survey instrument was a postal questionnaire.</p>
Rees & Bath (2000)	<p>Literature review relating to the needs and source preferences of women with breast cancer and their family members.</p>	<p>Considers papers published between 1988 and 1998.</p>	<ul style="list-style-type: none"> <li>• Women with breast cancer have distinct needs throughout their cancer journeys and these needs can change with time. <ul style="list-style-type: none"> <li>• Family members also have substantial needs for information.</li> </ul> </li> <li>• Women and their families often prefer verbal forms of</li> </ul>	<p>The literature reviewed by this article is now quite old (1988-1998) and therefore pre-dates the impact of the Internet. However the article was included here because it considers the information needs of family members as well as of breast cancer sufferers themselves and</p>



			<p>information from healthcare professionals.</p> <ul style="list-style-type: none"> <li>• Women are often dissatisfied with information from healthcare professionals and family members often perceive their needs to be ignored.</li> </ul>	<p>also because it considers information needs as distinct from preferences.</p>
Simon (2006)	<p>Qualitative in-depth one-to-one interviews and focus group interviews to explore women's perceptions and experience of new technologies (e.g. computers and mobile phones).</p>	<p>The 50 participants (ranging in age from early twenties to seventy plus) had varying experience of new technologies</p>	<ul style="list-style-type: none"> <li>• Women often have an ambivalent relationship with new technologies.</li> <li>• Many positive experiences and perceptions were identified but these were tempered by more sceptical or critical attitudes.</li> <li>• These feelings appear to co-exist rather than</li> </ul>	<p>In this UK study almost half the interviewees were employed in the library sector and may therefore not be representative of the general public. Of the remainder of the sample some were employed education and may therefore again may not be representative. However the author extended</p>

			contradict each other.	the sample to target women identified as new or non-users of new technologies. Overall, levels of education and of experience of new technologies were mixed.
Steinerová & Šušol (2007)	A series of questionnaire surveys in 16 academic libraries to consider users' perceptions of information-seeking.	1000 questionnaires were distributed to library users (mainly students, academic staff and researchers) with a response rate of 79.3% (57.3% men and 40.7% women).	<ul style="list-style-type: none"> <li>• Men prefer an individual approach to information-seeking whereas women used librarians' help more frequently and were more collaborative.</li> <li>• Women used catalogues and reference works more frequently and were more patient in information-seeking. <ul style="list-style-type: none"> <li>• The expectations of</li> </ul> </li> </ul>	A large-scale questionnaire survey from Slovakia focused on students and researchers. The advantage of questionnaire surveys over interviews is that they can facilitate a larger (and broader?) response however they can offer limited scope for in-depth analysis of participants' feelings and expectations. This study

			<p>men were more optimistic whereas women had a more careful approach.</p> <ul style="list-style-type: none"> <li>• Women confirmed stronger feelings of anxiety at the start of a search and of relief at the end.</li> <li>• When asked about feelings, men mentioned trust, disappointment and relaxation whereas women mentioned trust, disappointment and confusion and expressed more doubt.</li> </ul>	<p>included some qualitative analysis of open questions which allowed the authors to explore the more affective and social components of information behaviour as well as the cognitive components. Although it is possible to extract some general comparisons of approach between men and women some of the results, as discussed in the article, are slightly confusing, e.g. more men confirmed that information seeking took more time than</p>
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				they expected yet more women perceived lack of time more intensely than men.
Warner & Procaccino (2004)	A 10-page survey to assess the process of seeking health information by women and women's awareness of specific health and medical information sources. 47% of the surveys were distributed by mail and the remainder by person in urban, suburban and rural locations through libraries, churches, women's organizations and other public places.	Of 300 women, 119 responded to the survey. 80% were from suburban areas with 15% from rural and 5% from urban areas.	<ul style="list-style-type: none"> <li>• Participants were active seekers of health information and generally did make use of the information they found to improve health behaviours.</li> <li>• There was low awareness of specific health/medical resources such as MEDLINEplus and specific books. <ul style="list-style-type: none"> <li>• Women indicated some ambivalence to the information located (e.g. regarding ease of location and</li> </ul> </li> </ul>	Another study from the USA. The authors of this study point out the disadvantage to quantitative analysis mentioned above i.e. limited scope to explore responses. They suggest that they would have benefited from the opportunity to clarify responses through interviews with their participants. They also point out that their questionnaires were not distributed randomly and

			<p>usefulness).</p> <ul style="list-style-type: none"> <li>• A state of confusion and uncertainty exists which may be an opportunity for information providers.</li> <li>• There was a high use of family and friends as a health information seeking method.</li> </ul>	<p>that this may have affected results or the composition of the final sample (91% were white/Caucasian and just over half were aged 45-64).</p>
Williams-Piehot et al. (2005)	<p>A baseline questionnaire to assess monitor-blunter coping style. Participants then listened to a randomly-selected telephone message promoting mammography tailored to a coping style and shortly</p>	<p>Female callers accessing the New England regional office of the Cancer Information Service were asked to participate following their original call. 500 participants agreed to take part having been assessed for eligibility.</p>	<ul style="list-style-type: none"> <li>• Matched messages were especially effective for blunters. For monitors the matched message was more effective than the mismatched but the difference was not significant.</li> <li>• Although robust tailoring effects were</li> </ul>	<p>The authors of this US article identify some limitations with their study. Firstly the sample comprised mainly White, relatively educated, married women with adequate health insurance and secondly these women</p>

	<p>afterwards received a mailed information packet included other tailored information. Six months later participants received a telephone interview to assess take-up of mammography services since baseline.</p>		<p>noted after 6 months, the effectiveness of matched information faded after 12 months.</p>	<p>had called the Cancer Information Service and so were proactive in seeking information. Also the study relied on self-reporting of mammography uptake. The sample suffered attrition during the course of the study which, the authors feel, was partly due to lack of commitment to the study but also because of the nature of the study – women were often dealing with the stress of a sick or dying relative or friend. The authors also suggest that a control group could have been included.</p>
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**APPENDIX 4: LETTER TO ALL WOMEN REGISTERED AT COMMUNITY  
MENOPAUSE CLINIC ASKING WHETHER THEY WOULD BE WILLING TO  
PARTICIPATE**

Dear

Clinic Number:

We have received a request from a researcher at the University of Wales in Aberystwyth to take part in a study about how people find advice about the menopause and its management, and how they feel about the advice/information they receive.

Would you be prepared to take part? This would involve filling in a questionnaire. The researcher would not have your name or address unless you wished to give it, so your questionnaire would remain confidential. No-one in the clinic would see your completed questionnaire as you would send it direct to the university in Wales, so you could be totally honest in expressing your opinion about every aspect of the clinic.

We would hope that up to 500 people will fill in anonymous questionnaires. In addition we hope that a small number of people will feel happy to have a more in-depth, face-to-face discussion with the researcher about their experience of the clinic. If you would be interested in receiving a questionnaire and/or taking part in an interview please return the enclosed reply slip to the clinic in the prepaid envelope provided **by 7 January 2005**. It may not be possible to interview every volunteer as there is only one researcher and so numbers will have to be limited.

Thank you for taking the time to read this letter.

With best wishes,

[Signed by Lead Clinician at Community Menopause Clinic]

(Version 1 5/4/04)

## APPENDIX 5: INFORMATION SHEET FOR STUDY PARTICIPANTS

### FINDING ADVICE ABOUT THE MENOPAUSE:

#### Information sheet for study participants (version 4 7/7/04)

**About the researcher and the study:** I am a female PhD researcher from the University of Wales Aberystwyth, working with the [Community Menopause Clinic] to find out how women look for advice and information about the menopause. This research is funded by the Arts and Humanities Research Board.

**Benefits:** It is hoped that this study will give a better understanding of where women look for help at this time and of any problems they face. It is also hoped that the results of the study will help the [Clinic] ensure that they provide a sensitive and helpful service to clients.

#### What will happen in the interview (interview procedure)?:

- The interview will be held at a time and in a place convenient to the interviewee.
- The interview will probably last about 45mins–1hr.
- From choice the interview will be taped but the researcher accepts that some interviewees may prefer notes to be taken instead.

#### Confidentiality:

- Participation is entirely voluntary, if you decide not to be interviewed this will not affect your relationship with the [Clinic] in any way.
- The identity of all participants will be kept confidential, with pseudonyms (pretend names) used in the report and in any further publications.
- Findings from the interviews may be shared with the [Clinic] but individual participants will not be identified.
- All participants will be given the opportunity to read and comment on a transcript of their interview.
- All data will be stored securely at the researcher's home, only for as long as necessary and in accordance with NHS recommendations.
- Audio tapes will be transcribed anonymously and will be destroyed at the end of the study.
- This study has been accepted by the Local Research Ethics Committee.

[Contact details of researcher and Lead Clinician supplied]



## **APPENDIX 6: LETTER INVITING GENERAL PRACTITIONERS TO PARTICIPATE IN THE STUDY**

Dear

I am working with a PhD student from the University of Wales Aberystwyth, Alison Yeoman, who is studying women's perceptions of menopause advice and care in the [local] region.

She is doing this by means of an anonymous self-administered questionnaire which will be sent to all past and present patients of the [Community Menopause Clinic], if they have indicated their willingness to receive a questionnaire. This will be followed up with face-to-face interviews with a sample of these women (who will have been asked if they would be willing to participate). Alison would like to balance this with telephone interviews with a sample of GPs in the area. This interview would take about 15 minutes.

I enclose a reply slip and envelope addressed directly to Alison for you to indicate if you would be willing to take part in such an interview. Alison is keen to hear a range of views from GPs, for example those who have found the menopause clinic at the [Clinic] helpful and those who disapprove or disagree with the aims/organisation of the clinic.

Yours Sincerely,

[Signed by Lead Clinician from Community Menopause Clinic]

## **APPENDIX 7: INFORMATION SHEET FOR GENERAL PRACTITIONERS**

### **FINDING ADVICE ABOUT THE MENOPAUSE**

An information sheet for study participants (version 4 7/7/04)

#### *Purpose*

The purpose of this research is to investigate the formal and informal routes women take to find information and advice about the menopause. The researcher is a female Research Officer (specialising in health information) from the University of Wales, Aberystwyth and is studying for the PhD on a part-time basis. The study (partially funded by the Arts and Humanities Research Board) will focus on how women access information sources and the quality of their experience of interacting with sources.

#### *Benefits*

It is hoped that this study will give a better understanding of where women look for help at this time and of any problems they face. It is further hoped that the results will inform local decisions relating to the provision of menopause services.

#### *Interview procedure*

The interview will be held by telephone at a time convenient for the interviewee.

The interview will probably last about 15-30 mins.

From choice the interview will be tape-recorded. However the researcher accepts that some interviewees may prefer not to be recorded and, if so, notes will be taken instead.

#### *Confidentiality*

Participation is entirely voluntary. The identity of all participants will be kept confidential, with pseudonyms used in the report and in any publications written about the study. All data will be stored securely at the researcher's home, only for as long as necessary and in accordance with NHS recommendations. All participants will be given the opportunity to view and comment on a transcript of their interview. Audio tapes will be transcribed anonymously and will be destroyed at the end of the study. Findings from the interviews may be shared with the [Community Menopause Clinic] but individual participants will not be identified. This study has been accepted by the Local Research Ethics Committee.

[Contact details of researcher and Lead Clinician supplied]

**APPENDIX 8: LETTER TO VOLUNTEERS NOT SELECTED FOR INTERVIEW  
SAMPLE**

FINDING ADVICE ABOUT THE MENOPAUSE

18 August 2005

Dear

Thank you very much for volunteering to take part in our study looking at your experience of using the [Community Menopause Clinic]. [Lead Clinician] and I are delighted with the response to the study, which has been far greater than we hoped for (over 90% of the questionnaires were returned). I have been collating the responses from the questionnaires and can see that we have a lot of valuable information.

We are very grateful for your offer to take part in a follow-up interview but unfortunately the response was so good that, since I am the only interviewer working on the project, I was not able to talk to everyone who volunteered. I had to select a limited number of volunteers and I am afraid your name was not drawn in the selection. This selection was made on a totally random basis and I am sorry not to have had the opportunity to talk to everyone.

I am aiming to complete my report for the [Clinic] within the next couple of months and will produce summaries of the key findings which will be available via the [Clinic] if you are interested.

With many thanks again for your support and time and with all best wishes,

Yours sincerely,

**APPENDIX 9: LETTER TO WOMEN SAMPLED FOR INTERVIEW BUT WHOM IT WAS NOT POSSIBLE TO CONTACT**

Dear

I wanted to thank you for kindly volunteering to be interviewed for our study looking at your experience of using the [Community Menopause Clinic]. I randomly selected a sample of volunteers to be interviewed and your name did actually come up in the sample. I tried several times to contact you earlier in the summer but was unable to get in touch and didn't like to leave a phone message for reasons of confidentiality.

I am still working on the study though so if you feel that there is something you would particularly like to say, either about your contact with the [Clinic] or your experience of looking for information about the menopause, please do get in touch with me.

I am aiming to complete my report for the [Clinic] within the next couple of months and will produce summaries of the key findings which will be available via the [Clinic] if you are interested.

With all best wishes and many thanks,

Yours sincerely,

## APPENDIX 10: QUESTIONNAIRE

### FINDING ADVICE ABOUT THE MENOPAUSE

A STUDY BY [COMMUNITY MENOPAUSE CLINIC]AND  
THE UNIVERSITY OF WALES ABERYSTWYTH

*Thank you for agreeing to take part in our study. All information given in this questionnaire will be treated confidentially. The researcher will not know your name/contact details unless you choose to take part in a one-to-one follow-up interview.*

When you have completed the questionnaire (which may take around 20 minutes) please return it in the FREEPOST envelope supplied. RETURN BY DATE

If you would like any further information before completing the questionnaire please contact:

[Contact details for researcher and Lead Clinician]

Version 5 9/7/04

PLEASE COMPLETE THE QUESTIONNAIRE BY PUTTING A TICK IN THE APPROPRIATE BOXES [✓] OR BY WRITING YOUR ANSWER AS NECESSARY

Section 1: Finding advice about the menopause

1. Why did you first start to look for information and advice about the menopause?  
(Please tick all boxes that apply)

- Just out of interest [ ] 1.1
- Because I realised I was approaching menopausal age [ ] 1.2
- I knew someone who was going through the menopause [ ] 1.3
- I saw/heard something that sparked my interest [ ] 1.4
- I started to have symptoms [ ] 1.5
- I visited my GP without realising my symptoms were menopause-related [ ] 1.6
- Other (please give details below) [ ] 1.7

.....

.....

.....

2. Since you have been looking for advice about the menopause, what sources have you used?  
(Please tick all boxes that apply)

- Books [ ] 2.1
- Magazines [ ] 2.2
- Television and/or radio [ ] 2.3
- Internet [ ] 2.4
- Talking to friends/family/colleagues [ ] 2.5
- Contacting GP [ ] 2.6
- Contacting the [Clinic] [ ] 2.7
- Contacting other specialist organisation(s) (please give details below) [ ] 2.8

.....

.....

Other (please give details below) [ ] 2.9

.....

.....

.....  
3. What have been the issues you have most needed advice about?  
(Please tick all boxes that apply)

- Finding general information about the menopause [ ] 3.1
- Coping with symptoms (e.g. hot flushes) [ ] 3.2
- Benefits and risks of HRT [ ] 3.3
- Healthy living (e.g. diet and exercise) [ ] 3.4
- Alternative therapies [ ] 3.5
- Postmenopausal health [ ] 3.6
- Finding out more about a report you have seen/heard in the media  
(newspaper/radio/TV etc.) [ ] 3.7
- Other (please give details below) [ ] 3.8

.....  
.....  
.....  
4. Have you ever had problems finding the menopause advice you needed?

- YES [ ] 4.1
- NO [ ] 4.2

If YES, please give a brief example below:

.....  
.....  
.....  
**SECTION 2: YOUR EXPERIENCE AT THE [COMMUNITY MENOPAUSE CLINIC]**

5. How did you first hear about the [Clinic]?

- A friend told me about it [ ] 5.1
- My GP told me about it [ ] 5.2
- I went to a talk about it (please say where the talk was held) [ ] 5.3

Other (please give details below)

[ ] 5.4

.....  
.....

6. Were you happy with the appointment letter you received from the clinic?

YES

[ ] 6.1

NO

[ ] 6.2

Comments:

.....  
.....  
.....

7. Were you happy with the time you had to wait to get an appointment at the clinic?

YES

[ ] 7.1

NO

[ ] 7.2

Comments:

.....  
.....  
.....

8. Is there anything you would like to say about your visit to the clinic – is there anything that you thought was good about the clinic or that you were unhappy about?

.....  
.....  
.....  
.....  
.....



.....  
.....  
.....  
.....

SECTION 3: ABOUT YOU

9. Are you taking Hormone Replacement Therapy (HRT) at the moment?

YES [ ] 9.1  
NO [ ] 9.2

Comments:

.....  
.....  
.....

10. If you are/have been taking HRT did you start before your periods actually finished?

YES [ ] 10.1  
NO [ ] 10.2

Comments:

.....  
.....  
.....

11. If your periods have stopped, did this happen naturally (i.e. rather than stopping following surgery or some other medical procedure)?

YES [ ] 11.1  
NO [ ] 11.2

Comments:

.....  
.....  
.....

12. Please indicate your age by ticking the appropriate box:

Under 40 [ ] 40–44 [ ] 45–49 [ ] 50–54 [ ] 55–60 [ ] Over 60 [ ]

Thank you for completing the questionnaire. Please return it in the FREEPOST envelope supplied.

If you would be interested in taking part in a follow-up interview with the (female) researcher please either complete the slip below or contact the researcher directly (see contact details on page 1 of this questionnaire). You may have already returned the reply slip that came with the letter from the [Clinic]. If so, you **don't** need to fill in the form below.

The interviews would take place at a time and in a location of your convenience and would be on a one-to-one confidential basis. The interview would probably last for about 45 minutes to 1 hour and would be very informal.

The researcher is interested in finding out about your experiences of the menopause – about the kind of questions that concern you, where you look for advice and how you decide what is right for you.

I WOULD BE INTERESTED IN PARTICIPATING IN A FOLLOW-UP INTERVIEW.

NAME:.....

CONTACT DETAILS:

.....  
.....  
.....

## APPENDIX 11: GP INTERVIEW SCHEDULE

### Interview Schedule for General Practitioners (Version 3 27/5/04)

1. Have you ever referred a patient to the [Community Menopause Clinic]?
  
2. If yes, have you received any feedback from patients about the [Clinic]?
  
3. How [else] might you manage a patient suffering from menopause-related problems?
  - Is there a wellwoman clinic or nurse-run service?
  - Would you refer elsewhere than the [Clinic]?
  
4. How do you feel about the fact that the [Clinic] is a self-referral clinic?
  - How comfortable are you with the idea of patients using self-referral services?
  - How do you feel about complementary medicine?
  
5. How do you feel about the letters that are sent out by the [Clinic]?
  - Do they have an educational impact?

6. Has the information in the [Clinic] letters ever helped you to manage a patient?
  
7. What services would you like to see a district menopause clinic provide?
  
8. Would you like to make any comments about the service provided by the [Clinic]?
  
9. When patients come to talk to you about the menopause, how informed do they tend to be?
  
10. Have patients ever specifically asked you about the safety of HRT?
  
11. How do you yourself keep up to date with developments in the menopause field?
  
12. Are there any aspects of managing menopause-related issues that you find difficult?
  
13. Is there anything else you would like to say or ask?

## **APPENDIX 12: INTERVIEW SCHEDULE (ACCOUNTS OF THE MENOPAUSE TRANSITION)**

### INTERVIEW GUIDE (Version 2 10/2/04)

*NB: Information sheet and informed consent form.*

1. Would you like to start by telling me about your experience of the menopause so far.

- When you first started to think about it
- Symptoms and how you have felt about them
- Has it meant any changes to your life?
- Try to find out about life circumstances

2. Since you have started to think about the menopause, what has been your main concern?

- Is anything about the menopause concerning you at the moment?

3. When did you first decide to look for advice and information about the menopause?

- What prompted you to start looking?
- Where did you turn for advice?
- Have you needed to look for different kinds of advice at different times?

4. How easy have you found it to get advice and information about the menopause?

- Ways to identify and access sources of information (formal and informal)
- Interacting with the information sources
- Any problems?
- Try to think about relationship with GP/health professionals
- Does anyone else ever look out for information for you?

5. What have you tended to do with the information once you have found it?

6. Have you ever come across advice or information unexpectedly?

- Try to get some examples
- How does it happen?
- How often does it happen?

7. Have you ever found or been given advice or information that was unhelpful or you didn't trust?

- How did you decide that you were unhappy with the information?

8. Have you ever come across advice or information that conflicted with what you thought or knew?

- Had you been given other information previously that disagreed?
- How did you decide what to believe?
- Try to think about media coverage if not already mentioned

9. Who would you most likely turn to for support about the menopause?

- Support groups?
- Health professionals?
- Informal support networks?

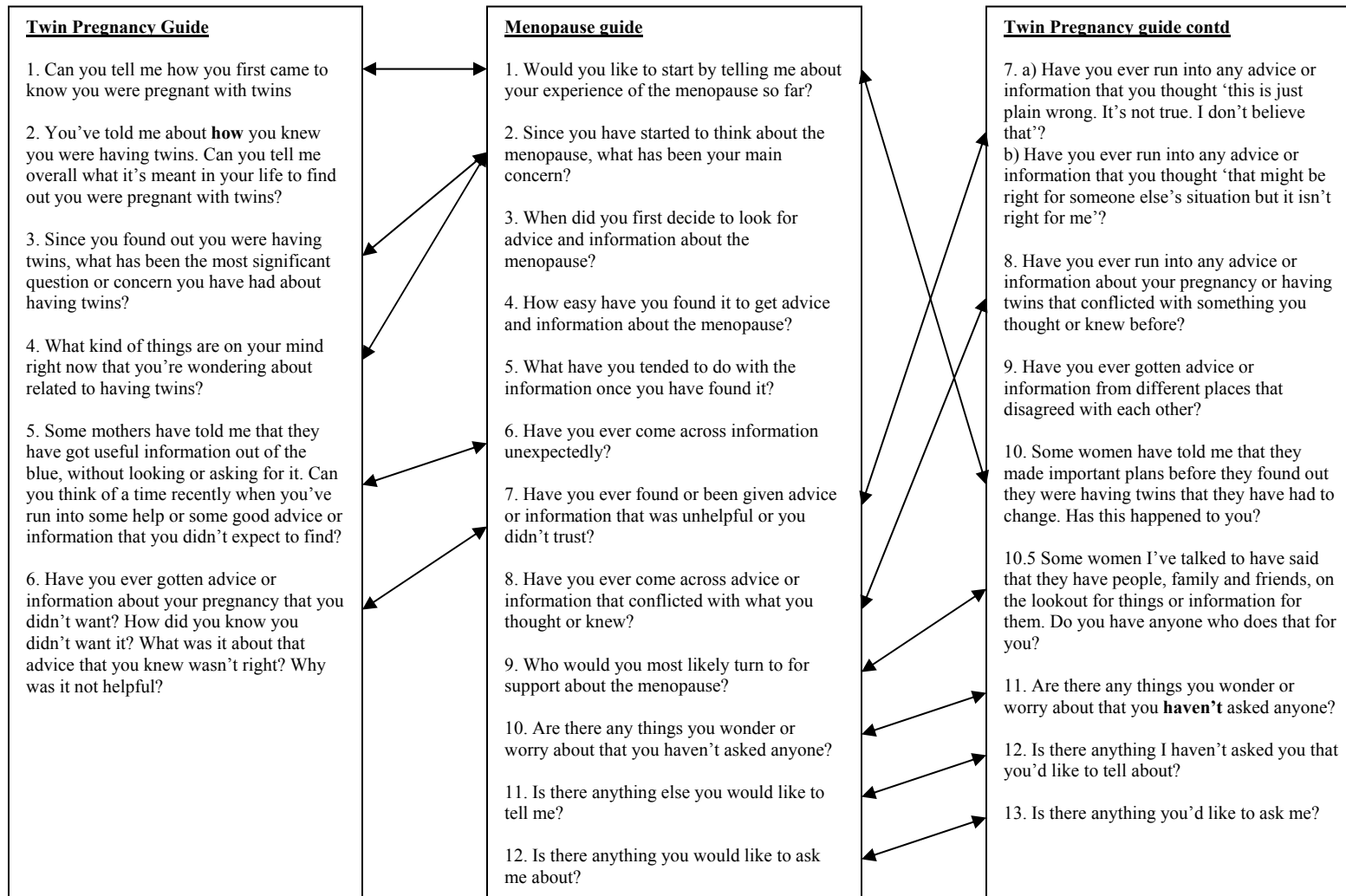
10. Are there any things you wonder or worry about that you haven't asked anyone?

- Think about reasons for this

11. Is there anything else you would like to tell me about?

12. Is there anything you would like to ask me about?

## APPENDIX 13: COMPARISON BETWEEN INTERVIEW GUIDES



## APPENDIX 14: CODING COMPARISON

### *Report from second-coder:*

I have done coding independently of yours, and then checked against your coding. I agree on the following codes and their allocation:

- 1) 3 2 1
- 2) 3 2 2
- 3) 3 8 1 1
- 4) 3 8 1 4 (after checking on the meaning)
- 5) 3 8 1 13 (although I think this requires a bit of interpolation - a problem of the model, possibly)
- 6) 3 8 1 14 (as above)
- 9) 3 8 4 3
- 10) 5 1 1 4
- 11) 5 1 2 5
- 12) 5 2 2
- 13) 5 2 6
- 14) 5 3 3

### *Queries*

7) 3 8 1 16 (I don't think I could be expected to find the miscellaneous!) [THIS NODE HAS SUBSEQUENTLY BEEN RENAMED. IT WAS ORIGINALLY CALLED 'MISCELLANEOUS' AS IT WAS USED AS A REPOSITORY FOR THE TEXT THAT DID NOT SEEM TO FIT NEATLY WITHIN THE CATEGORIES LIFTED FROM MCKENZIE'S MODEL ON INITIAL CODING. IT WAS RENAMED 'NOT COMFORTABLE FIT' TO MAKE THIS MORE EXPLICIT AND TEXT THAT I LATER DECIDED TO ALLOCATE TO AN EXISTING CATEGORY FROM THE MODEL WAS RELOCATED]

8) 3 8 2 (barriers to information seeking).I agree that you are being consistent in your application of the code, it is just that I probably wouldn't give the code that name - "perceived problems and reactions around information seeking and provision" seems to fit better for me. [THIS IS A VALID AND INTERESTING POINT AND IS DISCUSSED IN CHAPTER EIGHT – CONCLUSIONS].

For one of the barriers passages I used Connection failures in communicating, but this was guesswork on my part for McKenzie, as I don't have the details of the model with me. The section was the interviewee talking about the problems of explaining overheating.

Additional codes I used that you didn't include:

Sources of information: other women (but this was just a line) (3 8 4 5)

Positive comments about taking HRT (5 1 2 7)



**APPENDIX 15: COPY OF ATTRIBUTES TABLE FROM NVIVO**

<b>Document</b>	<b>Early Natural Menopause?</b>	<b>First coding pass done</b>	<b>Gender</b>	<b>Hysterectomy?</b>	<b>Role</b>	<b>Sample/ care home recruit?</b>	<b>Second coding pass done</b>	<b>Third coding pass done</b>	<b>Type of interview</b>
GP 1	N/A	YES	FEMALE	N/A	GP	YES	YES	N/A	TELEPHONE
GP 2	N/A	YES	MALE	N/A	GP	YES	YES	N/A	TELEPHONE
GP 3	N/A	YES	FEMALE	N/A	GP	YES	YES	N/A	TELEPHONE
GP 4	N/A	YES	MALE	N/A	GP	YES	YES	N/A	TELEPHONE
GP 5	N/A	YES	FEMALE	N/A	GP	YES	YES	N/A	TELEPHONE
GP 6	N/A	YES	MALE	N/A	GP	YES	YES	N/A	TELEPHONE
Community Menopause Clinic interview	N/A	YES	FEMALE	N/A	EXPERT INFORMANT	N/A	YES	N/A	FACE-TO-FACE
Notes from telephone conversation: community healthy living centre	N/A	YES	FEMALE	N/A	EXPERT INFORMANT	N/A	YES	N/A	TELEPHONE

<b>Document</b>	<b>Early Natural Menopause?</b>	<b>First coding pass done</b>	<b>Gender</b>	<b>Hysterectomy?</b>	<b>Role</b>	<b>Sample/ care home recruit?</b>	<b>Second coding pass done</b>	<b>Third coding pass done</b>	<b>Type of interview</b>
Angela	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Ann	NO	YES	FEMALE	YES	CARE HOME WORKER	YES	YES	YES	FACE-TO-FACE
Barbara	NO	YES	FEMALE	YES	CARE HOME WORKER	YES	YES	YES	FACE-TO-FACE
Belinda	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Charlotte	NO	YES	FEMALE	YES	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Deborah	YES	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Denise	NO	YES	FEMALE	NO	CARE HOME WORKER	YES	YES	YES	FACE-TO-FACE
Eileen	YES	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Eleanor	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE

<b>Document</b>	<b>Early Natural Menopause?</b>	<b>First coding pass done</b>	<b>Gender</b>	<b>Hysterectomy?</b>	<b>Role</b>	<b>Sample/ care home recruit?</b>	<b>Second coding pass done</b>	<b>Third coding pass done</b>	<b>Type of interview</b>
Emma	NO	YES	FEMALE	NO	CARE HOME WORKER	YES	YES	YES	FACE-TO-FACE
Erica	NO	YES	FEMALE	YES	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Eve	NO	YES	FEMALE	NO	CARE HOME WORKER	YES	YES	YES	FACE-TO-FACE
Fiona	YES	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Frances	NO	YES	FEMALE	NO	CARE HOME WORKER	YES	YES	YES	FACE-TO-FACE
Grace	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Gwen	NO	YES	FEMALE	NO	CARE HOME WORKER	YES	YES	YES	FACE-TO-FACE
Hannah	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Helen	YES	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE

<b>Document</b>	<b>Early Natural Menopause?</b>	<b>First coding pass done</b>	<b>Gender</b>	<b>Hysterectomy?</b>	<b>Role</b>	<b>Sample/ care home recruit?</b>	<b>Second coding pass done</b>	<b>Third coding pass done</b>	<b>Type of interview</b>
Imogen	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Isobel	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Jane	YES	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Janice	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Kate	NO	YES	FEMALE	YES	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Kathleen	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Linda	NO	YES	FEMALE	YES	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Louise	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Marion	NO	YES	FEMALE	YES	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE

<b>Document</b>	<b>Early Natural Menopause?</b>	<b>First coding pass done</b>	<b>Gender</b>	<b>Hysterectomy?</b>	<b>Role</b>	<b>Sample/ care home recruit?</b>	<b>Second coding pass done</b>	<b>Third coding pass done</b>	<b>Type of interview</b>
Nicola	YES	YES	FEMALE	YES	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Olivia	NO	YES	FEMALE	NO	LOCAL, NON CLINIC	NO	YES	YES	TELEPHONE
Rowena	YES	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Sally	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Sylvia	NO	YES	FEMALE	NO	VOLUNTEER	NO	YES	YES	TELEPHONE
Tracy	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Vicky	NO	YES	FEMALE	YES	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
Viv	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	TELEPHONE
PhD Journal memo	N/A	YES	N/A	N/A	N/A	N/A	YES	N/A	N/A

<b>Document</b>	<b>Early Natural Menopause?</b>	<b>First coding pass done</b>	<b>Gender</b>	<b>Hysterectomy?</b>	<b>Role</b>	<b>Sample/ care home recruit?</b>	<b>Second coding pass done</b>	<b>Third coding pass done</b>	<b>Type of interview</b>
Response by letter Maureen	NO	YES	FEMALE	NO	CLINIC ATTENDEE	YES	YES	YES	LETTER
Wellwomen Information	N/A	YES	FEMALE	N/A	EXPERT INFORMANT	N/A	YES	N/A	FACE-TO-FACE
Women's Health Concern	N/A	YES	FEMALE	N/A	EXPERT INFORMANT	N/A	YES	N/A	FACE-TO-FACE

## APPENDIX 16: EXTRACT FROM RESEARCH JOURNAL

6/01/2004 - 09:45:24

Spending day adding notes from Reinterpreting Menopause book to Procite. Am getting frustrated by it. Partly it's just tedious but also I find a lot of these kind of texts quite smug. The Fiona Mackie chapter and other texts like it. She says that women who effectively sail through the menopause (possibly because they are psychologically better able to cope being happy with their life-situation) can be used as a condemnation of those whose circumstances trap them in a negative experience of the menopause but she then goes on to spend the rest of the chapter somewhat smugly telling us how well she coped with all the menopause threw at her and urging other women to handle it the way she did. It's that 'if I managed without HRT so can you' thing which to me negates the very point that they seem to be making that menopause is not an imposed construct and that each woman's experience of it is equally valid: if a woman feels she is experiencing menopausal 'symptoms' it's simply because she is 'unable to engage with a deeper process of which they are facets'.

Was quite pleased to come across the Rothfield chapter though since she explains why menopause and pregnancy can be considered related experiences - useful when explaining why I chose to adapt Pam McKenzie's model.

27/01/2004 - 10:21:44

Went to [XXX] last week (21 Jan). Had a meeting with [XXX] first which was very interesting but I found out they have changed all the ethics procedures and I need to use the new Corec form and submit it to [XXX]. [XXX] gave me [XXX] name for further information. Phoned [XXX] today and she is emailing me all the relevant info. Has offered to help if I get stuck with the form. It has to go through their local panel as well. Also talked about the research design. [XXX] thinks I need to look at what other services are available to women - where else do GPs refer people? I can hopefully get a start on that from the interviews with GPs. She also thinks I should talk to some local women who have not gone to clinic. I said this was difficult for me because I don't have local contacts and [XXX] offered herself and her friends as volunteers if necessary.

Then went to meeting with [Lead Clinician] where we tidied up the last bits for the ethics submission. She has also sent me a list of doctors for the sampling. We agreed that it would be best to use the Wellbeing scales in the interviews and keep the questionnaire short. Discussed this with Chris on the Thursday but need to check it through again. Also decided roughly what questions to ask on the GPs interview schedule.

Apparently the submission date for the local ethics board is 2 February so not sure if I will get all this done in time. They sit every month though.

20/02/2004 - 12:26:27

Haven't filled this in for a few weeks so have a bit to add. 4-5 February 2004: Centre for Health Information Quality conference 'Better Information Better Communication in

Healthcare' at Church House London. Very good conference. Mainly about improving communication to patients but speakers included Roger Harrabin talking about the Kings Fund report. Plenty of information in black folder from the conference.

Went up to Aber last week and had meetings with Chris and with Anoush. The meeting with Anoush was informal over coffee. It was interesting and useful to chat to her and confirmed that I am not widely off-mark. It's also reassuring because she has a very practical approach to getting the PhD done. Gave me some useful references for reading. With Chris went through the ethics form that I had prepared in rough. Need to get on with this today and early next week because think it needs to be submitted at the start of March. Am finding it hard to get down to serious work at times though - am feeling sick quite a lot of the time.

Piloted the interview schedule and questionnaire with [XXX] a couple of weeks ago and made a few changes at her suggestion. Piloted the interview schedule, informed consent form and information sheet with [XXX] last night. Didn't have time to look at the questionnaire with her but might send that to someone else for a quick look through. I don't think I need to make more changes to the interview schedule but it is tricky to ask all the questions. Since the content is dictated to a certain extent by the need to reflect the questions Pam McKenzie asked I don't feel I can mess around with it too much. On the other hand it has to be flexible because some of the questions are very similar or do get covered out of sequence by interviewees in the course of the natural conversation. Have arranged to interview some of [XXX's] staff on 17 March so that will be the first real test. Need to familiarise myself more with the schedule before that so that I don't have to keep looking at it. Know from experience that this happens gradually though anyway.

26/02/2004 - 15:13:47

Struggling on with ethics form. What a nightmare!

27/02/2004 - 13:51:55

Spoke to LREC in [XXX] which helped clarify what I need to do with form a bit. Spoke to R&D office yesterday. Slightly confusing because they gave conflicting advice but have gone with LREC and done my best. Have printed forms and will post them to Chris in Aber. Need to ask [Lead Clinician] to write a letter saying she supports what I do, include [her] and also ask her to organise the signatures I need in [XXX] - clinical director of Trust . May have to get data protection officer too.

05/03/2004 - 21:18:24

Monday 1 March went to Information Literacy for Health LKDN/SCONUL/UMSLG joint workshop. Nothing too relevant for PhD though. Have received Chris's comments on GP interview schedule and ethics form. Need to get back to work on this but have had to give up my office to Martin while the front room is being decorated so a bit disrupted at the moment. Got on with some reading though which is good.



18/03/2004 - 13:58:19

Ethics form now finished. Have Chris's CV and signed supervisor's page. Need to send relevant bits off to [Lead Clinician] but should then be done. Went to [XXX] yesterday to do first interviews with care home staff. Managed to see seven of them which was great, four more than expected. It was really interesting and enlightening and touching too. It's more draining on an emotional level than the type of interviewing I am used to because it's such a personal issue and touches on things like relationships with family and partners. May reword the information sheet to make pseudonym clearer though because one interviewee said she didn't understand what it meant. found it a bit challenging because the women who hadn't volunteered in advance knew less about the project and although I explained that I am from the information studies rather than medical side they were asking questions about HRT that I had to explain I couldn't answer. The fact that they volunteered on the day also caused problems for the informed consent form which states that they have had more than 24hours to consider participating. I did point that out though and they were all still happy to sign.

23/03/2004 - 11:01:19

Just adding in some new books to Procite and thought I may have forgotten to note that I have decided not to include a quality of life measurement scale in the questionnaire. I didn't want anything too long and unwieldy but both [Lead Clinician] and I felt that a simple smiley faces type of scale was too simplistic and maybe a bit patronising. Discussed with Chris as well and decided to leave it out altogether. It would add complication to the analysis as well without being entirely relevant to the main thrust of the study.

Sent the relevant bits of the Ethics form to [Lead Clinician] for signatures.

15/04/2004 - 10:50:26

Still no reply from [Lead Clinician] with signatures. Have promised Chris I will chase her up so need to do this today. In the meantime have been getting on with reading - HSJs, BMS journal and books. Read Case 'Looking for Information' which was ideal for an overview of information studies theories and studies. Have passed it on to Chris but need to get it back and read again for ideas of what to follow up. Ideally should buy it but it's £60! Also reading Symon and Cassell 'Qualitative Methods' found the Template Analysis chapter particularly useful as in fact this is how I intend to analyse the interviews.

Still need to contact Data Protection officer. Emailed [XXX] at R&D office to ask for name and contact details of DP officer (8 April) but no reply yet. Also need to phone [Lead Clinician]. Wrote to her last week to remind her, ask about cost of stationery and also explain about pregnancy. Wanted to reassure her that it will not impact on the study. The area of main interest to [Lead Clinician] can be covered by the questionnaires which I will be able to send out and analyse even if I have stopped work. Currently negotiating with Chris over maternity leave and how my work will pan out when I come back.

Heard from [Lead Clinician] (telephone). She is seeing the head of department a week Monday. Will ask her to sign the forms and in the meantime will work on the costings. Mentioned that she is getting involved in a clinical trial but we both feel this will not impact on my study.

28/04/2004 - 15:21:00

Had signed forms back from [Lead Clinician] along with a few suggestions for changes to the form/GP interview schedule. Also managed to contact the Data Protection Officer. She sent back some suggestions which although they would make more work at the moment should hopefully save me some hassles later. Will need to contact [Lead Clinician] though to check out some of the answers.

30/04/2004 - 14:30:29

After giving careful thought to [Data Protection Officer's] suggestions realised that some would be problematic. Am pleased that she agreed the GPs don't need to be informed and have pretty much already covered the points she makes for the information sheets. Spoke to Chris about the other two points though. Agreed that it would suit me better to keep the opt out approach but don't mind compromising on this. The first point is a worry though - I doubt very much whether women attending the clinic were informed that they may be approached re research and doubt whether it is registered with the Information Commissioner for R&D purposes. However it would be difficult for us to go down the route of [Lead Clinician] asking women when they come in to the clinic - it would take so long to recruit a sizeable number. Had yet another moaning session with Chris about ethics forms and data protection. It does seem to take things a bit far sometimes and it's hard to believe anything ever gets done. Chris said I need to phone [Data Protection Officer] and plead my case - the initial questionnaire is really an internal audit (only needs to go through ethics because I am conducting it). Because it needs to be retrospective would find it difficult to go down the route of recruiting at sessions. Need to get a wide spectrum of responses. Chris also said to explain about limited time and pregnancy etc.

Spoke to [Data Protection Officer] and agreed to compromise about opting in rather than out. She is not willing to budge on the other issue though - says women may not want to receive a questionnaire at home which might embarrass them in front of the family or remind them of things they don't want to think about! As Chris pointed out this is ironic given that R&D have told me the correspondence has to be on Trust headed paper - just draws attention to it even more. Can see that this would be difficult to argue out of. Chris says she will speak to [Data Protection Officer] if necessary. [Data Protection Officer] says however that the clinic most likely is covered by an umbrella registration with Information Commissioner from PCT. Have spoken to [Lead Clinician] about this. Covered off the other issues with [Lead Clinician] who is happy to amend the opt out bit in the initial letter and reply slip. She thinks the clinic is covered because she has done research in the past and is about to start on a clinical trial anyway. Says she will take it up with them next week unless I can clarify it with the Trust R&D person. Have decided to try and contact [XXX] first as she may well know and is a good first contact point.

## APPENDIX 17: CODING REPORT

NVivo revision 1.3.146 Licensee: Alison Yeoman

Project: PhD User: Administrator Date: 13/07/2009 - 11:57:25  
DOCUMENT CODING REPORT

Document: PARTICIPANT INTERVIEW LOUISE  
Created: 16/01/2008 - 12:50:49  
Modified: 16/06/2009 - 11:32:50  
Description:  
ALISON YEOMAN INTERVIEW 39 JULY 2005

Nodes in Set: All Nodes  
Node 1 of 131 Alternative therapies coded to tree  
Passage 1 of 1 Section 0, Paras 23 to 28, 1004 chars.

23: ALISON: Have you tried any of the alternative remedies at all?

24: LOUISE: I haven't because I'm not a lazy character but having said that I am lazy when it comes to trying to sort things out, I like the one stop shop idea, go in, state the problem, get the answer and it doesn't strike me that would be a quick and easy solution, so no I haven't pursued that.

25: ALISON: When you say that about yourself does that mean then that you haven't really, have you looked much for information say like in the media or on the internet or anything?

26: LOUISE: No, I've gone to the GP and expected him to come up with the answers.

27: ALISON: And it sounds like you are quite happy with their approach anyway?

28: LOUISE: Yes the way I've been dealt with hitherto and quite relaxed in that respect, although I am aware that friends of mine have actually gone down the sort of natural therapy route, not necessarily successfully but are more keen to use that as a solution or part solution but I am lazy and hate sort of ferreting around for information.

---

Node 2 of 131 Awareness of the men copied to tree  
Passage 1 of 1 Section 0, Paras 4 to 8, 785 chars.

4: LOUISE: Well what started me off wondering if I had problems was feeling dizzy, light headed and I found myself walking from the office to the office car park sort of meandering and that concerned me seeing as I was driving  $\frac{3}{4}$  of an hour each way to work, so when it persisted I thought well something's altered in my life, quite what I don't know and that was when I went to the doctors and it was suggested that the menopause might be the problem.

5: ALISON: Had you had any inkling that it might be the menopause?

6: LOUISE: I'm not very up or terribly interested in the health side of things, which sounds terrible but I think I've been really blessed with excellent health and I've been

guilty of taking it rather for granted really.

7: ALISON: Did you go and see your GP at that point then?

8: LOUISE: Yes I did.

---

Node 3 of 131 Comments about JC recoded to tree

Passage 1 of 1 Section 0, Paras 7 to 18, 1270 chars.

7: ALISON: Did you go and see your GP at that point then?

8: LOUISE: Yes I did.

9: ALISON: What happened?

10: LOUISE: They prescribed me some HRT, you know the hormone replacement. I can't recollect it was some time ago, so it was one particular dose that seemed to fit the bill well enough for me. I continued with those and then when I moved to X I began to get similar symptoms arise again even though I was actually taking the medication. That sort of prompted me to go to my new doctor who then referred me to the clinic.

11: ALISON: When you went to the clinic how did you find that?

12: LOUISE: Very helpful, very informative and nothings too much trouble for them. I must say when I felt the effects of the initial treatment was wearing off it had taken me quite a few different pills to find the one that suited to me and I wasn't looking forward to going through the whole or a similar rigmarole again but they were concerned that I got the right pills, the right dosage and so on and very good indeed.

13: ALISON: Was that a while ago then?

14: LOUISE: Probably about 12-15 months ago.

15: ALISON: And you've been on the new pills since then?

16: LOUISE: Yes.

17: ALISON: Do you have to go back there or is it through your GP?

18: LOUISE: No I am able to go back if I feel there is a need or if I've got any queries at all but so far so good.

---

Node 4 of 131 HRT coded to tree

Passage 1 of 1 Section 0, Paras 7 to 18, 1270 chars.

7: ALISON: Did you go and see your GP at that point then?

8: LOUISE: Yes I did.

9: ALISON: What happened?

10: LOUISE: They prescribed me some HRT, you know the hormone replacement. I can't recollect it was some time ago, so I was one particular dose that seemed to fit the bill well enough for me. I continued with those and then when I moved to X I began to get similar symptoms arise again even though I was actually taking the medication. That sort of prompted me to go to my new doctor who then referred me to the clinic.

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14: LOUISE: Probably about 12-15 months ago.

15: ALISON: And you've been on the new pills since then?

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17: ALISON: Do you have to go back there or is it through your GP?

18: LOUISE: No I am able to back if I feel there is a need or if I've got any queries at all but so far so good.

---

Node 5 of 131 Impact on life copied to tree

Passage 1 of 3 Section 0, Paras 4 to 8, 785 chars.

4: LOUISE: Well what started me off wondering if I had problems was feeling dizzy, light headed and I found myself walking from the office to the office car park sort of meandering and that concerned me seeing as I was driving  $\frac{3}{4}$  of an hour each way to work, so when it persisted I thought well something's altered in my life, quite what I don't know and that was when I went to the doctors and it was suggested that the menopause might be the problem.

5: ALISON: Had you had any inkling that it might be the menopause?

6: LOUISE: I'm not very up or terribly interested in the health side of things, which sounds terrible but I think I've been really blessed with excellent health and I've been guilty of taking it rather for granted really.

7: ALISON: Did you go and see your GP at that point then?

8: LOUISE: Yes I did.

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Passage 2 of 3 Section 0, Paras 31 to 34, 981 chars.

31: ALISON: You mentioned friends, is it something that you talk to your friends about much?

32: LOUISE: Yes I think a lot of it from my perspective is trying to gauge how my problems measure up against their experiences, because you know the overheating thing is one aspect of it and I can only attribute, I think there might be more but you know it suggests the menopause, but I need only pick up a broom to sweep somewhere indoors and 2 strokes if you like of the broom and I am dripping, I'm not hot I'm not damp, I'm dripping, it's horrible I feel so anti-social but if I were to do anything more, or even consider lightly dusting around the house I've got to think right I need a shower.

33: ALISON: Oh how awful.

34: LOUISE: It is, this is why I think, am I peculiar, is there something untoward or is this something everybody puts up with and doesn't moan about, so yes from my

perspective I've been asking questions to a certain how big a problem it is, if its unusual or whether its just peculiar to me.

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Passage 3 of 3 Section 0, Paras 38 to 46, 1164 chars.

38: LOUISE: No though it would be nice if somebody could find, it's like hay fever this time of the year once you've got the right medication it's a doddle and I'd like to think the menopause could be the same but we haven't quite got there.

39: ALISON: The trouble is it's like you were saying everybody is so individual aren't they?

40: LOUISE: Yes well it certainly seems to be that way but you probably know more about that than I do having done the research, whereas I'm just liasing with the medical profession and friends and that's it.

41: ALISON: Well I'mnot a medical person myself and the more I read about it the more complicated it becomes.

42: LOUISE: Oh really.

43: ALISON: Yes.

44: LOUISE: I suppose we look to find some expert with all the answers but I suppose that's an expectation beyond the pail because as you've found it's quite a complex subject and I suppose it varies from woman to woman, the symptoms and the extent of it, so yes I can imagine you have found it rather complicated, I don't suppose there is any easy one solution to it, we shall see, it won't be long hopefully before I come out the other side.

45: ALISON: I hope so with this very hot weather it must be awful.

46: LOUISE: Absolutely.

---

Node 6 of 131 Info barriers copied to tree

Passage 1 of 2 Section 0, Paras 19 to 22, 1412 chars.

19: ALISON: Is there anything that's concerning you at the moment about the menopause?

20: LOUISE: Yes body malfunctioning in terms of over heating. There is so much in the way of medication that I would want to take and I got to the point where there was one dosage which seemed ok, the increased dosage I couldn't see any benefit in the increased dosage and I thought well no let's go back. It's only sort of minor milligrams in it. I have terrible problems with my body over heating and this weather at the moment is just horrendous. But I am not alone in that I just don't know whether I've got menopause problems in that connection plus something else, but I'm trying to sort that out with my doctor but it's a difficult thing to actually describe to somebody. You know I don't know how you react to heat and visa versa, trying to get people to appreciate how it is and how it feels so different for you is a very difficult task I've found. But that's the only thing that I can think of at the moment. The skin is altering but nothing much otherwise.

21: ALISON: When you go and see your doctor about things like that are you quite

happy with the experience of going there, do you find the doctor listens to you properly?  
22: LOUISE: Yes I think we've struck lucky with our doctor here he seems to be very well informed and again he's quite prepared to sort of run a battery of tests to try and pinpoint the actual cause, so yes no problems there.

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Passage 2 of 2 Section 0, Paras 38 to 46, 1164 chars.

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41: ALISON: Well I'mnot a medical person myself and the more I read about it the more complicated it becomes.

42: LOUISE: Oh really.

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45: ALISON: I hope so with this very hot weather it must be awful.

46: LOUISE: Absolutely.

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Node 7 of 131 Information behaviour copied to tree

Passage 1 of 1 Section 0, Paras 29 to 30, 433 chars.

29: ALISON: Would you say that's how you are in general then about things, or is it mainly for health things you wouldn't?

30: LOUISE: It sounds silly but if something really interests me you know I leave no stone unturned but if it doesn't really excite me it just a problem that needs resolution and I suppose because I've found that resolution in part if not wholly via the doctors route than I suppose I'm relaxed about doing anything further.

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Node 8 of 131 Interaction with prof copied to tree

Passage 1 of 2 Section 0, Paras 19 to 22, 1412 chars.

19: ALISON: Is there anything that's concerning you at the moment about the menopause?

20: LOUISE: Yes body malfunctioning in terms of over heating. There is so much in the way of medication that I would want to take and I got to the point where there was one dosage which seemed ok, the increased dosage I couldn't see any benefit in the increased dosage and I thought well no let's go back. It's only sort of minor milligrams in it. I have terrible problems with my body over heating and this weather at the moment is just horrendous. But I am not alone in that I just don't know whether I've got menopause problems in that connection plus something else, but I'm trying to sort that out with my doctor but it's a difficult thing to actually describe to somebody. You know I don't know how you react to heat and visa versa, trying to get people to appreciate how it is and how it feels so different for you is a very difficult task I've found. But that's the only thing that I can think of at the moment. The skin is altering but nothing much otherwise.

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---

Passage 2 of 2 Section 0, Paras 23 to 28, 1004 chars.

23: ALISON: Have you tried any of the alternative remedies at all?

24: LOUISE: I haven't because I'm not a lazy character but having said that I am lazy when it comes to trying to sort things out, I like the one stop shop idea, go in, state the problem, get the answer and it doesn't strike me that would be a quick and easy solution, so no I haven't pursued that.

25: ALISON: When you say that about yourself does that mean then that you haven't really, have you looked much for information say like in the media or on the internet or anything?

26: LOUISE: No, I've gone to the GP and expected him to come up with the answers.

27: ALISON: And it sounds like you are quite happy with their approach anyway?

28: LOUISE: Yes the way I've been dealt with hitherto and quite relaxed in that respect, although I am aware that friends of mine have actually gone down the sort of natural therapy route, not necessarily successfully but are more keen to use that as a solution or part solution but I am lazy and hate sort of ferreting around for information.

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Node 9 of 131 Sources of information coded to tree  
Passage 1 of 2 Section 0, Paras 23 to 28, 1004 chars.

23: ALISON: Have you tried any of the alternative remedies at all?

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---

Passage 2 of 2 Section 0, Paras 29 to 30, 433 chars.

29: ALISON: Would you say that's how you are in general then about things, or is it mainly for health things you wouldn't?

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Node 10 of 131      Support copied to tree  
Passage 1 of 1 Section 0, Paras 31 to 34, 981 chars.

31: ALISON: You mentioned friends, is it something that you talk to your friends about much?

32: LOUISE: Yes I think a lot of it from my perspective is trying to gauge how my problems measure up against their experiences, because you know the overheating thing is one aspect of it and I can only attribute, I think there might be more but you know it suggests the menopause, but I need only pick up a broom to sweep somewhere indoors and 2 strokes if you like of the broom and I am dripping, I'm not hot I'm not damp, I'm dripping, it's horrible I feel so anti-social but if I were to do anything more, or even consider lightly dusting around the house I've got to think right I need a shower.

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Node 11 of 131      (3 2 1) /Menopause services and advice/Community  
Menopause Clinic/Referral and awareness  
Passage 1 of 1 Section 0, Paras 10 to 11, 470 chars.

10: LOUISE: They prescribed me some HRT, you know the hormone replacement. I can't recollect it was some time ago, so I was one particular dose that seemed to fit the bill well enough for me. I continued with those and then when I moved to X I began to get similar symptoms arise again even though I was actually taking the medication. That sort of prompted me to go to my new doctor who then referred me to the clinic.

11: ALISON: When you went to the clinic how did you find that?

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Node 12 of 131 (3 2 2) /Menopause services and advice/Community  
Menopause Clinic/Comments about CMC service  
Passage 1 of 1 Section 0, Paras 11 to 18, 767 chars.

11: ALISON: When you went to the clinic how did you find that?

12: LOUISE: Very helpful, very informative and nothings too much trouble for them. I must say when I felt the effects of the initial treatment was wearing off it had taken me quite a few different pills to find the one that suited to me and I wasn't looking forward to going through the whole or a similar rigmarole again but they were concerned that I got the right pills, the right dosage and so on and very good indeed.

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17: ALISON: Do you have to go back there or is it through your GP?

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Node 13 of 131 (3 8 1 1) /Menopause services and advice/Information-  
seeking/McKenzie's model/Active seeking in connection  
Passage 1 of 2 Section 0, Para 4, 337 chars.

4: myself walking from the office to the office car park sort of meandering and that concerned me seeing as I was driving  $\frac{3}{4}$  of an hour each way to work, so when it persisted I thought well something's altered in my life, quite what I don't know and that was when I went to the doctors and it was suggested that the menopause might be the problem.

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Passage 2 of 2 Section 0, Para 10, 415 chars.

10: LOUISE: They prescribed me some HRT, you know the hormone replacement. I can't recollect it was some time ago, so I was one particular dose that seemed to fit the bill well enough for me. I continued with those and then when I moved to X I began to

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Node 14 of 131 (3 8 1 4) /Menopause services and advice/Information-seeking/McKenzie's model/By proxy in connection  
Passage 1 of 1 Section 0, Para 10, 415 chars.

10: LOUISE: They prescribed me some HRT, you know the hormone replacement. I can't recollect it was some time ago, so I was one particular dose that seemed to fit the bill well enough for me. I continued with those and then when I moved to X I began to get similar symptoms arise again even though I was actually taking the medication. That sort of prompted me to go to my new doctor who then referred me to the clinic.

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Node 15 of 131 (3 8 1 13) /Menopause services and advice/Information-seeking/McKenzie's model/Active scanning in communicating  
Passage 1 of 1 Section 0, Paras 31 to 32, 675 chars.

31: ALISON: You mentioned friends, is it something that you talk to your friends about much?

32: LOUISE: Yes I think a lot of it from my perspective is trying to gauge how my problems measure up against their experiences, because you know the overheating thing is one aspect of it and I can only attribute, I think there might be more but you know it suggests the menopause, but I need only pick up a broom to sweep somewhere indoors and 2 strokes if you like of the broom and I am dripping, I'm not hot I'm not damp, I'm dripping, it's horrible I feel so anti-social but if I were to do anything more, or even consider lightly dusting around the house I've got to think right I need a shower.

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Node 16 of 131 (3 8 1 14) /Menopause services and advice/Information-seeking/McKenzie's model/Nondirected monitoring in communicat  
Passage 1 of 1 Section 0, Para 28, 335 chars.

28: LOUISE: Yes the way I've been dealt with hitherto and quite relaxed in that respect, although I am aware that friends of mine have actually gone down the sort of natural therapy route, not necessarily successfully but are more keen to use that as a solution or part solution but I am lazy and hate sort of ferreting around for information.

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Node 17 of 131 (3 8 1 16) /Menopause services and advice/Information-seeking/McKenzie's model/Not comfortable fit

Passage 1 of 2 Section 0, Para 10, 39 chars.

10: I can't recollect it was some time ago,

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Passage 2 of 2 Section 0, Para 20, 650 chars.

20: nly sort of minor milligrams in it. I have terrible problems with my body over heating and this weather at the moment is just horrendous. But I am not alone in that I just don't know whether I've got menopause problems in that connection plus something else, but I'm trying to sort that out with my doctor but it's a difficult thing to actually describe to somebody. You know I don't know how you react to heat and visa versa, trying to get people to appreciate how it is and how it feels so different for you is a very difficult task I've found. But that's the only thing that I can think of at the moment. The skin is altering but nothing much otherwise.

---

Node 18 of 131 (3 8 2) /Menopause services and advice/Information-seeking/Barriers to information seeking  
Passage 1 of 4 Section 0, Paras 19 to 22, 1412 chars.

19: ALISON: Is there anything that's concerning you at the moment about the menopause?

20: LOUISE: Yes body malfunctioning in terms of over heating. There is so much in the way of medication that I would want to take and I got to the point where there was one dosage which seemed ok, the increased dosage I couldn't see any benefit in the increased dosage and I thought well no let's go back. It's only sort of minor milligrams in it. I have terrible problems with my body over heating and this weather at the moment is just horrendous. But I am not alone in that I just don't know whether I've got menopause problems in that connection plus something else, but I'm trying to sort that out with my doctor but it's a difficult thing to actually describe to somebody. You know I don't know how you react to heat and visa versa, trying to get people to appreciate how it is and how it feels so different for you is a very difficult task I've found. But that's the only thing that I can think of at the moment. The skin is altering but nothing much otherwise.

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Passage 2 of 4 Section 0, Paras 23 to 28, 1004 chars.

23: ALISON: Have you tried any of the alternative remedies at all?

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when it comes to trying to sort things out, I like the one stop shop idea, go in, state the problem, get the answer and it doesn't strike me that would be a quick and easy solution, so no I haven't pursued that.

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Passage 3 of 4 Section 0, Paras 29 to 30, 433 chars.

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Passage 4 of 4 Section 0, Paras 38 to 46, 1164 chars.

38: LOUISE: No though it would be nice if somebody could find, it's like hay fever this time of the year once you've got the right medication it's a doddle and I'd like to think the menopause could be the same but we haven't quite got there.

39: ALISON: The trouble is it's like you were saying everybody is so individual aren't they?

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41: ALISON: Well I'm not a medical person myself and the more I read about it the more complicated it becomes.

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43: ALISON: Yes.

44: LOUISE: I suppose we look to find some expert with all the answers but I suppose that's an expectation beyond the pail because as you've found it's quite a complex subject and I suppose it varies from woman to woman, the symptoms and the extent of it, so yes I can imagine you have found it rather complicated, I don't suppose there is any easy one solution to it, we shall see, it won't be long hopefully before I come out the other side.

45: ALISON: I hope so with this very hot weather it must be awful.

46: LOUISE: Absolutely.

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Node 19 of 131 (3 8 4 3) /Menopause services and advice/Information-seeking/Sources of information/Health professionals  
Passage 1 of 2 Section 0, Paras 23 to 28, 1004 chars.

23: ALISON: Have you tried any of the alternative remedies at all?

24: LOUISE: I haven't because I'm not a lazy character but having said that I am lazy when it comes to trying to sort things out, I like the one stop shop idea, go in, state the problem, get the answer and it doesn't strike me that would be a quick and easy solution, so no I haven't pursued that.

25: ALISON: When you say that about yourself does that mean then that you haven't really, have you looked much for information say like in the media or on the internet or anything?

26: LOUISE: No, I've gone to the GP and expected him to come up with the answers.

27: ALISON: And it sounds like you are quite happy with their approach anyway?

28: LOUISE: Yes the way I've been dealt with hitherto and quite relaxed in that respect, although I am aware that friends of mine have actually gone down the sort of natural therapy route, not necessarily successfully but are more keen to use that as a solution or part solution but I am lazy and hate sort of ferreting around for information.

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Passage 2 of 2 Section 0, Paras 29 to 30, 433 chars.

29: ALISON: Would you say that's how you are in general then about things, or is it mainly for health things you wouldn't?

30: LOUISE: It sounds silly but if something really interests me you know I leave no stone unturned but if it doesn't really excite me it just a problem that needs resolution and I suppose because I've found that resolution in part if not wholly via the doctors route than I suppose I'm relaxed about doing anything further.

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Node 20 of 131 (5 1 1 4) /Menopause and what it means to women/Treatments/Alternative therapies/Reasons not to take alt ther  
Passage 1 of 1 Section 0, Paras 23 to 28, 1004 chars.

23: ALISON: Have you tried any of the alternative remedies at all?

24: LOUISE: I haven't because I'm not a lazy character but having said that I am lazy when it comes to trying to sort things out, I like the one stop shop idea, go in, state the problem, get the answer and it doesn't strike me that would be a quick and easy solution, so no I haven't pursued that.

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---

Node 21 of 131 (5 1 2 5) /Menopause and what it means to women/Treatments/HRT/Challenge of getting it right  
Passage 1 of 1 Section 0, Paras 7 to 18, 1270 chars.

7: ALISON: Did you go and see your GP at that point then?  
8: LOUISE: Yes I did.  
9: ALISON: What happened?  
10: LOUISE: They prescribed me some HRT, you know the hormone replacement. I can't recollect it was some time ago, so I was one particular dose that seemed to fit the bill well enough for me. I continued with those and then when I moved to X I began to get similar symptoms arise again even though I was actually taking the medication. That sort of prompted me to go to my new doctor who then referred me to the clinic.  
11: ALISON: When you went to the clinic how did you find that?  
12: LOUISE: Very helpful, very informative and nothings too much trouble for them. I must say when I felt the effects of the initial treatment was wearing off it had taken me quite a few different pills to find the one that suited to me and I wasn't looking forward to going through the whole or a similar rigmarole again but they were concerned that I got the right pills, the right dosage and so on and very good indeed.  
13: ALISON: Was that a while ago then?  
14: LOUISE: Probably about 12-15 months ago.  
15: ALISON: And you've been on the new pills since then?  
16: LOUISE: Yes.  
17: ALISON: Do you have to go back there or is it through your GP?  
18: LOUISE: No I am able to back if I feel there is a need or if I've got any queries at all but so far so good.

---

Node 22 of 131 (5 2 2) /Menopause and what it means to women/Communication-based issues/Support  
Passage 1 of 1 Section 0, Paras 31 to 34, 981 chars.

31: ALISON: You mentioned friends, is it something that you talk to your friends about much?  
32: LOUISE: Yes I think a lot of it from my perspective is trying to gauge how my problems measure up against their experiences, because you know the overheating thing is one aspect of it and I can only attribute, I think there might be more but you know it

suggests the menopause, but I need only pick up a broom to sweep somewhere indoors and 2 strokes if you like of the broom and I am dripping, I'm not hot I'm not damp, I'm dripping, it's horrible I feel so anti-social but if I were to do anything more, or even consider lightly dusting around the house I've got to think right I need a shower.

33: ALISON: Oh how awful.

34: LOUISE: It is, this is why I think, am I peculiar, is there something untoward or is this something everybody puts up with and doesn't moan about, so yes from my perspective I've been asking questions to a certain how big a problem it is, if its unusual or whether its just peculiar to me.

---

Node 23 of 131 (5 2 6) /Menopause and what it means to women/Communication-based issues/Interaction with health professional  
Passage 1 of 2 Section 0, Paras 19 to 22, 1412 chars.

19: ALISON: Is there anything that's concerning you at the moment about the menopause?

20: LOUISE: Yes body malfunctioning in terms of over heating. There is so much in the way of medication that I would want to take and I got to the point where there was one dosage which seemed ok, the increased dosage I couldn't see any benefit in the increased dosage and I thought well no let's go back. It's only sort of minor milligrams in it. I have terrible problems with my body over heating and this weather at the moment is just horrendous. But I am not alone in that I just don't know whether I've got menopause problems in that connection plus something else, but I'm trying to sort that out with my doctor but it's a difficult thing to actually describe to somebody. You know I don't know how you react to heat and visa versa, trying to get people to appreciate how it is and how it feels so different for you is a very difficult task I've found. But that's the only thing that I can think of at the moment. The skin is altering but nothing much otherwise.

21: ALISON: When you go and see your doctor about things like that are you quite happy with the experience of going there, do you find the doctor listens to you properly?

22: LOUISE: Yes I think we've struck lucky with our doctor here he seems to be very well informed and again he's quite prepared to sort of run a battery of tests to try and pinpoint the actual cause, so yes no problems there.

---

Passage 2 of 2 Section 0, Paras 23 to 28, 1004 chars.

23: ALISON: Have you tried any of the alternative remedies at all?

24: LOUISE: I haven't because I'm not a lazy character but having said that I am lazy when it comes to trying to sort things out, I like the one stop shop idea, go in, state the problem, get the answer and it doesn't strike me that would be a quick and easy solution, so no I haven't pursued that.

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27: ALISON: And it sounds like you are quite happy with their approach anyway?  
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Node 24 of 131 (5 3 3) /Menopause and what it means to women/How  
menopause affects women/Women's awareness of the menopause

Passage 1 of 1 Section 0, Paras 4 to 8, 785 chars.

4: LOUISE: Well what started me off wondering if I had problems was feeling dizzy, light headed and I found myself walking from the office to the office car park sort of meandering and that concerned me seeing as I was driving  $\frac{3}{4}$  of an hour each way to work, so when it persisted I thought well something's altered in my life, quite what I don't know and that was when I went to the doctors and it was suggested that the menopause might be the problem.

5: ALISON: Had you had any inkling that it might be the menopause?

6: LOUISE: I'm not very up or terribly interested in the health side of things, which sounds terrible but I think I've been really blessed with excellent health and I've been guilty of taking it rather for granted really.

7: ALISON: Did you go and see your GP at that point then?

8: LOUISE: Yes I did.

---

Node 25 of 131 (5 3 4 1) /Menopause and what it means to women/How  
menopause affects women/Impact of menopause on life/More than just physical  
symptoms

Passage 1 of 1 Section 0, Paras 31 to 34, 981 chars.

31: ALISON: You mentioned friends, is it something that you talk to your friends about much?

32: LOUISE: Yes I think a lot of it from my perspective is trying to gauge how my problems measure up against their experiences, because you know the overheating thing is one aspect of it and I can only attribute, I think there might be more but you know it suggests the menopause, but I need only pick up a broom to sweep somewhere indoors and 2 strokes if you like of the broom and I am dripping, I'm not hot I'm not damp, I'm dripping, it's horrible I feel so anti-social but if I were to do anything more, or even consider lightly dusting around the house I've got to think right I need a shower.

33: ALISON: Oh how awful.

34: LOUISE: It is, this is why I think, am I peculiar, is there something untoward or is this something everybody puts up with and doesn't moan about, so yes from my

perspective I've been asking questions to a certain how big a problem it is, if its unusual or whether its just peculiar to me.

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Node 26 of 131 (5 3 5) /Menopause and what it means to women/How menopause affects women/Menopausal symptoms  
Passage 1 of 2 Section 0, Paras 4 to 8, 785 chars.

4: LOUISE: Well what started me off wondering if I had problems was feeling dizzy, light headed and I found myself walking from the office to the office car park sort of meandering and that concerned me seeing as I was driving  $\frac{3}{4}$  of an hour each way to work, so when it persisted I thought well something's altered in my life, quite what I don't know and that was when I went to the doctors and it was suggested that the menopause might be the problem.

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---

Passage 2 of 2 Section 0, Paras 31 to 34, 981 chars.

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No other nodes in this set  
code this document.

## APPENDIX 18: NODE TREE FROM NVIVO

NVivo revision 1.3.146 Licensee: Alison Yeoman

Project: PhD User: Administrator Date: 13/07/2009 - 12:06:54

### NODE LISTING

Nodes in Set: All Tree Nodes

Created: 28/04/2005 - 10:33:30

Modified: 28/04/2005 - 10:33:30

Number of Nodes: 102

- 1 (1) /GP responses
- 2 (1 1) /GP responses/Referral to CMC
- 3 (1 2) /GP responses/Self-referral
- 4 (1 3) /GP responses/Management of menopause patients
- 5 (1 4) /GP responses/Keeping up-to-date
- 6 (1 5) /GP responses/The informed patient
- 7 (1 6) /GP responses/Views on alternative medicine
- 8 (1 7) /GP responses/Views on services provided by CMC
- 9 (2) /Planning
- 10 (2 1) /Planning/Logistics
- 11 (2 2) /Planning/Questions to consider
- 12 (2 3) /Planning/Theory
- 13 (2 4) /Planning/Methods
- 14 (2 5) /Planning/Reflections on process
- 15 (2 6) /Planning/Ethics
- 16 (3) /Menopause services and advice
- 17 (3 1) /Menopause services and advice/Healthy-living centre
- 18 (3 2) /Menopause services and advice/Community Menopause Clinic
- 19 (3 2 1) /Menopause services and advice/Community Menopause Clinic/Referral and awareness
- 20 (3 2 2) /Menopause services and advice/Community Menopause Clinic/Comments about CMC service
- 21 (3 2 3) /Menopause services and advice/Community Menopause Clinic/Background to CMC
- 22 (3 3) /Menopause services and advice/Background to Wellwomen Information
- 23 (3 4) /Menopause services and advice/Background to Women's Health Concern
- 24 (3 5) /Menopause services and advice/Problems getting access to advice
- 25 (3 6) /Menopause services and advice/Challenges in giving advice
- 26 (3 7) /Menopause services and advice/Professional attitudes to menopause
- 27 (3 8) /Menopause services and advice/Information-seeking
- 28 (3 8 1) /Menopause services and advice/Information-seeking/McKenzie's model

- 29 (3 8 1 1) /Menopause services and advice/Information-seeking/McKenzie's model/Active seeking in connection
- 30 (3 8 1 2) /Menopause services and advice/Information-seeking/McKenzie's model/Active scanning in connection
- 31 (3 8 1 3) /Menopause services and advice/Information-seeking/McKenzie's model/Nondirected monitoring in connection
- 32 (3 8 1 4) /Menopause services and advice/Information-seeking/McKenzie's model/By proxy in connection
- 33 (3 8 1 5) /Menopause services and advice/Information-seeking/McKenzie's model/Connection failures
- 34 (3 8 1 6) /Menopause services and advice/Information-seeking/McKenzie's model/Identification failures
- 35 (3 8 1 7) /Menopause services and advice/Information-seeking/McKenzie's model/Failure to ask questions
- 36 (3 8 1 8) /Menopause services and advice/Information-seeking/McKenzie's model/Disclosure barriers
- 37 (3 8 1 9) /Menopause services and advice/Information-seeking/McKenzie's model/Lack of realization or comprehension
- 38 (3 8 1 10) /Menopause services and advice/Information-seeking/McKenzie's model/Connection failures in communicating
- 39 (3 8 1 11) /Menopause services and advice/Information-seeking/McKenzie's model/Counterstrategies
- 40 (3 8 1 12) /Menopause services and advice/Information-seeking/McKenzie's model/Active seeking in communicating
- 41 (3 8 1 13) /Menopause services and advice/Information-seeking/McKenzie's model/Active scanning in communicating
- 42 (3 8 1 14) /Menopause services and advice/Information-seeking/McKenzie's model/Nondirected monitoring in communicating
- 43 (3 8 1 15) /Menopause services and advice/Information-seeking/McKenzie's model/By proxy in communication
- 44 (3 8 1 16) /Menopause services and advice/Information-seeking/McKenzie's model/Not comfortable fit
- 45 (3 8 2) /Menopause services and advice/Information-seeking/Barriers to information seeking
- 46 (3 8 4) /Menopause services and advice/Information-seeking/Sources of information
- 47 (3 8 4 1) /Menopause services and advice/Information-seeking/Sources of information/Anecdotal
- 48 (3 8 4 2) /Menopause services and advice/Information-seeking/Sources of information/Media
- 49 (3 8 4 3) /Menopause services and advice/Information-seeking/Sources of information/Health professionals
- 50 (3 8 4 4) /Menopause services and advice/Information-seeking/Sources of information/PILs
- 51 (3 8 4 5) /Menopause services and advice/Information-seeking/Sources of information/Other women

- 52 (3 8 4 6) /Menopause services and advice/Information-seeking/Sources of information/Other sources
- 53 (3 8 4 7) /Menopause services and advice/Information-seeking/Sources of information/Library
- 54 (3 8 4 8) /Menopause services and advice/Information-seeking/Sources of information/Books
- 55 (3 8 4 9) /Menopause services and advice/Information-seeking/Sources of information/Internet
- 56 (3 10) /Menopause services and advice/Sources of info for professionals
- 57 (4) /Research issues
- 58 (4 2) /Research issues/Research impacting on participants
- 59 (5) /Menopause and what it means to women
- 60 (5 1) /Menopause and what it means to women/Treatments
- 61 (5 1 1) /Menopause and what it means to women/Treatments/Alternative therapies
- 62 (5 1 1 1) /Menopause and what it means to women/Treatments/Alternative therapies/Examples of trying alt therapy
- 63 (5 1 1 2) /Menopause and what it means to women/Treatments/Alternative therapies/Preference for non-medical approach
- 64 (5 1 1 3) /Menopause and what it means to women/Treatments/Alternative therapies/Reaction of GP
- 65 (5 1 1 4) /Menopause and what it means to women/Treatments/Alternative therapies/Reasons not to take alt ther
- 66 (5 1 1 6) /Menopause and what it means to women/Treatments/Alternative therapies/GP Views on alternative medicine
- 67 (5 1 2) /Menopause and what it means to women/Treatments/HRT
- 68 (5 1 2 1) /Menopause and what it means to women/Treatments/HRT/Practical disadvantages
- 69 (5 1 2 2) /Menopause and what it means to women/Treatments/HRT/Feelings and reasons for stopping
- 70 (5 1 2 3) /Menopause and what it means to women/Treatments/HRT/Concerns about risks
- 71 (5 1 2 4) /Menopause and what it means to women/Treatments/HRT/Acceptance of risks
- 72 (5 1 2 5) /Menopause and what it means to women/Treatments/HRT/Challenge of getting it right
- 73 (5 1 2 6) /Menopause and what it means to women/Treatments/HRT/Professional views
- 74 (5 1 2 7) /Menopause and what it means to women/Treatments/HRT/Positive comments about taking it
- 75 (5 1 2 8) /Menopause and what it means to women/Treatments/HRT/Negative comments about taking it
- 76 (5 1 2 9) /Menopause and what it means to women/Treatments/HRT/Taking it for cosmetic reasons
- 77 (5 1 2 10) /Menopause and what it means to women/Treatments/HRT/Unanswered questions about it

- 78 (5 2) /Menopause and what it means to women/Communication-based issues
- 79 (5 2 1) /Menopause and what it means to women/Communication-based issues/Need for one-to-one
- 80 (5 2 2) /Menopause and what it means to women/Communication-based issues/Support
- 81 (5 2 3) /Menopause and what it means to women/Communication-based issues/Taboo subject
- 82 (5 2 4) /Menopause and what it means to women/Communication-based issues/Women networking
- 83 (5 2 5) /Menopause and what it means to women/Communication-based issues/Shared decision making
- 84 (5 2 6) /Menopause and what it means to women/Communication-based issues/Interaction with health professional
- 85 (5 3) /Menopause and what it means to women/How menopause affects women
- 86 (5 3 1) /Menopause and what it means to women/How menopause affects women/Bone density
- 87 (5 3 2) /Menopause and what it means to women/How menopause affects women/Negative image of menopause
- 88 (5 3 3) /Menopause and what it means to women/How menopause affects women/Women's awareness of the menopause
- 89 (5 3 4) /Menopause and what it means to women/How menopause affects women/Impact of menopause on life
- 90 (5 3 4 1) /Menopause and what it means to women/How menopause affects women/Impact of menopause on life/More than just physical symptoms
- 91 (5 3 4 2) /Menopause and what it means to women/How menopause affects women/Impact of menopause on life/Gender issues
- 92 (5 3 4 3) /Menopause and what it means to women/How menopause affects women/Impact of menopause on life/Just a fact of life
- 93 (5 3 4 4) /Menopause and what it means to women/How menopause affects women/Impact of menopause on life/Positive attitude
- 94 (5 3 4 5) /Menopause and what it means to women/How menopause affects women/Impact of menopause on life/Hysterectomy and early menopause
- 95 (5 3 5) /Menopause and what it means to women/How menopause affects women/Menopausal symptoms
- 96 (5 4) /Menopause and what it means to women/History of menopause
- 97 (5 5) /Menopause and what it means to women/Menopause as recent phenomenon
- 98 (5 6) /Menopause and what it means to women/Views on what is needed
- 99 (6) /Search Results
- 100 (6 1) /Search Results/Single Text Lookup
- 101 (6 2) /Search Results/Single Text Lookup 2
- 102 (6 3) /Search Results/Single Text Lookup 3

**APPENDIX 19: INFORMED-CONSENT FORM**

**FINDING ADVICE ABOUT THE MENOPAUSE**

**Informed consent form (version 2 26/2/04)**

As a participant in this study I have read the Participant Information Sheet and have been given the opportunity to ask questions about the research. I have had more than 24 hours to consider participating in this study.

I understand that I am taking part in the study on a voluntary basis and that I am free to withdraw at any time, without giving any reason and without my medical care, legal rights and/or my relationship with the [community menopause clinic] being affected.

I understand that my interview will be recorded (either using a tape recorder or by note-taking) and accept that the results of the study will be used to produce a PhD thesis and may subsequently be used for further academic research including possible publications.

I understand that data relating to me will be anonymised through the use of pseudonyms (pretend names) and that all data including interview recordings will be stored securely.

I would like to receive a printout of the interview to check [  ]

**Interviewee Informed Consent Signature:**

**I agree that the data I have provided may be used, on the conditions explained to me, as outlined above.**

<p><b>Name (please print)</b></p> <p><b>Signature</b></p>	
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## **APPENDIX 20: LETTER AND FORM GIVING PARTICIPANTS THE OPPORTUNITY TO REVIEW THEIR TRANSCRIBED INTERVIEW**

Dear

### **FINDING ADVICE ABOUT THE MENOPAUSE**

Thank you for returning your Informed Consent form. I note that you requested the opportunity to read through your interview and I am therefore enclosing a copy of the transcript. Please note that I am using a number for your interview rather than your name and that you are identified only as INT (i.e. Interviewee) in the transcript. I will be very careful to make sure that you cannot be identified as a participant in the study.

Please read through the interview and have a think about whether you are happy for it to be used in the study (there will be a report to the [clinic], my PhD thesis and potentially papers in academic journals). When you have decided, please indicate your preference on the enclosed form and return it to me in the envelope provided by 17 October.

You will see that there are several choices on the form:

If you are happy for me to use the interview as it stands and to use some quotes from the interview please tick the first box.

Please tick the second box if you are happy for me to use the interview for my analysis but would prefer me to avoid using any quotes lifted directly from your text. I would like to reassure you that I would only ever use very short quotes (three or four lines at the most) and would not quote heavily from any one interview. As a researcher I need to demonstrate how I have used the interviews to form my conclusions, and quotes are a powerful way of showing this. They also give the interviewee a voice to speak directly to the people reading the report. However, I certainly do appreciate that you may prefer not to be quoted at all.

If you are happy for me to use just parts of the interview please tick the third box, cross out any sections you are not happy about on the copy and return it to me with the form.

Finally, you are of course entitled to withdraw your interview from the study altogether. This would not in any way impact on the care you receive – the [clinic] does not know which participants were selected for interview.

I hope you will feel able to continue with the study but I will respect any reservations you have about the use of your interview. If you have any queries about the analysis process please do not hesitate to contact me.

With best wishes,  
Yours sincerely,



## FINDING ADVICE ABOUT THE MENOPAUSE

### INTERVIEW NUMBER:

Please take your time to read through the enclosed transcript of your interview.

When you have had time to reflect on the interview, please tick one of the following boxes:

- I am happy for the researcher to refer to my interview in her analysis and to use short quotes from the interview if necessary.
- I am happy for the researcher to use my interview for her analysis but would prefer not to be quoted directly.
- I am happy for the researcher to use part of my interview for her analysis and to use short quotes but **NOT** the areas I have deleted on the transcript. (Please cross out any sections on the transcript that you do not feel happy about and return the transcript to me with this form).
- I wish to have my interview withdrawn from the study entirely.

Please then return this form to me in the envelope supplied by 17 October.

**APPENDIX 21: LETTER ACCOMPANYING COPY OF EXECUTIVE REPORT  
OF COMMUNITY MENOPAUSE CLINIC EVALUATION**

Dear

I would like to take this opportunity to thank you once again for helping with my research 'Finding Information about the Menopause' last year. I have completed my report for the [Community Menopause Clinic] and am currently incorporating the results into my PhD thesis.

I am enclosing a copy of the executive summary from the [Clinic] report in case you are interested in the results.

With all best wishes,

Yours sincerely,

**APPENDIX 22: SUMMARY PROFILES OF INTERVIEWEES**

<b>NAME</b>	<b>NATURAL MENOPAUSE/ HYSTERECTOMY</b>	<b>HRT-STATUS AT TIME OF INTERVIEW</b>	<b>RESEARCH NOTES</b>
Angela	Natural menopause but has been taking HRT since her 40s to combat depression so unsure when menopause occurred.	Had stopped taking HRT	Community menopause clinic interviewee (by telephone)
Ann	Hysterectomy	Had stopped taking HRT	Care home interviewee (face-to-face interview)
Barbara	Hysterectomy	Looking to stop/reduce her dose of HRT	Care home interviewee (face-to-face interview)
Belinda	Natural menopause	Taking progesterone as cannot take oestrogen	Community menopause clinic interviewee (by telephone)
Charlotte	Hysterectomy	Had reduced her dosage of HRT	Community menopause clinic interviewee (by telephone)
Deborah	Experienced an early natural menopause*	Taking HRT and would prefer to continue with it until nearer age 50	Community menopause clinic interviewee (by telephone)
Denise	Natural menopause	Not taking HRT	Care home interviewee (face-to-face interview)

<b>NAME</b>	<b>NATURAL MENOPAUSE/ HYSTERECTOMY</b>	<b>HRT-STATUS AT TIME OF INTERVIEW</b>	<b>RESEARCH NOTES</b>
Eileen	Experienced an early natural menopause	Taking HRT but wanting advice to ensure she didn't take it for too long	Community menopause clinic interviewee (by telephone)
Eleanor	Natural menopause	Not taking HRT	Community menopause clinic interviewee (by telephone)
Emma	Natural menopause	Not taking HRT	Care home interviewee (face-to-face interview)
Erica	Hysterectomy	Had stopped taking HRT	Community menopause clinic interviewee (by telephone)
Eve	Natural menopause	Had stopped taking HRT	Care home interviewee (face-to-face interview)
Fiona	Experienced an early natural menopause	Had stopped taking HRT	Community menopause clinic interviewee (by telephone)
Frances	Natural menopause	Had stopped taking HRT	Care home interviewee (face-to-face interview)
Grace	Natural menopause	Had stopped taking HRT	Community menopause clinic interviewee (by telephone)

<b>NAME</b>	<b>NATURAL MENOPAUSE/ HYSTERECTOMY</b>	<b>HRT-STATUS AT TIME OF INTERVIEW</b>	<b>RESEARCH NOTES</b>
Gwen	Natural menopause	Had stopped taking HRT	Care home interviewee (face-to-face interview)
Hannah	Natural menopause	Had stopped taking HRT	Community menopause clinic interviewee (by telephone)
Helen	Experienced an early natural menopause	Taking HRT	Community menopause clinic interviewee (by telephone)
Imogen	Natural menopause	Taking HRT	Community menopause clinic interviewee (by telephone)
Isobel	Natural menopause	Had stopped taking HRT	Community menopause clinic interviewee (by telephone)
Jane	Experienced an early natural menopause	Taking HRT and looking to increase the dosage	Community menopause clinic interviewee (by telephone)
Janice	Natural menopause	Taking HRT but had started to wean herself off	Community menopause clinic interviewee (by telephone)

<b>NAME</b>	<b>NATURAL MENOPAUSE/ HYSTERECTOMY</b>	<b>HRT-STATUS AT TIME OF INTERVIEW</b>	<b>RESEARCH NOTES</b>
Kate	Hysterectomy	Taking HRT	Community menopause clinic interviewee (by telephone)
Kathleen	Natural menopause	Taking HRT	Community menopause clinic interviewee (by telephone)
Linda	Hysterectomy	Taking HRT	Community menopause clinic interviewee (by telephone) but did not return informed consent form despite verbal agreement to take part at time of interview so no quotes are included from this interview
Louise	Natural menopause	Taking HRT	Community menopause clinic interviewee (by telephone)
Marion	Hysterectomy	Taking HRT	Community menopause clinic interviewee (by telephone)

<b>NAME</b>	<b>NATURAL MENOPAUSE/ HYSTERECTOMY</b>	<b>HRT-STATUS AT TIME OF INTERVIEW</b>	<b>RESEARCH NOTES</b>
Maureen	Natural menopause	Taking HRT	Community menopause clinic patient, responded by post
Nicola	Hysterectomy	Taking HRT	Community menopause clinic interviewee (by telephone but tape recorder malfunctioning so notes taken)
Olivia	Natural menopause	Not taking HRT	Participant from geographical area local to community menopause clinic but who had not attended the clinic (interview by telephone)
Rowena	Experienced an early natural menopause	Taking HRT	Community menopause clinic interviewee (by telephone)
Sally	Natural menopause	Not taking HRT	Community menopause clinic interviewee (by telephone)

<b>NAME</b>	<b>NATURAL MENOPAUSE/ HYSTERECTOMY</b>	<b>HRT-STATUS AT TIME OF INTERVIEW</b>	<b>RESEARCH NOTES</b>
Sylvia	Natural menopause	Not taking HRT	Participant contacted me having seen information about the project on the Internet (interview by telephone)
Tracy	Natural menopause	Had stopped taking HRT	Community menopause clinic interviewee (by telephone)
Vicky	Hysterectomy	Had stopped taking HRT	Community menopause clinic interviewee (by telephone)
Viv	Natural menopause	Had stopped taking HRT was using a 'natural progesterone cream'	Community menopause clinic interviewee (by telephone)

\*Early (premature) menopause should be defined ideally as menopause that occurs at an age less than two standard deviations below the mean estimated for the reference population. The age of 40 years is frequently used as an arbitrary limit, but many gynaecologists take <45 years (British Menopause Society, 2008). I have used the term 'early menopause' for participants who began their menopause transition under the age of 45 years since these interviewees considered their menopause to have started earlier than anticipated.



**APPENDIX 23: CATEGORIES OF INFORMATION PRACTICE FROM MCKENZIE'S MODEL WITH SUPPORTING EXAMPLES**

	<b>CONNECTING WITH SOURCES</b>	<b>INTERACTING WITH SOURCES</b>
<b>Active seeking</b>	<ul style="list-style-type: none"> <li>• Systematic know-item search</li> <li>• Seeking out known source               <ul style="list-style-type: none"> <li>• Asking pre-planned question</li> </ul> </li> <li>• Planning question strategy</li> </ul> <p>e.g. calling doctor between appointments; shopping for specific books; calling a friend for advice; contacting local community information service; contacting magazine support group</p>	<ul style="list-style-type: none"> <li>• Asking a pre-planned question</li> <li>• Active strategies such as: list-making/questioning techniques/counterstrategies to barriers</li> </ul> <p>(e.g. asking questions in consultation: finding ways of remembering things to ask; calling the doctor if an expected phone call didn't happen; using different sources to try and locate the same information)</p>
<b>Active scanning</b>	<ul style="list-style-type: none"> <li>• Semi-directed browsing in likely locations</li> <li>• Systematic observation of behaviour</li> <li>• Identifying opportunities to ask spontaneous questions               <ul style="list-style-type: none"> <li>• Active listening to conversations in likely locations</li> </ul> </li> </ul> <p>(e.g. keeping feelers out; browsing in likely information grounds; scanning bookshops or</p>	<ul style="list-style-type: none"> <li>• Identifying an opportunity to ask a question during an encounter               <ul style="list-style-type: none"> <li>• Actively observing people or behaviour or listening to conversations in likely locations</li> </ul> </li> </ul> <p>(e.g. during routine medical encounters; scanning print materials; observation and listening e.g. at multiple birth association meeting; opportunistic questioning; looking at other mothers to see whether they had managed to slim down following birth)</p>

	libraries; general Internet searches; watching a television programme about pregnancy that referred to twins)	
<b>Non-directed monitoring</b>	<ul style="list-style-type: none"> <li>• Serendipitously encountering a source</li> <li>• Accidentally overhearing a conversation <ul style="list-style-type: none"> <li>• Unexpected encounters with friends etc.</li> </ul> </li> <li>• Regular activities to stay informed without actively seeking twin pregnancy information</li> <li>• Often facilitated by high visibility of infant twins or by pregnancy</li> </ul> <p>(e.g. recognizing a source such as seeing a father with a pushchaire or finding a book sale; reading the newspaper)</p>	<ul style="list-style-type: none"> <li>• Observing behaviour or physical characteristics in unexpected settings <ul style="list-style-type: none"> <li>• Overhearing conversations</li> <li>• Chatting with acquaintances</li> </ul> </li> </ul> <p>(e.g. seeing/hearing things ‘out of the blue’; watching a father with a pushchair)</p>
<b>By proxy</b>	<ul style="list-style-type: none"> <li>• Making contact through the initiative of another agent <ul style="list-style-type: none"> <li>• Being identified as a potential information seeker by a potential source</li> <li>• Being referred to information sources by other people (lay and professional)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Being told</li> </ul> <p>(e.g. through stories of their own or others’ experiences; diagnostic information from health professionals; other people’s advice or opinions; offering of unsolicited advice)</p>

	<ul style="list-style-type: none"> <li>• Making connections through intermediaries/gatekeepers</li> </ul> <p>(e.g. being identified as an information seeker; having someone in the family who looked out for information on their behalf)</p>	
<b>Potential barriers</b>	<ul style="list-style-type: none"> <li>• Barriers identifying potential sources (e.g. lack of relevant information)</li> <li>• Uncertainty of appropriateness</li> <li>• Difficulty actually making connections (e.g. getting hold of a support group)</li> </ul>	<ul style="list-style-type: none"> <li>• Failure to ask questions <ul style="list-style-type: none"> <li>• Disclosure barriers</li> <li>• Lack of realization or comprehension</li> </ul> </li> <li>• Connection failures during communication (e.g. doctor leaves room)</li> </ul>
<b>Counter-strategies</b>		<ul style="list-style-type: none"> <li>• Persistence</li> <li>• Devising questioning strategies</li> <li>• Monitoring sources to keep process on track</li> </ul>

**APPENDIX 24: PAPER SUBMITTED TO THE *JOURNAL OF DOCUMENTATION***

Information behaviour of women: theoretical perspectives on gender

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## **Abstract**

**Purpose** – The aim is to examine whether there is a need to consider gender or sex differences as variables in information behaviour research, and if so how?

**Design/methodology/approach** – A metasynthesis approach is used. A preliminary framework to categorise information behaviour research on women is developed by integrating main themes from feminist research and information behaviour research. Within each category, studies are compared and contrasted, to identify similar and divergent themes. Themes are then compared across categories, to synthesise the main concepts.

**Findings** – The categorisation works for most studies, apart from a group of studies on health information use, communicating risk and decision making. The meta-synthesis indicates the importance of concepts such as situation (as mesh), intermediaries (as node with connections), and connecting behaviour. Gender-related, or rather, gender-ascribed constructs, such as concern for others, not gender alone are likely to be important variables in information behaviour.

**Practical implications** – The synthesis illuminates a different perspective on information behaviour, the network of information users rather than the individual information seeker.

**Limitations** – The meta-synthesis is a top-level synthesis, as the number of studies prohibited a more detailed approach. Further meta-synthesis of a few high quality research studies would help to confirm the findings.

**Originality/value** – This synthesis integrates some feminist research themes with information behaviour research, and the findings have implications for general information behaviour research.

# Information behaviour of women: theoretical perspectives on gender

## ***Introduction***

The aim is to examine whether there is a need to consider gender or sex differences as variables in information behaviour research, and if so, how. In many studies of the seeking and use of information by different groups, gender (sex) may be recorded as a demographic variable, but with no further examination of different behaviour that may be associated with women rather than men. This is, as Hupfer & Detlor (2006) point out, puzzling, as many studies have indicated sex differences in spatial orientation, attitude towards computers, and verbal skills – all factors that might influence information seeking preferences on the Internet and use of electronic information services. In other research, by virtue of the group chosen (e.g. battered women, lesbians, or the role of specialised libraries for women), there is more emphasis on gender issues in the sense of behaviour and attitudes associated with women, and characteristic of women. Women are often designated to be the primary providers of childcare and frequently have responsibility for managing the home and household. The situations they face on a day-to-day basis and the quality of their interactions with sources of information, both informal (e.g. peers) and formal (e.g. health and social care professionals) may therefore differ from those commonly faced by men. Feminist methodologies, which presume a distinctive approach to inquiry and methods, may have influenced the research approach in these studies. This paper first examines how current themes and trends in feminist research and information behaviour research may relate to each other. A preliminary framework to categorise information behaviour research, is then developed. The value of such a framework is debated by applying it to information behaviour research studies that have included women or studied sex or gender differences. Within each category the main debates are identified and some emergent ideas noted. Discussion of these themes across the categories leads to conclusions about the ways a feminist perspective has helped to uncover some neglected aspects in information behaviour research and how gender, or gender-related factors should be considered.

## ***Developing a preliminary framework***

Case (2007) suggests, in a review of information behaviour research, based partly on an earlier critique by Dervin, that current trends reflect a realisation that human information behaviour is more complex and interpersonal than previously assumed for research purposes. Context is important, information seeking is a dynamic process, and more information is not necessarily better. Information seeking is not necessarily problem solving, and information behaviour on the Web and social networking sites may be less to do with making sense of a situation than diversion and entertainment – and everyday life information seeking becomes a more dominant theme in information behaviour research. The themes in current information behaviour research appear, according to Case (2007) to include contextual factors, interpersonal information seeking (informal sources), everyday life information seeking and the dynamic process of information seeking. Context may be studied quantitatively, including demographic factors, or

qualitatively (Case, 2007) but it is important to distinguish two different perspectives. Context, may be viewed as context 'has' certain influencing variables, or context may be viewed as the result of interactions – context 'is', just as the debate about organisational culture contrasts the culture 'has' proponents from the culture 'is' proponents (Huczynski & Buchanan, 2001, p.638)

Hammersley (1995, p.45-65) identifies four themes in feminist methodology. The first is the gender asymmetry in power relations and the assumption of the more powerful group (men) as the more representative of human experience. The second is the importance of personal experience as opposed to scientific method, contrasting the female way of knowing with the masculine knowledge of scientific experiment. The third theme rejects the hierarchy in the researcher and research subject relationship. The fourth theme is the goal of the research as emancipation. Ten years on, these themes are still apparent. Evaluating the titles of the 20 most recent items in a search on the Web of Science in March 2008, using the string (feminist AND social AND method\*) suggested that the same four themes could broadly be used to categorise the current concerns of feminist methodology in social science, and that no particular theme dominated, with some research reflecting more than one theme. Dorothy Smith (2003, originally published in 1987) refers to 'women's standpoints' and the difficulty of remaking relations when the discourse of politics and culture has been developed almost exclusively by men. From this perspective, the first of Hammersley's themes is part of the problem, the second and third themes represent the dialogue about appropriate perspectives, standpoints, questions to ask in social science about how to examine women's experience. Haraway (2003, originally published in 1988) rejects a simple positioning and stresses the importance of 'webbed accounts', being critical and contested. Olesen (2008) critiques current feminist research trends and suggests the dominant theme is the question of knowledge(s) – whose knowledge, where is the knowledge obtained, by whom and from whom and for what purpose. She contends that the current situation is complex, with debates between standpoint theorists, post-modern and deconstructive theorists querying some of the previous assumptions of the feminist researcher. Hammersley's fourth theme, of emancipation, is still deemed relevant for social justice.

The themes that emerge from the feminist research, updating Hammersley's framework, are: 1) gender asymmetry, power relations (and assumed gender differences as well as similarities); 2) way of knowing, the knowledge(s) (Olesen, 2008); 3) the rejection of the hierarchy in the researcher-subject relationship, and questioning of assumptions; and 4) the goal of research as emancipation, and social justice.

The next step in developing a preliminary framework considers how the feminist research themes relate to information behaviour research trends. Sex differences in aptitudes and attitudes may have been invisible in much information behaviour research, and a better understanding of the range might emerge if such differences are considered explicitly. One part of the framework has to consider sex/gender differences, how and why these have been studied, and how socially ascribed gender-related constructs are treated. The caveat is the interpretation of statistically significant differences, if such differences are shown.

The second feminist theme, the importance of personal experience in feminist methodology, and the importance of methodology seem to relate to some of the approaches advocated for qualitative research on information behaviour. If context is

important in information behaviour research, feminist understandings of the person-in-situation, and situation-with-person may contribute to a better understanding of the dynamic process of information seeking. How have some of the concerns of feminism been reflected in information behaviour research, and new approaches in methodology? The third theme, the rejection of the hierarchy in the relationship between the researcher and the subject, has, to some extent, been reflected in the greater emphasis placed on research ethics now. The informed consent process for research trials (as advocated by the National Research Ethics Service in the UK) emphasises the importance of clear explanations to the research subject of what is involved in the research, what the benefits and risks are, and how the research subjects can learn more about the research. Hammersley (1995, p.59) argues that the emphasis on egalitarian and authentic approaches to the practice of research can become diverted from the consideration of the research situation and what could and should be done, in any particular investigation. The informed consent process is a process, and the guidelines only act to ensure that researchers and research subjects act fairly towards each other. Fairness is probably the best criterion to use for the third theme, rather than rejection of the hierarchy in the relationship. A better understanding of the power relations, and why some information seeking situations have been deemed worthy of research, and others not, should also be relevant to information behaviour research.

The last of the four feminist themes, is that of emancipation or empowerment, or social justice. Kuhlthau (1993) earlier focused attention on the importance of emotional aspects in information seeking and the recognition that information seeking may incur anxiety, and the emotional aspects of information seeking are explored in Nahl and Bilal (2007) Disentangling assumptions around uncertainty, anxiety and positive or negative affect in information seeking is difficult. We have moved away from viewing the user as an empty bucket (Dervin & Nilan, 1986) into which information is placed, and magically, the information decreases their uncertainty about decision making. On the other hand, what is the value of the information professional if provision of authoritative information not a key part of their role – perhaps it is the professionals who suffer uncertainty and anxiety? Professional concerns about end user searching may carry with them a tinge of anxiety on the part of the information professional that the users may be as successful as the information professional in searching for, and using information! A comparison of university web-based tutorials for information literacy illustrates that different assumptions of information seeking by information professionals are revealed (Sundin, 2008) – the knowledge of information sources, information searching as technique or process, or communication practice. Information behaviour encompasses use of information as well as seeking, and ‘information uses’, and purposes for social action should be another part of the framework. Shifting the emphasis to information uses removes the problem of dealing with anxiety reduction and some of the professional stereotypes involved.

The preliminary framework for appraising research on information behaviour and gender therefore comprises:

- Gender differences (how and why are gender differences in aptitudes, and attitudes examined?)



- Methodological variations (which studies have set out to use different techniques in studying women, which have not? Are some methodologies more appropriate for particular groups of women and if so, why?)
- Fairness (how is the context of information seeking of women considered, and how are power relations examined?)
- Emancipation (how is learning, or seeking meaning and purpose by women in information seeking considered?)

## **Methods**

The literature on information behaviour of women was retrieved from the following databases (LISA, LISTA, Web of Science, and Medline(PubMed)), for the publication years 1995-2007, and early 2008. The search terms used for the LISA and LISTA search were (women OR gender) combined with (information seeking OR information behavior/behaviour OR user behavior/behaviour). For the Medline search the search terms used were (Women OR Women's Health Services) AND (looking OR seeking OR information needs OR support needs OR decision making) (textwords) AND (Information services OR Consumer health information OR Health knowledge, attitudes, practice OR Computer Literacy OR Internet). The titles and abstracts retrieved were screened and items dealing with school-age girls were excluded. The search was limited by quality criteria (e.g. peer-reviewed journal articles (LISTA, LISA), items with abstracts (PubMed)). As the literature review was contributing to PhD research on an aspect of health information seeking, the articles concerned with health information seeking were grouped together for separate analysis. Much of the research in the health journals focused on reasons for seeking or not seeking treatment, and information services and support may have contributed to decision making but the extent of that support was not always explicit or a main topic of the research. For the review in this paper, only the main review articles for most health topics have been identified, e.g. on reasons why women delay in seeking treatment for heart problems. Coverage of the general range of research approaches in the health sciences literature has been limited to the topic area for the PhD research, perimenopausal care, and the health care of older women. There is a literature on gender differences in Internet use, which merges into the information seeking and information behaviour literature. We excluded research that was concerned mainly with attitudes towards computers and the Internet. Other approaches included consultation of large reviews, e.g. Case (2007) to help identify other studies on information seeking that may have used gender as a variable, or studies that had used models that included gender explicitly or implicitly as gender-related social issues in everyday life information seeking. Some other studies were identified from references at the end of articles, and later 2008, and 2009 studies discovered in the process of updating, have been included if the research significantly contributed to the discussion themes.

The preliminary framework was used to categorise the papers, and the studies that did not appear to fit into one or more of the four categories set aside for later consideration. The main and emergent themes from each group were then compared, together with any

themes emerging from the studies that could not be categorised neatly into one of the existing categories. This was a two stage compare and contrast exercise, first within each group of the framework, to identify common themes and the queries, and second, to consider those common themes and queries across the framework groups.

## ***Results for framework themes***

### **Gender differences**

Studies that have specifically included sex as a variable in information behaviour include some large scale studies such as the study by Lorence and Park (2007) of online health information seeking behaviour, cancer information seeking in the USA (Rutten, Squiers, & Hesse, 2006), both of which show that women are more active seekers of health information than men. Hupfer & Detlor (2006) explain such differences, for Web information seeking, in terms of gender-related self concept traits (self-orientation and other-orientation) – although sex may be a predictor, a better predictor could be gender related behaviour, or rather, culturally ascribed behaviour more usually associated with women – concern for others. There are gender differences in the type of health condition for which information might be required, and the pattern of situations for information seeking as well (Marton, 2003). Pálsdóttir (2003) found differences in health information seeking in Iceland between men and women, and a cluster analysis (Pálsdóttir, 2006) found that women predominated in the moderately active and active information seeking clusters. In contrast, a meta-analysis of factors affecting information needs among cancer patients concluded that gender made no difference (Ankem, 2006), and in a cohort of neurology outpatients, age was a more important factor than gender (Larner, 2006). Krizek et al. (1999) note gender differences in cancer support group participation but emphasise that the majority of both sexes do not participate in such groups. Steinerová & Šušol (2007) examined the information behaviour of users of 16 academic and research libraries in Slovakia. They were able to differentiate the less frequent analytic information processing (associated more with men) from the most common ‘S’ profile of collaborative and pragmatic style of information use which was slightly (but not significantly) more common among women, and a mixed approach of both (nearly a third of both women and men exhibited this behaviour). Women were more likely to declare they were less experienced in electronic information use, reflecting earlier findings of Internet use being associated with male undergraduates (social sciences) (He & Jacobson, 1996). Similarly, Huang (1999) noted that values attached to information resources may vary by gender. Weiser (2000), in a study of several hundred introductory psychology students, and more experienced Internet users (voluntary sample obtained online), found gender differences in type of Internet usage and preferences for particular applications – women using the Internet more for interpersonal communication and men using the Internet for games and leisure, but age and experience of Internet use were important factors, and some gender differences among the college students were far less apparent among the online sample. Smith and Whitlark (2001) segmented several thousand online users into different groups by gender (e.g. social Sally, Master producer among the female segments, and Viking gamer, and World citizen among the male segments). A longitudinal study of the use of electronic information services by students in the UK found no major differences in habitual information seeking routines between

male and female students, but female students were significantly more likely than male students to state that they had taken advice or had used training materials. (Urquhart et al. 2004). Rowlands and Nicholas (2008) found in a survey of faculty and student use of e-books (n=1819 responses) that gender, together with subject discipline and status (young researcher, undergraduate, or senior faculty) was a predictor. Their clusters included the independent female researcher (often medical or life sciences), and the 'conventional male undergraduate' (any discipline).

Other studies that include sex as a variable in information seeking include several on work or professional roles: Van Zijl & Gericke (2001) on South African visual artists, Hoff (2004) on use of ICT by members of parliament; Wilkinson (2001) on lawyers' use of information sources for problem solving (no gender differences found in the latter two studies). Cullen (1997), found that female general practitioners were less likely to consult specialists than their male counterparts. Rahman and Binwal (2000) examined the effect of several variables, including gender, on information seeking of scientists and technologists in Bangladesh (socio-economic variables influenced library use). Knight et al. (2005) found that age and gender did not impact on computer use in the workplace, unlike some earlier studies, but anxiety, as a moderating construct, did affect computer usage. Gender had no significant effect on online privacy concerns (Yao, Rice & Wallis, 2007).

Other studies examine library and everyday information seeking. Julien & Michels (2001) examined source selection differences in everyday information seeking, Yi (2007) considered gender differences in international students' perceptions, and Wu (2005) studied elicitation behaviour (although gender differences are not discussed in detail). Radford (1998) found that users indicated gender affected their choice of one librarian over another in a decision to ask a librarian for assistance in an academic library. Nicholas, Huntington & Williams (2001) considered gender as a variable in examining use of touchscreen kiosks. In an examination of gender differences in Internet searching, Heimrath and Goulding (2001) in a study of students and public library users, found that women were slower in taking up the Internet although interest was high. Some of the differences in patterns of usage could be related to gender-related differences in attitudes to work, leisure and family time.

Attitudes may be affected by the ability to use the presented interface effectively and efficiently. Cutmore et al. (2000) confirmed previous research in finding that males made use of landmarks in virtual environments more efficiently than females, but that those with lower visual-spatial ability (mostly females) could compensate if other clues were available. Sproull et al. (1996) notes that women and men react differently to different types of personalised 'human' interfaces, and Liu and Huang (2008) found gender differences in preferences for types of online reading and electronic document handling. Research in neuroscience (Hoag, 2008) confirms that male and female brains differ in the size of structures within them and how brain regions are used. Researchers suggest that some of the male and female differences in pain perception and prevalence of mental health conditions are linked to the ways in which some of their brain circuits operate. Where does this leave us on gender differences in information behaviour? A very simple count of the trends in either direction for information seeking behaviour shows that: Differences evident: Two large scale US studies on health (Lorence & Park (2007), Rutten, Squiers, & Hesse, (2006)) plus Cullen,(1997), He & Jacobson (1996), Heimrath

& Goulding (2001), Pálsdóttir (2006), Radford (1998), Rowland & Nicholas (2008), Smith & Whitlark (2001) Steinerová & Šušol (2007), Urquhart et al. (2004), Weiser (2000).

No differences evident: Ankem (2006) (meta-analysis), plus Hoff (2004), Knight et al. (2005), Lerner (2006), Wilkinson (2001), Yao, Rice & Wallis (2007).

Human-computer interface differences possible: Cutmore et al. (2000), Hoag (2008), Liu & Huang (2008), Sproull et al. (1996)

Gender-related or culturally ascribed differences noted: Heimrath and Goulding (2001), Huang (1999), Hupfer & Detlor (2006), Marton (2003).

The tentative conclusion seems to be that there seem to be differences between men and women in health information seeking behaviour, and that gender may be a moderating influence on attitudes towards technology (Ilie et al. 2005), and information seeking. The differences are not substantial, and often only evident with larger samples. Anxiety, risk avoidance, confidence, and self-efficacy may be moderated by gender, but the information seeking situation perhaps needs greater consideration, as the health information studies suggest – the type of settings in which women are more likely to find themselves may be as great an influence on observed behaviour as the differences that can be ascribed to differences in brain structure. For example, women are known to be more frequent users of primary healthcare facilities than men. This may be partly due to differences in willingness to consult a primary care practitioner, but the main reasons appear to be women's responsibility for childrearing and contraception, and the medicalization of domains that exclusively affect women such as pregnancy and the menopause. In fact, it is not until above the age of 65 that the numbers of men and women attending primary care practices evens out (Morris et al., 2004; Welsh Assembly Government, 2007). Feminists have long argued that women have been particularly disadvantaged by the traditional Western approach to medicine which they view as a patriarchal establishment that perceives women as being at the mercy of their bodies which would rule them in irrational and uncontrollable ways without the intervention of controlling (male) physicians (Oakley, 2007, Leng, 1997, Greer, 2000). Given the power dynamics in play during any patient–doctor encounter and the potential for the patient (or their advocate if the patient is a child) to be experiencing a whole range of emotions during the encounter (including possibly anxiety, uncertainty, embarrassment etc.), it is not surprising that context can impact on behaviour.

### **Methodological variations**

Qualitative research on information behaviour of women has used a wide variety of approaches, and women's perceptions of a problem have sometimes influenced their decisions to use qualitative research to explore gender differences (e.g. Malterud (1998) on women's experience of pain). Reconciling, debating and integrating research findings across human computer interaction studies, library and information science and communication research is hampered by the very different approaches and priorities favoured in the three disciplines (Dervin, Reinhard, & Shen, 2006). Human-computer interaction studies tend to be quantitative, information behaviour research uses mixed approaches. Dervin suggests that research should be seen as a four dimensional space of 1) philosophic examination of assumptions; 2) substantive theorizing about the real; 3) methodological consideration of the means of step-taking both in the realm of the abstract

(theorizing) and the realm of the concrete (e.g. observing, analysing) and 4) competent and systematic execution of method –and uncertainty occupies the space between. (Dervin, Reinhard & Shen, 2006). Williamson (2006) discusses social constructivist approaches, stressing the importance of understanding the individual sense making, and the shared meanings – the dissonance and the consensus, using multiple methods and reflecting back to the literature as well. In this approach, similar concerns to Dervin about step-taking, method and reflection on method and findings occur. For a study of breast cancer information needs and seeking, for example, the different voices and opinions of women were fully explored to identify consensus and differences. Some of the information behaviour research on groups of women has used a philosophical approach influenced by feminist methods. Dunne (2002) developed the ‘person-in-situation’ model to a ‘person in progressive situations’ model to explain changes in information behaviour in the lives of women experiencing abuse, as the abuse progressed. Similarly, Currie and Wiesenberg (2003) suggest that more emphasis is placed on sociocultural context, rather than purely psychological and personal factors, in research on women’s need for, and use of healthcare information. Carey, McKechnie & McKenzie (2001) emphasise, like Dervin, the importance of intertwining method and theory, questioning assumptions, as in the cases considered, careful reflection on the process of gaining access to the participants led to insights about the social practices, and the information grounds of the groups studied. The model of information practices (McKenzie, 2003) was based on an analysis of the way that participants (pregnant women expecting twins) constructed their accounts of information seeking and represented themselves. Other studies examine this theme of positioning, using positioning theory to examine the discursive positioning used by Canadian midwives (McKenzie, 2004) to arrive a better understanding of the ‘information ground’, and the constant negotiation of position between the midwife and the pregnant woman that inevitably determines the type of information that is provided and the way it is delivered. Position and cognitive authority was explored in another study of pregnant women (McKenzie, 2003). Prigoda and McKenzie (2007) later emphasised the construction of information practices by the group, the collectivist understanding of information practice when studying a long established knitting group in a public library. Burnett, Besant & Chatman (2001) used the theory of normative behaviour to examine small worlds, including that of feminist bookselling. Another group of studies have taken a quantitative approach to understanding the information and support needs, e.g. of breast cancer patients (Chalmers et al. 2001). Yoo & Robbins (2008) chose their group as their review of the evidence showed that women were active seekers of health information on the Internet and that women were often seeking information on behalf of others. They argue that Johnson’s Comprehensive Model of Information Seeking (see Case, 2007, p.132) that synthesises three theoretical frameworks (health belief model, Uses and gratifications, and a model of media exposure) or the Technology Acceptance Model are not entirely appropriate for modelling the type of health information seeking behaviour observed in women. There may need to be more emphasis on the perceived usefulness and value of particular resources related to the immediate task, which may be a proxy search. The theoretical frameworks used by Yoo and Rubin include an expectancy-value model of gratifications sought and media exposure, as well as the Theory of Planned Behaviour (with the

construct of Perceived Behavioural Control). In their proposed model, the intention to use a health related Internet site is governed by perceived behavioural control, attitude towards health related Web use, gratification sought (motivation) – and possibly past experience of health information use. Testing of the model in a questionnaire survey of middle aged women with children (n=700, response rate 354/700, 51%) showed that more positive attitudes, and gratification sought were better predictors of behavioural intentions than perceived behavioural control for this group of respondents (who were preponderantly better educated and better off than the norm). It is possible that other women might show a range of beliefs concerning the power of certain factors to influence performance (control beliefs).

The trans-theoretical model has been used to examine changes in women's attitudes towards mammography screening (Pearlman et al. 1997). This includes consideration of the woman's "information environment" and the authors note the influence of significant others in the women's social network in swaying the "decisional balance", in providing a sounding board – for themselves and for listening to others.

The methodological developments in information seeking among women could be seen as converging on similar themes, from opposite directions, but, it must be stressed, with different philosophies. The quantitative studies are exploring the uses, gratifications, the influences of the social environment on the individual. These studies acknowledge the importance of a wide variety of influences, and some account for interaction among those influences. Qualitative studies, however, are, generally, moving from the study of the individual information seeker, through positioning theory, to the construction of social practices to the collectivist understandings of the information practices of a group. The latter approach is more amenable to an understanding of the way information practices may become habits, but habits may change, and perhaps a quantitative approach may help in understanding which influences may affect the change. The research approach that may seem most appropriate or more convincing may depend strongly on the assumptions of the researchers, the way they see the world, and the anticipated outcomes of the research.

### **Fairness in research**

This categorisation includes the studies that have included women as a group of information users with emerging, possibly special needs, or needs that may have been ignored. Most of the specific health information seeking studies are considered within this group, as these deal with conditions only, or mainly experienced by women.

On emerging needs, there are studies of professional black women as leisure tourists in South Africa (Fairer-Wessels, 2004), women civil servants in Nigeria (Mabawonku, 2006), women in the IT profession (Choo & Marton, 2003), working women's information use and reading habits in a steelmaking city in India (Panigrahi, 1998) and the needs of scholars in women's studies (Westbrook, 2003).

Needs that may be ignored include studies by Fidishun (2007) on women's use of the public library, and the IT-based resources. Wiklund (1999) also considers women's use of IT, in a study of male and female postgraduate students, in their development of the research career and networks. Taylor (2002) studies the needs of transgender individuals, and Rothbauer (2004a, b) discusses doctoral research on the reading habits of lesbian women, and how the reading affected how they saw themselves.

Warner and Procaccino (2004) point out that few prior studies had examined the health information seeking behaviour of women – exceptions include the study by Gollop (1997) of Afro-American women's health information seeking. Bar-Ilan et al. (2006) examined how information contributed to longterm battles by women to maintain weight. Ankem (2007) categorised the type of sources, and source preferences for women with uterine fibroids seeking information about treatment options. Szwajcer et al. (2005) found that information needs about nutrition varied according to the stage of pregnancy. Wathen and Harries (2006) examined the problems of women living in rural Canada in locating relevant health information for themselves and for their families. They found that women are not only seeking information on behalf of others – the women themselves rely on informal advice to guide them in their information seeking. The idea of care was important, and intermediaries who seemed to understand the context in which the women operated were valued over some other more authoritative sources. The study by Lynda Baker (1996) of women with multiple sclerosis found that some cope by actively seeking information (monitors), others reject information, initially at least (blunters). McKenzie (2002) describes the strategies and counterstrategies used in, and for practitioner-patient encounters by pregnant women. Forssén & Carlstedt (2001) suggest that women's experiences may not be obvious to the primary care physician in the consultation, and that women tend to place responsibility for others' health above their own. Ignoring needs is a characteristic also noted by von Sadvoszky & Ryan-Wenger (2007) who examine Army women's sexual health information needs. Jamieson, Fletcher & Schneider (2007) may simply have used women with irritable bowel syndrome as a cohesive group for study but they were also interested in the interplay of physician support, or rather lack of physician support, support from friends and family, information seeking from diverse sources and trial and error, when women tried to identify problem foods in their diet. Similarly there are several studies that examine the specific needs and perceptions of women with coronary heart disease, a disease (wrongly) assumed to be a male problem e.g. Albarran, Clarke & Crawford (2007); MacInnes (2006). An earlier review of the literature on this topic is that of Lefler & Bondy (2004) that concludes that reasons for delay in seeking treatment are complex. Hart (2005) also reviews women's perceptions of the risks of heart disease in the nursing research literature. Polacek, Ramos & Ferrer (2007) review breast cancer studies to examine the reasons for incidence and outcome disparities. Fagerlin et al. (2006, 2007) examined reasons for differences in knowledge among breast cancer patients and their implications for informed decision making. Rankin et al. (2006) evaluated a peer to peer support programme for breast cancer patients. O'Leary et al. (2007) review the literature on use of information by early stage breast cancer patients, with 25 research articles meeting the inclusion criteria. They conclude that personal and contextual factors affect how information is acquired and used, echoing Polacek. There is, unsurprisingly, therefore, contrasting evidence on the acceptability and value of support groups, as Luker et al. (1996) found that memberships of a breast cancer support group could be a negative experience, but Avery and Braunack-Mayer (2007) found a support group helped some women with PCOS (polycystic ovarian syndrome). Brown et al. (2002) synthesised qualitative research on various health care decisions taken by women throughout their lives, and noted the following themes across the three

studies: women's information seeking behaviour; reliance on trusted information sources; the desire for information sharing; active involvement in the decision-making process; and accepting the consequences of the final decision. Meadows (2001) used a model of the popular and professional sectors to examine the problems women faced in transferring knowledge between the two – the communication breakdowns between practitioner and woman patient that McKenzie (2002) also considered.

Communication difficulties between practitioner and woman patient figure in many of the health studies. Knowledge sharing is difficult and contested. In circumstances where women are obliged to come into contact with professionals, for example in the context of healthcare or of domestic abuse (Harris et al., 2001) there can be a mismatch between the assumptions and attitudes of the professionals and those brought to the encounter by the women themselves. The stresses and constraints experienced by professionals and their reliance on traditional models of care can be interpreted by women as uncaring and dismissive. Women look at their information needs in the context of their whole lives but may struggle to find professional help that will do the same. The menopause provides a good example of women's information behaviour in a health context and of the challenges they face in trying to make sense of their own experiences and in accessing the help and advice they need. As with pregnancy and childbirth (McKenzie, 2001, Wolf, 2001) the menopause is an experience shared by many women yet individual to each woman. It carries a raft of social and cultural expectations (many of which are negative in the case of the Western interpretation of the menopause) and each woman must negotiate her own way through it. Medicine can provide relief from symptoms in the form of hormone replacement therapy (HRT) but the decision of whether or not to take HRT is complex given the shifting, and often conflicting, evidence about the risks and benefits associated with it. Furthermore, each woman must base her decisions in the context of her own interpretation of the menopause and her beliefs about how symptoms should be managed.

In summary, one theme that emerges out of these studies are those of communication difficulties and dealing with contested knowledge, particularly in health situations, requiring attention to the negotiations involved. The other theme which emerges is that of support and context in which support is delivered – what do women expect of a support network, and what, perhaps, does the support network expect of them? What do intermediaries do? And how large should the support network be ?

## **Emancipation**

Many of the studies of women's information behaviour in developing countries have a clear agenda, of documenting the information behaviour, and helping women to improve life for themselves, their families and their communities.

Some of the studies of women's use of IT fit into the category of empowerment (through technology). Fidishun (2002) found that women library workers' views of themselves, as information providers, affected their relationships with computers. Simon (2006) also studied this ambivalence, but concluded that this was both an active and critical response to technological change. Marcella (2002) found that Internet sites aimed at women could offer an alternative space for communication that women might welcome. In a previous publication, Marcella (2001) found that women valued information provided by the European Union for their education, professional and personal life.



Several of the studies based in developing countries have examined women's information needs as small entrepreneurs, e.g. in Uganda (Ikoja-Odonga, 2002), in Malaysia (Ndubisi & Kahraman, 2005). Mooko (2002, 2005) found far greater awareness of local community groups, as opposed to national level information, among women in rural Botswana. Olatokun (2008) indicates that unless gender issues in the use of ICT are addressed in Africa, women, particularly those in rural areas, will continue to be excluded by ICT.

Mehra et al. (2002) used participatory action research in a study of information seeking and use in the Afya project to foster better health and welfare among Black women. Adjah (2005) examined the implications for literacy services of the information behaviour of female adult literacy learners in Accra. Musoke (2007) studied the experiences of women and health workers in rural Uganda, and the interaction-value model developed supports the idea that health information seeking is driven not just by needs but by the perceived value and impact of the information. For Somali minority ethnic women living in the UK, informal resources provided an approachable route to finding other information resources (Davies & Bath, 2002). For women who feel vulnerable, such as abused women (Harris et al. 2001) the approachability of the service providers seems particularly important.

Many of the studies that fitted easily in this group were based in developing countries where the problems of inequality may be more urgent, or in situations where women were at a double disadvantage of discrimination by virtue of race and gender. The idea of an inviting space for personal development emerges from several of these studies. The research on positive psychology (Seligman, 2000) (see also <http://www.ippanetwork.org/>) attests to the value of subjective experiences: well-being, optimism and flow and happiness. The extent to which individuals are predisposed to look on the bright side of life, to reflect positively, may be genetically determined (Fox, Ridgwell & Ashwin, 2009), Interview advice for qualitative research often stresses the importance of reflective listening, to encourage the interviewee to reflect and expand on their experiences. Critical incident techniques are based around this principle (Urquhart et al. 2001).

Feelings of vulnerability may also be experienced by individuals who find themselves in the role of patient, a role in which women tend to find themselves more regularly than men. Along with her vulnerability, a woman seeking help for the control of menopause-related symptoms may bring a range of other emotions to the patient-physician encounter, possibly anxiety (about what is happening to her), confusion (about the safety of HRT), or maybe determination to seek out what she considers to be a more 'natural' solution to her problems. She also brings her own perceptions of the menopause and what it means in the context of her life, and the knowledge she has acquired through her use of informal information networks (Meadows et al., 2001). Women are known to place high value on interpersonal information sources such as family and friends. Women experiencing the menopause have identified menopausal women with medical backgrounds as particularly trusted sources of information and place high significance on the health status and experiences of their own mothers (Price et al., 2008; Marmoreo et al., 1998). Since the decision of whether or not to take HRT is central to discussions about information behaviour during the menopause transition it is worth examining this decision in more detail.

## Communicating risks and making decisions

Much of the literature pertinent to the doctoral research on the information behaviour of perimenopausal women fell into a category that loosely concerned ‘emancipation’ but was better considered separately under risk and decision making, in particular about hormone replacement therapy. This was a category that emerged, and was not in the original framework. Marmoreo et al. (1998) examined the role and influence of various factors in women’s decision making about hormone replacement therapy. Andrist (1998) suggests that the attention paid to the topic by the media is a strong influence, and Jones (1999) noted the importance of informal contacts among family and friends. Several studies indicate that women’s knowledge of hormone therapy is generally too low to make informed decisions (Coo, O’Connor & Hunter, 2001; Rigby, Ma & Stafford, 2007). There have been trials of decision making aids, and some of those have noted that women may be better informed but that may not affect their attitudes or decisions made (O’Connor et al. 1998), although other studies suggest that women who had better estimates of the likelihood of certain outcomes made more consistent decisions (Holmes-Rovner et al. 1999), with less conflict between women and their physicians (Légaré et al. 2003, Murray et al. 2001) or more realistic expectations (Dodin et al. 2001) or feeling of greater involvement in the decision making (Newton et al. 2001, Connelly et al. 2000). Other trials indicate the women like web-based tools (Barnabei et al. 2008) or prefer computerised decision aids to print tools (Rostom et al. 2002) in helping them prepare for decision making about hormone replacement therapy but another study indicates that the effectiveness of the tool may depend on the urgency of making a decision (Saver et al. 2007), or the confidence in the tool (Bastian et al. 2002). The conflicting messages from many of the trials suggest that other factors may be involved, and physician preference may be more influential than previously suspected (Clark et al. 2003). Patients’ understanding of risk is probably far more complex (Walter & Britten, 2002) than the rational decision making algorithms that may be used in decision aids such as the multi-attribute utility (MAU) decision model (Schapira et al. 2004) for menopausal hormone replacement therapy (HRT). Babio et al. (2006) consider women’s autonomy in making decisions about hormone therapy after the menopause comparing Web site information from Spanish sites with English sites, for government and other organisational sites. Several themes emerge from this rather confusing picture of women’s decision making, and attitudes towards information provided about hormone replacement therapy. Most studies did not employ a theory of health behaviour change (Painter et al. 2008 point out that over a third of their sample of studies on health behaviour used a model (mostly the Transtheoretical model, Social Cognitive Theory or the Health Belief model)). The Transtheoretical model, for example, stresses the importance of stages of change, decisional balance (the pros and cons of change) and self-efficacy (confidence in the ability to change). If the stage of change is important, and if previous beliefs and experience have some part to play, then it is not surprising that the evidence is confusing if studies have not clarified those aspects in their research design. The decision aids may be assuming the same starting point, whereas aspects of the stage or setting, e.g. urgency of decision, Saver et al. (2007) may predominate. Moreover, the less investigated aspects of interaction between patient and professional e.g. perceptions of physician preference, and confidence (or not) in those perceptions, deserve more attention.

## Discussion – integrating themes

Table 1 summarises the findings from the analysis of themes within each framework theme, including the new theme of communicating risks and making decisions.

Organising theme	Emerging similarities	Emerging differences and queries
Gender differences	Gender a moderating influence on some factors affecting information seeking – risk avoidance, self-efficacy, confidence? (Culturally ascribed gender differences)	Does situation make a difference – the settings in which women are more likely to be found?
Methodological variations	Influences of the social environment on information seeking – positioning theory	What defines a group of relevance to women? Group characteristics – how is the sphere of influence defined? How should interactions be studied?
Fairness in research	Communication between the professional and popular sectors problematic – contested knowledge	Expectations of a support network? What do intermediaries do – and how do they change in the process
Emancipation	Women can suffer double discrimination (and feel vulnerable)- value approachable information resources	Inviting space for personal development required? How and when should or could this happen?
Communicating risks and making decisions	Stage and situation may influence behaviour?	Unclear which factors affect information use – and when information may actually be used.

Table 1 Summary of findings from framework analysis

Looking across the organising themes, the next stage of compare and contrast was to map the queries to emerging similarities, to assess whether some resolution to the queries in one category could be found from the emerging similarities for another category, in the other column. And some debate among the sets of similarities or sets of queries may also illuminate.

Comparing the queries column with the similarities column, the queries about ‘space for personal development’, ‘support network’, ‘group characteristics’ and ‘situation’ map to ‘influences of the social environment on information seeking.’ Looking down the differences and queries, we find that there are questions about the space for personal development – is this a function of the support network? But how big does this support network need to be, and how is the sphere of influence assessed?

Emerging similarities	Differences and queries
Influences of the social environment on information seeking – positioning theory	Inviting space for personal development required?
	Expectations of a support network?
	Does situation make a difference – the settings in which women are more likely to be found?
	What defines a group of relevance to women? Group characteristics – how is the sphere of influence defined?

Table 2 Exploring situation, settings, and supporting within groups

The one important lesson of feminist methodology, and positioning theory in particular, for information behaviour research may be the move away from the ‘lone ranger’ model of the individual information seeker. The new approach appreciates how the situation affects the information seeker, and how the information seeker in turn changes their situation – their vantage knowledge point in the mesh of interactions – their knowledge node. This mesh is not a static construction, it is dynamic, changing in response to the interactions within it.

Another possible mapping is the question about the role of intermediaries to approachable information resources, stage and situation of information behaviour, and the culturally ascribed gender-related constructs. In this case, looking down the column of emerging similarities, the value of approachability seems to be concerned with the contested knowledge. And when knowledge is contested – are these the situations where the culturally ascribed gender differences appear more prominent, or is it better to think of situation, and what is happening – the behaviour making the situation, rather than situation making behaviour?

Emerging similarities	Queries
Women can suffer double discrimination (and feel vulnerable) - value approachable information resources	What do intermediaries do – and how do they change in the process?
Communication between the professional and popular sectors problematic – contested knowledge	
Stage and situation may influence behaviour?	
Gender a moderating influence on some factors affecting information seeking – risk avoidance, self-efficacy, confidence? (Culturally ascribed gender differences)	

Table 3 Exploring intermediaries, approachability and interacting

Turning next to looking across from queries (on intermediaries to similarities) we have questions about the functions of intermediaries and how the process of mediation affects the intermediaries. Intermediaries tend to be viewed as channels of communication filtering information from one network to another network, bridging two discrete groups. The contradictory findings about the value of a health support network for women suggest

that important factors are not just the timing of the support provided, or who provides the support, but the way women define a support network for themselves, particularly when knowledge is contested. Again, research has been influenced by the idea of the sole individual gatekeeper, another 'lone ranger' information seeker. What we could be looking for are the changing sets of connections – that a certain situation influences the knowledge node to strengthen some connections, or make new connections, for a varying period of time, and how that knowledge node affects other nodes. Several of the Internet health information seeking studies noted that women were seeking information on behalf of others, and this raises the question about how proxy or mediated information seeking should be viewed. McKenzie (2003) in fact distinguishes two stages of the information encounter: Connecting with sources and Interacting with them. When making connections, participants described the practices involved in identifying (or being identified by) and making contact with (or being contacted by) potential sources and the barriers that could inhibit the process (Stage One of the model). After initial contact with a source the quality of the actual interaction with that source (practices/barriers) forms Stage Two of the model.

Some of the characteristics of intermediaries and the support provided therefore need to be unpacked. Several of the studies refer to women's preferences for 'approachable' information resources. How is approachable defined – in terms of personal characteristics, or knowledge possessed or behaviour, or a mixture of all three? Knowledge sharing is difficult in some professional-patient encounters, women prefer information resources that are 'approachable'. Is there some relationship between the concept of self-efficacy, confidence in one's ability to execute courses of action to manage a situation, and the behaviour that is expected of 'approachable' information resources? Perhaps it is preferable to distinguish a connecting stage (and some attitudes or characteristics of other connections) and an interaction stage (with emphasis on the way the interaction happens and the outcomes). Perhaps this also might be explored through the type of 'helps' identified by Dervin (2003).

This type of meta-synthesis is similar to axial coding in grounded theory in trying to make connections between the existing categories, for some of the themes within each category. However, in making connections we also set some ideas against each other, to test and challenge, as well as trying to integrate the common themes. Figure 1 illustrates, within the limits of a two-dimensional display, the interconnections of a dynamic mesh, the ways groups of influence may include interconnected nodes, but reach out to others, and how intermediaries influence, but are in the process changed themselves.

The storyline that emerges is an agenda for information behaviour research, as well as a better understanding of 'gender and information behaviour'.

Turning first to gender and information behaviour what is apparent is the difficulty of making comparisons, like for like, with qualitative information behaviour studies that have focused on men. With the quantitative studies, depending on the sample size, and the questions asked, differences may well emerge. But the qualitative studies that focus on women have few parallels with qualitative studies that focus on men, in the same or similar settings. There are a few studies (e.g. Minion, 2008) but generally men's experiences are not explored in the way that feminist approaches have unpicked some of the power discourses for women. Library and information science research is not alone among the social sciences in taking assumptions at face value. A systematic review

(Emslie & Hunt, 2009) (published after the literature review was completed) examined qualitative research on men's experiences of heart disease. This notes that out of the 136 studies that collected data by gender, only 27 took a gendered approach, and the reviewers suggest that men are 'doing' gender when they are 'not doing health'.

The key ideas that emerge for general information behaviour research are:

**Situation as mesh.** Situation is dynamic, in an ever-changing mesh of connections, influencing and being influenced. (Table 2, and Figure 1)

**Intermediary as node with connections** – an intermediary as a dynamic set of connections. (Table 3 and Figure 1)

**Connecting behaviour.** Socially ascribed gender-related constructs in information seeking, such as confidence, self-efficacy may have some relationship with 'approachable' information resources, if we think more in terms of what 'approachable' information resources do, rather than just their traits of personality or knowledge possessed. (Figure 1, acting to change)

The type of intermediary here has a very different meaning to the usual meaning of intermediary in mediated searching, where the research emphasis has been on the development of the search strategy and use of terms in successive searching (Spink et al. 2002). The nearest equivalent is probably the technological gatekeeper idea that Thomas Allen described in organisational research, but even that role is not exactly the same. The gatekeeper's primary characteristic is that they keep in touch with information resources outside their immediate community and that they are looked to for advice from within their community (Sturges, 2001). Allen suggests that there could be networks of gatekeepers within the organisation – this seems closer to the idea of an intermediary as a node with connections, although the emphasis in this paper is less on the heroics of the occasional gatekeeper and the possibilities that there are more intermediaries, or the potential for more intermediaries.

## **Conclusion**

This paper resulted from questions asked during the literature review for the doctoral research on how feminism should fit into the research approach, and whether gender differences in information seeking matter. We used a framework based around themes from feminist research to try to organise research studies on 'information behaviour and women'. From a process of 'compare and contrast' within each organising theme, the similarities and differences, and queries emerged. We then looked across those similarities and differences to discern whether there were other organising concepts which could provide a better explanation, to help integrate the apparent similarities with the emerging differences and queries.

There are gaps, and to fill out some of the 'key ideas', particularly in 'connecting behaviour', metasynthesis of individual research studies may help to reveal which of the so-called gender-related constructs are important for information behaviour research. There are also gaps in our knowledge of how to deal with 'information use', although this framework suggests that information seeking and use are not as separate as we tend to assume. Seeking may be connecting and connecting may be using.

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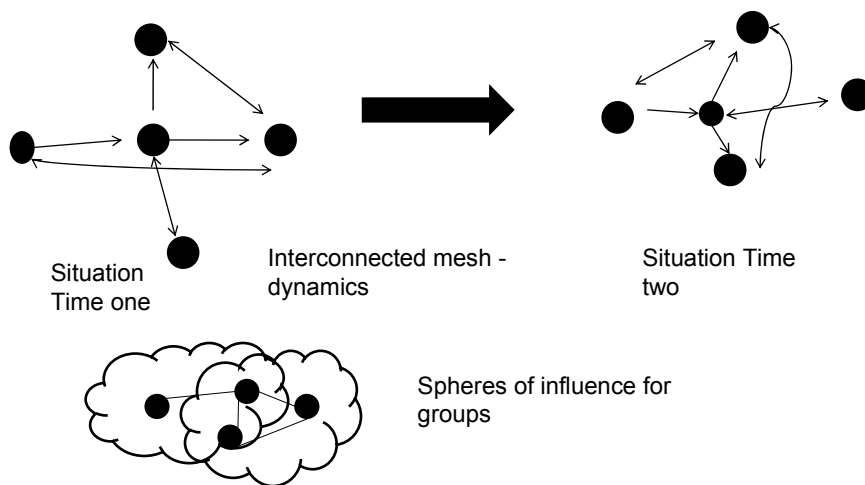


Figure 1

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