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Making sense of evolving health information: Navigating uncertainty in everyday life

by

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For my mother, Ursula Lilly Taylor (Kuppenheim), who continues to inspire me.

ABSTRACT

While evidence-based practice and knowledge translation (or transfer) has garnered much attention, research has not focused on health information as provisional and emergent, and on knowledge translation (KT) as a process of social construction. The challenge of evolving information is magnified within everyday life contexts where informal and formal sources mediate health information. This qualitative study explores the experiences of women as they respond to and make sense of uncertain health information mediated by diverse sources (including health professionals (HPs), media, internet, and intrapersonal and interpersonal sources). A medical case in which evidence is explicitly evolving – health management during the menopause transition – facilitated exploration of information use and personal health management. Using a social constructionist approach and social positioning theory, and semi-structured interviews (narrative and 'elicitation' approaches) with information seekers and HPs, this study draws attention to women's complex information worlds, their engagement with information sources, their independent information seeking and interpretation, the pervasive influence of the internet, the role of intrapersonal sources, and the facilitating roles valued when women gathered information from HPs. Findings highlight the influence of the 'symptom experience'; women's desire to align lived experience with perceived 'normal' experiences; and notions of responsibility engendered by upheavals in conventional medical knowledge. Data analyses demonstrate: construction of menopause-related information was influenced by women's construction of evidence as research, material object, negotiated belief, and lived experience; women positioned themselves as autonomous, collaborative and/or dependent information seekers and decision-makers, and positions were influenced by context and perceived quality of interactions with HPs; a predominant feature of health information behaviour was complementarity, not competition or displacement; and social contexts were critical to knowledge construction. Findings raise new considerations related to KT as an on-going, personal process of social construction, and the contribution of interdisciplinary research: theory from Library and Information Science facilitated investigation of information sources and behaviour, positioning theory brought focus to relational elements, and the Promoting Action on Research Implementation in Health Services (PARIHS) framework facilitated exploration of KT as a process shaped by evidence, context and facilitation. The study has implications for women's health, health literacy and shared decision-making.

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CHAPTER 1
INTRODUCTION

Much has been written about evidence-based practice (EBP) within health fields, and the challenges encountered when striving to translate medical knowledge into practice; however, little attention is paid to the fact that evidence itself is provisional, emergent and incomplete (Upshur 2001) and that knowledge translation (KT) involves an on-going process of social construction (see appendix A for a list of acronyms). The dilemma presented by evolving health information is magnified for people making health decisions within the context of daily life: within this context individuals are frequently assimilating and responding to health information mediated by a wide range of formal and informal sources including health professionals (HPs), the media, internet sources, advertising, and personal contacts. Research that explores the changing and evolving nature of health information and the experience of individuals as they interact with and integrate health information from diverse sources and within the context of their everyday lives is limited. In this dissertation I explore how people respond to, make sense of, and use uncertain and/or evolving health information. Focusing on health information behaviour (IB) within the context of a specific illustrative medical case where medical evidence is explicitly evolving facilitates exploration of the diverse factors that influence health decision making and the use of health information in everyday life.

This research study focuses on how people experience changing and evolving health information. Specifically, I explore the experiences of women as they respond to, make sense of, and use (or do not use) uncertain and/or evolving information about hormone therapy (HT) and management of the menopause transition; the ways in which different information sources facilitate women's understanding of and response to changing information in this area of health and wellness management; how women's positioning with respect to information sources influences health IB; and how women construct and make sense of evolving health information encountered through formal or informal sources and within the context of their everyday lives. This exploratory research is informed by the view that health information is not something that is *implemented* with linearity of cause (research evidence) and effect (evidence-based health behaviours), but rather it is *translated* into practice through a constructed process that is based on ‘factual’ and experiential knowledge as well as on reflection, context, and inter- and intrapersonal influences.

1.1 Evolving health information: An illustrative medical case

Precipitated by the unexpected 2002 publication of results from the Women’s Health Initiative (WHI) study (Rossouw et al. 2002), management of health concerns during the menopause transition has undergone dramatic and rapid change in recent years. For this reason the WHI and the resulting, on-going controversy about menopausal HT provides an effective case study within which to explore uncertainty and its effect on health information use in everyday life. Peterson et al. (2004) note, “rarely has 1 study had the impact that the Women’s Health Initiative trial has had on the prescribing and use of HT” (2310). The influence of the WHI did not, however, occur within a vacuum. The effect of this landmark research study and the many subsequent articles published in the scientific and popular press was amplified by the context within which new information was released, it was influenced by the personal situations of women and the HPs advising them, and it was facilitated by information sources, new communication technologies, and interpersonal relationships.

Ongoing ambiguity about management of health concerns during the menopause transition clearly positions health knowledge as a ‘work-in-progress.’ This stands in contrast to the positivistic assumption commonly held as self-evident: that health practices can be determined by objective research evidence that is empirically documented and implemented directly into clinical practice. By focusing on the experiences of women as they encounter and integrate information about HT and menopause, I draw attention to health IB within the context of uncertain and/or evolving health information, the varying ways in which diverse information sources facilitate understanding of health information and the tensions experienced by women as they make sense of information from formal and informal sources, and to KT as an on-going process of social construction.

1.2 Development of research objectives

Both interdisciplinary professional experience and close interaction with the literature in health fields and in the Social Sciences kindled my interest in the tensions between positivistic and constructionist perspectives within health fields. Latour and Woolgar’s (1986) book, *Laboratory Life: The Construction of Scientific Facts*, for example, demonstrates that while researchers at the Salk Institute for Biological Studies claimed to be “scientists discovering facts,” they were in fact “writers and readers in the business of being convinced and convincing others” (88). ‘Facts’ were therefore “thoroughly understandable in terms of their social construction” (107). My Master of Library and Information Studies thesis, a content analysis of consumer and medical articles related to menopausal HT, provided similar insights (Genuis 2004b). I found that rather than communicating a factual representation of immutable truth, “published articles produce and shape meaning, and create belief” (Genuis 2004a, 207). These findings prompted my interest in how people within the context of everyday life integrate health information from multiple information sources and then translate that knowledge into use; specifically, how they “access, use, and interpret information about controversial or changing areas of medical practice” (Genuis 2006, 983).

My interest in evolving health information and the way health evidence is constructed stems from the first hand observation that HPs are inculcated with the assumed self-evident notion that health care should be based on black and white ‘facts’ and that the focus of shared decision making (SDM) should be the effective communication of those facts. A myth of certainty is frequently created, which reinforces notions of “medicine as a precise science independent of context and people" (Griffiths, Green, and Tsouroufli 2005, 516); and uncertainty is presented as something to be conquered rather than something to be explored and navigated within the context of the individual. Even though I recognize that patients often express a desire for certainty, my personal experience and academic exploration leads me to wonder if acknowledging the inherent uncertain and evolving nature of health information will not only stimulate contextually situated discussion of the pros and cons of health care options, but will also allow patients to have an authentic voice in health decision making.

Furthermore, I am concerned that women's natural life transitions are constructed as problems requiring medical intervention and supervision. This not only positions women as passive recipients of health information and medical care, it also influences the way HPs approach women: normal transitions are medicalized and real health concerns may be overlooked. I believe that in order to facilitate evidence-based, patient-centred health practice, attention must be given to women's perspectives on their own health care and to understanding how women interact with and make sense of health information from a range of sources and within the context of their everyday lives.

Three primary concepts have contributed to my research interests and to the objectives of this dissertation: the intrinsic uncertainty of health information, the importance of understanding how health information is constructed and translated into use within the context of everyday life, and the relevance of IB research to health fields.

1.2.1 Uncertainty

Although uncertainty within health fields can be illustrated by specific situations where varying perspectives are evident in the literature or where practical application of evidence is uncertain, some scholars suggest that uncertainty is an inherent aspect of health information. Wood, Ferlie and Fitzgerald (1998) note that even established medical 'fact' represents only a moment in time within an on-going, indeterminate process of knowledge development. Much attention in health fields, however, centers on evidence as static discoverable fact, a focus which belies the intrinsically provisional nature of health information and which potentially marginalizes critical elements influencing health information use. The provisional nature of health information is highlighted by the unanticipated results of the WHI: once considered the optimum therapy for healthy menopausal and postmenopausal women this landmark study provoked rapid change in clinical practice and ongoing ambiguity about how to translate evolving information about HT into practice within the lives of individual women.

1.2.2 Need for knowledge translation

The literature clearly and consistently documents a gap between evidence and practice (Grol and Grimshaw 2003). Knowledge *transfer* is an insufficient construct since "knowledge that has been transferred has not necessarily been utilized" (Aita, Richer, and Heon 2007, 147). The notion that knowledge from a complex information world is *translated* into use via a multifaceted and contextually situated process provides a more robust framework. KT research, however, tends to focus on HPs and their adoption of 'best practices.' To my knowledge, research does not explore KT as a process of social construction undertaken by people involved in personal health management. Since HPs are most likely to involve patients in SDM in situations of uncertainty (Salkovskis and Rees 2004), it is critical to gain insight into the health IB of individuals as they navigate situations where health information is evolving, and to explore how people translate knowledge from formal and informal sources into use within the context of everyday life.

1.2.3 Relevance of information behaviour research

Information behaviour is of significant, although largely unrecognized, relevance within health fields. While researchers in health fields tend to focus on professional settings and the implementation of research knowledge, IB research explores a broad range of behaviours, information contexts, and populations, as well as outcomes that include the use and non-use of information, and end-products which may consist of knowledge, opinion, intuition, evaluation, and affective response (Dervin 1992). Furthermore, IB research emphasizes the influence, interplay, and integration of a complex information world – information arising from informal everyday life interactions, from formal information sources, and from various hybrid sources such as the internet. This broad approach is highly relevant in situations where health information is explicitly uncertain and/or evolving and in an exploration of the wide range of behaviours exhibited by people as they intentionally and unintentionally gather, integrate and use health information.

1.3 Specific research problem

The objective of this dissertation is to explore how uncertain and evolving health information is experienced and constructed, and to investigate how that experience influences health IB and the translation of knowledge into everyday life use. Specifically I explore (1) the experiences of women as they respond to, make sense of, and use uncertain and/or evolving information about HT and menopause; (2), the ways in which varying information sources facilitate women's responses to changing and uncertain health information; (3) how women position themselves (e.g. as autonomous, as collaborative decision maker, or as dependent) when engaging in health IB, and the influence of that positioning on IB and on the translation of knowledge into use within women's lives; and (4) how the construction of uncertain and/or evolving health information encountered via both informal and formal channels influences health IB, including decision making, KT, and encounters with HPs. This exploration provides insight into the tensions experienced by women as they engage with changing or uncertain health information and contributes to theoretical understanding of KT within the context of everyday life.

1.4 Theoretical framework

This dissertation is based on human information behaviour theory and a social constructionist approach, which aims at identifying "general sensemaking practices on the basis of which people orientate themselves in their everyday and working lives" (Talja, Keso, and Pietiläinen 1999, 761), and notions of meaning-making that incorporate an active, process-oriented view of IB (Dervin 1992). Interviews with participants are viewed as "reality-constructing, meaning-making occasions" where meaning is not merely revealed through questioning, it is "actively and communicatively assembled in the interview encounter" (Holstein and Gubrium 1995, 4). The Promoting Action on Research Implementation in Health Services (PARIHS) framework is used as a heuristic for exploring the interplay between evidence, context and facilitation. In addition, social positioning theory facilitates exploration of the dynamic aspects of information encounters and illuminates the interactions of individual women with their sociocultural context and the influence of social interactions on health IB. Additional theory is incorporated as appropriate in the results and discussion chapters (chapters four to seven) and facilitates exploration of emerging themes.

1.5 Research questions

Semi-structured interviews and qualitative research methods are used to investigate the guiding question: What sense-making and IBs are elicited by uncertain and/or evolving health information? This guiding question is explored by addressing the following overarching research questions:

1. What are the experiences of women as they respond to, make sense of, and use uncertain and/or evolving information about HT and menopause?
2. In what ways do information sources (including HPs, informal interpersonal interactions, and the media) facilitate women's varying responses to uncertain/evolving health knowledge? And what are the

tensions experienced by women as they make sense of information that is facilitated in different ways by formal and informal information sources?

3. How do women position themselves (e.g. as autonomous, as collaborator, or as dependant) when encountering/seeking/exchanging health information, and how does that positioning influence further health IB?
4. How does the construction of uncertain and/or evolving health information encountered via diverse mediums and within various contexts influence health IB (including decision making), KT, and encounters with HPs?

In keeping with principles of qualitative methodology, research questions are shaped in the results and discussion chapters by themes which emerged during the research process (Marshall and Rossman 2006).

1.6 Significance of research

This research contributes to understanding of women's health IB in situations where health information is uncertain and/or evolving, as well as to knowledge of how context influences health IB and what forms of facilitation women favor or perceive as useful when making sense of changing evidence related to HT and menopause. Insight is provided into the experiences of women as they interact with and integrate health information from formal and informal sources and within the context of a non-crisis, everyday life health situation. The study draws attention to the evolving and provisional nature of health information and to the challenges of navigating health information in a complex information world. The study furthermore makes theoretical contribution by providing insight into KT as an on-going process of social construction, as well as insight into the use of social positioning theory and PARIHS core elements as lens for guiding exploration of KT in everyday life contexts.

1.7 Dissertation outline

This dissertation consists of eight chapters. The literature review in chapter two takes the following format: an overview of the illustrative medical case chosen to give context for this exploration of evolving health information is provided; the comprehensive nature of IB is defined and attention is directed to IB within the context of everyday life and to the relationship between IB and uncertainty; women's health IB is explored; theoretical perspectives are considered; qualitative inquiry is reviewed with emphasis on interview methods; and finally, research gaps are identified. In chapter three the research methods used in this exploratory study are described. Given the qualitative nature of this study, results and discussion are presented in concert; each of the four research questions are addressed in separate chapters beginning in chapter four and carrying through to chapter seven. Chapter eight is the dissertation's conclusion chapter. This is followed by an appendix detailing the acronyms used in the dissertation, seven appendices providing further details related to research methods, and one appendix which provides descriptions of participants.

CHAPTER 2

LITERATURE REVIEW

Before embarking on an investigation of women's experiences with uncertain and/or evolving health information it is valuable to consider what has been published in the academic literature about hormone therapy (HT) and the Women's Health Initiative Study (WHI); information behaviour (IB), particularly women's health IB; theoretical considerations related to evidence-based practice (EBP), knowledge translation (KT), and social positioning theory; qualitative inquiry as a means of accessing women's experiences; and current gaps in the research. The following literature review begins with an overview of the illustrative case which provides context for this exploratory research: the history of HT as long-term preventative therapy for healthy menopausal and postmenopausal women is briefly reviewed; the impact of the WHI on women and health professionals (HPs) is discussed; and finally, literature related to the influence of the media and the controversy arising from the WHI is reviewed. The scope of information behaviour (IB) is then explored with particular attention to everyday life information seeking (ELIS) and the relationship between IB and uncertainty. This is followed by discussion of women's health IB: focused attention is given to literature related to women as active health information agents, the complexity of information sources influencing women, and women's focus on 'well-being.' In order to provide background for this interdisciplinary exploration of women's health IB, theoretical consideration is given to EBP and KT. The Promoting Action on Research Implementation in Health Services (PARIHS) framework is then explored with specific attention to its core elements (evidence, context, and facilitation) and their relationship to the illustrative case study. Limitations of PARIHS are discussed and it is proposed that this framework provides a heuristic which supports a social constructionist viewpoint while facilitating exploration of factors that critically influence women's health IB. This is followed by brief elucidation of social positioning theory and its limited application in the fields of Library and Information Science (LIS) and

Nursing. In order to provide background for using qualitative methods for this research study, literature related to qualitative methodology and interviewing is reviewed. Finally, the literature review is summarized and research gaps are identified.

2.1 Illustrative medical case: Management of the menopause transition

In July 2002 the routine acceptance of HT for prevention of long-term disease in healthy menopausal women was challenged when results from the largest randomized clinical trial of HT, the WHI, indicated that "overall health risks exceeded benefits from use of combined estrogen plus progestin for an average 5.2-year follow-up among healthy postmenopausal US women" (Rossouw et al. 2002, 321). Over the next year, as further findings demonstrating negative sequelae or lack of therapeutic benefit were published (Manson et al. 2003; Rapp et al. 2003; Shumaker et al. 2003; Wassertheil-Smoller et al. 2003), it became increasingly clear not only that long term use of combined estrogen plus progestin was associated with increased risk for breast and ovarian cancer but also, contrary to expectations, HT did not decrease cardiovascular disease. This information, which was communicated, discussed and debated in literally hundreds of articles and editorials published in the scientific and popular press (Naughton, Jones, and Shumaker 2005), represented a dramatic departure from the previously accepted and articulated view of menopause as a treatable medical condition. As a result there has been both profound change in clinical practice and in attitude towards the use of long-term HT, as well as ongoing uncertainty about how to translate these new findings into practice within the lives of individuals (*cf*. Genuis 2006; Hersh, Stefanick, and Stafford 2004; Wathen 2004). Because of the dramatic impact that the WHI had on HT use and more broadly on the clinical approach to medical management of women in the menopause transition, an overview of this illustrative case provides a strong basis for exploring how women experience uncertain and/or evolving health information and how evolving information challenges individuals as they engage in health IB and as they seek to translate health information into use within the context of their everyday lives.

2.1.1. HT as preventative therapy

Although the current challenges faced by women and HPs as they seek to navigate uncertain information about HT were not anticipated prior to 2002, the history of menopausal HT demonstrates that uncertainty and contradiction has plagued this area of clinical practice since its inception (Oudshoorn 1990). Descriptions of menopause as a deficiency disease that might be ameliorated by HT began to appear in scholarly articles in the late 1930s and 1940s (Bell 1990); and, in 1966, New York gynecologist Robert Wilson wrote the book *Feminine Forever*, which presented HT as the optimal long-term preventative treatment for healthy menopausal and postmenopausal women. A best seller in both North America and Europe, Wilson's book played a significant role in propelling HT beyond academia and into the mainstream of clinical medicine and everyday life (Love 2003). Promoting the notion that menopause produced estrogen deficiency of such proportions that a woman's entire social, psychological, and physical well-being was doomed, Wilson promised the elimination of menopause, a return to youthful vigor, the indefinite postponement of the ravages of aging, and the final physical and mental emancipation of women.

By the mid-1970s estrogen was being widely used to treat menopausal symptoms such as hot flashes and mood swings. Studies showing that estrogen could lead to endometrial cancer, however, initiated widespread uncertainty and prescriptions for the estrogen medication, Premarin, fell from 28 million in the United States in 1975 to 14 million in 1980 (Love 2003). In the 1980s prescriptions of HT began to increase again as estrogens were combined with the oral progestin Provera, which had been shown to protect the uterus from cancer. Furthermore, with the 1986 United States Food and Drug Administration (FDA) announcement that the rate of bone loss in postmenopausal women could be reduced by taking estrogens (Stadel, Colman, and Orloff 2003) and with aggressive pharmaceutical marketing to both physicians and the public (Kaufert and Lock 1997), HT gained the momentum it had lost in the 1970s. The frequency of menopause-related, medical and consumer articles increased in the 1980s and, unlike texts from the previous decades, menopause was explicitly or implicitly identified as a deficiency disease (Topo 1997).

In the 1990s a second potential indication for the use of long-term preventative HT began to be actively promoted: HT as a means of reducing heart disease in women. Over this decade observational studies, which suggested an increased risk of coronary disease following natural menopause, and studies demonstrating that HT affected specific cardiovascular risk factors were used to promote the cardioprotective capability of exogenous estrogen. Despite widespread promotion and adoption of HT for the primary prevention of heart disease, medical evidence continued to evolve: (1) subsequent analysis threw the interpretations of prominent observational studies into question (Stampfer, Colditz, and Willett 1990); (2) two large clinical trials demonstrated that HT did not provide cardioprotection for women (Grady et al. 2000); and (3) in 2001 the American Heart Association reversed previous recommendations and issued an advisory stating that there was no evidence for using HT to prevent heart disease and that it is contraindicated for women with existing heart disease (National Women's Health Network 2002).

In 1994 an observational study concluded: “increased incidence of Alzheimer’s disease in older women may be due to estrogen deficiency and …. estrogen replacement therapy may be useful for preventing or delaying the onset of this dementia” (Paganini-Hill and Henderson 1994, 256). While comprehensive review articles concluded that despite plausible biological mechanisms and observational studies there was insufficient evidence to support assertions that estrogen prevents or treats dementias (Haskell, Richardson, and Horwitz 1997; Yaffe et al. 1998), estrogen’s potential impact on brain function led many to view the link between aging, dementia and hormonal changes following menopause as “logical and compelling” (Beckmann 1997, 295). HT as a ‘cure’ for cognitive dysfunction or as protection against future dementia thus became a significant area of inquiry, dissent, and uncertainty in both the medical and consumer literature (Meyer 2001; Love 2003).

For at least two decades prior to the unanticipated publication of WHI results, analysis of risks versus benefits appeared to support the use of HT for both disease prevention and symptom control. By the end of the 1990s postmenopausal hormones had become one of the most commonly prescribed drugs in the United States (Naughton, Jones, and Shumaker 2005). Despite this widespread adoption of HT as a long-term preventative therapy for menopausal women, knowledge about HT was rapidly evolving even during the pre-WHI years and women were experiencing uncertainty as they sought to navigate evolving information about menopause and HT (*cf*. Lyons and Griffin 2003; Winterich and Umberson 1999). With the early and unexpected publication of WHI results in July 2002, this case emerged as a vivid example of the challenges arising from uncertain and evolving health information.

2.1.2 Impact of the WHI on women and health professionals

When the respected *Journal of the American Medical Association* published the news that the WHI had been prematurely halted due to health concerns, the news reverberated through medical and consumer publications and "had a major impact in the United States and worldwide as scientists, physicians, the pharmaceutical industry, and women began to grapple with the dissonance created by their beliefs and the empirical data on actual risks" (Naughton, Jones, and Shumaker 2005, 166).

The effect of the WHI was profound and rapid. Within a short period of time there were reports that the majority of women in studied populations had heard of the WHI and had responded by discontinuing or changing HT regimes, and/or by seeking further information (*cf*. Barber et al. 2004; Breslau et al. 2003; Ettinger et al. 2003; Wegienka, Havstad, and Kelsey 2006). A national telephone survey carried out in the United States in the first month following the initial publication of WHI findings, for example, found that "64% of the women interviewed had heard something about [the WHI] study from the media or from talking to others," 57% were worried about how they would be affected by the findings, and 13% had already stopped taking HT (Breslau et al. 2003, 33). Population-based usage data demonstrates decreased HT use in all subgroups of age, race, education and region subsequent to the premature cessation of the WHI (Kelly et al. 2005). In addition, the majority of physicians have modified their clinical approach and menopausal prescription of HT has declined significantly (*cf.* Blumel et al. 2004; Buist et al. 2004; Hersh, Stefanick, and Stafford 2004). Guay et al. (2007), for example, found that less than one year after the publication of WHI findings, HT prescriptions in Quebec had fallen by 28%.

Notwithstanding the significant impact of the WHI on the use of HT as a long-term preventative therapy, symptom management has emerged as a considerable challenge for many women (Schonberg and Wee 2005). Lawton et al. (2003) report that six months following the initial release of WHI results, 58% of respondents to a survey conducted in New Zealand had stopped taking HT, however, 18% restarted HT because of the return of symptoms or having a hysterectomy; and Wegienka, Havstad and Kelsey (2006) found that 24% of those who stopped HT resumed use because of menopausal symptoms. Other published surveys report that the majority of women continuing HT despite WHI findings cite intolerable menopausal symptoms as their reason for continuing therapy (*cf.* Barber et al. 2004; Kelly et al. 2005; Taylor, MacLennan, and Avery 2006).

In the wake of declining menopausal hormone use and on-going concerns regarding symptom management, increased attention has been directed towards complementary and alternative approaches to menopause management (*cf.* Daley et al. 2006; Ma, Drieling, and Stafford 2006; Schonberg, Davis, and Wee 2005; The Florida Behavioral Health Research Consortium et al. 2006). While this development stands in contrast to the small percentage of pre-WHI medical and consumer articles that focused thematically on alternatives to HT (Genuis 2006), it perhaps fulfills a need illuminated by pre-WHI qualitative studies in which women expressed uncertainty about HT as a long-term therapy and a desire to learn about HT alternatives (Hunter, O'Dea, and Britten 1997; Stephens, Budge, and Carryer 2002; Winterich and Umberson 1999).

The WHI has had a profound influence on women’s health care since its results were first published in 2002 and, as study participants continue to be monitored, results from this study continue to emerge and influence women and HPs. More recently published results of the WHI follow-up study of the estrogen-plus-progestin clinical trial, for example, found that overall risks including risks of stroke, blood clots, and breast cancer remained high three years after women stopped taking combination HT (Heiss et al. 2008). In a National Institutes of Health (2008) press release Dr. M. S. Lauer, director of the National Heart, Lung, and Blood Institute Division of Prevention and Population Sciences, concludes: “While it is reassuring that heart attack risk decreased and that the risks for stroke and blood clots did not grow after the women stopped taking hormones, this study provides further evidence that five years of combination hormone therapy is harmful. All the accumulated risks do not simply disappear.”

Furthermore, the impact of the WHI has not been limited to changes in the management of the menopause transition. The prominence of controversy with respect to HT use during the menopause transition has also led to examination of sociocultural influences on health practices and policies (*cf*. Naughton, Jones, and Shumaker 2005), and to unprecedented examination of the drug promotion practices of pharmaceutical companies. For example, Fugh-Berman (2010) examines documents revealed in the course of litigation against a pharmaceutical company by women with claims related to the development of breast cancer as a result of HT. This author concludes that the systematic publication of ghostwritten reviews and commentaries in medical journals “almost certainly contributed to widespread use of HT among millions of women who had no medical indication for the drug” (9).

For the purposes of this study, what is most important about new and ongoing findings related to management of health and well-being during the menopause transition is that they reinforce the emergent nature of medical knowledge in the area of menopausal HT and highlight the challenges experienced by women as they seek to make sense of evolving information within this context.

2.1.3 Influence of the mass media

The literature identifies healthcare providers and the media as the sources of WHI and HT information most commonly cited by women following the premature cessation of the WHI (*cf*. Barber et al. 2004; Ekstrom 2005; Heitmann, Greiser, and Dörin 2005; Rolnick et al. 2005). While reliance on HPs as information providers is not surprising and many women continue to look to physicians for general menopause information (Genazzani et al. 2006), post-WHI surveys reveal that women cite information obtained through the popular press as a primary influence on their understanding of HT risk and on decision making (Barber et al. 2004; Bestul et al. 2004; Ettinger et al. 2003; Rolnick et al. 2005). While the limitations of media provided health information are well documented (*cf*. Cassels et al. 2003; Moynihan et al. 2000; Woloshin and Schwartz 2002), the WHI highlights the complex and emerging role of this relatively new player in the dissemination of health information (Pines 2005).

The mass media not only affects consumers, it also influences HPs (Grilli, Ramsay, and Minozzi 2002; Phillips et al. 1991). With news of the premature cessation of the WHI released simultaneously in consumer and medical publications, HPs were presented with the immediate challenge of interpreting new scientific information before there was opportunity for thorough reading or evaluation, and prior to the publication of official treatment guidelines (Archer 2007; Hemminki 2004; Pines 2005). This challenge is on-going as new information about HT has been appearing regularly in the lay press since July 2002 (*cf*. Gorman et al. 2002; McCullough 2007) and the communication of health information is no longer restricted to the domain of the traditional patient-caregiver interaction (Pines 2005).

While the rapid decline of HT prescribing and use “dramatizes the influence of the media and the Internet on the practice of medicine in the 21st century" (Archer 2007, 29), the role of the mass media as an important information source is supported by a Cochrane systematic review. Grilli et al. (2002) note that both in cases of planned media publicity campaigns and in cases of unplanned media coverage "mass media are the leading source of information about important health issues" (2). These information sources have been found to influence "individual health behaviours, health care utilisation, health care practices and health policy" (2). This review, however, highlights a critical challenge: while the influence of the mass media is clear, the specific impact is difficult to measure. This raises questions about how consumers integrate information encountered in the popular press with information they receive from HPs. These challenges draw attention to the need for qualitative research, such as this dissertation, which explores how individuals experience a range of informal and formal information sources and how these experiences influence IB and decision making.

2.1.4. Controversy, uncertainty and WHI results

Despite pervasive promotion and widespread acceptance of HT prior to 2002, this therapy was not without controversy among feminists, social scientists, HPs, and researchers; and despite the incontrovertible impact of the WHI on clinical practice, controversy and uncertainty about HT continues. The majority of physicians have modified their clinical approach to menopause management; however, uncertainty about HT remains even among physician specialists in gynecology. Bonassi et al. (2005) report that Brazilian gynecologists' intention to prescribe HT decreased and the usefulness of lower doses was reinforced as a result of the WHI; however, most survey participants (66.3%) believed that WHI results were applicable only to the single HT regimen used by patients in the study. Moen, Stein-Tore, and Ole-Erik (2005) found that although there were significant changes in attitude from being more liberal to being reluctant to prescribe after the WHI was published, Norwegian gynecologists' "personal attitude to their own or spouse use of HT was not affected [by WHI results]" (93).

In November 2002, Kaplan et al. (2004) found that 40% of surveyed Israeli gynecologists were limiting HT to patients with postmenopausal symptoms; however, despite contrary evidence produced by randomized controlled trials (RCTs), 40% of participants continued to believe in HT's cardio-protective potential. The literature also suggests that there is inconsistency in how WHI findings are communicated to patients by HPs. There is a lack of agreement between HT-related recommendations made by 'expert' panels (Ettinger et al. 2006), and HPs use a wide range of approaches when talking about medical uncertainty with patients (Griffiths, Green, and Tsouroufli 2005). Furthermore, recently trained HPs are more likely to look for HT alternatives whereas faculty who completed training 10 or more years prior to the 2002 release of WHI results are more likely to recommend HT for most menopausal symptoms (The Florida Behavioral Health Research Consortium et al. 2006).

The WHI has also stimulated confusion and uncertainty for women who were trying to understand how to use HT-related information within the context of their own lives (Barber et al. 2004; Rigby, Ma, and Stafford 2007; Sawka et al. 2004). Hendrix (2003) points out that although the WHI revealed new information about the consequences of HT, emerging information has complicated choices for both providers and patients. Wathen (2006b) notes, "while information may in fact become more clear as medical research evolves, this does not necessarily translate into a reduction in confusion and anxiety on the part of those making health-related decisions" (490-1). Confusion about application of WHI findings has resulted in the view that HPs are not meeting women's needs for information and guidance (Ma, Drieling, and Stafford 2006) and consequently women are turning to other sources for health information.

Given the uncertainty that continues to surround WHI findings, it is valuable to summarize the primary points that have engendered criticism of the WHI trial and controversy about application of WHI findings: only one HT drug regimen was tested; results may not be applicable to women who initiate short term HT at the time of menopause for symptom relief; early termination of trials reduced the precision of estimates related to long-term effects of treatment on primary and secondary outcomes; the absolute numbers of participants suffering adverse events was small although results were statistically significant; and finally, women will be unlikely to forgo HT because "it makes them feel better and improves their quality of life" (Naughton, Jones, and Shumaker 2005, 167). Other factors raising uncertainty about the relevance of WHI results relate to the selection criteria and age of study participants. While the strengths and weaknesses of each of these points have been debated in the medical literature, what is most relevant for the purposes of my dissertation research is that despite the profound effect of the WHI on clinical health care, "evidence-based care for the well woman, like many areas of medicine, is rapidly evolving" leaving both patients and health care professionals confused and uncertain about the evidence base for menopause management (Richardson 2005, 21). In addition, little is known about how people experience uncertain health information and thus "the process of negotiating evidence and its uncertainties is an evolving area of study" (Wathen 2006b, 490). In order to explore how women experience uncertain and/or evolving information about menopause and HT it is first necessary to consider the notion of IB, particularly IB within the context of everyday life and within the context of uncertainty.

2.2 Information behaviour

Beginning in the 1970s, LIS researchers began to branch out from a focus on information systems and services to the study of user-centered information activities. Scholars point to Dervin and Nilan (1986) as being the first to identify the paradigmatic shift to user-centred approaches, and to posit human beings as actively constructing as opposed to passively processing information. With this change in theoretical position, the literature gives evidence of a move from quantitative to qualitative methods, and an increasing inclination to seek "understanding of processes and behaviour, rather than description of system use" (Wilson 1994, 35). Information began to be viewed as "that which modifies a user's internal knowledge structure" and "conceptualizing the information-to-knowledge continuum as it is internalized by users rather than as an objective product destined for the passive recipient" was identified as a critical area of study (Westbrook 1997, 319).

There is now growing consensus in LIS that "design of information systems and services can be improved by moving away from an content-institution-system-centered approach to one that seeks to understand the experience and perspective of the 'human' information user" (Thomas and Nyce 2001, 105). This shift in perspective has led to research into the cognitive, behavioural and affective dimensions of information seeking and use – although even within user-oriented research there is still neglect of the more experiential aspects of information behaviour (Julien 1999b). Most recently LIS researchers have moved towards "an appreciation for the socially constructed nature of 'mental states,' and the embeddedness of mental activity within a social and cultural context" (Thomas and Nyce 2001, 106).

Since Dervin and Nilan (1986) identified the conceptual shift to a user-oriented perspective within LIS research, scholars have used a variety of terms to refer to both specific elements of and the totality of user-centred information activity. However, this area has emerged as a well defined research field within LIS and has come to be identified as *information behaviour* by scholars and major textbooks in the field (*cf.* Case 2007; Fisher, Erdelez, and McKechnie 2005). It should be noted that the notion of *information practice* is also relevant to this study as this concept draws attention to the social contexts of users, the less formal and undirected aspects of information seeking as it occurs in everyday life contexts (McKenzie 2003b), and "the continuity and habitualization of activities affected and shaped by social and cultural factors" (Savolainen 2007a, 126). While discourse on information practice informs this study, this investigation focuses on individuals' experiences and behaviours as they are triggered by specific needs or motives related to uncertain and/or changing health information. Thus, information behaviour has been adopted as an "umbrella concept" (Savolainen 2007a, 109) for this investigation.

Information behaviour is currently understood as a broad concept that spans a range of human behaviour from deliberate and purposeful information seeking to “simply being aware, being conscious and sentient in our social context and physical environment” (Bates 2002, 4). Wilson (2000), lays out the breadth of this area:

> Information behaviour is the totality of human behaviour in relation to sources and channels of information, including both active and passive information seeking, and information use. Thus, it includes face-to-face communication with others, as well as the passive reception of information as in, for example, watching television advertisements, without any intention to act on the information given. (49)

Furthermore, affect is an increasingly relevant variable in IB (Fisher and Julien 2009). Information behaviour research is, therefore, understood to focus on a personal, affective and experiential perspective: “information behavior focuses on how people experience information – their needs, seeking, managing, giving and use – both purposefully and passively in the varied roles that comprise their everyday lives” (Fisher and Julien 2009, 1).

2.2.1 Everyday life information behaviour

While investigation of work-related IB has been a primary focus within the LIS literature (Harris and Dewdney 1994), research trends have recently demonstrated “greater emphasis on the study of ordinary people and their everyday life information seeking” (McKechnie et al. 2002, 124). Since Savolainen (1995) first described ELIS as a means by which people “orient themselves in daily life [or] solve problems not directly connected with the performance of occupational tasks” (267), other scholars have detailed the diverse array of IBs that are a part of ELIS. (1) Information may be encountered incidentally while individuals are engaged in other tasks or looking for other information (Erdelez 1999; Williamson 1998) or it may involve active information seeking or scanning (McKenzie 2003b). (2) ELIS involves constructing information based on the values and specific socio-cultural environment of the individual (Spink and Cole 2006). And (3), ELIS moves rapidly, fluidly and not necessarily systematically between IBs and levels of engagement with sources (McKenzie 2003b). Savolainen (1995) identifies health as a primary concern for individuals engaged in ELIS and in recent years there has been significantly greater interest in health IB within the context of everyday life (*cf*. Case 2007; Fisher and Julien 2009; Wikgren 2003). With the growing public availability of medical information and current emphasis on shared decision making (SDM) in health fields (Salkovskis and Rees 2004; Walter et al. 2004), it is increasingly important that scholars seek to illuminate health IB which takes place within the context of everyday life.

2.2.2 Information behaviour and uncertainty

Although eminent scholars within LIS "point toward feelings of uncertainty, ambiguity, or uneasiness as the root cause of information needs" (Case 2007, 81), IB in situations where information is undergoing ongoing change has received little attention. Dervin's (1999) sense-making theory suggests that humans struggle with incomplete understanding of reality. Through a process of *sense-making* people engage in various IBs to bridge the gaps in their understanding and achieve an end-product which consists of knowledge, opinion, intuition, evaluation, and affective response (Dervin 1992). Wilson (1994) notes that future research should consider "integration of information from multiple sources, and the manner in which conflicting information is resolved" (Wilson 1994, 41). While not directly considering the resolution of conflicting information, Sonnenwald (1999) situates IB within the context of reflection and evaluation of change. This author suggests a range of possible IBs including the decision to ignore change and the decision to seek information in response to change. Godbold (2006) highlights the multi-directionality of IB and "the myriad paths that can be taken through the different modes of information behaviour, from confusion to revelation and back again" (n.p.). While these scholars address the changing nature of information and the subsequent action (or inaction) that change may engender, there is a paucity of literature related to the experience of individuals as they navigate evolving health information. Because of the lack of research on this topic within LIS, and because health care is an area where information is always evolving and where the integration of new information is critical, study of IB within this context is apposite.

2.3 Women's health information behavior

Women's health is a major area of study within health fields and women's health IB has been identified as a developing area of study within LIS (Ankem 2007; Case 2007). Within the context of this research project three areas warrant focused discussion: women as active health information agents, the complexity of information sources influencing women, and women's focus on 'well-being.'

2.3.1 Women as active health information agents

Research demonstrates that women are active information agents who gather, seek and store health information for both themselves and others, particularly for family members (*cf.* Macias, Lewis, and Shankar 2004; Stoller 1993; Wathen and Harris 2006). Studies about women seeking breast cancer information are abundant and these studies focus attention on women as active information seekers in situations where there is an acute health concern (*cf.* Ariail, Watts, and Bowen 2006; Cappiello et al. 2007; Lieberman and Goldstein 2005). In numerous studies, however, women are cited as playing broad and complex roles. Studies point to women not only as important sources of health information (*cf.* McKenzie 2002; Wyatt et al. 2005), but also as primary health information managers who use "just-in-time," "just-because," "just-in-case," and "just-at-hand" strategies as they gather and manage health information for their households (Moen and Brennan 2005, 648). Harris and Wathen (2007) point to the gate-keeping role that women play for themselves, family members, and for others in their personal networks. While many studies focus on women as active information seekers in situations of acute medical need (e.g. breast cancer) and others focus on women's critical roles as health information managers and decision-makers within their households, to my knowledge there is little research on the experiences of women in their roles as active health information agents exhibiting a range of IBs within the context of non-crisis, everyday life health situations.

A handful of studies contrast the health IB of men and women. Wyatt et al. (2005), for example, found that women have much more diffuse networks than do men and that whereas men talk about health primarily with their physicians and partners, women draw on their social networks of family, friends, neighbors and colleagues. Other studies report that women are more involved in health-related decision making and gathering health information than are men (*cf.* Kahn 2001; Macias, Lewis, and Shankar 2004). Urquhart and Yeoman (2010), however, reach the "tentative conclusion" in their extensive examination of gender and IB that although "there seem to be differences between men and women in health information-seeking behaviour. . . . the differences are not substantial, and [are] often only evident with larger samples" (119-120). These scholars further note that sociocultural factors and a paucity of qualitative studies which focus on men challenge scholars who seek to understand gender and IB.

2.3.2. Information sources

Women interact with a complex array of information sources when engaged in health IB. These sources may be formal or informal and include HPs, health organizations, publications such as books or magazines, the internet, and interpersonal relationships (*cf.* Suter et al. 2007; Warner and Procaccino 2004; Wyatt et al. 2005). While the figures within individual studies vary, primary sources of information about menopause, the WHI, and HT include physicians, the media (e.g. newspapers, magazines, and television), friends and family, and the internet (*cf.* Castelo-Branco et al. 2006; Ekstrom 2005; MacLennan, Taylor, and Wilson 2004; Theroux 2005). Genazzani et al. (2006), for example, surveyed European women and found that the main sources of information on menopause were doctors (63%), magazines/newspapers (52%), friends/relatives/colleagues (26%), and the internet (7%). Information on HT risk was primarily obtained from magazines/newspapers (49%), television/radio (32%), and 28% received risk information from their doctors. On the other hand Hoffman, Hammar et al. (2005) found that 43.8% of women received information about HT from newspapers/magazines; 31.7% from TV or radio and 18.3% received new HT information from HPs.

While the internet is not a central area of investigation in studies about women and menopause information, women, health and the internet is emerging as an area of investigation (Klein-Fedyshin 2002). Recent studies indicate that online information seeking is transforming traditional models of health communication and women have been identified as one of the groups most likely to access online health information (Fox 2005). Warner and Procaccino (2004), for example, found that “despite skepticism by the respondents about its reliability, the Web was a highly preferred method for locating health-related information” (720). It is interesting to note that in their sample of 300 women, the highest frequency of online health information seeking fell in the 35 to 64 age range. Given the rapid growth of online use in all areas of everyday life, it is not surprising that an escalating number of people are relying on the internet for important health information (Madden and Fox 2006). Furthermore, the internet’s hybrid nature – health resources may be formal (e.g. information from the National Institutes of Health website) or informal, interpersonal and interactive (e.g. online support groups or blogs) – makes it a potentially important influence on women’s experience with evolving health information.

While the importance of interpersonal information sources for both professionals and lay people is well established (*cf*. Case 2006; Fisher and Julien 2009; Pajarillo 2007; Thompson et al. 2001), an additional information source which is introduced in the literature is intrapersonal information sources (Stephens, Carryer, and Budge 2004; Wathen 2006b). Julien and Michels (2004) draw attention to intrapersonal aspects of IB in their detailed analysis of individual IB in daily life situations. These scholars highlight the importance of exploring not only relevant aspects of the situation and interpersonal behaviour, but also the importance illuminating intrapersonal elements that fundamentally influence IB within everyday life situations. Although some scholars place health beliefs within the parameters of personal context (see section 2.5.2), intrapersonal sources of guidance may also be considered internal information sources. Wathen (2006b) notes, “In the face of confusing or insufficient information from their usual trusted sources (e.g. physicians, the media etc.), women turn to their personal feelings and beliefs” (488-9). In this study women’s accounts of intrapersonal influences are examined in order to explore how women themselves situate their feeling and beliefs.

What is clear from the literature is that different sources facilitate access to varying aspects of information related to menopause, the WHI, and HT. Three examples follow: (1) Sveinsdottir and Ofafsson (2006) found that 51% of participants reported that they received information about menopause from the mass media, whereas 96% received information about the WHI from this source; (2) Genazzani et al. (2006) found that physicians were the primary source of menopause information for 63% of women whereas only 28% received information about HT risk from this source; and (3) while women view physicians as the most reliable source of information for menopause symptom management, they do not have confidence in their physicians’ ability to provide information about the range of treatment options for symptoms management (Ma, Drieling, and Stafford 2006). Women are therefore faced with the challenge of integrating multiple information sources and varying perspectives when navigating information related to menopause and HT. With patient preference and SDM becoming increasingly important in medical decision making (Salkovskis and Rees 2004) and the increasing tendency for women to rely on health information from multiple sources (Macias, Lewis, and Shankar 2004), the question of how women experience and make sense of information has become critical to understanding women’s health IB.

2.3.3 Focus on health as ‘well-being’

Women are increasingly engaging in health IB within the context of ELIS and “either before, instead of, or unrelated to a visit to a doctor” (Warner and Procaccino 2004, 714). Although this is in part because physician-provided information does not meet their needs (Hoffmann et al. 2005b; Macias, Lewis, and Shankar 2004), it is also because of the ‘wellness movement,’ the increasing perception that individuals should take greater responsibility for their physical well-being and health-related decisions (Cangelosi and Markham 1994). Furthermore, women include aspects of nutrition, fitness, family relationships and more within the parameters of wellness (Fox 2005; Macias, Lewis, and Shankar 2004; Wathen and Harris 2006). This broad definition of health inevitably expands the range of sources that women deliberately or incidentally draw from within the course of their everyday lives.

Focus beyond the traditional symptom and disease emphasis of many HPs highlights health IB as a complex undertaking which involves cognitive, emotional and psychological elements. Wathen and Harris (2006) note that interpersonal information sources “provide context about the health issue in question, links to more formal sources such as books, etc. and, importantly, validation, comfort and support” (n.p.). Other scholars have also noted that the emotional experiences and psychological support associated with information transactions can be at least as important as the quality of the information itself (*cf.* Pettigrew 1999; Williamson and Manaszewicz 2002; Wright, Holcombe, and Salmon 2004). Focus on wellness also brings attention to health IB as a process rather than an event. Suter et al. (2007), for example, note that for women seeking to manage menopausal symptoms “information gathering was an ongoing process; as women’s symptoms changed, their information needs changed also” (87).

2.4 Theoretical considerations

Once viewed as the optimum preventative therapy for healthy menopausal and postmenopausal women, current uncertainty about the use of HT presents evident support for the view that even established medical information represents “a transient moment in an indeterminate process of stabilization and destabilization” (Wood, Ferlie, and Fitzgerald 1998, 1730). Uncertainty provoked by the unanticipated results of the WHI brings attention to the provisional nature of health information and highlights the importance of critical analysis of fundamental epistemological assumptions and theories that undergird health information use and health practice. Theoretical consideration of EBP and its positivistic underpinnings and KT theory draws attention beyond evidence as implementable ‘fact’ to a constructionist view of health IB. This is followed in subsequent sections by in-depth consideration of the PARIHS framework’s core elements as a qualitative lens for exploring the broad range of factors which influenced health IB following publication of WHI results; and, consideration of social positioning theory and its application within the context of this research project.

2.4.1 Evidence-based practice

The idea that health care should be based on the best available research evidence is not new to modern medicine. The means of achieving this principle, however, has been formalized through the principles of EBP, a relatively young paradigm that has come to dominate education, research, and practice within health care fields. A primary element of EBP, and one which some view as a key contribution to health research and clinical practice, is an emphasis on the hierarchy of evidence (Hurwitz 2004). This formal ordering of evidential reliability suggests a linear progression in which the higher a study is ranked within the methodologically determined hierarchy, the closer to objective truth it is assumed to be and the greater confidence end-users assume in its clinical application

(Evans 2003). Although attention has more recently been directed towards *strength of evidence* (*cf*. Colema, Talati and White 2009; Gugiu and Gugiu 2010) (the idea that the hierarchy of evidence provides an insufficient warrant for the superiority of a study if one is considering, for example, evidence derived from a poorly designed RCT versus evidence provided by a well-designed non-RCT), EBP in health fields continues to focus primarily on quantitatively derived evidence and to promote positivistic knowledge claims (Tonelli 1998).These positivistic claims are, however, intrinsically challenged by the evolving nature of health information. A recent study, for example, found that although systematic reviews are ranked highest within the hierarchy of evidence, a significant proportion of these studies are outdated within a short period of time, sometimes before they are even published (Shojania et al. 2007). Furthermore, despite the methodological rigor with which these meta-analyses are conducted, their clinical value is compromised because they commonly fail to provide the "clinically nuanced contextualization" (Laupacis and Straus 2007, 2) which would allow end users to weigh findings and determine application to individual patients and in situations of evolving practice.

While some scholars are beginning to recognize that evidence hierarchies which privilege empirically derived knowledge are not applicable in all circumstances (Norman 1999), the influence of these hierarchies permeates health fields. As a result, experiential and value-based aspects of health decision making are commonly positioned as secondary to empirical evidence (Tonelli 1998), and scholars are forced to defend the legitimacy of knowledge derived from qualitative research (*cf*. Given 2006; Côté and Turgeon 2005). Although concern about the misapplication of RCTs and the neglect of knowledge not amenable to RCTs (*cf*. Kotaska 2004; Lockwood 2004) has encouraged scholars to develop evidence hierarchies that facilitate the evaluation of qualitative research (*cf*. Cesario, Morin, and Santa-Donato 2002), the linear ordering of evidential reliability continues to promote a positivistic theoretical stance and an understanding of research knowledge as an objective information 'package' which is available for 'uptake' by clinicians and patients. This perspective belies the complex, non-linear process entailed in the utilization of health information by both clinicians and patients (*cf*. Dopson and Fitzgerald 2005; Kitson, Harvey, and McCormack 1998).

Although the EBP literature commonly presupposes the validity of an epistemologic framework that positions clinical studies as the optimum source of health knowledge, there is evidence of a shift towards a more integrated view of knowledge (Tonelli 1998). Moving away from the disregard for clinical intuition and experience expressed by early EBP scholars (Evidence-Based Medicine Working Group 1992), Sackett et al. (2000) have defined EBP as "the integration of best research evidence with clinical expertise and patient values” (1). Lockwood (2004) takes this definition one step further: “evidence, as moderated by clinical expertise and filtered by our basic individual values, will be the basis of excellent health care” (1035). And, more recently, the notion of *narrative evidence-based medicine* has brought focus to patient perspectives by highlighting the importance of situating patients within their own stories in order to help HPs make sense of patients’ experiences (Goyal et al. 2008). Although this more integrated view of EBP acknowledges the complexity of clinical judgment and the critical role of patient perspectives, the integral inclusion of contextual factors within this definition has been largely overlooked and EBP remains a primarily “cognitive-rational enterprise” (Bensing 2000, 17). In order to explore health IB in situations of evolving health information one must therefore look beyond EBP and its epistemological limitations to theoretical frameworks which incorporate a broader spectrum of factors influencing the utilization of health information and a fundamental understanding of health knowledge as provisional, emergent and incomplete (Upshur 2001).

2.4.2 Knowledge translation

The basic premise of EBP, that clinical decisions be based on sound research evidence and clinicians be equipped with tools that facilitate currency with the burgeoning literature, has had a significant impact on health care in North

America and the UK (Norman 1999). In spite of this impact, however, the gap between evidence and practice remains one of the most consistent findings in health research (Grol and Grimshaw 2003). Theory development and research related to the evidence-practice gap has resulted in a new and influential area of study, *knowledge translation* (sometimes used interchangeably with *knowledge utilization*) (Schryer-Roy 2005).

Theories within the field of KT clearly articulate a wide range of contextual factors which, in addition to published research evidence, critically influence the implementation of knowledge in everyday health practice. Some theories, for example, emphasize the role of attitudes, perceptions and intentions, while others focus on social interaction and influence, and yet others explore organizational and economic factors that influence how evidence is implemented in health care practice (Grol et al. 2005). A key feature of these various theories is that instead of a linearity of cause (research evidence) and effect (evidence-based health practice), change is viewed as a constructed process that entails interaction between multiple factors, all of which demand detailed attention in order to understand and facilitate the implementation of new knowledge.

Notwithstanding recognition that the translation of knowledge to practice is a complex and contextually situated process, close examination of KT literature reveals two distinct theoretical stances. The first perspective maintains positivistic presumptions and is based on the premise that one is seeking to implement specific practice guidelines or ‘best practices.’ From this perspective the goal of KT is to understand and manage contextual factors while seeking to bridge the evidence-practice gap. This perspective is, however, challenged by areas of practice where health information is emerging or evolving and where, consequently, there is acknowledged uncertainty within the literature, practice guidelines are not clearly delineated, or there are differences in the interpretation of evidence. Wathen (2006b), for example, notes that following publication of WHI results there was both an absence of practice guidelines and a paucity of practical information available to women who wished to stop using HT.

Furthermore, Ettinger et al. (2006) note that current consensus-based recommendations for HT vary between panels of medical experts.

Most recently a second, constructionist theoretical perspective can be found within KT literature. Gherardi (2006) contends that knowledge is not static; it represents a constructed process that is based on both research and experiential knowledge as well as on reflection, negotiation of meaning, situational factors, and material artifacts. This perspective is similar to findings within IB research where information is viewed as "that which modifies a user's internal knowledge structure" (Westbrook 1997, 319) and interest focuses on how both formal and informal information is applied as people seek to make sense of their lives and situations (Julien 2002). A constructionist perspective also highlights the social nature of KT: knowledge is converted into use through a process of interpretation, social influence, and debate within communities of practice (Fitzgerald et al. 2005). Social constructionism therefore draws attention to the translation of knowledge as an active process in which new understanding is constructed from encountered information, existing knowledge structures, personal experience, and socio-cultural environments (Talja, Tuominen, and Savolainen 2005).

2.4.2.1 KT within the context of everyday life

Although KT can be broadly understood as a process that transfers research results and research based knowledge from knowledge producers to users, definitions of KT commonly focus at the system level. A widely used definition comes from the Canadian Institutes of Health Research (CIHR) (2009): "knowledge translation is a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system." Micro level theory tends to focuses on HPs (Grol et al. 2005); however, KT theory can also be applied to women as they seek to *translate* health information within the context of everyday life use and personal health decision making. Choi (2005), for example, notes that KT entails a process whereby research knowledge is integrated and simplified into a product "suitable for use by decision makers" (93). While decision makers are commonly viewed as HPs, current focus on SDM, particularly in areas of medical uncertainty (Salkovskis and Rees 2004), facilitates the view that individuals may also engage in a process of KT as they respond to, make sense of, and use health information encountered within the context of medical appointments, everyday exposure to health research communicated through media sources, internet exploration, or informal interpersonal exchanges. Schryer-Roy (2005) notes that KT is a subtle and iterative process that "tends to occur through a process of 'creeping,' where background assumptions and the concepts that frame discourse are gradually transformed" (3). This description highlights the personal, contextual, and constructed view of KT that is taken within the context of this research project.

2.4.2.2 KT and information behaviour

KT theory presumes that health information does not remain static and that clinical practice and decision making should be modified by changing health evidence. Theories within this field of study can therefore effectively illuminate the study of IB within the context of uncertain or evolving health information. The PARIHS framework, for example, which suggests that successful implementation of change is "a function of the relation between the nature of the evidence, the context in which the proposed change is to be implemented, and the mechanism by which the change is facilitated" (Kitson, Harvey, and McCormack 1998, 150), provides core elements which coincide with concepts found within IB research and which highlight KT as a contextually situated and socially constructed process. Because these core elements are described qualitatively rather than quantitatively (Rycroft-Malone et al. 2002), they have been used as a framework for shaping semi-structured interviews and for qualitative analysis of interview data (Alkema and Frey 2006). It is fruitful to explore the PARIHS framework in greater depth as it provides a simple and yet comprehensive lens which supports a social constructionist viewpoint by facilitating exploration of the diverse factors that contribute to women's health IB.

2.5 PARIHS: A heuristic for exploring KT and uncertainty

The core elements of the PARIHS framework (evidence, context, and facilitation) provide a heuristic which facilitates comprehensive exploration of health IB in situations where there is uncertainty because of evolving health information, and a lens for exploring the range of factors that influence post-WHI health IB.

2.5.1 Evidence

While evidence as a positivistic object has come to dominate discussions within health fields, the PARIHS framework notes that research evidence is “only one part of the picture in clinical decision-making” (Rycroft-Malone et al. 2002, 175). Emphasizing that different evidence is needed to answer different clinical questions, this framework draws attention to experiential, social, and tacit aspects of evidence. The acknowledgment of an evidence spectrum is critical in situations where different perspectives are evident in the literature, where published health information is evolving, and where the application of evidence in practice is uncertain.

In the late 1990s and early 2000s, for example, the literature provided varying perspectives on the benefits of HT. Medical publications emphasized the benefit of this pharmacological intervention and ‘patient compliance’ was viewed as the primary barrier to appropriate menopause management (Pitkin 2002). Qualitative studies, on the other hand, illuminated a different perspective: women were likely to take HT on a short-term basis for vasomotor symptoms, but many felt apprehensive about HT’s long-term implications and viewed this therapy as undesirable except in circumstances where symptoms were ongoing and distressing (*cf*. Hunter, O'Dea, and Britten 1997; Stephens, Budge, and Carryer 2002). While quantitative research evidence suggested that compliance was inappropriately low, qualitative research focused on women’s experiences and revealed that women were choosing to use HT primarily for hot flashes. Given that actual HT compliance rates approximated the number of women suffering from this symptom (Hunter, O'Dea, and Britten 1997), compliance rates might be viewed as appropriate for patient-centered clinical practice where there is a broad understanding of evidence.

The PARIHS framework asserts that the evidence base for health practice is rarely constant and, furthermore, that “the production and use of evidence is a social as well as scientific process” (Rycroft-Malone, Seers et al. 2004, 84). This stance is critical to the exploration of IB in the face of evolving health information. In the case of HT, there is clear indication that the evidence base continued to evolve even as support for this therapy was growing. For example, despite increasing acceptance in the 1980s and 1990s of HT as a long-term preventative therapy for healthy menopausal women, studies were being published that raised concerns about HT. Although these studies had little immediate impact on HT use and, in the short term, were largely “disregarded in lieu of the less credible evidence that fit the prevailing paradigm” (Herrington and Howard 2003, 519), they demonstrate that even as health practices conformed to the established paradigm, the evidence base was evolving dramatically. This draws attention to the production and use of evidence as a simultaneously social and scientific process. Haas et al. (2004) point out that dissemination of new information that conflicts with current wisdom may have a cumulative impact on health practices. This suggests that pre-WHI studies raising concerns about HT as a long-term preventative therapy, while not having immediate impact on clinical practice, influenced the social and scientific environment into which WHI results were released, thus contributing to the WHI’s significant impact on HPs’ and patients’ behaviours.

While HPs frequently strive to “creat[e] a myth of certainty around what is inherently uncertain through the way the medical evidence is presented and discussed” (Griffiths, Green, and Tsouroufli 2005, 516), navigating menopause and HT in the post-WHI era inevitably “involve[s] complex decision making in the face of uncertainty” (Walter et al. 2004, 121). The PARIHS framework contributes to this complex process and to effective health IB in the face of uncertain scientific evidence by highlighting a range of potential sources of evidence available for clinical application, specifically: research, clinical experience, patients, clients and carers, and local context and environment (Rycroft-Malone, Seers et al. 2004). While elucidation of this range of evidential sources contributes to comprehensive understanding of evidence, evidence does not effect change within a void; context is a critical element for the successful implementation change.

2.5.2 Context

Despite the largely unacknowledged importance of context within EBP literature, context has been recognized as a fundamental component for the implementation of health care change (Grol et al. 2005). The PARIHS framework makes significant theoretical contribution to health fields by positioning context as a core element for the successful translation of knowledge into clinical practice. While the WHI provided research evidence that produced a dramatic shift in attitude towards and use of HT, its influence on attitudes and behaviour did not occur within a vacuum. Understanding HT use and the impact of the WHI demands "engaging not only with the science of [HT] but also the social, political, and institutional context" (Krieger et al. 2005, 746).

While Krieger et al. (2005) highlight macro-level contextual influences such as the women's movement, industry, and regulatory agencies, the literature also draws attention to the critical role of personal context in the IB of HPs and patients. Allen and Mansfield (2004) found that underlying health beliefs and cognitive frameworks strongly influenced physicians' understanding of evidence and their approach to treatment decisions in the post-WHI era; and Fugh-Berman and Scialli (2006) note that medical specialties have "discrete patterns of socially determined beliefs" (127) which influence information use in clinical practice. Health beliefs are also central to women's health IB: a longitudinal study of women's decision making before and after the publication of WHI results substantiates the "central role of health beliefs in conditioning health-related behavior over and above past behavior" (Gerend et al. 2006, 162). Furthermore, a meta-analysis of 16 qualitative studies found that contextual factors such as attitude, beliefs and values were primary factors influencing women's information use in the process of HT related decision making (Schapira et al. 2004). The concept of personal context is closely related to notions of intrapersonal information sources found within LIS research. Semi-structured qualitative interviews with women who had been or who were currently navigating uncertain information about the menopause transition provided an opportunity to examine emerging themes related to intrapersonal information sources and personal context.

Although the biomedical discourse, which suggests "context free concepts of health and health risk" (Griffiths, Green, and Bendelow 2006, 1088), continues to be a dominant force in health care, the inclusion of clinical expertise and patient values as moderating elements within the definition of EBP (Sackett et al. 2000) provides support for the notion that evidence is operationalized through a filter of individual, social and institutional contextual factors. The heuristic provided by the PARIHS framework facilitates explicit recognition of context as a central element of KT and lends theoretical support to the view that context is not "backcloth to action" (Fitzgerald et al. 2005, 156); rather, it is a multidimensional and interacting element which is critical to an understanding of IB in situations where health information is uncertain and/or evolving. Although macro-level contextual factors are highly relevant to discussions of menopausal HT, my dissertation research is concerned with the experiences of women and is therefore primarily concerned with context from the perspective of the individual.

2.5.3 Facilitation

Facilitation, the "process of enabling (making easier) the implementation of evidence into practice" (Harvey et al. 2002, 579), has been identified as the most influential element in overcoming barriers to the translation of knowledge into clinical practice (Ellis et al. 2005). Although this PARIHS element may be viewed as a distinct intervention designed to achieve a specific change in clinical practice, scholars note that facilitation can occur at a variety of levels and that multiple individuals may formally and informally enable individuals or health teams to "analyze, reflect and change their own attitudes, behaviors and ways of working" (Stetler et al. 2006).

Information behaviour research supports the view that navigating new information is a complex process which benefits from intervention by a mediator or facilitator (*cf*. Kuhlthau 2004; MacIntosh-Murray and Choo 2005). This finding is applicable in health fields. Medical uncertainty is a "key aspect in understandings of contemporary interactions between health professionals and patients" (Griffiths, Green, and Bendelow 2006, 1078) and although practitioners have traditionally functioned as authoritative information sources, HPs are increasingly taking the role of facilitator within a SDM model (Salkovskis and Rees 2004; Walter et al. 2004). Guided by Newman's (1997) theory of health as expanding consciousness, Tommet (2003) describes the role of nurses during times of medical uncertainty as being "to facilitate the process of pattern recognition through a nurse-[patient] partnership, enabling [patients] to find meaning in their life situation, including opportunities for action" (245). This study found that participation in a facilitating, relational process allowed insight, self-organization, and decision making, whereas encounters with health care workers who focused strictly on medical care and procedures increased disruption and confusion. It is interesting to note that the notion of facilitating pattern recognition in order to increase understanding of alternatives and facilitate decision making bears resemblance to Dervin's (1992) sense-making theory, which incorporates notions of life as an encounter with discontinuities in knowledge and an active, process-oriented view of IBs.

HT decision making is described as "representative of clinical decision-making in the face of scientific uncertainty" (Legare et al. 2005). It is relevant to note that uncertainty about HT is stimulated and maintained in part by the way evidence is being communicated to women and HPs. The widespread circulation and discussion of WHI study results in the consumer press occurred simultaneously with the presentation of this new research in medical journals and prior to the publication of official treatment guidelines. This left many physicians unprepared for both the challenge of translating these unexpected research findings into clinical practice and their role as a facilitator for SDM. These challenges were magnified by that fact that WHI results demanded "an abrupt change in practice, performed often in front of the patient" (Allen and Mansfield 2004, 939). In addition, Pines (2005) notes that a large proportion of HPs rely on the mass media for medical information and thus this medium has become in itself an important facilitator of health information: "information and opinions obtained from the media have become major determinants in the patterns of drug use" (364). Woloshin and Schwartz (2002) note that press releases from medical journals to the mass media and online communications have become routine means by which new health information is communicated to both consumers and HPs. Notwithstanding its potential for poor quality and generalized rather than individualized health information, the mass media is widely cited by post-WHI studies as a primary source of consumer information about the WHI and as having a significant influence on HT use (Breslau et al. 2003; Barber et al. 2004; MacLennan, Taylor, and Wilson 2004; Heitmann, Greiser, and Dörin 2005; Hoffmann, Lindh-Astrand et al. 2005; McIntosh and Blalock 2005). Although clearly a double-edged sword (it empowers individuals by providing direct access to research evidence, while at the same time presenting information that may be incomplete or biased), the mass media has become a significant facilitator in the communication of evolving health information and a powerful means of influencing patient/health provider dialogue.

Current practices related to the communication of novel research evidence suggest that a broad view of facilitation as it occurs on a variety of levels both formally and informally must be taken when exploring health IB. Wathen (2006b), perhaps inadvertently, draws attention to the integration of evidence, context and facilitation which undergirds health IB: "simply obtaining facts about [HT] is only one aspect of a larger multi-factorial process of becoming *informed* about [HT] in a contextually relevant way that can then allow decisions to be made" (478). My study moves beyond investigating how women obtain medical information and examines how different forms of facilitation influence women's experiences with evolving and uncertain health information.

2.5.4 Limitations of the PARIHS framework

Fundamental to the PARIHS framework is the view that implementation of evidence in practice is a function of the "dynamic simultaneous relationship" between evidence, context and facilitation (Rycroft-Malone et al. 2002, 174). This fundamental schema provides an effective lens for exploring women's experiences with evolving health information. There are, however, two potential concerns that must briefly be considered. These concerns relate to the positivistic positioning of context and the limited view of facilitation promoted by some scholars.

Despite recognition of context as a fundamental influence on change in health care, concept analysis within the PARIHS framework narrowly defines the sub-elements of context as culture, leadership, and evaluation that delivers feedback and contributes to change (McCormack et al. 2002). Resources have also been suggested as an additional element of context (Rycroft-Malone, Harvey et al. 2004). Contextual elements are thus positivistically positioned as objective entities available for enumeration and elaboration. Notwithstanding this limited perspective, the PARIHS framework has potential to draw attention to a post-modern view of context. For example, context from the PARIHS perspective plays a critical role in the availability of information resources, the means by which evidence is communicated to HPs, and the roles that different communities of practice play in the implementation of evidence. This inevitably brings focus to post-modern contextual elements such as the reserve of themes and points of view that frame interpersonal communication and influence the IB of individuals. A broader socio-cultural perspective on context emerges when the PARIHS framework is viewed as a heuristic for examining factors influencing KT. This perspective has potential to align with a social constructionist perspective and with the view that actors are “embedded in complex, multiple, overlapping, and dynamic contexts, elements of which include sociality, culture, institutional rules and resources, technological change, and power relationships” (Courtright 2007, 291).

While the fundamental premise that evidence, context, and facilitation are all critical to KT provides a strong basis from which to explore how individuals make sense of and use evolving health information, the PARIHS framework is secondarily limited by a narrow view of facilitation. Specific concept analysis within the context of this framework limits facilitation to situations where an appointed facilitator helps or enables a specific and planned change in practice (Harvey et al. 2002). This narrow perspective not only ignores the facilitating role of different information sources and communication media, it also ignores the facilitating role that different types of relationships may entail. Social network theory, for example, indicates that whereas weak social ties play a critical role in facilitating the communication of new information between groups, change in practice is most likely to be stimulated by strong ties (*cf*. Granovetter 1973; Weenig 1993). Furthermore, in areas of health care where evidence is evolving, facilitators cannot enable specific practices; their role must be to promote informed and SDM. This study follows the lead of scholars who have used the PARIHS framework, but who have at the same time moved beyond narrow definitions of facilitation and described this core element as occurring in a variety of ways, both formally and informally (Stetler et al. 2006).

While the noted limitations must be considered, they can be overcome if PARIHS elements are viewed as a heuristic for exploration rather than as a positivistic framework. In its recognition of the equal and critical contribution of evidence, context and facilitation, this heuristic contributes to the exploration of IB in situations where health information is evolving. In order to understand health IB in situations of uncertainty, it is necessary to view evidence not as something that is *implemented*, but rather as something that is *translated* into practice through a highly contextual process that is facilitated formally and informally by individuals, information sources, and communication media.

Finding an effective theoretical perspective for exploring uncertainty in a field that is dominated by the linear concepts of the evidence-based paradigm is challenging; however, the PARIHS framework provides a lens that supports a social constructionist viewpoint while facilitating exploration of factors that critically influence health IB. The view that evidence, context, and facilitation make equally vital contributions to the translation of health information into everyday practice provides an effective theoretical perspective for exploring the uncertainty that followed the publication of WHI results and for exploring women's experiences as they respond to, make sense of, and use evolving health information. In addition to looking to evidence, context, and facilitation as guiding concepts for exploring women's experiences with changing health information, this dissertation draws on social positioning theory as a means of illuminating the interactions of individual women with their sociocultural context and the influence of social interactions on health IB.

2.6 Social positioning theory

Social positioning theory is a constructionist framework "that has proven useful for studying the relationship between interactional practices and information seeking" (McKenzie 2004, 685). The concept of 'positioning' contrasts with the more static and formal concept of 'role' (Davies and Harré 1990), and draws attention to the dynamic aspects of encounters and the multiple 'storylines' that are used both unintentionally and intentionally to construct identity within social interactions (Julien and Given 2002). Van Langenhove and Harré (1994) describe 'positioning' as "the use of rhetorical devices by which oneself and other speakers are presented as standing in various kinds of relations" (362). These relations exist as reciprocal to other positions and include "relations of power, relations of competence (knowledge/ignorance), relations of moral standing (trustworthy/trusting) and so on" (Van Langenhove and Harré 1994, 362). Positioning relates to both context and facilitation as it brings focus to "the interaction of the individual and the sociocultural context" (McKenzie 2004, 685) as well as the "social complexities that inform individuals' information behaviors" (Given 2005, 334).

Within the context of LIS, social positioning theory has been used to explore individual identity and the influence of social interactions on IBs (Given 2005). Application of this theory is, however, limited (Given 2002; Julien and Given 2002). Within the context of health IB it has been used to facilitate exploration of pregnant women's information seeking (McKenzie 2002; McKenzie 2003a) and investigation of how the visibility of health status affects IB (McKenzie and Carey 2000). Within the nursing literature (as represented by CINAHL and Dissertation Abstracts) use of social positioning theory is also limited. It has been used to explore the relationship between First Nations women and nurses (Browne 2003), the development of professional identity (Lentz 2007; Phillips, Fawns, and Hayes 2002) and mental health care experiences (Platzer 2004).

Although not identified as such, examples of positioning can be found in the medical literature. Within pre-WHI literature, for example, postmenopausal women are positioned as unhealthy patients in need of medical intervention: "at this time [menopause] a series of biological transformations takes place and each of those will interfere with the lifestyle and well-being of the last period of a woman's existence" (Genazzani and Gambacciani 2001, S49) . At the same time medical publications positioned women as non-compliant recipients of recommended HT treatment (*cf.* Kaplan et al. 2002; Pitkin 2002; Thompson 1995). In post-WHI literature, however, women tend to be positioned as participants in SDM (*cf.* Salkovskis and Rees 2004; Schonberg, Davis, and Wee 2005; Walter et al. 2004; Welton et al. 2004). Griffiths, Green and Bendelow (2006), in their investigation of uncertainty and three areas of health concern for women (breast screening, HT, and bone densitometry) conclude that medical uncertainty has had a dramatic impact on the relations between women and HPs and is a key consideration when seeking to understand interactions between HPs and women.

Social positioning theory adds depth to this dissertation project by moving analysis beyond women's accounts of health IB as transparent representations of experience and providing a metaphor for exploring how women position themselves and others in the personal stories they relate, and how that positioning shapes their health IB. This perspective is particularly relevant to the qualitative exploration of health IB within the context of everyday life: it offers a means of understanding how women represent and justify information sources as authoritative (McKenzie 2003a, 261) and how they identify themselves with respect to formal and informal information sources. Because subject positions are dynamic and changeable depending on the circumstances of the speaker, they provide insight into women's contexts and how they experience facilitation. Social positioning theory therefore also contributes to understanding of how women respond to, make sense of, and use uncertain and/or evolving information about HT and menopause.

Social positioning theory draws attention to interpersonal elements of constructionism and to the meaning that is made between people. Constructionism has also, however, been used in a general sense by LIS scholars to represent people as actively constructing as opposed to passively processing knowable reality (*cf*. Dervin and Nilan 1986; Kuhlthau 2004). Information from this perspective is viewed as something that is "moved and shaped in unique ways by each perceiver" and within the context of the individual's relationships with other people as well as their time and space (Dervin 1983, 169). Although *constructivism* has been recently used to represent the view that the individual mind constructs reality within the context of an external world, it is also acknowledged that "there is no single correct way of labeling metatheories or drawing the lines between positions" (Talja, Tuominen, and Savolainen 2005, 94). This research is situated within a social constructionist viewpoint in order to highlight translation of knowledge as a process in which people draw on intrapersonal contexts, interpersonal encounters, existing knowledge structures and experiences, and socio-cultural environments as they construct 'sense' (consisting of knowledge, opinion, intuition, evaluation, and affective response (Dervin 1992)) from evolving health information.

2.7 Qualitative inquiry

This exploratory research is based on interpretivist knowledge claims and a social constructionist perspective which focuses on emergent realities, process, context, and the assumption that meaning is created between people. The goal of the project is to generate insight into women's experiences with uncertain and/or evolving health information about HT and menopause, and priority is given to revealing patterns and connections, rather than determining causality (Charmaz 2006). In order to accomplish this goal, qualitative methodology, which addresses questions that tend to begin with 'what,' 'how,' 'why,' or 'in what way does' (Greenhalgh 2002), and which seeks to explore processes that are context dependent (*cf*. Donaldson, Rutledge, and Ashley 2004; Tripp-Reimer and Doebbeling 2004) is most appropriate. Furthermore, since health information is a primary area of concern for individuals engaged in ELIS (Savolainen 1995) and since this exploration seeks to illuminate the experiences of women as they respond to, make sense of, and use uncertain and/or evolving information within the context of their everyday lives, qualitative inquiry is the optimal means for revealing relevant data.

2.7.1 Qualitative interviewing as method

Qualitative interviewing complements a social constructionist approach to research and provides rich data which facilitates exploration of the research questions posed in this study. As noted by Warren (2002), the "epistemology of the qualitative interview tends to be more constructionist than positivist" since participants are viewed "not as passive conduits for retrieving information" (83) but as actively involved in constructing meaning from various perspectives. Furthermore, the "topic of qualitative interviews is the everyday lived world of the interviewee and his or her relation to it" (Kvale 1996, 30). Thus, qualitative interviewing, which accepts "people's knowledge, views, understandings, interpretations, experiences, and interactions" as meaningful properties of the reality being researched (Mason 2002, 63), is an apposite research method for exploring women's experiences in situations where health information is uncertain and/or evolving.

Seidman (1998) notes that the goal of qualitative interviewing is not to find specific answers or test hypotheses, rather, at the root of this research method is "interest in understanding the experience of other people and the meaning they make of that experience" (3). The purpose of qualitative interviewing is, therefore, to listen to the conveyed meaning, derive interpretation from the respondent's talk, and "unveil the distinctive meaning-making actions of interview participants" (Warren 2002, 86). The 'stories' that women tell during interviewing (for example, their thoughts and actions when they encounter information about HT in the media) are accordingly viewed as a constructive process of "selecting constitutive details of experience, reflecting on them, giving them order, and thereby making sense of them" (Seidman 1998, 1). Becker (1997) notes that narratives are performative and empowering, and that through stories people constructively "organize, display, and work through their experiences" (25).

Interviewed women did not indicate that they had specifically analyzed the influence of and their reaction to changing health information encountered within the context of their everyday lives; rather, participants' narratives were "oriented towards making their own and others' acts meaningful and understandable" (Tuominen, Talja, and Savolainen 2005, 328). Interviews, therefore, were a means of generating description and "produce[ing] and build[ing participants'] experience, emotions, identities, and social worlds" (Tuominen, Talja, and Savolainen 2005, 328-9). In other words, they demonstrated "the capacity to be interactional contexts within which social worlds come to be better understood" (Miller and Glassner 1997, 109).

Seidman (1998) observes that it is not possible to completely understand another human being; however, interviewing allows access to the context of experience and thus provides a way of understanding the meaning of various actions. Context is used "to place people and action in time and space and as a resource for understanding what they say and do" (Patton 2002, 63). Furthermore, interviews are "particularly suited for studying people's understanding of the meanings in their lived world, describing their experiences and self-understanding, and clarifying and elaborating their own perspective on their lived world" (Kvale 1996, 105). The capacity of qualitative interviewing to tolerate both contrasting and emerging perspectives uniquely allows exploration of the multiple layers of women's experiences with uncertain health information and different levels of listening, which then allows different levels of analysis and deeper understanding (Seidman 1998).

2.7.2 Approaches to qualitative interviewing

Many texts dealing with qualitative interviewing attempt to further delineate various approaches to this research method through formal definition of different types of qualitative interviews. Johnson (2002) and Seidman (1998), for example, focus on 'in-depth interviewing,' while Holstein and Gubrium (1997) describe the 'active interview,' and Rubin and Rubin (2005) highlight 'responsive interviewing.' Many of these differentiations, however, are simply shades within the same spectrum. These specific approaches highlight individual features of qualitative interviewing: Johnson (2002) focuses on the potentially personal nature of revealed information and the articulation of multiple views and perspectives; Seidman (1998) notes that interviews should go to sufficient depths so that surface considerations of representativeness and generalizability are replaced by "a compelling evocation of an individual's experience" (44); Holstein and Gubrium (1997) describe the interview as "an occasion for constructing" (120); and 'responsive interviewing' is identified as a dynamic iterative process in which the interviewer modifies questions to match knowledge and interests of participants. While these individual descriptions focus on specific facets of qualitative interviewing, real life qualitative interviewing commonly draws on a variety of these features.

Within the spectrum of qualitative interviewing, interview focus is shaped by research goals, and the object, topic or concept of interest. The dissertation is primarily exploratory and thematic since interviews specifically explore the challenges women face when navigating changing health information. Because a specific context (navigating information related to management of the menopause transition) is used to elicit participant reflection on changing and uncertain health information, participants were encouraged to ‘tell the story’ of their experiences, thus incorporating narrative elements into the interview. While a narrative approach can be used in conjunction with a semi-structured question and answer format, the emphasis of this approach remains on the perspective and experience of the participant as related in “their own language, using their own terms of reference, and emphasizing actions or participants which they regard as being significant” (Bates 2004, 16). Petersen (2006) notes that patient narratives provide critical insight into the “untapped resource” (32) of patient experience and that understanding of this tacit knowledge will improve patient care and quality of life.

Use of elicitation techniques within the context of qualitative interviewing can also be used to elicit tacit understanding and subconscious thoughts. While critical incident technique focuses on direct observation of people performing tasks or participant recall of past experiences (Borgen, Amundson, and Butterfield 2008), Johnson and Weller (2002) point out that techniques which focus on ‘in the moment’ presentation of elicitation material have “an exploratory or emergent character” (492) which enable researchers to “better understand, describe, capture, and model tacit knowledge” (512). These scholars point out this approach can be “one element in a long sequence of data collection” (494) and that elicitation can be particularly useful where the researcher seeks to elicit “properties, features, or reactions that are directly and/or indirectly relevant to the content area” (495). Elicitation techniques are also suggested as a basis for contrast and comparison across participants. Although this approach to qualitative interviewing has received limited attention in the literature, this may be because it is used without identification. Vardeman and Aldoory's (2008), for example, report that they presented contradictory newspaper articles to focus groups in order to elicit reflections and behaviour intentions with respect to fish consumption. This approach was described, but was not identified as a specific interview approach.

Because this study focuses on a specific medical context and on the overarching issue of health IB in situations where information is uncertain and/or evolving, semi-structured interviews and open-ended questions are used to generate meaningful, situated knowledge relevant to the area of inquiry. Mason (2002) outlines a general strategy for planning and designing semi-structured qualitative interviews. This strategy begins with overarching research questions and mini-research questions, and then progresses to the development of actual interview questions. This author emphasizes cross-referencing of all levels in order to ensure that "each big research question has a set of corresponding mini-research questions, and each of these has a set of ideas about interview topics and questions" (70). This strategy facilitated the development of the semi-structured interview as well as potential interview probes.

2.7.3 Methodology: Linking method to outcomes

The strategy or plan of action that lies behind the choice and use of a particular method and links the choice and use of methods to outcomes is critical to research design. While there is generalized acceptance that qualitative research includes elements of grounded theory (Charmaz 2002) such as coding and categorization of data and the emergent nature of relevant issues and ideas (*cf.* Gillham 2005; Rubin and Rubin 2005; Seidman 1998; Wengraf 2001), variations arising from research focus and disciplinary background can be found.

In order to explore how women experience uncertain and/or evolving health information, how the construction of that information impacts health IB, and how women position themselves in terms of uncertain health information, the methodological approach used in this dissertation incorporates Kvale’s (1996) ‘ad hoc’ approach to generating meaning from qualitative interview data. This is described as an eclectic approach using “a variety of commonsense approaches to the interview text …. [which] can be used to bring out the meanings of different parts of the material” (193). These methods may include the following: (1) techniques that facilitate understanding of relationships between data including noting patterns/themes, seeing plausibility, and clustering; (2) counting to see how much of something is there; (3) making comparisons or contrasts to sharpen understanding; (4) subsuming particulars under general headings, or factoring, or seeing relations between variables, or finding intervening variables – variant approaches to seeing relationships on a more abstract level; and (5) building chains of evidence or developing conceptual/theoretical consistency in order to assemble coherent understanding of data. Kvale (1996) notes “the most frequent form of interview analysis is probably an ad hoc use of different approaches and techniques for meaning generation” (203). Other authors also call attention to the eclectic methodological possibilities for approaching qualitative interview data: Rubin and Rubin (2005), for example, observe that “analysis entails classifying, comparing, weighing, and combining material from the interview to extract the meaning and implication, to reveal patterns, or to stitch together descriptions of events into a coherent narrative” (201). Kincheloe (2001), defending the use of methodological bricolage, suggests that “any single research perspective is laden with assumptions, blindnesses, and limitations … researchers must learn a variety of ways of seeing and interpreting in the pursuit of knowledge” (682).

While intrapersonal dimensions of health IB are critical to understanding women’s experiences with uncertain health information, exploring the construction of uncertain and/or evolving health information and how women position themselves in terms of this information requires attention to “the embeddedness of mental activity within a social and cultural context” (Thomas and Nyce 2001, 106). How participants experience changing health information is therefore understood as being embedded in culturally and institutionally bound discourses that not only “allow reality to be ‘known’ from a certain angle,” they also supply the reserve of “themes and points of view that we use in sense-making” (Talja 1997, 75). This study captures something of the continuum that Sundin (2000) identifies: “from a focus on the individual’s subjective experiences towards a focus on the culture and its collective discourses through which the individual speaks” (217). Sundin (2000) further suggests that descriptive, interpretive and discursive approaches can be used at different levels in the qualitative analysis of data within a single study. This approach entails several interpretations of the same text, something that Kvale (1996) suggests “will not be a weakness, but a richness and a strength of interview research” (212).

Although discourses or ‘macro-level phenomena’ for investigation emerge from interview data, interview questions are loosely structured according to themes suggested by the research questions and with consideration of the three core elements: evidence, context and facilitation. Consequently, these themes are evident in the interview data (Rubin and Rubin 2005).

2.8 Summary and research gaps

Literature related to the WHI, changes in clinical practice and uncertainty provoked by the WHI, and IB in general and women’s health IB in particular is critical to this dissertation. This body of literature highlights the importance of health information within the context of everyday life and accentuates the lack of literature illuminating women’s experiences with uncertain and/or evolving information in non-crisis health situations such as those related to HT and menopause management. Furthermore, although theoretical consideration of EBP and KT calls attention to the evidence-practice gap, it also underscores the challenge of translating evidence into practical use in situations where health information is uncertain and where ‘best practices’ are evolving or disputed. Existing KT research focuses on the evidence-practice gap in situations where there is an imperative that should be integrated into clinical practice (e.g. hand washing); to my knowledge research does not explore health IB within the context of uncertain and/or evolving health information and thus attention has not been given to KT as an on-going process of social construction.

Consideration of EBP and KT also highlights the critical role of patient perspective in situations of uncertainty. Research has focused both on producing evidence and on how HPs implement or do not implement evidence; however, little attention has been focused on the patient or consumer as a partner in Sackett et al.'s (2000) three pronged definition of EBP. Salkovskis and Rees (2004) note that an important part of health care must be to gain insight into patients' experiences and to understand the ways in which they wish to be involved in treatment decisions. Perhaps ironically, these scholars found that SDM is most likely in situations of greatest uncertainty and where HPs do not have a clear idea of the 'best' course of action.

By identifying evidence, context and facilitation as key factors in the implementation of change, the PARIHS framework supplies a heuristic which draws attention to KT as a process of social construction and which provides impetus for integrating study of information and information sources (evidence) with investigation of context and facilitation. These latter elements (context and facilitation) draw attention to the interplay between the inter- and intrapersonal. For example, health beliefs and personal values have been identified as influencing health decisions; however there is little research on how they affect health IB and how they interact with other information sources. Literature about social positioning theory is relevant to this investigation because it provides insight into both inter- and intrapersonal processes by illuminating how women position themselves in relation to varying information sources and how that positioning influences their response to and the sense they make of evolving health information.

Research on the effect of new technologies and the media on people's experience of changing health information and on HP/patient dialogue is commonly restricted to accounts of what information is used and how often. Identifying sources, however, does not facilitate understanding of the influence, interplay, and integration of a complex information world, nor does it illuminate the tensions experienced by women as they make sense of information from formal and informal sources. Research that illuminates the women's experiences as they make sense of changing health information encountered via diverse mediums and within various contexts therefore makes critical contribution to understanding health IB and understanding the translation of knowledge into everyday life use.

This literature review demonstrates a number of important research gaps. The existing literature does not explore health IB within the context of uncertain and/or evolving health information and consequently little attention has been given to the experience of individuals as they respond to, make sense of, and use (or do not use) evolving health information. Research does not explore the varying ways in which diverse information sources facilitate understanding of health information and the tensions experienced by women as they interact with and integrate health information mediated by the wide range informal and formal sources encountered within the context of everyday life. There is insufficient understanding of how women position themselves with respect to information sources, the influence of context on positioning, and the interaction between positioning and health IB. And, attention has not been given to KT as an on-going, multifaceted process of social construction which occurs within the context of everyday life. Addressing these research gaps makes a critical contribution to understanding of women's health IB and to improving patient-centred health care.

In the following chapters the research methods which facilitate exploration of these research gaps are described and results and discussion are presented. While the reviewed literature in this chapter provides a foundation for this dissertation and illuminates the research gaps which provoked this investigation, data analyses draw attention beyond this literature. In chapters four to seven further literature is introduced as it illuminates findings and emerging themes.

CHAPTER 3
RESEARCH METHODS

This chapter addresses the following: rationale for this investigation, research objectives, research questions, definition of key terms, research design (including ethical considerations), data analysis and management, research quality, my role as researcher, and study limitations.

3.1 Research rationale

3.1.1 Why this study is important

With increasing interest in the information behaviour (IB) of "ordinary people in everyday life situations and health contexts" (Fisher and Julien 2009, 317) and increasing focus on KT within health fields, this investigation contributes both theoretically and practically to knowledge in Library and Information Science (LIS) and health care fields. Understanding the health IB of women as they deal with uncertain and/or evolving health information provides valuable insights regarding patient experience and the contexts in which medical change occurs, ingredients that Rycroft-Malone et al. (2002) identify as critical for change within medical systems. This research also contributes to understanding of how context and varying forms of facilitation are perceived by or influence women making sense of uncertain/evolving evidence related to hormone therapy (HT) and menopause. Study results provide insight into health information as provisional and into knowledge translation (KT) as a multifaceted process. This research is also important to the study of women's health. Women are actively involved in seeking and managing health information as well as health decision making; yet, to my knowledge, this study uniquely investigates women's experiences as they make sense of evolving and uncertain information about the menopause transition.

3.1.2 Reasons for research study

The significant evidence-practice gap in health care has brought focus to principles of evidence-based practice (EBP) and KT, however, little attention has been paid to the emergent nature of health information and the challenges faced by people as they engage in health IB within the context of uncertain and/or evolving information and within the context of their everyday lives. Attention has therefore not been given to KT as an on-going process of social construction. There is also insufficient understanding of the influence of experiences of women as they respond to and make sense of uncertain health information, the varying ways in which diverse information sources facilitate understanding of health information, and how positioning influences women's health IB. By addressing these research gaps, this dissertation contributes to understanding of women's health IB in everyday life situations and to patient-centered health care.

3.1.3 Guiding philosophy and assumptions

This investigation is based on interpretivist knowledge claims and a social constructionist perspective which focuses on emergent realities, process, context, and the assumption that meaning is created between people. "People's knowledge, views, understandings, interpretations, experiences, and interactions" are accepted as meaningful properties of researched reality (Mason 2002, 63). The process of communication is viewed as the constructive transformation of facts and details, and interviews are viewed as dynamic meaning-making occasions (Holstein and Gubrium 1995). While attention is focused primarily on women's individual experiences as they respond to, make sense of, and use uncertain and/or evolving information about HT and menopause, participants' experiences with evolving health information are understood as being embedded in culturally and institutionally bound discourses. In keeping with Sundin (2000) and Kvale (1996), interview transcripts are approached from descriptive, interpretive and discursive perspectives and interpretation is layered. Because this study explores women's experiences within the context of their everyday lives, qualitative methodology is appropriate and data analysis focuses on emerging themes, patterns and connections.

3.2 Research objectives

The objective of this research project is to better understand, from the patient's perspective, how uncertain and/or evolving information is experienced and to explore how that experience influences health IB and the translation of knowledge within women's personal lives. The study explores how women have experienced and made sense of uncertain and evolving health information related to the management of the menopause transition and how that experience and understanding influences health IB, decision making, and the context of medical encounters. Investigation of women's positioning as they encounter, seek and exchange health information illuminates the tensions experienced by women as they navigate uncertain health information mediated by both informal and formal sources. Data is gathered through semi-structured qualitative interviews with women who have previously or are currently engaged in information gathering or decision making related to HT and/or menopausal/postmenopausal health concerns, and with a sample of health professionals (HPs) acting as information providers to women who are navigating changing information related to menopause. This research contributes to understanding of patient perspective – it also contributes to knowledge of how context influences health IB, what forms of facilitation women favour or perceive as useful when making sense of uncertain/evolving evidence related to HT and menopause, and how the women's positioning influences their health IB.

3.3 Research questions

Semi-structured interviews and qualitative research methods are used to explore the guiding question: What sense-making and IBs are elicited by uncertain and/or evolving health information? This guiding question is explored by addressing the following overarching research questions:

1. What are the experiences of women as they respond to, make sense of, and use uncertain and/or evolving information about HT and menopause?
2. In what ways do information sources (including HPs, informal interpersonal interactions, and the media) facilitate women's varying responses to uncertain/evolving health knowledge? And what are the tensions experienced by women as they make sense of information that is facilitated in different ways by formal and informal information sources?
3. How do women position themselves (e.g. as autonomous, as collaborator, or as dependant) when encountering/seeking/exchanging health information, and how does that positioning influence further health IB?
4. How does the construction of uncertain and/or evolving health information encountered via diverse mediums and within various contexts influence health IB (including decision making), KT, and encounters with HPs?

In keeping with principles of qualitative methodology, data analyses reveal emerging themes and those themes direct the focus of further analysis and discussion.

3.4 Definition of key terms

Term definition requires careful consideration as terms in themselves frequently carry political and discursive meanings which position individuals and concepts in relation to other individuals and concepts (Julien 1999a). Choosing appropriate terms for study participants was, therefore, challenging. Definition of terms begins with discussion of the two groups of study participants: women and HPs. This is followed by definitions of the following terms: menopause and postmenopause, HT, bioidentical hormones, health IB, and KT.

Women: The primary focus of this study is on women who have previously or are currently engaged in IBs related to the management of the menopause transition. While these women may be viewed as *patients* within the context of the health care system, this investigation focuses on women's experiences within the context of their everyday life – this includes information encounters within the context of the health system, everyday media encounters, interpersonal communication with friends and family, and more. Moreover, *patient* potentially positions study participants as passive information recipients – individuals who undergo the action of others as opposed to being active agents (*OED Online* 2010. This study, however, focuses on the full range of IBs (occurring both in formal and informal settings) as well as on women's experiences as they actively construct health information. The term *consumer,* on the other hand, positions individuals outside the health care system and focuses attention on health information as a commodity or service. Although this term is commonly used within the context of *consumer health information*, this again implies the delivery of a product and does not accurately represent study participants who universally sought information from and constructed sense based on a range of sources. Furthermore, participants' positioning included both an autonomous consumer-like position and a dependant patient-like position – and these positions varied both between women and within individual interviews. Use of either *patient* or *consumer* would, therefore, not accurately represent interviewed women. *Ordinary* or *regular* has been used by some authors to express the idea of people within the context of their everyday lives as opposed to within the context of a particular role (*cf*. Lind and Salo 2002; Fisher and Julien 2009). For some, however, these terms sound disparaging and connote "people who are generally unexceptional" (Gordon-Till 2005, 157). For the purposes of this research project, therefore, the term *women* is used to represent the primary research participants.

Health professionals: Although the HPs who are interviewed as a means of triangulating women's experiences may be women themselves, these participants are identified as *health professionals* (HPs) in order to differentiate between them and the women whose experiences are the focus of this research project. These participants consist of professionals working within health care settings and providing medical care, advice or counsel to women who are dealing with health concerns related to management of the menopause transition. HPs come from different communities of practice (physicians, nurses, pharmacists, dieticians, and an alternative health practitioner) and both women and men are represented in this sample. It should be highlighted that the general term *participants* is used in this dissertation to refer to the primary study sample (women navigating the menopause transition); when referring to HP participants, the specific terms, *HPs* or *HP participants*, are used.

Menopause refers specifically to the cessation of menstruation; however, for the purpose of this investigation, the more colloquial definition of menopause is used: the period of time during which sex hormone production decreases and regular menstrual periods come to an end. In some medical texts this broad period of time is also described as the *perimenopause*, and in European texts and older North American texts this time period is referred to as the *climacterium. Postmenopause* is used in this study to describe the physiological state of women following the cessation of regular menstrual periods; and the *menopause transition* is used to refer to the broad stage of life which incorporates perimenopause, menopause, and, for those women who continue to experience symptoms related to the cessation of menstrual periods, postmenopause.

Hormone therapy: Although previously referred to as *hormone replacement therapy* or *HRT*, the more neutral phrase, *hormone therapy* or *HT*, has come into widespread use since the unanticipated cessation of the Women's Health Initiative study (WHI) in 2002. While the notion of *replacement* evolved as a representation of the view that postmenopausal women suffer from a deficiency disease that should be resolved through the exogenous replacement of hormones (Worcester and Whatley 1992), HT is a neutral term that can be applied to variations of menopausal HT, and to the delivery of hormones in varying dosages and by varying methods.

Bioidentical hormones: There is no single well-understood definition for *bioidentical HT*; however it is generally understood to refer to exact copies of endogenous human hormones, as opposed to hormones with different chemical or nonhuman structures. They are also described as 'natural,' "which can be confusing because bioidentical hormones are synthesized, while some estrogens from a natural source, such as equine urine, are not considered bioidentical because many of their components are foreign to the human body" (Holtorf 2009, 74). These forms of hormones are generally associated with pharmacy compounding – an attempt to meet specific hormonal deficits as identified by saliva or blood testing. While the use and efficacy of *bioidenticals* is controversial in traditional medical settings (*cf*. Chervenak 2009; Holtorf 2009), celebrity attention to this form of HT (for example, Somers 2006) followed by Oprah's focus on bioidenticals in television broadcasts early in 2009 popularized the notion of bioidentical HT for women in the menopause transition.

Information behaviour: The parameters of *information behaviour* (*IB*) are elucidated in the literature review (see section 2.2). *Health IB* is used within the context of this study to refer specifically to the totality of human behaviour related to health information and the sources and channels by which health knowledge is communicated.

Knowledge translation (*KT*) refers to the process whereby women respond to, make sense of, and use (or do not use) health information encountered within the context of their everyday lives. This may include encounters with health information or research communicated by HPs, the media, internet sources, or interpersonal sources. The process by which translation occurs is modified by the multifaceted contexts of information users and by their view of information relevancy (Jacobson, Butterill, and Goering 2003). Within the context of this dissertation, KT is viewed as a socially constructed process which is based on research and experiential knowledge as well as on reflection, negotiation of meaning, situational factors, and material artifacts (Gherardi 2006). (See section 2.4.2. for a more detailed discussion of KT.)

3.5 Research design

In the following section ethical considerations for the study are reviewed. This is followed by discussion of sample populations and qualitative interview structure. In this study two sample populations were interviewed: women who had been or were, at the time of data gathering, engaged in health IB or decision-making related to menopause or HT; and HPs providing care or information to women navigating the menopause transition. Semi-structured qualitative interviews were used to explore the research questions.

3.5.1 Ethical considerations

The qualitative scholar working with human participants must ensure that all aspects of research are carried out in an ethical manner which adheres to standards laid out by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (CIHR, Natural Sciences & Engineering Research Council of Canada (NSERC), & Social Sciences & Humanities Research Council of Canada (SSHRC) 2005) and with particular attention to issues related to qualitative research (Social Science and Humanities Research Ethics Special Working Committee (SSHWC) 2008). In order to fulfill ethical requirements this dissertation study was approved by the Health Research Ethics Board (HREB) – B as well as the Education, Extension, Augustana (EEA) Research Ethics Board (REB) as the University of Alberta, Canada. It also received Covenant Health Administrative Approval for recruitment of participants at a menopause clinic administered by Covenant Health (see appendix B for ethics and administrative approval letters).

An information letter was used to inform participants about the purpose of the research project, procedures related to the interview, information about the researcher, and instructions for contacting the researcher (see appendices C and D for information letters for women and HPs respectively.) At the time of the interview participants were asked to sign a consent form (see appendix E) indicating participant awareness of research purpose, main features of research design, anonymity, dissemination, and the right to withdraw from the study (Kvale 1996). Consent was obtained with consideration of Seidman’s (1998) observations: “thoughtfulness and care in the process of going over the [consent letter] with the participant" (62) will enable the interviewer to deal with potential uneasiness participants might experience related to the formalities of informed consent. Because of the nature of qualitative analysis, withdrawal was permitted until the time that the interview was transcribed.

Confidentiality was maintained throughout the research process. Pseudonyms were assigned to transcripts and were used at all research stages subsequent to the interviews; I was the only person with access to the cross referenced list of actual names and pseudonyms; and, careful attention is given to how qualitative data is reported in the results and discussion chapters. It is, for example, common to use extensive quotations in published accounts of qualitative interview research (Charmaz 2002). Care was therefore taken that participants are not inadvertently identified by quotations. Furthermore, on a few occasions even the pseudonyms for HP participants were not included (quotations were identified only as originating from a HP) in order to ensure confidentiality within this small population and sample.

Although consideration of research consequences for participants, and potentially for the community or group represented by the participant, must be a part of ethical considerations (Kvale 1996), this investigation falls within the risk level identified by the Social Science and Humanities Research Ethics Special Working Committee: "to the extent that harms exist in this type of research, they rarely exceed the sorts of harm we are exposed to and experience in everyday life, and are more likely to arise outside the research context" (SSHWC 2004, 23). Furthermore, potential beneficial consequences of involvement in qualitative interview research have been identified (Patton 2002). Kvale (1996) asserts that research should benefit not only the research community, but also "the human situation investigated" (111). He notes that interviews are likely to have positive consequences for individuals: "just listening to what people have to say for an extended period of time as well as the quality of the listening, can make an interview a unique experience" (116). Demonstrating genuine interest in the experience of participants and in their stories therefore not only facilitated rapport, it also helped to make the interview itself a rewarding experience for participants. In fact, a number of interviewed women communicated that participation in this investigation validated their experiences during the menopause and moved them forward in terms of making sense of this life transition (for example, it encouraged them to initiate further information seeking, to seek information from a HP, or to feel more comfortable with existing management strategies).

The literature indicates that the researcher is responsible for managing and maintaining data in an ethical manner following data collection (*cf.* Gillham 2005; Kvale 1996; Sieber 1998). Data management followed guidelines provided by the *Tri-council policy statement: Ethical conduct for research involving humans* (CIHR, NSERC & SSHRC 2005) and consideration was given to confidentiality, safe date storage and an ethical rendering of the data into communicable knowledge.

While ethical research practices were considered and planned prior to commencing investigation, I also realized that, when working with human subjects, unexpected ethical challenges may emerge during the research process. In anticipation of this possibility I planned to follow Patton’s (2002) advice: know who you can go to for advice or support. In two situations I sought advice from my dissertation supervisors. First, as I was interviewing one participant I discovered that she was not specifically in the menopause transition, despite having responded affirmatively to inclusion criteria which were clearly outlined in an email. Because this participant was, nonetheless, engaged in information seeking with respect to the menopause transition, data from this interview was included in analyses. Second, I discussed with my supervisors a participant who identified as being in this life transition although her description of symptoms suggested that she was likely additionally suffering from a more serious concern. Although I was left with a sense of unease by this interview, I deemed it inappropriate to express my concerns to the participant for the following reasons: I am not a health professional, the participant was under the care of a physician and was making a deliberate choice to follow alternative treatments despite medical advice, and the interview was clearly established (by design and according to ethics approval) as a site for discussion of information behaviours and navigation of evolving health information, not specifics with respect to medical treatment. Although my concern for the participant was confirmed, my actions were confirmed as appropriate given the parameters of this study.

3.5.2 Sample populations

Population selection and sampling is theoretically informed by concepts elucidated in the literature review and by the research questions which guide this qualitative exploration. This study focuses on the experiences of women who have in the past or are currently engaged in decision making or information gathering related to HT and/or concerns related to the menopause transition. For the following reasons focus on this demographic effectively facilitates investigation of how changing and/or uncertain health information is experienced within the context of everyday life, and how that experience influences IB and the translation of knowledge into practice: (1) relatively recent dramatic changes in accepted medical practice have significantly impacted health care for women navigating this life transition; (2) the history of changing practices and the ongoing clinical ambiguity related to menopause management has been exhaustively documented in the medical literature; and (3) widespread media coverage of evolving research and changing practice with respect to menopause management has left few women (and HPs) unaware of the uncertain nature of information in this area of health management. Furthermore, women have been identified as active information agents who gather and manage information drawn from a complex range of formal and informal sources. Interviews with women navigating this life transition and with HPs providing care and/or information to women therefore provide rich data which illuminates the construction of evolving health information within the context of everyday life.

3.5.2.1 Sample 1: Women

Participants: Twenty-eight women who had in the past or were, at the time of the interview, engaged in decision making or information gathering related to the menopause transition were interviewed. Final sample size was guided by two principles: *theoretical saturation*, that is, when new information was no longer being provided by participants and further interviews appeared to yield little new knowledge; and, *sufficiency*, that is, participants reflected a reasonable range of approaches that might be found within the sample population "so that others outside the sample might have a chance to connect to the experiences of those in it" (Seidman 1998, 47-8). Sample size is this study was guided in part by the desire to interview women who were recruited both in community settings and at a publicly funded menopause clinic. A range of participant numbers are reported in the literature; Kvale (1996), for example, reports that the number of participants in qualitative interviews tend to be around 15, plus or minus 10, and Miles and Huberman (1994) suggest that data saturation is commonly reached with approximately 15 to 20 participants.

Inclusion criteria: Women who reported that they had been or were currently engaged in health IB or decision making related to HT and/or concerns related to menopause participated in the study.

Sampling: The goal of sampling was to gather rich qualitative data related to the ways in which Canadian women experience changing and evolving health information within the context of their everyday lives. *Theoretical sampling*, guided by the literature and research questions, was used to select participants. *Purposive sampling* was demonstrated by the recruitment strategy. Recruitment occurred in the following settings: a publicly funded menopause clinic, physicians' offices, stores selling natural health produces. Although maximum variation would be ideal, participants were selected based on the order in which they expressed interested in the project and confirmation that they met selection criteria. Interviewed women were representative of the population in that they spanned a wide range of decades, from the 30s to 70s; and their health IB entailed a variety of approaches, mediums and sources (e.g. reliance on HPs, use of consumer health resources, natural health information sources, interpersonal networks, and more). *Snowball sampling* was used; participants and other interested parties gave my name to appropriate individuals who might be interested in sharing their experiences. Finally, the sample was, in part, a *sample of convenience* as I sought to interview individuals who are geographically accessible for qualitative interviews. All participants were, therefore, residents of a single Western Canadian province.

In order to recruit study participants, notices were placed in two health food stores; three HPs either placed notices in their offices or said they would give recruitment aids to interested patients; recruitment aids were handed out and/or mailed to patients at the menopause clinic; and women who heard of the study told others about it. See appendix F for participant recruitment aids. I am aware of two women who sent information about the study to all of their email contacts, and a number of the interviewed women asked me if they could pass on information about the study to their contacts. As a result of these various awareness-raising events, women contacted me either by email or by telephone. I did not ask women how they heard about the study; although some women volunteered the information and women from the menopause clinic told me that they were contacting me in response to information from the clinic. During initial contact with potential participants (by telephone or email) I communicated inclusion criteria to them in order to confirm compliance with study parameters and to ensure that the women were comfortable with the research process (for example interview recording) and aware of ethical requirements (for example, signing the consent letter). Interviews at a mutually acceptable time and location were set up at the time of the initial telephone contact or following an additional contact in which I sent interested participants the information letter. In all cases I emailed the full information letter to interested participants. Women then responded either by establishing an interview time/location or by confirming an interview which had been set up at the time of the initial telephone call. Field notes were kept, which included accounts of initial contact with participants.

3.5.2.2 Sample 2: Health professionals

Participants: In order to further illuminate data gathered during interviews with the sample of women, a small sample of HPs (12) were interviewed beginning after 17 interviews with women were completed. The goal of these semi-structured interviews was to gain HPs' perspectives on patients' menopause-related IB and interpersonal interactions between HPs and patients, as well as to gain insight into the roles HPs play in facilitating the translation of knowledge within the context of everyday life. Creswell (1998) notes that when using theoretical sampling, data from initial interviews with a primary homogeneous sample (women who are navigating changing information related to the menopause transition) can be illuminated by subsequent interviews with a heterogeneous sample (in this case, HPs). Because the focus of this investigation is on data arising from interviews with women, a smaller number of HPs were interviewed.

Inclusion criteria: HPs acting as information providers to women who are navigating changing information related to menopause.

Sampling: Theoretical sampling was used in order to gather rich qualitative data related to the ways in which HPs contribute to and view women's experience with changing and evolving health information about HT and menopause. There was an element of convenience to the sampling as I interviewed HPs who are accessible for qualitative interviews. HP participants were recruited at two publicly funded menopause clinics in one Western Canadian city, through personal contacts, and by referral (snowball sampling). For example, after receiving administrative approval for recruitment at one menopause clinic, HPs at that clinic sent recruitment notices to individual HPs working at a second menopause clinic and provided me with email addresses for follow-up. Six of the HPs were recruited through personal contact: one of the interviewed woman was married to a HP and encouraged me to contact her spouse by telephone; contact with another HP was provided by a HP I am related to but did not interview; I was acquainted with three of the HPs and directly contacted them (by telephone, email, and in person) as I was aware that they had cared for women in this life transition; and one of the interviewed HPs passed on my email to a colleague who contacted me. Interviewed HPs included members of the North American Menopause Society (NAMS) who were certified menopause practitioners (NAMS 2011). See appendix F for HP participant recruitment aids.

3.5.3 Qualitative interviews

All participants in this exploratory study participated in one, audio-recorded interview. Trustworthiness of the data was advanced through the use of a robust sample size, and triangulation. Many qualitative scholars note that triangulation is an effective means by which to “corroborate, elaborate or illuminate the research in question” (Marshall and Rossman 2006, 202). For this research project findings were triangulated in three ways: triangulation through the use of two interview techniques with the primary sample group; triangulation of qualitative data sources in the form of two distinctive groups of participants; and theory triangulation (Patton 1999). This latter form of triangulation involves “using different theoretical perspectives to look at the same data” (Patton 1999, 1196) and for this investigation incorporates human information behaviour theory, a social constructionist approach, the Promoting Action on Research Implementation in Health Services (PARIHS) framework, and positioning theory. Other theoretical perspectives are incorporated based on themes which emerged from during data analyses. Because of the significant time commitment demanded by multiple interviews with a large number of participants, particularly with a sample involving HPs, triangulation was viewed as a preferred means of improving research trustworthiness without impeding data collection.

During the interview, strategies such as neutral agreement, asking for additional information, summarizing and paraphrasing was used to encourage dialogue clarification (Schensul, Schensul, and LeCompte 1999). Because interviews are viewed as sites for social construction, member checking with participants was not solicited following data collection. While it is critically important that the words and spirit of interviews are represented without distortion, I believe that for this research study the ethical and academic responsibility for translating data into knowledge rests with the researcher.

Interviews took place in a neutral safe locations that were accessible to participants, comfortable for them, and amenable to recording. These included participants’ homes, places of work, HPs’ work spaces, my office on the university campus, and public spaces (for example, a coffee shop, book store, and hospital meeting room). I conducted all aspects of interviewing. Participant parking was reimbursed as needed and, following completion of the interview, a small gift (a coffee card) was given to interviewed women as an expression of appreciation for participation. Parking reimbursement and appreciation tokens were self-funded. Verbal thanks were given to HP participants, and, in two cases, I purchased beverages for HPs interviewed in coffee shops. Within 24 hours of interviews, field notes based on notations made during the interview and on impressions of the interview were recorded.

3.5.3.1 Interviews with women

Interviews with women lasted between approximately 40 and 80 minutes (with a mean of approximately 60 minutes) and focused on women's experiences as they responded to, made sense of, and used information about HT and menopause. Two interview strategies were used in order to yield rich descriptive data related to the sense-making and IBs elicited by uncertain and/or evolving health information: a narrative approach and elicitation.

Narrative approach: A semi-structured and narrative approach was primarily used in order to allow participants "scope to articulate their experiences in their own terms" (Petersen 2006, 34). This approach facilitated participants' constructive processes as they related, interpreted and drew together their health related experiences (Becker 1997; Petersen 2006). A semi-structured format allowed interviews to be guided by questions and themes while at the same time allowing the order, wording, and inclusion of specific questions to be modified in response to the interview situation (Bernard 2000; Robson 2002). Questions were open-ended and, in addition to maintaining interview momentum, probes stimulated richer description and participant interpretation. PARIHS elements (evidence, context, facilitation) provided a heuristic which theoretically guided semi-structured interview, thus facilitating insight into information sources (evidence), the circumstances and context of the individual woman (context), and the manner and means by which information was delivered (facilitation). Reflection on the interaction between different information sources (informal and formal) and women's approaches to finding or receiving information provided insight into how women position themselves in relation to information sources, including HPs. See appendix G for the interview guide for semi-structured qualitative interviews with women participants.

Elicitation: Based on Johnson and Weller's work (2002), an 'in the moment' elicitation technique was used in order to elicit response to changing and potentially conflicting health information encountered in the popular press. Following the narrative portion of the interviews, women were presented with recent, contrasting media accounts of emerging research related to Vitamin D use by women. The goal was not to present participants with exact items they might have previously viewed; rather, the goal was to utilize a familiar format and to present information that would elicit response and reflection about health information encountered within the context of everyday life. Discussion focused on aspects of the articles which provoke the participants' interest. Based on information from *Media Digest* (Canadian Media Directors' Council 2007-2008) I selected elicitation material from sources with the highest readership (female readership and age of readers is taken into consideration), sources that covered health related topics, and sources likely to be accessible to the sample population. I explored newspaper articles (the *Edmonton Journal*); three Canadian consumer magazines (*Reader's Digest*, *Chatelaine*, and *Canadian Living*), and items from the CBC (Canadian Broadcasting Corporation) and CTV websites, the two English language national commercial networks. Because these latter sources represent not only online sources but also stories related to health that are carried on television, radio and in the popular press, I chose to use three articles which appeared on the CBC website. Two articles ("Take vitamin D to reduce cancer risk, Canadian Cancer Society advises" (CBC 2007a) and "Vitamin D lowers cancer risk in older women: Study" (CBC 2007b)) were initially presented to the women for consideration and discussion. This was followed by presentation, consideration and discussion of a third contrasting article ("Calcium, vitamin D not linked to reduced breast cancer risk: Study" (CBC 2008)). These articles were chosen based on their subject matter (a relatively unthreatening topic of potential interest which allowed focus to be on the conflicting nature of the information and on media portrayal of health information), and the strong contrast represented by the articles. Use of the elicitation technique facilitated insight into tacit understanding and subconscious thoughts about evolving health information and media-mediated health information.

3.5.3.2 Interviews with health professionals

Semi-structured interviews with HPs lasted approximately 30 minutes. Interviews focused on HPs' view of patients' health IB and their perspective on interpersonal interactions between HPs and women in situations where health information is uncertain and/or evolving. Core elements from the PARIHS framework theoretically informed the interview structure. Exploration centered on evidence and information sources used by women navigating the menopause transition, how women's contexts and the context of patient/professional interactions influence HPs' roles as information providers, and the role HPs play in facilitating the delivery of information and the translation of information into everyday life use by women. See appendix H for the interview guide for semi-structured qualitative interviews with HPs.

3.5.3.3 Developing semi-structured qualitative interviews

Elements of Mason's (2002) progressive strategy (see section 2.7.2) were used for developing the semi-structured outline and open-ended interview questions for this qualitative investigation. The relationships between themes of interest, research questions, and interview questions were evaluated. This ensured that interview questions had the potential to elicit information that related back to research questions and themes of interest.

Two pilot interviews with women were conducted, transcribed, and analyzed using NVivo software. Initial analyses of the pilot interview data was used to modify the interview guide and methods (for example, the elicitation format was clarified following pilot interviews). Interviews with pilot study participants were folded into the sample. Interview structure remained similar after post-pilot modifications.

The interview guide for HP interviews was re-evaluated following the first HP interview. Perhaps because these interviews began after experience was gained from interviews with the women and because the guide was specifically based on the heuristic provided by PARIHS core elements (evidence and information sources, facilitating role when evidence is evolving, and, role of patient context), this interview guide was used for all 12 HP interviews.

3.6 Data analysis

Qualitative data analysis essentially consists of “taking things apart and identifying their constituent parts, “ locating patterns and themes, and reassembling data “in ways that begin to resemble a coherent explanation or description” (LeCompte 2000, 150). Many scholars have identified analytic phases to guide progression from collected data to explanation, understanding and interpretation. These phases are commonly iterative, however they fundamentally involve data organization, immersion in the data and identifying items of interest, generating categories or sets of interest, data coding and interpretation, and meaningful representation of data and interpretation (*cf*. Creswell 1998; LeCompte 2000; Marshall and Rossman 2006; Seidman 1998).

For this theoretically guided, exploratory research project open coding using thematic analysis and Kvale’s (1996) ‘ad hoc’ or eclectic approach to generating meaning from qualitative interview data was used (see section 2.7.3). Since interviews were theoretically guided and based on themes of interest, these concepts were necessarily evident in the interview data (Rubin and Rubin 2005) and provided initial guidance for coding and analysis. In keeping with the nature of the guiding questions, descriptive, interpretive and discursive approaches, which involved several interpretations of the same text, were incorporated in data analysis. Liamputtong and Ezzy (2005) identify theory building as “an ongoing dialogue between pre-existing theory and new insights” (266); therefore, understanding of emerging themes and patterns developed as this dialogue between existing theory and findings took place during the analysis process.

Initial analysis included close reading of interview transcripts. The text was subsequently analyzed using NVivo software, a qualitative analysis program which I have experience using and a tool which enhances credibility because of its powerful assistance with data organization and coding, and also because of the extensive and accessible audit trail it produces (Seale 2002). Data was categorized according to emerging themes. Each theme was systematically analyzed and in some cases divided into sub-themes; in a few cases the NVivo text searching capacity was used to explore emerging themes. Interpretation of qualitative data is a reflective and iterative process; consequently close reading of passages continued throughout analysis in order to maintain a view of overarching themes, discourses and positions. Interviews were examined for conformity and variation from themes and representative quotations from the interviews are included in the results and discussion chapters of the dissertation.

In addition to coding, memos were used during the coding process to keep track of theme development, to elaborate concepts, and to facilitate abstraction. Memos included both those directly related to coding and facilitated by NVivo software, and those which I kept separately in the form of notes about overall research development and extensive 'writing notes' which incorporated related published literature.

3.7 Data management

Interviews were recorded and downloaded; transcription was facilitated by Express Scribe Transcription Playback Software (NCH Software n.d.). In order to preserve confidentiality, pseudonyms were immediately assigned following interviews and were used subsequently to identify participants and all related data. Data management followed guidelines provided by the *Tri-council policy statement: Ethical conduct for research involving humans* (CIHR, NSERC & SSHRC 2005). Interview transcripts will be kept for at least five years following the completion of the research in order to facilitate publication of research results.

3.8 Research quality

In their historic work Lincoln and Guba (1985) identify *credibility*, *transferability*, *dependability*, and *confirmability* as the four critical criteria for judging the soundness of interpretive qualitative research. Other scholars endorse these criteria as a means of enhancing the quality of qualitative work (*cf*. Bradley 1993; Marshall and Rossman 2006).

Credibility refers to the "adequate representation of the constructions of the social world under study" (Bradley 1993, 436); it requires appropriate identification and description of the subject as well as credible inferences from data. For this research study credibility is established through in-depth description of the complexities of the research processes. In addition, the following measures are taken to strengthen credibility: (1) triangulation of interview approaches, data sources, and theory; (2) data interpretation from descriptive, interpretive and discursive perspectives; (3) identification and exploration of negative instances; (4) discussion and debriefing with peers; and (5) careful documentation at all research stages.

Because transferability depends on similarities between the original and a subsequent research context, the burden of proof for the application of findings from one context to another rests primarily with subsequent researchers (Marshall and Rossman 2006). In order to facilitate transferability, I provide thick description of the topic, research methods, research context, data, and interpretations. Logical and conceptual links between data, interpretation, theoretical frameworks and/or conceptual underpinning are clearly communicated. Triangulation also strengthens the potential usefulness of this research study in other settings.

It is critical that qualitative scholars account for the changing context within which research occurs, and that "the logical inferences and interpretation of the researcher make sense to someone else" (Marshall and Rossman 2006, 203). Attention to these two requirements establish the study's dependability and confirmability. These concerns are addressed through detailed and descriptive research notes documenting the research process, coding decisions, emerging themes and interpretations, and conceptual linkage to theory. The generous integration of participant quotations within the research results and discussions improves confirmability by allowing interpretations and conclusions to be traced to source material.

3.9 My role as researcher

In qualitative research the interviewer is viewed as the research instrument (*cf*. Seidman 1998; Kvale 1996). It is therefore critical to consider the role of the researcher as a scholar and as an individual within the context of the research project. Patton (1999) points out that although there is no definitive list that must be addressed to establish researcher credibility, professional and personal characteristics, and attributes may influence the research process.

Both my academic and personal background facilitate my role as researcher in this investigation. I have training in the health sciences (Bachelor of Science in Occupational Therapy) and have worked with patients and other HPs within both hospital and community settings. This undergraduate training prepared me for exploring the tensions people experience as they seek to interpret health related information within the context of their everyday lives: occupational therapy is uniquely focused on facilitating the day-to-day function of patients and focuses on bridging the gap between health settings and the everyday life worlds of patients. My graduate work also facilitates my role in this current project: a Master degree in LIS provides me with a strong academic background related to information studies, particularly IB; and, my Master thesis, a content analysis of medical and consumer articles (*Exploring the role of medical and consumer literature in the diffusion of information related to hormone therapy for menopausal women*), gives me significant grounding in the literature related to the WHI and HT (Genuis 2004).

I furthermore believe that my proximity in life circumstances to the women participants facilitated rapport during interviews. I also have close family ties within the health professions and this, in addition to my own background and experience in the health sciences, facilitated communication with HP participants. I believe that my understanding related to medical knowledge structures, the health care system, communication patterns within health settings, power structures within the health care system, and people's health IB, facilitated communication with sample populations and investigation of the research questions.

The view of the researcher as an unbiased and passive collector of facts has been deconstructed in the literature (*cf.* Charmaz 2006; Latour and Woolgar 1986) leaving scholars with the conclusion that "all researchers bring their own preconceptions and interpretations to the problem being studied, regardless of the methods used" (Patton 1999, 1204). Within the context of qualitative research this conclusion is not troubling: the critical feature is that researchers be transparent about their underlying assumptions and biases. Three primary preconceptions are relevant to this research project. (1) I view personal health information gathering as a positive activity for individuals. (2) I believe that women are ultimately responsible for decisions about health management, but view cooperative decision making as the preferred objective for interactions between women and HPs. And, (3) in contrast to the biomedical view of menopause found within many medical contexts, I view menopause as a natural life transition that is "mediated through cultural understandings and socioeconomic conditions" and as a process that "touches on many aspects of women's lives, from women's physiology and intrapsychic experiences to social structures and norms" (Gonyea 1996, 418).

3.10 Study limitations

This dissertation inevitably has limitations. Exploration of sense-making and IBs elicited by changing and uncertain health information is unavoidably limited by the choice of a specific medical case as context for investigation. Although there may be some limitation based on using a case where the initiating incident (the publication of WHI findings) occurred seven years prior to data collection, continuing ambiguity related to management of this life transition, ongoing prominence in the medical and consumer press, and the findings themselves suggest that the chosen context for investigation has retained currency for both women and HPs.

Potential limitations are also associated with the sample population. Efforts were made to recruit women who had had a range of experiences during the menopause transition; however, it is possible that participation in the study had greater appeal for those women who had experienced symptoms and related challenges during this life transition. These women were likely motivated to seek information, to self-identify as information seekers, and to therefore respond to recruitment notices and volunteer for the study. For the same reason there may have also been greater consultation with formal information sources (HPs) by interviewed women. It should also be noted that data gathering was limited geographically (and occurred in a setting where health care is publicly funded) and, therefore, generalization to other jurisdictions may be limited.

Chosen theoretical frameworks and theories add depth to data interpretation; however limitations inevitably arise from the choice of specific conceptual lens. Findings were shaped by the theories which framed the investigation and potentially by the heuristic provided by the PARIHS framework. Research methods may have also imposed limitations on this investigation. Unlike ethnographic methods entailing direct observation of behaviour, data collection relied on the perceptions of participants. While this fulfilled the purpose of the study, data unavoidably reflected not the actual experiences of participants, but rather the meaning that individuals constructed from their experiences. Finally, there are numerous topics and/or news articles which could have been chosen for the elicitation portion of the interviews. It is possible that other articles would have provoked different responses, considerations and discussions, which may have brought forth other themes and conceptual linkages.

3.11 Conclusion

This chapter has provided rationale for this dissertation, research objectives and questions, definitions for key terms, and explanation of research design. Data analysis and management, research quality, my role as a researcher, study limitations and ethical considerations have also been elucidated. In the following chapters results and discussion will be presented with each of chapters four through seven sequentially addressing the research questions. Chapter eight will conclude the dissertation.

CHAPTER 4

RESULTS AND DISCUSSION: EXPERIENCES OF WOMEN WITH UNCERTAIN AND EVOLVING HEALTH INFORMATION

In order to gather rich qualitative data related to women's experiences as they responded to, made sense of and used (or did not use) evolving information about the menopause transition, women who had in the past or who were currently engaged in health IB related to menopause or hormone therapy (HT), as well as health professionals (HPs) acting as information providers to women navigating the menopause transition were interviewed. As described in chapter 3, theoretical, purposive, and snowball sampling methods were used (section 3.5.2).

There was positive community response to recruitment notices for women participants and to subsequent snowball sampling. Eighteen women were interviewed before ethics approval for recruitment at a menopause clinic was achieved; at this point theme saturation was also beginning to be evident. Recruitment in the community was therefore closed in order ensure that the final sample included women who were actively involved with pursuing health information via traditional formal channels, more specifically, through the health care system. It is interesting to note that interest in the project had not waned when community recruitment ceased and interviews with approximately 5 women were subsequently turned down. During the course of community recruitment I was contacted by a small number of women who were interested in menopause but who had not yet participated in any independent information seeking or decision making related to menopause or HT. These women did not meet inclusion criteria and were not interviewed. One participant was pre-menopausal but was actively seeking both formal and informal information about this life transition. Ten women were recruited through a menopause clinic and interviewed (recruitment notices were both handed out at information sessions and mailed to patients; interested women were invited set up interviews at a convenient time), thus bringing the final number of women participants to 28. At this point both theoretical saturation and sufficiency (Seidman 1998) had been reached. Although more women were interviewed than the 15 to 20 initially proposed, the range of experiences tapped by utilizing two recruitment contexts and the resulting rich and diverse descriptions justify this larger sample and strengthen the findings of this interpretive qualitative study. As detailed in chapter 3 (section 3.5.2), data from interviews with women participants were illuminated by data from interviews with a smaller sample of HPs. This sample of 12 included six HPs who were recruited through the menopause clinic and six who were recruited through community contacts.

In this chapter I will provide context by describing study participants; this will be followed by analysis of interviews and exploration of the experiences of women as they responded to, made sense of and used evolving information about the menopause transition. Beginning with findings related to women as active information agents, I will then address women's perceptions of health, wellness and menopause symptoms. This will be followed by exploration of data as it relates to uncertainty and menopause, particularly uncertainty about menopause as a life stage, and uncertainty about menopause management.

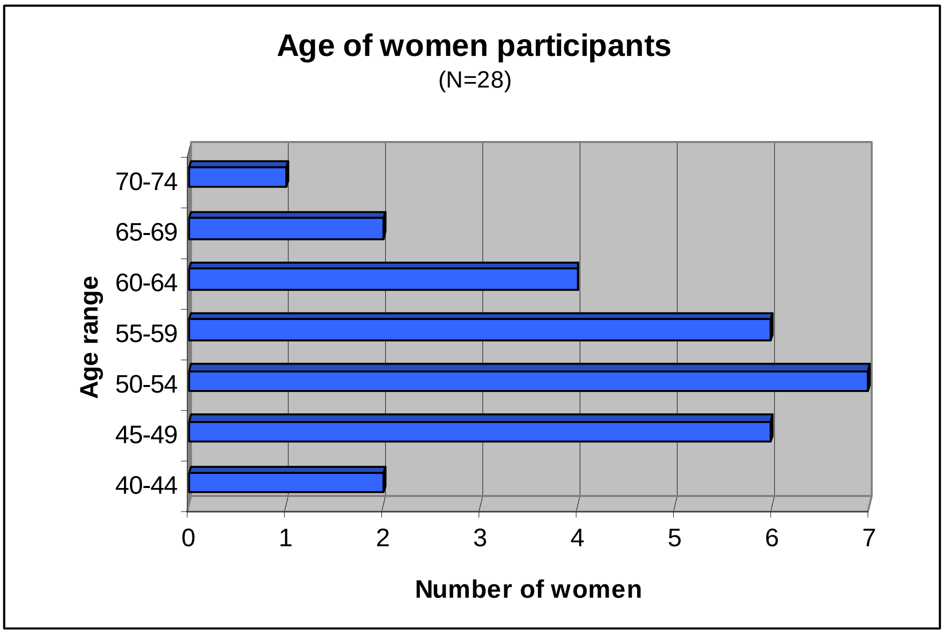
4.1 Description of Participants

Prior to examining the experiences of women as they responded to, made sense of, and used health information about the menopause transition, discussion of demographic and descriptive characteristics of the participants is warranted. This provides details with respect to the depth and breadth of the sample of women and health professionals interviewed. Furthermore, it contributes to a more nuanced understanding of the contexts in which the women participants' information needs arose, information seeking occurred, and management of health and well-being took place.

4.1.1. Description of women

At the time of their interviews, participants ranged in age from 43 to 72 years of age with the majority being in their 50s. Two participants provided a mix of contextual information (e.g. approximate age of symptom onset or menopause, or years since menopause) which allowed age approximation within a five year span. For this reason, age of women participants is provided in five year increments (figure 4.1).

Figure 4.1 Age of women participants



Because of the challenges defining menopause (see section 3.4) and the variations evident even within the health literature, self-reported menopause status is reported. Table 1 summarizes current age range and self-reported menopause status, and HT use of individual women participants.

Table 4.1 Summary of menopause status and HT use: Women participants

Pseudonym	Age	Menopause status	Prescription HT use
Anita	45-49	Perimenopausal	Current
Beverly	55-59	Postmenopausal	Never
Camille	45-49	Perimenopausal	Current
Cherri	55-59	Unsure	Current
Christy	50-54	Postmenopausal	Past
Dale	40-44	Perimenopausal	Current
Dana	50-54	Unsure	Never
Faye	55-59	Perimenopausal	Current
Gwen	50-54	Perimenopausal	Never
Hazel	40-44	Perimenopausal	Never
Irene	50-54	Postmenopausal	Current
Jane	65-69	Postmenopausal	Past
Jill	45-49	Postmenopausal	Never
Joyce	65-69	Postmenopausal	Past
Laura	45-49	Postmenopausal	Current
Lillian	70-74	Postmenopausal	Current
Lisa	45-49	Postmenopausal	Never
Monica	55-59	Postmenopausal	Never
Muriel	60-64	Postmenopausal	Past
Naomi	50-54	Postmenopausal	Current
Nicole	60-64	Postmenopausal	Past
Pat	55-59	Postmenopausal	Never
Paula	55-59	Postmenopausal	Never
Roslyn	50-54	Perimenopausal	Current
Sue	60-64	Postmenopausal	Current
Sylvia	60-64	Postmenopausal	Current
Thea	50-54	Perimenopausal	Current
Vicky	45-49	Premenopausal	Never

The majority of women in the current study came from a relatively homogeneous cultural environment (Caucasian, apparently middle class, living in a single geographic vicinity in Western Canada). Three of the participants were French Canadian and three immigrated to Canada, one from Europe, another from South America and one from India. One of the immigrant women came to Canada as a married adult with a small child; one came to Canada with her family of origin when she was a young adult; and the third came alone as an unmarried adult.

Appendix I provides descriptive paragraphs about each interviewed woman. These are based on interviews and field notes, and provide the women participants' perspectives on the timing of their menopause transitions and some basic demographic information related to education, employment and family. Because of the frequently indeterminate nature of menopause onset, the range of terminology and understanding associated with this life transition, and the narrative interview approach, descriptions of menopause and demographic details are not consistent. For example, while Jane related that menopausal symptoms began after her hysterectomy at 42 years of age and Dale pinpointed her first symptoms as occurring at 34 after the birth of her child, Gwen identified herself as being in perimenopause but was unable to pinpoint onset of this life phase: "I don't know, a couple of years now. Probably 2 years really." And while Monica was familiar with the more formal definition of menopause and reflected "I probably officially entered it about 2 1/2 years ago," Dana disputed classic definitions: "I think that this is menopause. I think by the time I quit bleeding, that will be the end of menopause. I know that's not, that's not what they think menopause is, I know that." A further challenge for defining menopause status is posed by HT. For some women, monthly bleeding is re-initiated or continues as a result of HT. In this case women are likely to rely on the colloquial definition of menopause as the time period when sex hormones decrease and regular menstrual periods come to an end. Specific details with respect to demographics were inconsistent because of the nature of narrative qualitative interviewing which focuses on participants' stories and their own construction of events. While women were routinely asked about their activities, work history, and education, this was not the focus of the interview and women chose to answer with varying detail and focus.

4.1.2 Description of health professionals

Twelve HPs were interviewed, with the first HP interview falling between the 17th and 18th interviews with women participants (sample 1). This allowed themes which were emerging from the interviews with women participants to be brought forward to the HPs for consideration and reflection. Because of the small community from which these participants were drawn and for the purposes of this dissertation HPs are not identified as working at the menopause clinic or working in other settings. All HPs, however, fit the inclusion criteria and were acting in some capacity as information providers to women who are navigating changing information related to menopause. Five of the Sample 2 participants work in a menopause clinic (not necessarily exclusively), one is an academic who has experience as a clinician, five work in community settings, and one worked previously in both the community and a menopause clinic but recently retired. HP participants represented a range of medical disciplines, with the summary provided in Table 4.2. Stated disciplines represent participants' training, as opposed to current job titles. For example, some participants were designated as 'educators' within the context of menopause clinics; however, they were trained in a variety of disciplines.

Table 4.2 Health professionals: Summary of demographics

Gender	Discipline	Place of employment
10 - female 2 - male	4 - Family doctors 2 - Dieticians 2 - Nurses 2 - Pharmacists 1 - Alternative health practitioner 1 - Specialist physician	5 - Community 5 - Menopause clinic 1 - Academic/community 1 - Retired

The sampling method used in the selection of HP participants was, in part, purposive. While to my knowledge most of the professionals working in the menopause clinics are female, there are many male HPs (primarily physicians) who deal with women in the menopause transition. Furthermore, a theme emerging from interviews with women highlighted the perception women had of receptivity to menopausal concerns among female vs. male physicians. I was, therefore, purposive in recruiting male participants to this sample of HPs. In addition, it has been found that the majority of women seek information and/or products from complementary and alternative medicine (CAM) sources (Wathen 2006). Therefore, participants with a CAM practice or interest were also interviewed: one alternative health practitioner who specializes in nutrition was interviewed as well as a physician who has extra training in the use of bioidentical hormones and CAM approaches to the management of menopause.

As noted in the section 3.5.2.2, the goal of interviews with HPs was to gain their perspectives on women's health IB and to explore themes relevant to interactions and relationships between women and HPs. This allowed insight into the roles HPs played facilitating the translation of knowledge with respect to the menopause transition. Relevant quotations and insights from HPs' interviews will be included as they are germane to the themes being discussed. Themes which drew the most comments from HPs were related to information sources (chapter 5) and positioning (chapter 6).

4.2 Women as active information agents

Women who were recruited to this study were likely to be active information seekers and to be involved in seeking information related to menopause. Both the poster and short (half page) recruitment notice stated that the study was looking for "women with a personal interest in menopausal or postmenopausal interest" and that the purpose of the study was to explore women's experiences making sense of health information about menopause and related issues. While there was variation in the women who responded, findings confirm that recruitment goals were met. Participants were active seekers of health information and, with some variation, had or were engaged in information seeking related to menopause. This group of participants therefore facilitated in-depth exploration of the information behaviour demonstrated by women as they seek, gather and store information about health in general, and more specifically, about the menopause transition. Three prominent themes related to participants' activities as information agents emerged from the interview data. (1) Participants were ready for information seeking challenges in the area of health and had specific approaches for investigating concerns which presented themselves within the context of everyday life. (2) They habitually gathered health information from multiple sources as they addressed everyday questions about health and well-being. And, (3) women gathered health information for a wide range of purposes as they addressed everyday life health concerns and concerns about the menopause transition.

4.2.1 Women's readiness for health information seeking

The first question for the interview with women was related to general health information seeking strategies. Participants were asked personally tailored variations of the question, "If you or a family member had a specific concern about health or well-being, how would you go about exploring that concern?" With three exceptions, every woman immediately provided a plan for investigating a concern about health. The three exceptions were Vicky, who launched directly into a detailed discussion of her disillusionment with the traditional medical system; Lillian, who, without delay, began relating her experience leading up to a hysterectomy in her early 30s; and Sylvia, who responded, "I don't think we give it much thought. We're healthy. My whole family is healthy." In these three cases this introductory question was not specifically addressed at a later point in the interview. While some women responded to this initial question in a generalized way, others provided a specific concern (for example, a recent diagnosis with diabetes, caring for a disabled family member, concerns about the health of a spouse) and discussed their information behaviour within the context of that particular concern.

A close exploration of participants' answers to this initial question demonstrated that the women who were interviewed had internal strategies or approaches for exploring health concerns. These strategies primarily entailed sequential exploratory tactics involving multiple sources but which began with (1) autonomous exploration (including the internet, or reading books), (2) going to an interpersonal information source (including family, friends, and acquaintances), or (3) consulting an authority figure (usually a physician, in one case an alternative health practitioner, and in another case, a pharmacist). Thirteen of the 25 women who answered this question began with autonomous exploration of information sources; 6 said that they would begin by consulting an authority; and 6 explained that they would begin exploring a health concern by talking to an interpersonal information source. Table 4.3 summarizes women's exploration strategies.

Table 4.3 Strategies for exploring concerns about health or well-being

Participant	**Exploring a concern about health or well-being**	**Strategy**
Anita	"It always worked for me first of all, looking for information, like name – I don't know – books? The internet. So *before* I meet with the doctor I already know or have an idea about the things that are happening – so for me it's just gathering all the information that I can through books or the internet. The library is important to me."	Autonomous exploration (self) → Authority (Authority)
Beverly	"Family, of course. I think modeling…. And then you know, friends, networking, just hearing around, then I usually either go to books or to the internet to find out information when I do have questions…. The odd thing from the health food store, you sometimes go and ask a question to a pharmacist or something like that."	Interpersonal (Interp) → self → authority
Camille	[Specific context: menopause] "Oprah. She's a great fountain of knowledge. And through her I read some things from, is it Christina Northrop? The menopause doctor. And then of course on-line . . . . and go to my doctor"	Self → authority
Cherri	"I might discuss it with my husband who's a family physician and I might discuss it with a friend of mine who's working as a nurse, a public health nurse. I might go to see my family physician, think through the options, ask some questions, make my decision from that. If it's major…if for example a close family member or myself was diagnosed with cancer or some life threatening disease, I would do a really thorough investigation on my own."	Interp → authority → self
Christy	[Specific context: diabetes] "OK, so I recently became diabetic. Which meant that my first thing that I did was hit the web, and just look for	Self → interp

	anything that was, had some sort of authority to it …. contacted friends and other people that I knew who were diabetic.”	
Dale	“I love my doctor and everything, but you can’t always just rely on their information because they can’t know everything. I do a lot of research, reading, talk to people……I had tried going on the internet a lot, looking for things, just Googling and trying to find thing. The library, their books.”	Self
Dana	“I read. I read about it first. I research it on my own before I seek a health professional’s opinion – To the library, the library or the book stores. The internet, I’ll probably check that out.”	Self → authority
Faye	“I’m very intentional – I have to go, be thorough, get out 10 books and read them all to find out as much as I can about it…… I don’t just go to the Mayo Clinic site, for example, I go to the library, I look at self help books. I go to Audrey’s Bookstore, I get sort of lay people books as well as Mayo Clinic or professional journal articles. And I talk to friends.”	Self → interp
Gwen	[Specific context: diabetes] “My primary source has been my doctor, Dr [P.] And she has, you know, given me other places that I can go to. You know for instance now with the diabetes I’m going to the [local care] network.”	Authority
Hazel	“First of all, I Google and find out what they say – the experts have to say on some of the websites, Web MD and … all that, and then I’ll talk to friends. And then I go to the doctor.”	Self → interp → authority
Irene	“I’ll look on the internet quite often. Or – I do a lot of reading. And then I’m very close to our family doctor so I’ll just have to give him a call”	Self → authority
Jane	[Specific context: a question about nutrition] “I have colleagues I could ask or I have sources through Dieticians of Canada, that type of thing.”	Interp → authority
Jill	“You know probably, go on the internet and check out, OK what, or what you think might be…. just go from there and, eventually, a doctor.”	Self → authority
Joyce	“I have used other people I know, like [R,] just because she’s in the health field so I sometimes ask people. When I was living in Boston when I was in my 20s, there was a book that we all bought, the Boston Women’s Health Collective …. The stuff that in the media we hear about, I *kind* of listen, I kind of take it with a grain of salt.”	Interp → self

Laura	"I go to the doctor and…I go to the internet, probably the most."	Authority → self
Lisa	"Ask [M (employer, a holistic nutritionist)]. OK. And if she can't answer my question, then she'll refer me to either, you know, Doctor X, Doctor Y, Doctor Z, or Doctor T – all the different, OK? And depending on which one she thinks would be best able to handle. And then I would do see a naturopathic doctor. And, in the meantime, waiting for an appointment of course, because there's always that wait time, I would go on the internet, ask other people I know"	Authority → self
Monica	[Specific context: seeking care for son] "I joined an interest group …. I learned more from the guest speakers, who were doctors and other professionals, than I ever did from the pediatrician."	Interp → authority
Muriel	"I'd go to the internet first. I think probably that's the first thing. I do have several relatives that are connected with the health field. So I generally would poll them to see if they have any ideas. If there's any umbrella organization, for example, like with cancer… I would go to the Cancer Board to see if they had people that could help me."	Self → interp → authority
Naomi	'Typically what I would do is look it up on the computer first and then – you know, google it, and then proceed to journals. Perhaps speak with other health care professionals… physicians or nurses, even OTs or PTs, depending. And certainly colleagues and friends, definitely".	Self →interp
Nicole	[Specific context: illness of family member] "There was a point at which it got where I was really seriously concerned. In that case the first person I absolutely went to was a former student of mine – So I tend to look for ways of short cutting the system."	Interp
Pat	"And usually, you know, traditional. Usually my first – investigation would be to phone my family doctor and, and ask. Once in a while I'll also call Health Link, you know, and get their assessment – if I don't have a health concern and I'm just curious about something? I'll probably go on the Net and look for information on that."	Authority→ self
Paula	"I'd probably go to my doctor . . . if there was medication that I did not know anything about, the first thing I do, and he knows this, is I go home	Authority → self → interp

	and it’s like ‘Yeah, OK. You’re going home and do a search, right?’ So that I go onto the internet or I would come to the library, but probably most likely I’d go on the internet and I would search the name of the drug . . . . And I talked to other people. I also talked to other people. You know, I’d say to them, ‘Have you ever heard of this? Have you ever been on this?”	
Roslyn	[Specific situation: new diagnosis] “I would have probably just have gone straight to the doctor . . . at that point I started doing a little bit of research on the computer, going to get some books, looking at magazine articles, so that was the first time I ever had to do – you know, taking it on myself to look at a health issue.”	Authority → self
Sue	[Specific situation: menopause] “I remember going to a health food store . . . . started reading up on it a lot, and then I would say . . . I started to talk to my doctor . . . . things on TV, little bits, snippets here and there, but I think a lot of it was my own reading and kind of research into it.	Self → authority
Thea	[Specific situation: menopause] “I would probably research it online. I’m big on that. Reading up on stuff like that . . . . [I] went straight to my doctor.”	Self → authority

Women responded without hesitation to this first question related to general strategies for health information seeking. They portrayed their information seeking as a fluid process which moved across and between a wide range of sources. Moreover, they described their approach as a familiar series of interlinked steps. For example, Dana immediately outlined her approach: she would first read independently before seeking input from a health professional. She also explained that she would go to the library or book stores, and that she would explore on the internet. Pat noted that the purpose of her information search would influence her strategy. She related that she would immediately consult a doctor about a personal health concern, whereas if she was simply curious about something health related she would explore online information.

Although many studies have explored women’s health information behaviours (*cf.* Warner and Procaccino 2004; Wathen and Harris 2006), these data support the notion that when confronted with an information need, women look to personal patterns or templates to navigate the many information sources in their worlds. This is consistent with information seeking theory which asserts that people follow habitual information seeking patterns (Harris and Dewdney 1994); however, this study demonstrates the seamless integration of the internet into these searching strategies and the fluid manner in which women move between informal and formal information sources. While Wathen and Harris (2006) note that “women often begin their information gathering by consulting informal, interpersonal sources” (n.p.), a general principle also noted by Harris and Dewdney (1994), these data suggest that the availability of online health information has perhaps changed this information seeking pattern. Most women’s strategy for exploring a health related question began with autonomous exploration of a range of sources, most notably, the internet.

4.2.2 Gathering health information from multiple sources

In addition to women’s readiness to articulate an information searching strategy, women spoke of habitually gathering health information from multiple sources as they addressed everyday health concerns and concerns about the menopause transition. In fact, all of the women interviewed described a mix of information sources. It is interesting to note that every woman in the sample mentioned the internet as an important source of information, and all of the women spoke of seeking or receiving information from HPs (including alternative practitioners). Other information sources included books, newspapers, magazines, television, radio, other people (for example family members, friends, colleagues, and acquaintances), and personal internal or intrapersonal information sources. While information sources are discussed in depth in chapter 5, this chapter explores themes more specific to participants’ experiences as information agents. Three themes with respect to the use of multiple information sources were evident in the data. Information sources were not perceived as standing alone, but rather they were perceived as complementing one another, as pointing or leading indirectly or directly to one another, and as serving different purposes.

4.2.2.1 Information sources complement one another

While there were tensions for women as they navigated formal and informal information sources, particularly when they were specifically problem solving (for example, struggling with symptom management), participants described very fluid information seeking which incorporated and bridged between multiple sources. Paula, for example, explained that she would consult her doctor and, if he wanted to prescribe a medication, she would first do her own exploration (internet, library, and interpersonal sources) in order to gain personal understanding of the recommended treatment; Monica said, “I’d go to various places. I’d go to the internet, I suppose. I would, ah, ask around. Talk to my doctor. And then, you know, pull together. I wouldn’t go to just one source”; and Roslyn explained that in her search for information about menopause “I had magazines, books, the internet, listened to other people, what they had gone through, what they’d tried to help themselves at that point. And I borrowed a bunch of books from a friend of mine who had also gone through menopause and had a really tough time.” While these quotations demonstrate that women use multiple information sources, they also demonstrate that these sources are viewed by women, not as competing but as complementing sources of information which enrich one another. Information sources appeared to be valued for the varying perspectives which were presented.

Interviewed HPs were aware that women accessed a range of information sources which informed their understanding of menopause. Yvonne, for example, noted, “So there’s always been some book. It just changes, the name.” While women tended to move between sources without viewing them as competing entities, HPs were more discriminating and were thus more likely to judge the credibility of the source. For example, Gail, a HP participant, positioned sources such as the North American Menopause Society (NAMS) and Oprah as conflicting information sources; whereas Sue and Camille (two of the interviewed women) valued both information from Oprah and information from a menopause clinic. Information from the latter source was guided by NAMS standards.

4.2.2.2 Information sources point to other resources

This view of complementing information sources was reinforced by participants' appreciation for information sources which directly or indirectly pointed to other resources. Naomi noted that friends referred her to specific books related to her information need, while Lisa told me that she would read books recommended by trusted websites. Vicky emphasized repeatedly the importance of health resources recommended by trusted interpersonal sources. And Hazel, who was having significant health challenges related to menopause and did not know how to effectively convey her concerns to HPs, related: "So then I talked some more with some friends and they said, 'Okay, go back to your doctor and say this is what you want' [i.e. a specific procedure]. So I checked that out on line and it seemed that women who had had it, and it even showed the procedure on YouTube – how to do it." Women particularly appreciated when HPs pointed to health information which augmented information exchanged in the direct HP-patient encounter. Nicole explicitly demonstrated this perspective:

> I felt confident with her. The way in which she handled me and treated me. The kinds of resources, I mean even with the [an unusual medical condition], she provided actual print information. Not from a pharmaceutical company, from her medical text! She even brought out her medical text and said, 'Now look. This is what we've got and see this is what it looks like, and everything.' So I thought, 'OK. This is somebody I relate to, this is somebody I have respect for. I think I want to head in this direction, at least right now.'

Irene told me that she favored using the Mayo Clinic's website for health information – a resource which was first suggested to her by her physician. And Naomi related, "I had a very good endocrinologist, a young fellow. Really, really, really good. And he is the first physician except for the [menopause clinic], that gave me an article."

While some interviewed HPs shared secondary information sources with women, others felt ill prepared for this activity. Wanda and Clare, for example, both cited their own lack of knowledge as a reason for not pointing women to internet sources. One of the interviewed family doctors, however, explained that she occasionally searched the web in order to better understand the menopause information her patients were encountering and in order to point them to resources. “It’s hard to go after every particular topic. I have done it for some. One of the last ones I would have done – looking for different, like natural, more natural herbal remedies, supplements, for [menopause]. Because we get very medical information.” Those HP participants working in menopause clinics had prepared information resources for women and were more likely to feel comfortable pointing women to selected information sources.

4.2.2.3 Information sources serve different purposes

Finally, women gathered information from multiple sources in order to meet a range of information needs. While Christy differentiated between theoretical and practical information needs (the internet provided theoretical knowledge to enhance information provided by her HP, while she consulted interpersonal sources for practical tips about living with a new diagnosis), Cherri differentiated based on “how severe the problem is and whether it’s potentially life threatening.” Interestingly Cherri stated that if the problem was minor, she would discuss if with a relative who is a physician, a friend who is a nurse, and her family physician. If, however, she or a close family member were diagnosed with a life threatening or serious disease, “I would do a really thorough investigation on my own. I wouldn’t just go to the doctor, receive the information and go away and say ‘good.’ I would do a lot of investigation as to treatment options.” For Cherri this thorough personal information search included research at a library, exploration of both the scientific literature and internet resources, and consultation with specialists both locally and potentially abroad. A further example is provided by Lillian who gathered “basic” information about her blood pressure from her doctor and then visited the local health food store to gather specific information about supplements and foods which might improve her blood pressure. “One said you take garlic. . . . And then the other lady said, she takes, if you eat three sticks of celery and an apple every day your blood pressure would go down.”

4.2.2.4 Exploring women's use of multiple information sources

While previous studies have focused on how different information sources provide varying aspects of information related to menopause, the WHI or HT (see section 2.3.2), these data demonstrate not only that participants valued a wide range of information sources, but also that they appeared to view them as potentially complementing elements of a search process. The research literature suggests the women are aware of the varying perspectives provided by different sources (Suter et al. 2007), and that individuals frequently prefer a range of information sources which facilitate exploration of different facets of a health concern (Brashers 2001). Interviews with participants demonstrated that women appreciated the range of perspectives that these sources provided (evident by the use of different sources for different information needs) and that referral from one source to a second source built trust and reinforced the notion that sources were complementary. While research has demonstrated the critical role of trust, for example Brown et al. (2002) note that trust in the relationship between physician and patient "enhanced the women's sense that the source of information was reliable and in her best interest" (227), these data suggest that referral to further information sources is not only contingent on trust, it also plays a role in building trusting relationships between women and HPs.

4.2.3 Gathering health information for a variety of purposes

Participants gathered health information for a wide range of specific and non-specific purposes. They collected information for both themselves and for others; they gathered in order to prepare for formal encounters with HPs, to confirm information received from a variety of other sources, and/or to supplement existing knowledge; they collected health information out of general interest and as an incidental everyday life activity; and they accumulated information and 'filed it' for unspecified purposes.

4.2.3.1 For oneself and for others

Women have been identified as commonly seeking information both for themselves and for others, particularly for family members (Harris and Wathen 2007; Moen and Brennan 2005) (section 2.3.1 for details). This was strongly supported by the interviews. Although women scanned and gathered information for a range of specific purposes, when women talked about their health information seeking in a broad sense, or when they answered questions about their use of specific sources (e.g. media sources, the internet, interpersonal contacts) the majority of women identified special interest in health information which was relevant to themselves or to family members. For example, when asked about health in the media, responses included the following: (1) “if there was something on Alzheimer’s. Alzheimer’s is a really interesting – of great interest because my father and his whole family has been afflicted with Alzheimer’s, so obviously this is interesting to me” (Nicole); (2) “anything that is related to a condition where I know someone that has that condition. So if it is a migraine thing. I will actually sit there and read the article. If there is a diabetes thing, if there’s an epilepsy thing. So, you know, any of the conditions that are there in the family or somewhere I’ll read thoroughly” (Christy); and (3) “if we saw *anything* that had the headline with one of my husband’s medications” (Jane). Thea was particularly specific in identifying the parameters of her interest. While she knew what she would be drawn to read (“My dad passed away [from cancer]. So I’d read this”), she also knew what she would not be inclined to read: “And you know what, I’m not going to research it unless it affects something that my children are going through or something.” Thea noted that if she “just stumble[d] across” a health show on television “I’ll – ‘Oh, this is about menopause’ – I’m gonna sit down because I have it. OK, if it was a thing on something else and I don’t have it, I’m not going to watch it.” Additional support for participants’ tendency to collect health information which was directly relevant to their own or a close associate’s health needs is provided by the following examples:

> When I hear a problem either with a friend, or you know, from – even my hair dresser, [who has] headache problems right now. . . .Then you know you tend to research it a little bit more in order to help them. (Jill)

> My neighbor friend, she reads the newspaper from back to front and if there's anything on menopause she cuts it out for me. . .She goes, '[Sue], here's something for you.' She does that with other things but definitely the menopause. (Sue)

Furthermore, during the elicitation portion of the interview women pointed to words which evoked personal identification and therefore drew their attention and motivated them to engage with specific articles. The following quotations provide examples of this personal identification: "if it had the word 'menopause' in it, I would – this is what would *really* get my eyes open" (Sue); "this one appeals to me because 'older women' [quoting from article headline]. I don't know if I'm 'older' yet, but I guess that's older" (Jane); and "yeah, 'cancer,' the whole thing, 'women,' 'older women'" (Thea).

4.2.3.2 To prepare for formal encounters with HPs

Most of the interviewed women gathered health information prior to seeking information or medical help from a HP, and many women went to HPs only after they had exhausted their personal information finding capabilities or when they required access to a specific medical service (e.g. hormone assessment, a prescription, or a physical examination). However, almost half of the women interviewed (13 of 28) noted that they gathered health information *specifically* as a means of preparing for formal encounters with HPs (primarily physicians). Joyce, for example, explained, "women talk to other women and friends," thus exchanging information and forming an "informal referral system," a process which serves as a means of "preparing to talk to formal sources." Other women also very specifically noted that they gathered health information in order to prepare for encounters with HPs. Lillian, the oldest participant in this study, stated:

> Oh, it is different. Thirty years ago the doctor was THE doctor. And you just trust them. You had cancer, they wouldn't tell you, so you wouldn't get worried about yourself. The doctor was the only sole source of information and you trusted him. And that was it. And if he made a mistake, you probably never know. But now people might Google things before they go to the doctor.

The following examples are representative of participants' comments about gathering health information in preparation for encounters with HPs:

> So I went to the library and looked it up and got whatever articles I could from the library and read it over and decided that I was having menopause symptoms, and what I needed to do was ask my doctor to do the hormone testing thing. (Muriel)
>
> Unless I'm in a great deal of pain, I don't want to go to a doctor first. I'd rather do my own reading so I get a little bit educated or talk to some other people. (Faye)
>
> It always worked for me first of all, looking for information. . . . Books. The internet. So *before* I meet with the doctor I already know or have an idea about the things that are happening. (Anita)
>
> I went to the library and I took out all these books on breast cancer, and I had a meeting with the surgeon. I had three pages of questions. (Joyce)

Data from interviews with HPs supported the notion that women gathered information in preparation for encounters with HPs. Health professionals were most likely to see their role as one of helping women interpret the information they brought with them. Wanda noted, "So they'll come to me with a book – 'Well, I've read this about menopause' and 'I've read that' - and 'What do you think about this?'" And Denise commented, "They'll come in with an array of information and not know sometimes how to interpret it or what to do with it." Francis noted that more recently women had started reading more and as a result already had firm ideas about treatment: "They talk and they argue and they say 'Well, can you find something else for me? Are you sure that this is the best way?' . . . . I'd say to myself – 'Why [is] the patient coming to see me if she already made up her mind that she is not going to listen to my advice?'" These observations confirm findings discussed in section 6.1 – many women presumed that they were autonomous and self-directed information seekers and decision makers with respect to the management of the menopause transition. Francis' apparent frustration with women who did not appear to be open to the advice of HPs is illuminated by discussions of shared decision making (SDM) in the health literature. In this context SDM is characterized by the notion that HPs communicate information to patients and then help them understand the information and make treatment choices based on the best available medical evidence (Légaré and Brouillette 2009).

4.2.3.3 To evaluate and confirm

In addition to gathering information in preparation for encounters with formal information sources, participants very frequently engaged in information seeking and gathering in order to evaluate and potentially confirm information they had received from other sources. Across the sample of women participants, a range of potentially confirming sources was noted; however, most commonly participants related that they were (1) seeking information from HPs to confirm information encountered elsewhere, (2) confirming information from a HP in other sources, or (3) seeking confirming information on the internet. Examples of these primary confirming information sources follow.

Laura explained that when she had symptoms, she went to the internet and explored what those symptoms might mean. She then went to her physician seeking information which would confirm or disprove the possible diagnosis she had derived from internet sources. “So then I go, and on the internet it says what the symptoms are. And I’m thinking ‘Oh, I have a few of those.’ And then I go to her, and I say ‘well, I either have irritable bowel syndrome or I have colon cancer, or I have …celiac disease.’” Other women, for example Beverly, Faye, Gwen and Joyce specifically noted that they would seek additional information from a trusted HP if they encountered uncertain health information in the media. Faye exemplified these participants; she noted that if she had a doctor’s appointment she might “see if there’s any contrasting information.” Confirmation of health information encountered in the media was likely highlighted because in the elicitation portion of the interview women were directly asked how they would make sense of contradictory health information encountered in that medium.

Pat gathered health information in order to confirm information provided by her physician: “What I do with my medications, with my diabetic medication specifically, is I will look them up on the internet and see, you know, check several sources to make sure I’m getting kind of reasonable information.” And Paula explained:

> The first thing I do, and he knows this, is I go home and it's like 'Yeah, Okay. You're going home and do a search, right?' So that I go onto the internet or I would come to the library, but probably most likely I'd go on the internet and I would search the name of the drug, like I say, if it was a medication. And search everything I possibly could about it: positive effects, negative effects, and then I'd let him know what I thought about it.

The most common source for confirming health information was the internet. In the examples provided under the last point, both Pat and Paula went online to seek confirming evidence for information given to them by HPs. Paula also went to the internet to confirm information she encountered in the print media. And, Muriel looked to gather additional online information in order to evaluate previously encountered online sources: "I tend to use several [websites] and collect that information and then sometimes I print it out and compare them." Joyce used the internet to gather additional information which might help her evaluate information emailed to her by an interpersonal source: "Before I had any conversation with her, I plunked it into Google to just see if I could find how they define it." And Nicole listed a number of sources, including the internet, from which she would gather evaluative or confirming information: "You can bet your bottom dollar I'd be on the net, I'd be phoning my brother, I'd be phoning my gynaecologist, I would be pushing the system to say 'OK, where is the truth in this?"

4.2.3.4 To supplement knowledge

Many participants gathered health information in order to supplement existing knowledge. Dana, for example, noted, "I already knew a lot about that. But I just checked out the different, um, solutions to it. Cures or whatever." And Pat said, "I just like to know sort of the ins and outs of things, is why I would look things up." While in these two cases the women were supplementing knowledge out of interest, many woman gathered supplemental information because they were not getting the information they wanted from their physicians. Roslyn, for example, received an unexpected diagnosis and was referred to a specialist, "and that was the end of the appointment. And I was sort of standing there, okay. So at that point I went to the computer to look up [my diagnosis] to see what that was."

Two primary sources of supplementary information were the internet and interpersonal sources. There are numerous examples of the internet as a means to gather health information for the purpose of supplementing knowledge: when Lillian wanted to learn more about a supplement she was taking, she explained, "Then I Googled it"; Beverly related that she used the internet "to look up something I've already been exposed to, kind of when I want more information on something…"; and Christy noted, "I was looking first for a confirmation of what she had said, expansion of the information because she hadn't given me or I hadn't taken in thoroughly the info. Because I kind of went away and said 'what about this' you know, and, 'why is this?'" Interpersonal sources were also very important to participants who gathered health information in order to supplement their knowledge. Camille and Thea exemplify gathering supplemental knowledge via interpersonal sources: "I really just talked to some girlfriends or something and you know, 'This is what I'm feeling.' And they would say, 'Maybe you should check about menopause because it sounds like you've got the symptoms" (Camille); and, "I sort of thought, you know what, I'm going to look at how other people alleviate it then" (Thea).

4.2.3.5 For general interest

In addition to the specific purposes discussed thus far, interview data indicates that participants commonly gathered health information out of general interest or as a part of everyday life information scanning. Pat and Christy's comments were representative of this theme: "So yeah, just - you know, it's just a matter of interest rather than anything else. Not, pertaining to me specifically, but 'Oh, looks what's out there now'" (Pat); and Christy noted that she would watch a health oriented television show if it were about a "really obscure, interesting disorder where you would never have known about it. But you know, that is really more on the entertainment level, or the stretch your mind level." Paula indicated that she would even actively investigate a health related question out of general interest:

> You know, it's something that, that – you know, turns my interest. Right? Like okay, I don't know much about that subject or it hasn't affected me or impacted me, but I've heard of or I know someone that

> has, so yeah, I will ask questions or I'll come to the library or again, I'll go online and do some research. You know, maybe it may not impact me, but just because I don't have it doesn't mean that I shouldn't be knowledgeable about various studies or various drugs.

Women also gathered information that they encountered as a part of everyday life information scanning. Although Christy watched television health features only if they were interesting, she did report that she, like many participants, regularly read health features which appeared in the newspaper. Many other participants mentioned health information which was gathered as a result of everyday life information scanning of a variety of sources. Beverly, for example, paid attention to health information included in the religious programming which she regularly watched; Laura noted that although her small town newspaper had poor news coverage, she regularly read an 'Ask the Doctor' style column in the paper; and Lisa collected health information from the free magazines which she routinely picked up from her local health food store. These examples demonstrate that participants were active information agents who gathered health information from a wide range of sources not only for specific purposes, but also as a matter of general interest.

4.2.3.6 In order to 'file it' for potential later use

While researchers have identified strategies which women use for managing and physically storing health information of relevance within a household (Moen and Brennan 2005), data from this study suggest that women also 'file' nonspecific health information for potential use in the future. Dana noted, "I read everything that I can on everything. . . . I guess I file it. I file it in my mind." And Jill explained: "Whether it goes into the recycle bin or whether it goes into, 'Hey, this is information for later on' or 'this is information I can use right now.' And you learn to – go to the stuff you know, and just constantly pull things" (Jill). Naomi and Faye referred to health information residing in an almost physical sense in their minds: "When I see information in the Journal or the paper, I sort of scanned this and it sits somewhere" (Naomi), and "…that's a pool of information in my head, all of which is about health and health maintenance" (Faye). Women also mentally 'filed' information which they thought might be of relevance at a later time. Christy, for example said, “And so I kind of looked at it and said to myself, ‘Well, this is something I’ll ask about the next time I go in.” And Nicole demonstrated this mental filing of health information when she related that she had been “really interested” in an article which was published three years previously; now she had renewed interest in the topic and was planning to follow up on the information from that article when she visited a specialist in a few weeks. Sonya, one the interviewed HPs, provided support for this notion that women filed health information for later use:

> That’s the other thing that’s amazing with health information and women is they’ll read something and I think they rip it out and put it somewhere. Or a phone number or something. And then months later they’ll say, ‘Oh, I read that article.’ And they’ll follow up with it, I guess when they have a bit more time . . . . They really do act upon things. Or even if we do an interview in the Journal you’ll get calls even a year later saying, ‘I saw that in the paper’ and I guess they just sort of need it now, right, so – tucked to the side in the event that they needed that phone number or whatever it may be.

4.2.3.7 Exploring women’s information gathering

Consistent with literature on women’s information behaviour (Warner and Procaccino 2004) interviews demonstrated that women gathered health information for a range of purposes. While information gathering has been noted as a means of improving self-efficacy prior to encounters with HPs (Wathen 2006), each of the purposes which emerged from the current data contributed to empowering women as primary stakeholders in their own health and wellness. Women’s interest in gathering information to supplement knowledge, out of general interest, or to ‘file’ for future use all serve to improve women’s control over their own health and to facilitate informed decision making. Macias, Lewis and Shankar (2004) observed that women’s access to online health information has given women greater control over their own health and has contributed to a changing balance in women’s relationships with HPs (Macias, Lewis, and Shankar 2004). Although women’s information gathering may threaten traditional authority structures within healthcare systems, focus on SDM within the health literature (Légaré and Brouillette 2009; Salkovskis and Rees 2004) suggests that patient information gathering should be viewed as a positive contribution to the patient-HP relationship. Furthermore, participants' interest in information gathering and their appreciation for HPs who point them to secondary information sources (for example, articles or websites) suggests an opportunity for HPs. By making high quality, personally relevant health information available to women, HPs will facilitate individual responsibility for health and well-being (a central notion within the context of the 'wellness movement' (Cangelosi and Markham 1994)) as well as foster relationships between women and HPs.

4.3 Women's perceptions of health, wellness, and menopause symptoms

Two primary themes related to self perception and the menopause experience became apparent through data analyses: positioning with respect to wellness in the presence of health challenges and the symptoms experienced during menopause. The first theme is demonstrated by three sub-themes, *positioning self as 'healthy,' too young for menopause,* and *experiencing 'normal.'* These sub-themes provide insight into notions of wellness and menopause as a negative symbol. The second primary theme explores the profound impact which symptoms have on women's self perceptions and experience of the menopause transition.

4.3.1 Wellness and menopause

4.3.1.1 Positioning self as 'healthy'

In-depth analyses of women's interviews reveals that participants tend to position themselves as 'healthy,' despite symptoms or diagnoses which challenged well-being or health. This positioning commonly occurred in close proximity or as a prelude to discussion of health challenges, thus serving as a discursive disclaimer for notions of illness. This was demonstrated in two ways by interview participants and might be thought of as the 'I'm healthy, but…' or the 'healthy except for this' positions. The first representation of this theme was by women who positioned themselves as healthy in a general sense; secondly, this theme was demonstrated by women who positioned themselves as healthy prior to menopause. Sylvia and Pat’s comments were representative of the first representation of this theme.

> *Sylvia*. Despite suffering from severe, disruptive hot flashes, long standing and ongoing challenges with symptom management, and tensions with doctors over the prescription of HT, Sylvia stated early in the interview: “We’re healthy. My whole family is healthy.” This statement represented Sylvia’s view of herself as a healthy person who just happened to be having a difficult time in one area of health – in a sense she bracketed her menopause experience and her challenges with symptom management and positioned herself as ‘healthy.’
>
> *Pat*. Beginning with her first statements, Pat presented herself as healthy and as having a laid back approach health. “I guess what my first question would be is, what is a health concern? Typically when, I’m usually a very healthy person, but when something isn’t quite right or there’s, you know, something, I’ll usually give it a few days to a week to see if it’s going to hang around.” It was not until almost half way through the interview that Pat briefly outlined other details of her medical history, which included two chronic diseases which required on-going and likely life-long pharmaceutical intervention as well as some behavioural alterations. Despite noting these diseases, Pat continued: “But normally? Regular health stuff? I don’t get sick.”

A second variation of this theme is exemplified by Roslyn and Thea, who acknowledged their health challenges related to menopause and positioned themselves as healthy prior to menopause onset.

> *Roslyn*: Roslyn explicitly positioned herself as healthy prior to menopause in her first statement: “Prior to going into the menopause period in my life, I’d never been sick. Neither had my kids.” Later in her narrative she noted, “[Menopause] was a confusing time for me. And steadily my health was getting worse and worse.” Roslyn’s previous statement, “I’ve never been sick,” supported rhetorically by the statement “neither had my kids,” discursively positioned her as ‘healthy except for this’ and functioned to support her hope that the challenges and distress she had experienced with menopause were temporary.
>
> *Thea*: For Thea, menopause brought disruptive and severe symptoms. Near the beginning of the interview and shortly after describing her significant challenges related to the menopause transition, Thea noted, “I’ve been pretty healthy other than the main issues in my life, like pregnancies, asthma – always had asthma, you know.” In this case Thea both bracketed her asthma (which she later notes as an ongoing

> issue which was managed by her doctor) and demonstrated a perception of herself as generally healthy; and, like in Roslyn's case, presented the notion of health prior to the current menopause challenges.

Compromised health is thus positioned as an aberration or temporary state.

4.3.1.2 Too young for menopause?

While the positioning self as 'healthy' draws attention to notions of wellness as a subjective experience of health (Mackey 2009) (discussion in section 4.4.1.4), a contrasting discourse was evident in the interview data. This discourse positioned menopause as a symbol of aging and, while it was made evident in women's descriptions of themselves, it was also made evident when women described what others, particularly HPs, said about them.

Perhaps not surprisingly, those women who positioned themselves as 'too young' for experiencing menopause tended to be those who began experiencing symptoms in their 30s and early 40s. One exception to this was Faye, who had a child in her mid-40s followed by the onset of menopause symptoms. In this case the notion of being young was influenced by the context of having young children (at one point she described menopause as being "in the early years of her life, two young kids. . ."). While some participants explicitly positioned themselves as 'too young,' other participants positioned themselves as young by comparing themselves to other women who were stereotyped as aged and overweight. Camille, for example, explicitly positioned herself as 'too young' and explained that HT was reasonable given her age: "It made sense that yes, I should at my young age, I should still have those hormones in me." A little later in the interview Camille alluded to the theme of youth by comparing herself to her mother: "I remember when my mom was 40, 45, and she wasn't like I am now. They say that 40s, the new 20s kind of thing or whatever." Anita's comments were representative of this theme. She explained that she did not fit in with other women she met at her child's school "because I look different, I look younger, I look fit. And they're fat, older looking women, although they're my age."

In addition to explicit statements and descriptions of self, participants highlighted the notion of being 'too young for menopause' by relating what others said about them. Some of this positioning came from friends and acquaintances: “And people would say, ‘You’re too young for that.’ And I’d go, ‘Well actually no, I’m not. And I’m pretty well done’” (Paula). However, most of the situations in which participants were positioned by others as ‘too young’ were described within the context of encounters with HPs who did not take women’s menopause concerns seriously. The following quotations exemplify this finding: “With my menopause symptoms I started showing signs younger than a lot of women do, so my one family doctor, she moved, but I don’t think she took me very seriously” (Dale); and, “So there was a male doctor who I saw and he was like, ‘Oh, you are young to be having menopause.’. . . And he brushed it off” (Hazel).

4.3.1.3 Experiencing ‘normal’

A theme which emerged prominently from data analysis was that women seek to determine that, despite symptoms, their menopause experience is ‘normal.’ A few respondents noted that not everyone shared their experience of symptoms. Anita, for example, noted incredulously at one point: “And then there’s this whole group of women that didn’t have symptoms. They’re lucky enough not to have symptoms of menopause. They didn’t even know and they don’t pay attention to that.” However, data suggest that viewing the menopause experience as ‘normal’ was an important lens for women. Laura, who experienced natural but premature menopause, commented specifically on the notion of being normal:

> I remember, a friend of mine when I was a lot younger, he says, ‘All you want to know is that what you’re going through is normal.’ You know, that it’s a normal stage of your life for where you are. And so I think about that because – and so for me as a person I kind of think, that’s all I want to know. Is that everyone else is going through similar stuff. So if it’s, you know, it’s only if it’s abnormal then you’re kind of more worried.

Perimenopause and accompanying symptoms can alienate women from their own bodies and from their perceptions of being physically normal. As discussed in section 4.4.1.1, participants positioned themselves as ‘healthy’ and therefore ‘normal’ even when they were experiencing noteworthy health challenges. Plunged into experiences which may be unexpected, unknown and seemingly uncontrollable, encounters with information or interpersonal experiences which realign personal experience with ‘normal’ experience can provide significant comfort – even before any steps are taken to alleviate symptoms. Hazel, for example, was comforted to discover that her overwhelming fatigue might be explained by low iron levels: “I’m thinking that makes you tired all the time, so it is normal. Because it’s not like me at all.” And despite significant challenges with menopause management, Anita commented, “[It’s a] normal thing in your life. I mean, you will have to go through it and there are a lot of things that can help you.”

Many women experienced a kind of relief when they discovered that some variation of their own experience was shared with other women in the menopause transition. Women reported deliberately looking for information in order to determine or confirm that they were ‘normal.’ Laura, Pat, and Hazel provide examples of this deliberate exploration of information sources. Laura reported, “”I guess I look up on the internet to see if, ‘Oh yeah, oh yeah it seems like that’s normal for most people my age to going through something like this.” Pat also described using the internet for this purpose: “And so I’d look for that to find out what normal is, or try to define what normal is.” For some women it was a ‘diagnosis’ which led to a search for normalizing information. Hazel related: “They [the “doctors”] said it’s probably perimenopausal. So I thought, okay, that’s the word. And then I got a book. . . . So I thought ‘Okay, so that’s what it is. It’s normal. I just have to deal with it.’”

In addition to purposive information seeking, participants’ interactions with other women served to normalize the menopause transition. Dale, for example, lived in a small centre where she did not feel supported by the knowledge of HPs. Consequently she talked to other women about her menopausal symptoms and asked, “Does this seem normal?” Monica noted that she works with a number of women in her age group and their informal conversation about symptoms “normalizes the situation.” And Joyce attended a seminar related to menopause and spoke of a profound connection she experienced: “The biggest thing was to not feel that you were not normal because the experience you were having was different from someone else's. . . you're all women and you're all dealing with menopause."

Finally, participants reported that encounters with popular media sources also served to normalize personal experience: "When I saw a woman [on Oprah] that was – has been treated, but it was like a testimony from her before the treatment and after. And you know, I feel so much like her, I have been through that. And I think that tons of people are going through the same thing, so it makes you feel better. You're not alone. You're not crazy" (Anita). Encounters via the media also provided Thea with reassurance. However, she was reassured not by her experience of menopause being 'normal,' but by the notion that her experience of uncertainty was 'normal.' "I just felt a little bit better in knowing that the women that were on that show went through the same thing I did where they weren't getting information and they had a long wait to get any, and what is the information that you should be reading, what is true, what is false, what is – what is it?"

Ginman et al. suggest that empowerment in health matters is symbolic of a healthier life (2003). In the case of participants, it appears that confirmation of the 'normalness' of their experiences served not only to affirm the reality of their experiences; it was also empowering as it represented a first step towards problem resolution and was thus indeed symbolic of a potentially healthier future.

4.3.1.4 Considering notions of wellness and aging

The three previous themes which were brought forward by qualitative interviews draw attention to the tension women experienced between notions of menopause as a natural life transition (NLT) and menopause as a negative representation of ageing. Self perceptions of being 'healthy' and 'normal' support notions of menopause as a natural transition and 'health' as a broad construct. This construct is best described by 'wellness' literature as it extends beyond disease and to social, emotional, mental, spiritual and physical well-being (Kiefer 2008). On the other hand, the 'too young for menopause' theme reinforces a biomedical discourse in which menopause is viewed as a deficiency disease (Harris 2008) and a "forever young" discourse in which menopause is "seen as a negative symbol of the ongoing aging process" (Hvas and Gannik 2008b, 179). It is interesting that some participants noted this latter discourse as occurring within the context of visits with physicians. While perhaps perceiving 'too young' as a compliment to middle aged women, these physicians were reinforcing culturally embedded notions of menopause as a negative representation of aging.

Although interviews focused on women's experiences as they responded to evolving information about menopause, some of the participants spoke to their experience navigating these conflicting discourses.

> Now my biggest quasi, and the quasi is in capital letters, is wrinkles. And just the whole thing about – there are just some days and I look at my face and I feel like I look really old and I don't like what I see in the mirror. And there are other days when that's not an issue. And I'm still having to come to terms with that. I am not an advocate of face lifts or Botox – I, just, the whole idea of it is abhorrent. But I'm also increasingly aware, in a sense, the subtle and not so subtle cultural pressure to look younger, or to be younger." (Nicole)

Other women (for example, Paula, Naomi, and Lisa) were aware of the negative association between menopause and aging and deliberately sought to normalize the experiences of women by talking openly in their everyday lives about menopause symptoms and their own experience of them.

A phenomenological lens suggests that participants' conceptions of health during menopause were facilitated by bracketing or "containment of experience" (Mackey 2009, 109). By focusing on a broader concept of what might be constructed as 'normal,' women were able to preserve notions of health, despite disease diagnoses and other physical challenges. Based on a phenomenological study of perimenopausal women, Mackey (2007) notes that "the embodiment of menopause meant that although changes and symptoms of menopause were experienced, they were only one experience among many" (43).

4.3.2 The symptom experience

The notion of a universal ‘symptom experience’ for women in the menopause transition is contested by research indicating that individual and cultural factors influence how women perceive, experience and manage menopause symptoms (Hall et al. 2007; Hunter and Rendall 2007). Clinicians in North America, however, suggest that there are a constellation of symptoms that are generally attributed to menopausal estrogen decline (Martin and Manson 2008). It is worthwhile noting, that from a cultural perspective, the sample of interviewed women was relatively homogeneous (see section 4.1.1). For the purposes of this study, symptoms were accepted as described and attributed by participants. This is consistent with a social constructionist approach in which understanding is constructed from personal experience, encountered information, existing knowledge structures, and sociocultural environments (Talja, Tuominen, and Savolainen 2005). Furthermore, feminist research suggests that there is a gap with respect to research which reflects “women’s own views and experience with menopausal symptoms” (Im 2007).

During the narrative portion of the interview, participants were asked to relate the story of their menopause experience. The question was framed with slight variations as some women brought their menopause experiences into the interview at earlier points in the conversation. The components of the question as outlined in the semi-structured interview guide follow: participants were asked to share the story of their experience during menopause, to share how they learned what they felt they needed to know in order to manage this life stage, and how this learning influenced their decision making. The intent was to make the question open ended, thus allowing women to answer it according to their own terms of reference. The interview with Nicole provides an example of how the question was expressed during an actual interview: “I’m wondering if you could share with me your story of what you experienced in menopause. How you learned the things you learned. How you integrated that to make decisions about how you managed this life transition.”

Despite the shaping of the interview question (which focused non-specifically on the menopause experience and then drew attention to the influence of information seeking and sources), almost all of the interviewed women prominently situated discussion of menopause symptoms within their narratives. The two exceptions were Vicky, who had not yet experienced the menopause transition, and Pat, who did not spontaneously mention symptoms and, when questioned, did not report any. For each of the other participants, however, symptoms were inextricably linked to their accounts of menopause. Twenty of the remaining 26 participants linked their menopause narrative to their symptom experience within the first few sentences of their menopause 'story.' In Lisa's first sentence, for example, she said, "The first thing, and again, I didn't associate it at the time, I started having troubles with my menstrual cycles, like very very painful." Other examples include the following: Sylvia, who noted within her first few sentences that hot flashes interfered with her work; Camille, who in her first recorded comments mentioned hot flashes, irregular periods, mood alteration, and sleep disturbance; and Lillian, who in the second sentence of her menopause narrative related, "My period just became wacky." Five of the remaining six participants began their menopause narratives by focusing on other topics. Two began by discussing information seeking, two began by talking about their mother's menopause experience, and one began with an account of exploring herbal menopause remedies. In all of these cases, however, participants brought in aspects of their symptom experiences immediately after these initial topics. For the remaining participant, the menopause narrative was told within the context of a complicated personal and family medical history making it difficult to clearly identify symptoms which were attributed to menopause and symptoms which were attributed to other health challenges.

A range of common and less common menopause symptoms have been identified in the research literature and are described in consumer health resources (*cf*. Martin and Manson 2008; NAMS 2006; Gold et al. 2000). Symptoms which were attributed to menopause by study participants include the following: hot flashes, mood disturbances, sleep disturbance (with or without night sweats), changes in menstrual patterns and flow (e.g. irregular cycles, heavy flow), sexual challenges (decreased libido, vaginal dryness), memory problems, itchy skin, weight gain, and onset of allergies. Because interviews emphasized the perspectives and experiences of participants as related in their own words and according to their own terms of reference (Bates 2004), it is not possible (nor was it the intent of this study) to document exact numbers of women experiencing given symptoms. It can be noted that, as documented in other sources (Gold et al. 2006), hot flashes were the most common symptom identified by participants. Mood disturbances, night sweats, and menstrual changes were also common in this group of women; three woman linked weight gain with this life stage, two women mentioned itchy skin, and one woman identified menopause as the reason for onset of severe allergies.

Two themes related to symptoms were evident in the stories women told about their menopause experiences. First, symptoms are experienced within an individual context and can be best understood by giving priority to women's stories and perspectives. And secondly, in their menopause 'stories, women linked the experience of symptoms closely with recognition of information need and information seeking.

4.3.2.1 Symptoms, context and women's stories

While many studies use check lists or Likert scales in order to quantify the symptom experience, women's narratives make an important contribution to deeper understanding of the symptom experience from women's perspectives. Stories provide insight into (1) the influence of women's personal context on the experience of symptoms, (2) challenges inherent in defining menopause symptoms, and (3) women's construction of the symptom experience based on common interpretive repertoires.

Women's personal contexts played an important role in how they portrayed their symptom experiences. Cherri, for example, had found herself raising grandchildren and her narrative focused on her physical needs with respect to practical tasks. She related few specific details with respect to symptoms and spoke of these symptoms within the context of her responsibilities. She explained:

"I found that some of the symptoms of menopause were becoming really quite uncomfortable. And if my youngest child was 15 or 12 at the time, and I didn't have more responsibility for younger children, I could have coped with that." Because of symptoms that she identified as being precipitated by estrogen deficiency, Cherri chose to deal with her symptoms by taking HT. While women's symptom experience cannot be compared in terms of the severity, it does appear that women's context can influence how they view symptoms. Sylvia, for example, highlighted her work context as critical to her inability to tolerate hot flashes: "I can't do [my work] in 30 degree weather when I've got hot flashes." Sylvia chose to commence HT; however, at the time of the interview, Sylvia's context had changed. She was working in a different setting, she was experimenting with exercise as a means of controlling vasomotor symptoms, and she was quite keen to stop HT. With the passage of time (she had been in the menopause transition for 10 years) and her more flexible work schedule Sylvia was beginning to consider alternative approaches to her symptoms. Thea also related how her symptom experience was influenced by her work context: "I couldn't even do my work. I'd be doing a presentation in front of a bunch of men and my whole suit would just soak."

Hazel and Dana provide one further example of the influence of personal context on symptom portrayal. Both of these women experienced changes in menstrual patterns with heavy and ongoing flow. Hazel was distressed by these changes, viewed them as pathological, and was actively engaged in seeking information and pursuing medical intervention in order to ameliorate the situation. Dana, in the other hand, did not like physicians ("I think that most of them are stupid") and despite that fact that her bleeding was attributed by HPs to a potentially life threatening diagnosis, she viewed it as a natural symptom of menopause which did not require medical intervention. She focused her information seeking on resources which she could explore independently (for instances books at the library and the internet) and on guidance from intrapersonal sources – specifically, Dana explained that when choosing information sources or making decisions, "my gut tells me." While a quantitative survey may reveal two women with menstrual changes, these two participants demonstrate the value of research which reflects women's own views and experiences. By exploring personal narratives, one gains insight into the contextualized symptom experiences and its influence on women's information needs, seeking and use.

Women's narratives also highlighted challenges which women experienced identifying menopause symptoms. For example, while Gwen attributed perceived memory loss to her medical history ("I've had a lot of surgeries in the last couple of years and lots of anesthetics so my memory isn't quite a sharp as it used to be"), Laura jokingly referred to her "menopausal brain," thus attributing memory loss to the menopause transition. In contrast, Anita noted memory problems but did not specifically attribute this symptom: "I can't remember right now, you know, memory loss." Whereas women tended to mention vasomotor symptoms whether they had them or not, many women did not make any comments about their memory. This may have been because memory was not a perceived problem for other participants; conversely, this may have been because participants did not view this as a symptom of menopause. In fact, despite its inclusion in lists of menopause symptoms, memory decline is a contested symptom of this life transition (Im 2007). While women may perceive and self-report an increase in forgetfulness during menopause (Mitchell and Woods 2001), a longitudinal study found that decline in working memory and perceptual speed is not associated with this life stage (Meyer et al. 2003).

Some women specifically identified the difficulty in ascribing a given symptom to menopause: "I had trouble sleeping for a while but it was hard to tell. Was that the grief [two family members had passed away]? Was it the menopause issues?" (Naomi); "And I had night sweats but, you know, never thought it would have been menopause" (Jill); and Dale, who reported a history of premenstrual syndrome (PMS) and entered the menopause transition while in her 30s, said, "I thought it must just be having the baby and hormones were all messed up." While Jill and Dale eventually determined that their symptoms were related to menopause, Naomi was not able to definitively identify the cause for her sleep disturbance.

A number of qualitative studies have been published identifying discourses which mediate women's accounts of the menopause transition (*cf.* Hyde et al. 2010b; Winterich and Umberson 1999; Hvas and Gannik 2008b). These studies support the notion that women draw on varying interpretive repertoires to construct their experiences of the menopause transition. Exploration of interview data demonstrates that participants in this study constructed their experience of symptoms by drawing primarily on two commonly available interpretive repertoires: the biomedical and the NLT. The biomedical discourse is widely available and was demonstrated by participants (for example, Cherri, Camille and Thea) who discussed symptoms within the context of deficiency or changing hormone levels and looked to medical management as a means of managing symptoms. The NLT discourse is also widely available and brings focus to menopause as a natural stage of life. This discourse draws on other interpretive repertoires noted in the literature, particularly the "health-promoting discourse" (Hvas and Gannik 2008a, 165). The NLT repertoire was also evident in participants' interviews (for example, Jill, Lisa, and Dana). Paula's comments exemplify this discourse: "Hot flashes still happen. They're a *natural* thing. . . . . I mean, yes, I've been embarrassed because I've been sweating. At the same time, I'm not going to run away and hide in a dark hole and take hormone pills."

Analysis of interview data does, however, demonstrate that these discourses do not represent stable positions for women. Participants moved between discourses at different stages in their lives and depending on their experiences. Anita, for example, adopted a biomedical interpretive repertoire when she began to suffer from severe menopause symptoms: "You have to think about it and make a decision because right now you are suffering all the consequences of this imbalance, right?" Later in the interview when she spoke of difficulty talking to other women about menopause she adopted a NLT discursive stance and observed, "[It's a] normal thing in your life. I mean, you will have to go through it." Jane's narrative exemplified the utilization of contrasting discourses within the interview context. This participant explained that following a hysterectomy in her early 40s she had been extremely concerned about osteoporosis and estrogen deficiency. She reported, “I just was concerned about the fact that when my estrogen ran out, I wanted to keep it going. . . . I had insisted on [HT]. It wasn’t a matter of being convinced by my doctor.” Despite this biomedical approach to symptoms, Jane also utilized a NLT interpretive repertoire later in the interview when she began to talk about her uncertainties with respect to HT and variation in estrogen levels over the life span. “How do I know when to cut back? Cause you don’t know how long humans are – sort of have estrogen for awhile and then they stop.”

The use of multiple discourses and the fluid ways in which women draw on different interpretive repertoires has been noted in other qualitative studies (Hvas and Gannik 2008b; Stephens, Budge, and Carryer 2002). While the use of shifting repertoires may be a feature of this population, it is also possible that it is related to the evolving nature of health information in this area and the challenges women face as they navigate uncertain information about symptoms and menopause treatment. In fact, the reported IB of many of the participants suggests that they drew on both biomedical and NLT discourses in their search for information: they sought information about symptoms from health food stores or alternative practitioners at the same time as from physicians or the menopause clinic (for example, Lillian, Irene, and Sue).

4.3.2.2 Symptoms as a motivation for information seeking

Although menopause is uneventful for many women, this life transition presents significant challenges to those women who struggle to manage disruptive symptoms. Recruitment notices for the study stated an explicit interest in “women as they hear about, read about, and try to make sense of changing health information about menopause” and noted that sources of interest included the media, internet, interpersonal sources and HPs. In addition, recruitment occurred in the community and at a menopause clinic, the latter site providing access to women who deliberated sought medical intervention for menopause symptoms. Although one cannot conclude that women in this sample suffered from symptoms disproportionately to the general population, the vast majority of women discussed symptoms as an integral part of their menopause narrative, perhaps suggesting an association between symptoms and those women who identify themselves in some way as information seekers. In fact, analysis of interview data suggests that women's notions of health and wellness were challenged by the symptoms they experienced and therefore participants linked the experience of symptoms closely with recognition of information need and subsequent information seeking. Thea, for example, explicitly linked her symptoms to her need to find information which would allow her to deal with symptoms: "I feel that I was driven in trying to solve those symptoms, for sure. [My symptoms] were really taking over my whole enjoyment factor in life."

While women in this sample looked to a wide range of information resources, there was a strong inclination for women to visit their doctors at some point when seeking information specifically about symptoms. This thematic link between symptoms, information need and information seeking, including via formal sources, can be illustrated by examining the stories of menopause related by Laura and Jill.

> *Laura*: When Laura began experiencing symptoms she went to a health food store seeking information and remedies. These remedies, however, did not have the desired impact and Laura related: "I wasn't getting a period, right? So then you're sporadic, and then you're not sleeping. And you're having hot flashes and night sweats and, it's brutal. It's brutal. So then when I wasn't sleeping. You're not functional the next day . . . . So that's why I ended up going to the doctor."
> *Jill*: This participant demonstrated a strong inclination towards using the internet and interpersonal information sources when seeking information. She indicated that the internet was a primary resource for exploring symptoms which she or her family might be experiencing, and that HPs were only accessed as a last resort. When she began experiencing menopause symptoms, however, she realized that she had some information gaps and, uncharacteristically, went to the doctor. In fact, Jill (for whom English is a second language), described how unusual it was for her to seek information from a HP: "When all of a sudden you go to the doctor the first time, because I go, you know. . . 'OK, you have to have a check up,' and I never had I think a full check up until I was 40. Then I thought, 'I better.'" Although HT was not an option Jill considered and she demonstrated an disinclination towards any medical intervention, she drew attention to the information seeking aspect by noting that her visit to the doctor was "just to find out."

Following consultation with physicians, Laura and Jill each continued to seek information about menopause. Consistent with her NLT interpretive repertoire, Jill looked to diet and exercise to manage her symptoms; Laura commenced HT, a decision which she viewed as provisional and likely to be moderated in time and with additional information. This latter approach to HT as a provisional decision is consistent with a recently published study which indicates that women viewed HT as both a means for temporary relief from symptoms and the beginning of an ongoing discussion about menopause management (Hyde et al. 2010a).

Interviews with HPs confirmed the association between symptoms, information need and information seeking. Amy observed, “For the most part [women seen at the clinic have] been struggling with their symptoms for a while, so they’ve often looked for information.” And Mark noted that women come to him specifically for information related to symptoms relief: “I think they’re basically looking for information. Yeah, they’re consulting me as far as what’s best for them. And they want, like I told you before, to be functional . . . so they don’t have night sweats and sleep disturbance and all the things that – if you can give them something that helps with that.”

These findings are supported by the literature which indicates that women actively seek information when confronted by decisions related to menopause management (Wathen 2006b). Furthermore, although women look to a wide range of sources for information about menopause (*cf*. Castelo-Branco et al. 2006; Ekstrom 2005; Theroux 2005), physicians are viewed by women as the most reliable source of information for menopause symptoms (Ma, Drieling and Stafford 2006) and concern about symptoms is the most common factor prompting women to discuss the menopause transition with their physicians (Singh et al. 2005).

4.4 Uncertainty and menopause

Changing health information was noted as a topic of interest in both the recruitment notices and in the interviews (highlighted by the elicitation portion of the interviews); therefore, it is not surprising that uncertainty was a prominent feature in the accounts given by women. Notwithstanding this declared research focus, uncertainty and controversy has been a well publicized part of the history of menopause management in recent years (see section 2.1), and one which the literature suggests was undoubtedly familiar to study participants from both samples (Breslau et al. 2003; Buist et al. 2004; Hersh, Stefanick, and Stafford2004). Uncertainty as it related to the following two themes figured prominently in women's stories about their menopause experiences: uncertainty about the life stage itself, and uncertainty about menopause management, particularly HT.

4.4.1 Uncertainty about menopause as a life stage

Women frequently noted fundamental uncertainty and knowledge gaps with respect to menopause as a life stage. These perceived knowledge gaps inevitably contributed to the link between this life transition and uncertainty. In particular, two themes related to this uncertainty emerged from data analysis: deficit of advance or preparatory knowledge about menopause, and ambiguity about the onset and duration of this transition. This uncertainty was exacerbated by a perceived lack of information from formal information sources and the notion that concerns about menopause and accompanying symptoms were not being taken seriously by physicians.

4.4.1.1 Lack of preparatory information about menopause

Analysis of data revealed that women perceived a noteworthy lack of preparation for the menopause transition. Sylvia, for example commented, "We know very little about it. Like I didn't even know when they considered you in your menopause." This sentiment was echoed by many participants: "Menopause to me was, you know, you're going to be lucky at about 48 or 50 or somewhere in that area, you're not going to be living with this gift [menstruation] anymore and you won't have to worry about it anymore and you'll be done" (Thea); and, "That was something that I didn't know. I had never talked to anybody about menopause and to me it was something that only happened when you're 55 and up. I had no idea about anything" (Anita). Camille contrasted the lack of preparation for menopause with the preparation young women receive for adolescent development: "But adolescence you're prepared for. You know, when you hit like 13, 14, 12, whatever, you're going to be going through this."

While the challenges inherent in providing information prior to the onset of this life transition were acknowledged by some participants (Roslyn, for example, noted that the wide age range of onset made delivery of preparatory information difficult), many participants suggested that information about menopause should be a routine part of health care for women. Sylvia explicitly suggested a life stage approach to preparing women for this transition:

> What I would like to see is maybe women in their twenties have got a pamphlet about what to expect in their twenties when they go for their regular Pap smear. In their thirties, what to expect in your thirties? In your forties, what to expect in your forties? And some of the problems and how to deal with some of those problems. It could be very simply done as far as I'm concerned, if they have the knowledge to do it. What to expect with menopause. Here are some of the things that – here are some of the ideas that we've got. But nothing has been constructively done that way. If you go into a doctor's office, there's all kinds of stuff about smoking. There's all kinds of stuff about all our hazardous stuff but nothing about our ordinary physiological day to day dealings.

And Sue expressed a similar notion: "I wish that [information] was given *to* us when you reach a certain age or you see your doctor or something is said at that point, 'Go here; get information.' I wish that was what it was. Or it could be."

One of the interviewed HPs commented specifically on preparing women for the menopause transition.

> So that would be primarily what they would ask me about is treatment for symptoms. Some women will ask me ahead of time. Like some women that are quite young will say, 'Well, I think I'm perimenopausal' when – and then they're sort of starting to get information – wanting to know like what does it actually mean. So then we kind of go through what defines menopause. As far as other kinds of issues – women will ask for symptom management. (Clare)

Like other HPs, Clare highlighted that women visited HPs primarily when they were experiencing problematic symptoms. She implied that requests for preparatory information were uncommon. While interviewed women suggested that HPs should provide advance information about menopause, HPs appeared to be responding to the concerns which patients brought to them, thus demonstrating an orientation towards illness and symptom management as opposed to health promotion. Although the literature indicates that symptoms or distressing changes in physical function are the most common factors leading women to discuss menopause with HPs (Hyde et al. 2010a; Singh et al. 2005), results from this current study reinforce previous findings (Huston, Jackowski, and Kirking 2009) and suggest that HPs are important sources of information for women in this life transition and, therefore, should take steps to initiate these discussions with their patients.

4.4.1.2 Uncertainty about the course of menopause

Perhaps aggravated by the perceived lack of preparatory information, uncertainty about the onset of menopause and the perimenopause period was a prominent feature of women's stories. Uncertainty about menopause onset was particularly prominent among those who were younger when this life stage began:

> Menopause crawled upon me and I was not aware that it was menopause until a few years after. Because I thought, 'I'm *way* too young.' (Jill)
>
> It didn't even cross my mind that this would be happening to me at that kind of an age. That I just actually, I probably took more pregnancy tests at that time in my life than I ever did, thinking that I might be pregnant. (Camille)
>
> I first started noticing changes that didn't make any sense to me because I was healthy. (Anita)

In each of these cases, women rationalized their uncertainty by positioning themselves as outside stereotyped notions of menopause, that is, positioning themselves as too young and healthy. Women's uncertainty continued through perimenopause. Gwen noted, "You know, even with the periods and stuff. It's not regular. Sometimes it goes away and I think, 'Oh good, I'm finished.' And then, guess what? It comes back again with a vengeance. Now, sometimes it comes earlier, sometimes it comes later, sometimes it doesn't come for a couple of months – I just don't know what to expect."

4.4.1.3. Lack of information about menopause from HPs

Analyses of data suggest that uncertainty during the menopause transition was exacerbated by a perceived lack of information about menopause from HPs and the notion that concerns were not being taken seriously by physicians. Sylvia, for example, pointed out “You know, like information for women is just really not – we don’t really know what our bodies are doing. And I think that the medical field doesn’t yet know.” Dale summarized an encounter with a HP by saying that the information provided was “sort of wishy-washy and no direct answers.” And Faye related:

> But I went in and they had one physician there, and she really didn’t have many more insights other than, well, you can take this antidepressant or you can take HRT. That’s about all she said and I just – well, I know that stuff. What about doing better? And aren’t there any more options and what about this and can you answer this question and how about this research and does this conflict or is this confirming, and she just didn’t know nearly as much as I thought. I just really didn’t get anything out of that.

Many of the women described situations where their concerns about menopause were dismissed as unimportant or they felt that their concerns were not being addressed at all. Nicole commented that she no longer trusted physicians and explained, “I guess my main concern is, how can you always continue to say that all of us, as women, are depressed? Just depressed. And that’s as far as it goes.” And Camille said, “I didn’t find a lot of sympathy. I didn’t find a lot of – not sympathy but *understanding* kind of thing. ‘This is what you go through, kind of deal with it.’” A number of women described incidents where their regular doctors dismissed their concerns as inconsequential: “His message was, ‘Suck it up,’ you know? ‘If you are in menopause, this happens to everybody. I know lots of women’ – you know, that sort of thing. ‘I have lots of patients and they just get used to this. It’s over in a couple years and they’re just fine’” (Muriel); and, “My doctor just sort of really did say ‘suck it up, you know, back in the old days, [Thea], women went through this. And I mean, it’s not a big deal and it will soon pass and whatever’” (Thea). The desire to biomedically legitimize the physical experience of menopause was confirmed by Hyde et al. (2010b) who found that a subset of their participants were distressed by the uncertainty which was provoked by HPs' lack of recognition of women's menopause status.

4.4.1.4 Women's responses to uncertainty

Despite this lack of information from HPs, participants were active information seekers in response to uncertainty about menopause as a life stage. (This was not entirely surprising since women who were interested in information about menopause were recruited as study participants.) Active information seeking in response to uncertainty about menopause included going to visit a physician, reading books and articles, searching the internet, and talking to friends, families and co-workers. Twenty-four of the 28 participants responded to their uncertainty about the menopause onset by actively seeking information. Nine reported going to their physicians as a first response to experiencing menopause. Cherri, for example, stated: "I recognized that I needed to do something about the menopausal symptoms, and so I went to a gynecologist and I told him, 'This is what's happening. What do you suggest?'" Three of these nine participants who consulted physicians as a first response to menopause uncertainty had hysterectomies, which may have played a role in their information seeking. Fifteen participants addressed uncertainty about menopause as a life transition by pursuing information independently before consulting HPs. Sue commented, "I knew that I was going into like menopause, but I didn't have a lot of resources at the time. And then I ended up – I remember going to a health food store and thinking I should look at some Black Cohosh and things like that. . . . So then I really started reading up on it a lot." Information seeking for 23 of the 24 information seekers did, at some point, involve a physician; the remaining woman relied on independent information seeking and consultation with alternative health practitioners. Of those four women who did not actively seek information, two relied on information as it was provided by HPs, and two did not seek information. Monica encountered information from interpersonal sources, but described her menopause experience by saying, "I just sort of let it flow"; and Pat did not specifically seek information about menopause and described going through perimenopause when she was between doctors because of a geographical move.

Although the majority of participants did at some point actively seek information from physicians, it is important to note that their uncertainty was not necessarily mitigated by the consultation. Hazel, for example, was left with distressing uncertainty after visiting her doctor ("They just give you brief information and tell you to see the specialist. And even the specialists don't seem to have the time"), and Muriel noted that the doctor "really didn't have a definitive answer one way or the other." Thea's uncertainty was similarly unresolved by her visit to her long-term family doctor: "I went straight to my doctor, which I've had for 12 years, thought he would be the best one to help me out because he knows me and he knows about my asthma and everything else. So I'm thinking, you know, what's going on with me here? I really didn't get any answers from him." In all of these cases, women continued seeking information to legitimize their bodily experiences, despite the lack of affirmation from HPs.

4.4.1.5 Exploring uncertainty about menopause as a life stage

Although uncertainty is widely thought to be a central part of the illness experience (Babrow, Kasch, and Ford 1998; Neville 2003), the uncertainty which participants experienced with respect to the menopause as a life transition blends uncertainty about illness with uncertainty related to 'normal' human development. Although the majority of women responded to uncertainty about menopause as a life stage by actively engaging in information seeking, narratives of the menopause experience suggest that, for almost all of the participants, this information seeking occurred following some physical experience which drew attention to the menopause transition. For some participants information seeking followed the experience of a medical event or procedure (for example following a hysterectomy), whereas for others, information seeking occurred following the experience of menopause symptoms (for example, hot flashes, sleeplessness, or mood disruption). A number of women directly referred to learning about this life phase vicariously by observing their mothers, learning which would have occurred in part prior to the onset of menopause. For example, Cherri reported, "I think it probably started when I was a kid because I'd hear my mom talking with her friends about menopause." Only one participant, Vicky, reported seeking menopause information prior to personal experience with the transition. Interview data indicate that even among this group of active information seekers, menopause was not a topic that stimulated preparatory information gathering. Although the lack of active preparatory information seeking was not addressed explicitly in the interviews, it is possible that this played a role in the uncertainty women experienced following the onset of this life stage. It is, therefore, worthwhile to consider why these active information seekers did not seek advance information about this inevitable stage of life.

While each woman's narrative represented unique reflections on personal experience, menopause has been identified as a "bio-psycho-socio-cultural process" (Hunter and Rendall 2007, 261) which is constructed within a given culture. Current cultural construction of menopause in North America includes a biomedical discourse in which menopause is constructed as a "disease and endocrinopathy" (Harris 2008, 968), as disruptive and debilitating (Hall et al. 2007), and as "a threat to the ideals of youth and thinness that women are required to maintain" (McKinley and Lyon 2008, 376). Interview data suggest that women are influenced by this cultural construction; hence, participants positioned themselves as 'healthy' or too young for onset of this life transition (see section 4.3.1). Since attractiveness for middle-aged and older women is primarily associated with not looking 'old' (McKinley and Lyon 2008), it is perhaps this construction of menopause which prevents women from engaging in preparatory information seeking. Findings do, however, clearly suggest that, in retrospect, women would value generic advance information about this life stage, perhaps within the context of regular medical checkups. It is important to keep in mind that people are consciously or unconsciously influenced by the culture they live in and by the way other people talk and think (Hvas and Gannik 2008b). By *not* introducing information about this transition to women prior to menopause onset, HPs inadvertently strengthen stereotypes about this life stage and reinforce cultural barriers to preparatory information seeking.

Uncertainty is also engendered by menopause-related nomenclature (see section 3.4), by the inherent subjectivity in interpreting or applying scientific information (Brashers 2001) and the uncertainty which is intrinsic to the application of population derived evidence to individuals (Griffiths, Green, Bendalow 2006). This suggests that, to some degree, uncertainty about the menopause transition is inevitable. For example, a brief exploration of three websites which were noted to be reputable by interviewed HPs demonstrates that uncertainty with respect to menopause onset may not be resolved by viewing these reputable consumer health information sources.

1. The Society of Obstetricians and Gynaecologists of Canada (SOCG) links information seekers to menopauseandu.ca. On this website, explanation of menopause onset is provided: "Women can start experiencing the physical and emotional changes that come with menopause earlier, but for most of us, it is in our late 40s or early 50s when our monthly cycle begins to change" (SOGC n.d.)
2. NAMS defines menopause, identifies the average age as 51, and provides information about menopause onset: "Physical signs of menopause begin many years before the final menstrual period. This menopause transition phase is called perimenopause (literally meaning "around menopause"). It can last 6 years or more, and by definition, ends 1 year after the final menstrual period" (NAMS 2006, 3).
3. The Mayo Clinic website describes onset as well, "Women start menopause at different ages. In your 40s, or even as early as your 30s, you may start noticing the signs" (Mayo Clinic 2010)

This information demonstrates not only that the age range for menopause is broad (potentially spanning three decades), but that the information itself varies. Whereas menopauseandu.ca informs women that onset is more likely in the late 40s and early 50s, NAMS suggests that onset occurs "many years" before age 51. In light of the medical literature which documents a range of 'average ages' for natural menopause in North America (*cf.* Al-Azzawi and Palacios 2009; Lisabeth et al. 2009), it is clear that despite potential uncertainty, information about menopause onset and duration must be presented in generalizations. Although the uncertainty which many women experienced may not be completely avoidable, Brashers (2001) points out that "accepting uncertainty is an adaptive mechanism" (484). Consistent and frank communication by HPs and by consumer health sources with respect to the range of potential menopause parameters may help women feel comfortable with the inevitable uncertainties of this life stage.

4.4.2 Uncertainty about menopause management

The second primary area of uncertainty which was prominent in participants' accounts of navigating information related to menopause was the management of this life stage. This prominence was likely influenced by research goals and recruitment aids which stated an interest in "your experiences as you find and use (or do not use) menopause information." Data from the interviews shows that those women who were markedly less concerned or interested in menopause management (Pat and Vicky) reported engaging in less information seeking about menopause in general. Vicky briefly engaged in purposive information seeking via formal channels in order to learn advance information about this life transition; and Pat did not specifically seek information about menopause and was content with the notion that her doctor would provide necessary information if required. For the vast majority of participants and for the interviewed HPs, uncertainty of menopause management was a dominant theme. Two major themes were highlighted by data analysis: the relationship between uncertainty about menopause management and information seeking; and uncertainty with respect to HT.

4.4.2.1 Uncertainty about menopause and information seeking

Data demonstrates that participants' active information seeking in response to uncertainty about menopause as a life stage (see section 4.4.1.4) did not reach a terminal point; rather, it appeared to be the beginning of an ongoing process as women explored information about the management of menopause. Women tended to explore a range information sources, encountering both 'biomedical' and the 'natural' interpretive repertoires (Hvas and Gannik 2008b) as they sought information. Gwen, who was a more passive information seeker than many of the women in the sample, nonetheless provides an example of ongoing information seeking from a range of sources representing both a 'natural' and a ‘biomedical’ approach to health management. Based on information from a friend, Gwen adopted a ‘natural’ approach to menopause management and tried an over-the-counter remedy, “HRT . . . a Swiss formula hormone replacement therapy.” Gwen highlighted a natural interpretive repertoire by specifically identifying the remedy as a “Swiss” formula and providing extra information, “It was a vitamin or an all natural health thing.” After approximately one year, Gwen was unhappy with this method of management and sought information from her physician who suggested low dose thyroid medication. In this case Gwen adopted a biomedical stance and related, “[The doctor] really keeps a good check over my system.” Faye provided another example of ongoing information seeking in response to uncertainty about menopause management. Faye was an active information seeker. She noted, “I don’t want to go to a doctor first. I’d rather do my own reading so I get a little bit educated or talk to some other people.” When she first experienced symptoms, she read and talked to other people, received advice about diet, exercise and creams, and tried some of the suggested approaches. Using a ‘natural’ interpretive repertoire, Faye explained that she had a “long bias against taking any kind of hormones or HRT . . . . I didn’t want to mess with my hormones.” Still struggling with symptoms, however, she consulted with a number of HPs. Faye was disappointed with the information provided and, based on her own experiential learning, Faye discovered that exercise provided some relief from symptoms. Further menopause symptoms, however, motivated an ongoing information search. This time Faye found the information exchange helpful: “I felt like I was engaged with somebody who would really be patient with my own decision making process and yet was able to kind of stand up to that still and say, ‘But here are the things that you might gain from.’ . . . . She wasn’t put off by my own need to do research beyond what she might be telling me.” Based once again on the experiential learning (amelioration of symptoms after medication trial), Faye eventually decided to use a form of HT. Faye explained her decision in part by stating that this was a low dose formulation whereas “early HRT stuff just seemed to be higher doses.”

Analyses of interview data suggest that divergent information about menopause management encouraged ongoing search for information.

> It [encountering varying health information] encourages me to keep looking to find additional information and maybe clarify the information. (Dale)
>
> There are several just sort of generalized pharmaceutical sites and I use them as well. And I tend to use several and collect that information and then sometimes I print it out and compare them and have a look. Because it depends, it seems, on how they're looking at the drug. They're not all looking for the same symptoms. They're not all telling you about the same side effects, it seems. (Muriel)

Furthermore, the uncertain and even controversial nature of information about menopause management appeared to play a role in leveling the playing field between formal and informal health information. This is clearly demonstrated by the way women moved easily between informal and formal sources: Lillian took the advice of women working at a local health food store just as seriously as she took the advice of her doctor; Muriel acted on information about HT (regarding cessation of therapy) which she received from other women her age, just as she had previously acted on the advice of a physician when she initiated therapy; and Camille gave the information about HT which was provided by Oprah the same level of credibility which she accorded information from a menopause clinic she attended.

4.4.2.2. Uncertainty about HT

A central issue for women who were navigating uncertainty about menopause management was the decision to consider and use (or not use) HT. While women talked about a range of therapeutic lifestyle interventions (for example diet, exercise, or positive attitude), every woman in the sample was aware of HT. Pat had the fewest comments about HT ("I really didn't have any knowledge [about HT] before hand and didn't acquire any") and yet even this participant noted, "I knew hormone therapy was out there." Women were not necessarily familiar specifically with the WHI (for example Sylvia, Camille, and Joyce), but most were aware of health concerns, particularly cancer, and controversy related to this intervention. Three participants reported that they went to physicians because they wished to use HT (Laura, Jane, and Irene). The majority of current or past HT users, however, described uncertainty about HT before being guided by a HP to an understanding that HT was a reasonable decision in their individual case. This most commonly involved explanation and rationalization based on age, risk/benefit ratio, quality of life issues, or the normalizing of hormone use. The following quotations are representative of participants' experiences:

> But also the reason why I was very leery about starting HRT was because of the studies that came out that women, breast cancer with Hormone Replacement Therapy and stuff. So I was really reluctant to start anything. But the one point that my GP was good with is he explained to me that at the age that I was, with me taking these hormones, it's the hormones that I should have had anyway. (Camille)
>
> I had always been dead against hormone therapy . . . . She [a HP]was telling me she believed that it was worth the risk, and she – this is how she explained it to me: the risk is like this [gesture, spread fingers]. The benefits to you are like this [gesture, spread arms] . . . . But I was willing to try it at that point. (Roslyn)
>
> [I viewed HT as] very risky and – almost taboo. That if you pursue [HT], you're taking life in your hands, type of thing. And then talking to [HPs] it's like, 'Well it's just birth control pills.' No more, no less than what they were when I took them 20 years ago. But it's not birth control; it's called my hormone therapy. But it's same type of thing, right? (Dale)

A conspicuous theme which emerged from conversations with women who were taking HT was the use of qualifying statements which constructed their use of HT as being lower risk than alternative HT use. These statements frequently set up comparisons between safer (low dose) vs. more dangerous (high dose) HT. Laura, for example, described her hormone regime, "as low a dose as possible." Women also commonly described active steps to lower their doses; the following quotes exemplify these comments: "I often asked if I could cut back the amount or whatever. And I was on a pretty low dose because it was just for that one thing" (Jane); and "I started out on huge dose and then they gradually reduced it down to mini-pills" (Christy). Thea had not yet found a regime of HT which dealt effectively with her menopause symptoms and described each of her trials as 'low dose': "So I chose the lowest dose of the estrogen and the Prometrium because I don't like risking my health . . . . So we went on three months of the Pill, the lowest dose." For some women, the 'safer HT' discourse included comparison between natural (bioidentical) vs. synthetic HT. Faye, for example, noted, “But also they seemed to be developing a few more lower dose and bioidentical stuff. Just things that offered a few more options.” And Anita explained, “I started with the bioidentical hormones, right? . . . . Because they said to me that it was probably the best thing.” These statements demonstrate a modification of the ‘biomedical’ discourses identified in previous studies and discussed in section 4.4.2.1 and perhaps an affinity towards the ‘natural’ interpretive repertoire (Hyde et al. 2010b). While maintaining a biomedical discourse (menopause as a deficiency disease), they suggest a ‘health-promoting’ discourse (Hvas and Gannik 2008b) (i.e.‘healthier’ choices in the form of lower dose HT) and a ‘natural’ discourse (Stephens, Budge, and Carryer 2002) (i.e. bioidentical HT makes use of natural substances).

Renee, who was one of two HPs in the sample who were familiar with and positive about bioidentical HT, provided supporting evidence for women’s preference for HT which is constructed as more natural and therefore lower risk. She observed, “So oftentimes when people would say things and they’d want things, I would say, ‘Well, I think that we should do things as natural as possible.’ And everybody would agree with that. You don’t get anybody say, ‘No. I want the horse estrogen.’ That doesn’t happen.” The construction of “bioidentical’ as lower risk was, however, contested by other interviewed HPs. For example, Amy explained: “One of the messages that [women] give out is the bioidentical compounded hormones are completely safe and the so-called synthetic are bad and harmful. And so we just sort of explain that really to a certain extent all the hormones are the same, they come from the same places and risks and benefits are the same.”

Analysis of data also demonstrated what Stephens, Budge and Carryer (2002) identify as a ‘drug’ interpretive repertoire. This draws on imagery from illegal drugs use and was used by women “to oppose the medical use of pharmaceuticals or pills” (Stephens, Budge, and Carryer 2002, 337). This was particularly prevalent in conversations with women who were opposed to hormone use.

> If I take pills it suppressed some of the stuff and then I don’t *know* how my body is really feeling. (Jill)
>
> I’m sorry but I don’t do drug pushers [physicians]. I don’t do drugs, you know, that’s not my thing. I want to know why. I want to fix why this is happening to me, not take a prescription to cover it up. (Lisa)
>
> I talked to my doctor and he talked to me about there’s different, gave me variables, because he knows I’m not a pill popping lady . . . . I wasn’t prepared to go and take pills to help me through hot flashes. Yeah, they OK, that’s – I don’t know, hot flashes still happen. They’re a *natural* thing. (Paula)
>
> Oh well, yeah, they then they talk about hormone therapy and I go ‘Ah well, I can live with it [symptoms].’ I’d rather not be on any more pills. (Monica)

In each of these examples, negative images of drugs are evident: “take pills,” “do drug pushers,” “pill popping,” and “on . . . pills.” Symptoms were presented as ‘natural’ whereas “pills” were presented as an unnatural alternative. Even for those who used HT, this imagery was evident: “So I was good, you know, I got down to the lowest dose, decided I could make do with some night sweats and something, yeah, because I’m kind of against taking pills. This is something that really bothers me so I wanted to take the minimum that I could” (Muriel). Interviewed HPs also noted this interpretive repertoire. For example Sonya commented, “So many women, the first thing they do when they sit down beside you is say, ‘I don’t like taking medication. I don’t want to be on anything.’ I have yet for a woman to sit down and say, ‘I would like to be on something.’

Muriel’s discomfort with HT, as demonstrated in the previous paragraph, brings attention to a final theme with respect to uncertainty about HT: the decision to use HT did not mark a resolution of uncertainty or a termination of menopause related information seeking; rather, it is just one decision in the course of a longer information seeking process. For example, Thea, who had not yet stabilized on a suitable HT regime, spoke of the many questions she had about the therapy: “Questions like how long do you think I’m gonna be on this now or like how long is it before we decide we’re going to hone it back? Or do we hone it back, get the symptoms back full force again, and then go at it again?” Data analysis demonstrated that even for women who found relief from HT, uncertainty provoked questions and ongoing interest in information about HT. In particular, women asked questions about cessation of therapy. Anita, for example, had experienced significant symptom relief from HT and while being uncomfortable with the notion of long-term HT, was also concerned about how cessation might impact her well-being. “I feel uncomfortable with the idea that I will be like this for the rest of my life . . . . Because I know that I am not going to leave it . . . . I’m almost sure if I leave this treatment, my life is going to be a mess again.” Anita positioned HT as a temporary treatment, thus indirectly positioning this therapy as ‘unnatural.’ Participants viewed HT as a provisional decision. This finding is consistent with Hyde et al. (2010b) who note that most women tend to view HT as “temporary relief and not a long-term panacea” (349).

4.4.2.3. Exploring uncertainty about menopause management

Given the widespread coverage of changes in menopause management since the first publication of WHI results in 2002 (*cf.* Genuis 2006; Naughton, Jones, and Shumaker 2005), it is not surprising that women experienced uncertainty with respect to managing this life transition. Furthermore, the many articles exploring decision making during menopause (*cf.* Légaré and Brouillette 2009; Welton et al. 2004) and the data from interviews with HPs indicate that the management of menopause remains an area with some uncertainty for HPs as well. For example, Connie commented, “I think one of the main things we try and get across to women is that hormone therapy isn’t – it’s not a recipe – so you know, what works for one person may not work for another.” Later in her interview, this HP also noted, “There’s different menopause clinics out there, too . . . so I think there’s a little bit of different information that’s being given at different clinics.” Another HP noted, ““[Women have] got to understand that whatever they choose is trial and error, because everybody’s body is different. And so just trying to get that in their mind that right away: ‘We don’t know if it’s going to work for you. We have to use this trial and error process’” (Gail). And Denise, recounting the many changes in menopause management over the span of her practice as a HP, observed, “Nothing in medicine is etched in stone.”

Exploring women’s experiences as they responded to, made sense of and used information about menopause management within this context of uncertainty provided unique insight into patient perspective. In addition to the uncertainty engendered by the specific topic and by the plethora of information on that topic, women were also faced with the uncertainty associated with interpreting and applying scientific information (Brashers 2001), and with the challenge of navigating the many discourses on menopause which are ubiquitous in texts and in ‘talk’ (Hvas and Gannik 2008a, 2008b).

In this study, uncertainty about menopause management was closely associated with information seeking and gathering. Women sought out and encountered information which contributed to ongoing decision making and sense-making processes related to menopause management. While confirming that women navigating this life transition used a wide range of information sources, with HPs being a primary information source (Wathen 2006), this study also suggested that women moved easily between formal and informal information sources, at times ascribing similar relevance to a range of sources. For those women who chose to use HT, the decision was most commonly viewed as reasonable in their own individual case – a sense-making process which is noted by Welton et al. (2004). These researchers found that the decision to take HT was viewed as highly personal and contingent on individual factors. Although a ‘biomedical’ discourse was prevalent in the information women encountered (most women, for example, visited their physicians as a part of their menopause related information gathering and all of the women were at least aware of the debate about HT use), a contrasting affinity for a ‘natural’ interpretive repertoire was also evident in the women’s conversations. This affinity was demonstrated by HT users’ emphasis on using ‘low dose’ and bioidentical formulations. In addition, the positioning of HT as unnatural, as demonstrated by women’s ongoing information seeking with respect to therapy cessation, indirectly reinforced the ‘natural’ menopause discourse.

4.5 Conclusion

In this chapter interviewed women and HPs were described and the first research question was addressed: the experiences of women as they responded to, made sense of and used evolving information about HT and menopause were presented and discussed. Women were found to be active and engaged information agents even as significant uncertainties with respect to this life stage were revealed. In the next chapter, specific information sources which emerged from the interviews with the women and HPs are investigated.

CHAPTER 5

RESULTS AND DISCUSSION: INFORMATION SOURCES AND WOMEN'S RESPONSES TO EVOLVING HEALTH INFORMATION

Participants interacted with a complex array of information sources as they navigated the menopause transition. Consistent with the research literature, information was both encountered and deliberately sought by participants (*cf*. Bates 002; Williamson 1998); it included both consumer oriented and scientific resources (*cf*. Ekstrom 2005; Warner and Procaccino 2004; Wikgren 2003); and it was mediated by a wide range of formal, informal and hybrid sources (*cf*. Ankem 2007; Genazzani et al. 2006; Wikgren 2001). As noted in section 4.2.2, all of the interviewed women described accessing a broad range of information sources with the following being mentioned at least once within the interview data: HPs (including alternative health practitioners), interpersonal contacts (for examples, family, friends or colleagues), intrapersonal sources, employees in health food stores, the internet, books (consumer health and textbooks), libraries, magazines, scientific journals, printed material from health organizations (for example, public health units and disease specific consumer organizations), and the media (newspaper, television and radio).

It is important to note that unlike surveys which require identification of specific information sources (for instance, Warner & Procaccino 2004) or quantitative studies seeking to determine preferred information sources within the context of specific tasks (for instance, Xu, Tan, and Yang 2006), women in the current study were invited to tell their stories in their own words. Women were asked about a range of sources (for example, interpersonal contacts, newspapers, magazines, media) if these sources were not spontaneously brought forward; women responded according to their own interests and with varying specificity and depth. Laura's response to a direct question about health programming on television typifies the ambiguous responses given by some participants; she responded, "There's not much on TV," and then proceeded to discuss internet searching. It was not, however, the intent of this study to quantify information sources; rather, the goal was to explore how women interacted with and integrated information from a range of information sources as they responded to personal health information needs.

In this investigation of women's information behaviour in response to uncertain health information, the following emerged as important information sources: HPs, interpersonal and intrapersonal information sources, the internet, the media, and libraries. These sources are explored in the following chapter. The order of discussion was chosen so as to begin with traditional formal sources (HPs), move to sources which relate to the individual (inter- and intrapersonal sources), continue with sources which are tied more closely to popular culture, and conclude on a more traditional note with libraries. In conclusion, *source consistency* as a means of evaluating authority and credibility is discussed.

5.1 Health professionals as sources of information

5.1.1. Health professionals as information authorities

HPs, particularly physicians, were viewed by many participants as foremost authorities with respect to health information. While going to a HP for information did not emerge as the most common first response information seeking strategy for women looking for information related to a general concern about health or well-being (see section 4.2.1), or for those seeking information in response to initial uncertainty about the menopause onset (see section 4.4.1.4), HPs emerged as important information sources in both of these situations. Consulting a HP was frequently an information seeking step which followed independent exploration of information sources (for example, the internet, books, or interpersonal contacts). Where it became especially apparent that HPs were viewed as foremost information authorities was during the elicitation portions of the interviews. At this point in the interview, women were presented with conflicting health information published in the news media. In response to contrasting health information half of the women said that they would talk to their doctors in order to make sense of the information. Sue and Joyce were representative of many participants: Sue stated, “I would probably then take that to the doctor or somebody to do with menopause and say, ‘What do you think of this?’”; and Joyce observed, “I’ve got to see my doctor in the next little while so I think I would probably ask her about this.” Joyce also pointed out that “checking with friends” was not an effective strategy in situations of conflicting health information because “they’re not going to know any more than I do.” Also representative were the contrasting responses of these two participants to the preceding interview questions about information seeking. In response to a general concern about health, Sue reported that she would first look for health information independently, while Joyce noted that she would talk to other people and then engage in independent information seeking. In response to menopause concerns both Sue and Joyce reported looking for information independently before eventually seeking information from a doctor.

These findings suggest that while independent health information seeking was a prominent strategy, confrontation with concerning or conflicting health information provoked participants to look to HPs as authorities who would play a role by helping them make sense of uncertain medical information. Beverly made this association clear: “I am not, first of all, not trained to identify what is correct, incorrect. So I would put a little trust in someone like Dr. [E] . . . because it’s not my area of expertise. So I would have a hard time saying which is, what is valid and what is not.” Sonya, a HP participant, provided support for this notion of HPs as authoritative sources who help women make sense of health information encountered in the media: “I think health professionals still carry a lot of credibility in most people’s mind . . . . They will read these headlines in newspapers but I think a lot of them still sort of vet it by a HP.”

The issue of HPs’ ‘expert’ knowledge emerged at other points during the interview. Gwen, who tended to rely on her physician’s guidance commented, “Whatever my doctor suggests, I will consider it. And most suggestions she gives me, I take. Because I think she has a better spectrum of what she knows about.

And I don’t.” And Thea, who had demonstrated personal initiative and tenacity when seeking information about the onset of menopause symptoms, noted “I could read so much and then when I come to Dr. [M], I mean, there’s certain things that – I ask her this, and there’s certain things that are – out of my realm.”

In addition to data supporting the notion that HPs are crucial information sources for many women, analysis of data highlighted the critical role *trust* played in mediating women’s confidence in information provided by health professionals. Dana, for example, stated early in the interview, “I don’t like doctors.” Despite this assertion and her strong dependence on an intuitive approach to health decision making, this participant agreed to go on a medication simply because a trusted physician recommended it: “I did it for three months and I never missed a dose of it. But I knew there was something wrong with it. But I had decided to put my hands, my life in [the doctor’s] hands basically and I thought ‘Okay, fine I’ll go with that.’ Didn’t like it. I was relieved when . . . he took me off it because it wasn’t working.” Dana’s decision in this situation was based solely on recently developed trust in a particular physician and was strikingly atypical of her encounters with HPs as described consistently throughout her interview. Roslyn, who “had always been dead set against hormone therapy,” provided another example of making a decision based on trust in an individual HP. When a physician suggested she consider HT, Roslyn said, “I just thought I could trust her. You know, that what she was telling me she believed that it was worth the risk.” On this basis Roslyn elected to begin using HT.

The theme of *trust* as a critical component of information delivery and the HP’s role as an information authority was specifically noted by interviewed HPs. Yvonne, for example, spoke of developing relationships with women and noted, “I think the biggest thing is getting that sense of trust.” She also pointed out that if trust does not develop, “it [communication or information delivery] doesn’t always work as well.” And Denise also pointed to trust as a vital ingredient in the HP’s role as an information provider. When asked to share her thoughts on the contrast between women’s approach to health information in the media vs. health information from HPs, Denise responded, “I get the feeling that they rely on us to help them try and sort out what this barrage of information is. And most of my patients I’ve known for a long time so I’ve got a pretty trustworthy relationship.”

The notion that trust is significantly associated with the sources women chose for obtaining information about menopause (Huston, Jackowski, and Kirking 2009) and that trust influences how people actually use information (Tio et al 2007) is supported by the literature. “Perceived knowledge and helpfulness” has been identified as playing an important role in women’s trust of HPs (Huston, Jackowski, and Kirking 2009, 152), with HPs willingness to discuss a range of information sources and treatment alternatives being a sign of both helpfulness and a lack of bias. In this study, trust not only mediated women’s confidence in HPs, but willingness to help women “sort out” (Denise) or “vet” (Sonya) information from other sources as well as referral to other information sources (see section 4.2.2.4) contributed to women’s relationships with and trust in HPs.

Despite women’s use of multiple information sources, the literature supports the notion that HPs are a foremost authority for women seeking health information (*cf.* Ankem 2007; Wyatt et al. 2005). Warner and Procaccino (2004) found that 100 percent of the women they surveyed were likely to seek health information from a doctor, nurse or other medical professional. While these quantitative results do not illuminate the nuances of women’s information seeking or how seeking information from a HP might fit within information seeking strategies, they do support the findings of this study: the vast majority of participants did, at some point in their information seeking, look to HPs as authoritative sources of health information.

5.1.2 Health professionals as information deterrents

A related theme which was apparent in the data was the notion the HPs were *not* trustworthy information sources and, in fact, represented a barrier to information. This theme drew attention not so much to HPs’ role as information authorities, but to the critical role that trust played in mediating health information. Without the establishment of trust, participants were less likely to integrate information provided by HPs. Nicole spoke for many of the participants when she clearly elucidated the central role trust plays in the relationship between women and HPs: “I will easily find another physician if we can’t establish a rapport so that I can feel like I can actually trust the person and the information that’s coming from them. So for me the biggest thing is trust.” Furthermore, based on the finding that the majority of participants included HPs in their information seeking strategies and that many looked to HPs as health information experts who play a discriminating role in situations of uncertainty, unsatisfactory interactions with HPs emerged as a noteworthy barrier to health information. A number of participants specifically identified HPs as information barriers: “I’ve found that the biggest drawback to finding out information has been actually the doctors themselves” (Monica); “Problem is that the doctors never know. Most of the time they have *no* idea. . . . They don’t even have an interest in things sometimes” (Anita); and “I haven’t had a very satisfying experience with going to the doctor. They just give you brief information and tell you to see the specialist. And even the specialists don’t seem to have the time” (Hazel). Although Irene offers a contrasting view to the latter notion that HPs do not have time to deal with patients’ information needs (“Dr. [O], the one I have, sits there and talks to you and like, you know, asks you questions. You feel like you’re a person when you’re there”), Hazel’s specific concern about time was echoed by other participants (for example Anita and Monica). Some scholars suggest that, in fact, it is the perception that HPs, particularly physicians, impede access to information or do not have enough time to answer questions which leads women to seek other information sources (Warner and Procaccino 2004). Other scholars have noted that poor communication on the part of HPs leads to women’s lack of confidence in the ability of HPs to provide appropriate health information (Ma, Drieling, and Stafford 2006).

Analysis of data suggested that, perhaps in response to the perception that HPs can impede the information search, women developed specific strategies for retrieving information from this source. Most commonly, women viewed deliberate question asking as a means of retrieving information from HPs: “I have learned to bring very specific questions” (Christy); “It’s my job to take my concerns to my physician” (Pat); and Sue related that when two of her friends were unsatisfied with information from their common physician she told them, “That same doctor, I find a lot of information from. I question her about the tests and the studies that were all done. . . . You have to ask questions.” Sue, who was a very confident outgoing woman added, “There’s introverts and extroverts . . . I don’t think that a person [who] doesn’t ask questions or is kind of shy should be treated less.” Other women used other strategies. Dana, for example, was very suspicious of HPs; nonetheless, she valued the information which could be derived from medical testing. She explained her strategy: “I think the best thing that you can do is just go to a doctor, yes; but try not to do what they tell you to do. Just go for their tests, and – don’t do, don’t take the medicine they’re giving you.” And Jill simply avoided HPs, “*unless* there’s something that I *know* I cannot find on my own.”

5.1.3 Physicians and gender

The issue of female vs. male physicians emerged as a very prominent theme when participants discussed HPs as sources of health information. Participants credited the way they were treated and the provision of information about menopause to the sex of the physician they were dealing with. Both Gwen and Laura, for example, ascribed their physicians’ information sharing to gender and age. “Her being a female doctor, I really like that. Because she goes through the same kind of things. So she does come up – she gives a lot of good ideas” (Gwen). And Laura explained that her doctor frequently provided her with information in the form of “loose-leaf papers that she’s printed off herself, I think. Cause she’s – she’s at my age, like, she’s *there*. So she’s going through [menopause] too.” This notion of shared experience with the menopause transition was reinforced by reciprocal statements by female HPs. For example Denise, a family doctor, related that her age contributed to the trusting relationships she had with her patients, “I think plus the phase of life that I’m in, being in that same age frame of being perimenopausal – postmenopausal – I get the question, ‘What would you do?’” And Renee, a HP who saw primarily female patients similarly noted, “I’m aging with my patients – it becomes more personal to me.”

Even without specifically identifying physicians as being in the same life transition, participants positioned female physicians as more understanding and helpful than their male colleagues. Roslyn had a negative experience with her male physician who disregarded her distressing symptoms: “The doctor I had that was male, when I was telling him I was in menopause [he] treated me like I was crazy and wasting his time.” When she found a physician who validated her symptom experience, she attributed that understanding to the fact that the physician was female: “At that point I changed doctors and I had a really amazing female doctor in Alberta. She’s amazing because she’s female. . . . She asked me to write down all the symptoms.” Similarly the relief that Thea experienced when she was finally seen at a menopause clinic was ascribed to the gender of the HPs: “I did feel a satisfaction in knowing, ‘Okay, I think I’m in the right place. I think there’s women now willing to listen to me versus these men [physicians Thea had previously seen as a patient] that all just sort of like sluffed me off.’” And Naomi explicitly contrasted the information sharing of female vs. male physicians:

> My GP, I’ve given her articles to read and she’s read them. Absolutely. They can’t know everything. They’re GPs. So if I can get an article out of a – like a medical journal, right? Or some other article, and it’s a good article, I give it to her. Because she then in turn will give it to other women. So I do that all the time with her. . . . Now I’ve had male physicians that – forget that. Don’t even try that, right?

Participants also used gender as a discursive signal which identified the information sharing, helpful physician vs. the physician who was not able or willing to address participants’ concerns: “I want somebody who’s not going to put me down and it’s very difficult to find doctors that are like that. . . . You want a *female* doctor” (Vicky); “It was all male doctors and that doesn’t help” (Irene); and, “My doctor was – I love the man to death, but he’s a man” (Thea).

Although these findings stand in contrast with articles in the medical literature which suggests that women do not show strong preference for female obstetrician-gynecologists (*cf*. Fisher et al. 2002; Johnson et al. 2005; Zuckerman et al. 2002), they are supported by studies which demonstrate that attributes such as bedside manner or physician communication style influence patient satisfaction (Christen, Alder, and Bitzer 2008; Liang et al. 2006; Plunkett, Kohli, and Milad 2002). For example, Christen, Alder and Bitzer (2008) found that it was not gender but gender-related communication skills that were critical to patient satisfaction and compliance. Their results demonstrated that patients "were significantly more satisfied with female physicians regarding the relationship and the consultation process," however, "once a patient-centred communication style – which was more likely to occur in female physicians – was controlled for, physician gender was no longer important for patient satisfaction and compliance" (1480). Similarly another study found that "female-sex role congruent communication style leads to higher patient satisfaction when women see a female physician" (Schmid Mast, Hall, and Roter 2007, 16).

Results from this current qualitative study suggest that when participants identify physician gender, they are actually identifying qualities related to communication. While this was demonstrated by the quotations provided previously, it is also demonstrated by negative incidents reported by women. Two participants described being berated aggressively by physicians; in each of these cases the physicians were female. Sylvia had been on HT for severe vasomotor symptoms when a new physician refused to renew her prescription. When Sylvia was asked during the interview "How did she [the physician] explain that to you?" She responded:

> She just yelled at me. She just yelled at me. She wouldn't explain it. She just said, 'You're at risk for breast cancer.'. . . There was no reasoning with her. She was just like off the wall and she just took me totally by shock. I practically left the place crying because I was just like, 'What have I done to myself?'. . . . I found out later [that] maybe she'd had breast cancer and so it was an emotional thing for her.

The second negative incident occurred when Muriel independently decided to stop taking HT. Her physician was angry because she had stopped therapy without consultation. During the interview Muriel raised her voice to imitate the loud angry voice of the physician and quoted, “Just when we started to get a bead on, just when we were getting somewhere with it, and now you’re going to get fat . . . and then you’ll be in here with all the complaints that that brings, because that’s the first thing that happens with my patients that go off of these medications. They! Get! Fat!” In both of these cases it was apparent only by the pronouns used that these were female physicians. Neither Sylvia nor Muriel specifically noted physician gender as having any significance.

It is possible that the tendency to highlight gender when women HPs are associated with good communication skills and men are associated with poor skills (and conversely failing to highlight gender when women HPs demonstrate poor communication skills) is based on stereotyped views of gender. Based on a content analysis of popular women’s magazines Kincheloe (2004) concluded there was existing gender-bias in the way male physicians were portrayed, bias which might impact physician-patient relationships. On the other hand, physician communication influences women’s satisfaction with medical encounters (Liang et al. 2006) and female physicians have been shown to demonstrate “more patient-centred communication, including the establishment of a good therapeutic relationship with a focus on partnership building” (Christen, Alder, and Bitzer 2008, 1481). Since participants valued a partnership approach to menopause management and tended to position themselves as responsible for their own health decisions (see chapter 6), the strongly expressed preference for female HPs as information sources has implications for all HPs who work with women in this life transition.

5.2 Interpersonal information sources

Results from this investigation confirmed what has been identified as a central tenet of the information behaviour field: people tend to seek easily accessible and interpersonal sources (for example family, friends, or colleagues) (Case 2007; Harris and Dewdney 1994). Results also confirmed findings which identify interpersonal contacts as important sources of information for women making decisions about menopause management (*cf*. Genazzani et al. 2006; Theroux and Taylor 2003). While interpersonal information sources were noted as being critically important by the vast majority of participants, one participant maintained in both the narrative and elicitation portions of the interview that she did not gather health information from interpersonal information sources. When asked whether she would talk about general health concerns to people outside formal health contexts, Pat responded, “Not really, no. No”; when discussing menopause specifically this participant said, “My circle, family or friends . . . not a lot, no. Very little discussion of menopause”; and in the elicitation portion of the interview Pat noted, “If I’m talking to friends, I’m going to talk about fun stuff.” Furthermore, two women demonstrated ambivalence about interpersonal information sources. Anita observed early in the interview, “People . . . are so misinformed. And they don’t understand anything because they don’t have information. And so they do arrive at the wrong conclusions. I don’t want to hear that.” However, later in the interview this participant suggested that women navigating the menopause transition would benefit from a “centre for women,” not only for information seeking, but also because “even to talk with somebody who is going through the same things that you are going through will help you.” Joyce also demonstrated ambivalence. Although interpersonal relationships were an important source of information for this participant, she noted that she would be unlikely to talk to friends about the conflicting information presented in the elicitation portion of the interview “because checking with friends, they’re not going to know any more than I do. Because we’d all be sort of reading the same thing.”

Interviews with HPs supported the importance of interpersonal sources for women navigating the menopause transition. Observations made during interviews with HPs include the following: “Word of mouth, you know, talking to friends that have been – ‘Oh, well, I’ve been to see this person. They’ve said such and such,’ so – the transfer of information through word of mouth is quite powerful” (Wanda); and “That’s [women’s] biggest source, is their colleagues and their family members, peers. It’s woman to woman” (Sonya). Although the sample of HPs was small, it is interesting to note that interpersonal exchange with peers was also an important source of information for these participants. Mark, for example, related that after the unexpected results of the WHI were published in 2002 “I talked to a lot of my colleagues. . . . I depended a lot as well on what other people were saying. . . . it’s pretty hard to go it alone and say, ‘this is *my* stand.’” This finding is confirmed in previously published literature which highlights HPs reliance on human information sources (Dee and Stanley 2005; Gorman 1995).

Information from interpersonal sources served a range of purposes for the interviewed women. Purposes included the following: provided access to information not available through formal sources (for example, practical information about diet (Christy), and more ‘up to date’ information than is possible within an evidence based model of practice (Dana)); facilitated gathering information about or referral to additional information sources, health practitioners, or products (for example, Beverly and Lillian); and supplied information which supported decision making processes (for example, Hazel). In addition to these reasons for accessing interpersonal information sources, two prominent themes emerged from the data: women valued interpersonal sources who had biomedical expertise, and women valued interpersonal sources because they offered access to experiential knowledge. Both biomedical and experiential knowledge contributed to women’s use of interpersonal sources as they made sense of uncertain health information. A third salient theme which emerged from the data was the role which mothers played in women’s approaches to the uncertainties of menopause management.

5.2.1 Interpersonal sources and biomedical authority

Many women in this sample demonstrated the importance of biomedical authoritative knowledge not only by seeking information from HPs, but by seeking information from interpersonal contacts with biomedical qualifications. Cherri, for example, noted that if she came across conflicting health information she might check the information with “my friends who are public health nurses. Not ones who got their degrees 20 yrs ago and haven’t used it since; but ones who are active now.” Muriel said, “I do have several relatives that are connected with the health field. So I generally would poll them to see if they have any ideas.” Similarly Joyce commented that she would talk to a particular friend who is a nurse, “just because she’s in the health field.” Later in the interview when Joyce again noted the biomedical knowledge of an information source I asked her if experience in a health field facilitated trust. Joyce’s responded, “To *some* degree, yeah. Had to be friends first. This is a friend that I trust. He knows me. Who I am. And oh, by the way, they have this experience.” Joyce therefore positioned trust in the interpersonal connection as prerequisite to her trust in the provided biomedical information.

Even when women were not specifically seeking information from sources *because of* biomedical qualifications, participants drew on ‘category entitlement’ in order to strengthen the authority of information sources – membership in a particular category was presented as evidence for the authority of the information provided (Potter 1996). When commenting on her decision about vitamin D supplementation, Laura, for example, related a relative’s perspective on the topic and added “she’s in the nutrition field, you know.” Gwen also used category entitlement when she described decisions about menopause management, “A friend who’s a nurse told me what they [sic] do.” By invoking the biomedical authority of the information source, both Laura and Gwen suggested that the information provided a basis for decision making, despite the uncertainty of the context (conflicting information about vitamin D (Laura) and conflicting information about menopause management (Gwen)).

The invocation of authority has been identified by McKenzie and Oliphant (2010) in their exploration of discursive tensions between ‘natural’ and ‘biomedical’ forms of knowledge. These scholars noted that when making claims about interventions related to childbirth, both women and midwives frequently “invoked authoritative sources to support their cases” (33). Interviews with HPs in this current study demonstrated that these professionals also invoked authority in order to strenghthen their positions with respect to menopause management and to establish notions of certainty while acknowledging the multiple options women face. Amy, for example, acknowledged a range of options with respect to HT and the controversy about synthetic vs. bioidentical HT. However, she explained, “we provide them with a lot of information that’s sort of guideline based.” Similarly Connie noted that she is very careful not to be critical of the many approaches to menopause management. She explained that she handled different perspectives by “telling [women] that we’re an evidence based clinic. So our practice is based on evidence based guidelines from the Society of Obstetricians and Gynecologists.” In both of these cases, the invocation of ‘guidelines’ or ‘evidence’ suggested that information supporting a different perspective may not be authoritative. Clare provides an additional example: “I’ll just tell them, ‘I don’t think there’s really any evidence for that’ or ‘that hasn’t really been shown to be effective’. . . . it’s sort of like your reality check. This is what I believe about this certain product or practice or whatever. And then let them decide.” In this example Clare was particularly clear in invoking the authority of her biomedical knowledge (“I don’t think there’s really any evidence for that”), thus advancing potential certainty in decision making (“your reality check”), while at the same time acknowledging uncertainty by accepting women’s decisions about menopause management (“let them decide”).

5.2.2 Interpersonal sources and experiential knowledge

Findings from this study confirmed that interpersonal information sources are of central importance to women navigating the menopause transition, and that women valued the connection between interpersonal sources and biomedical knowledge; however, evaluation of women’s statements revealed that participants most frequently commented on and valued the experiential knowledge gained from these sources. Participants indicated that they deliberately sought interpersonal sources in order to better understand their own menopause experiences: “People that I know that have dealt with that issue. I would go and ask them" (Lisa); "First of all I listened to what my sisters had went through" (Dana); and "If we're in a group or discussion, or one on one discussion – I will ask them about their experiences" (Cherri). This knowledge, which is "based on wisdom and know-how gained through reflection upon personal lived experience" (Schubert and Borkman 1994, 228-9), was valued as a means of normalizing the menopause experiences ("I'm blessed with working with a number of women my age. So that's the networking thing again. It's the – 'Is it hot in here, or just me?'" (Monica)); however it was particularly valued as a means of gaining insight into lived experience related to management of menopause symptoms. The following quotation is representative of the many comments made about experiential knowledge gained from interpersonal sources: "So you'd hear all of us talking about how are you doing with your hot flashes or night sweats or memory or aches and pains and you know, drying up, and all this sorts of information. Everybody is just telling well, what worked for them" (Naomi).

Women also related that they learned about specific products or substances through interpersonal sources: Hazel, who was suffering from ongoing bleeding and low iron levels, learned that a prescription for Slow Fe would be covered by insurance and she could therefore avoid the cost of over-the-counter medication; Monica related that a colleague brought a Wild Yam cream (reported to be a natural progesterone product) to work and that a number of the women tried the product; and Muriel sought information through interpersonal contacts about a specific food which she had heard was contraindicated when taking blood pressure medication. In each of these cases the information given was not theoretical information about the product, it was experiential knowledge which added value for the participant. Hazel learned about financing a supplement; Monica, who told me that her mother looked on health food stores and products as "sort of voodoo," had the opportunity to both learn about and experience a 'natural' product; and Muriel spoke to someone who was both taking blood pressure medicine and eating the supposedly forbidden food – a food which Muriel was fond of.

Although almost all of the participants highlighted information received from family, friends, colleagues or acquaintances, some did not specifically identify these as information sources. Jane, for example, tended to focus on formal information although she said that she talked about health with family members and people at work. When I asked her if she would consider these people to be sources of health information, she responded, “I think they are – but I wouldn’t really think of it that way.” Likewise Dale commented, “I find my female friends are really good resources, not necessarily for information, but just to gather ideas and thoughts to help in my research, I guess you could say.”

Warner and Procaccino’s (2004) findings support the notion that women value the experiential knowledge of peers. These researchers found that “people with the same condition” (715) were a likely source of health information for 89.4% of their participants. Consistent with research focusing on the information seeking of pregnant women (McKenzie 2003a), ‘lived experience’ provided a form of authority which allowed participants of the current study to contest the category entitlements of other authorities, particularly the authority of biomedical knowledge. Nicole, for example, was close friends with a woman who lost multiple relatives to breast cancer. Despite her own low cancer risk, her friend’s experience provided Nicole with the authority to challenge biomedical knowledge: “I think having witnessed that dilemma with her, that also just turned me off HRT. I just felt it was too much of a quagmire and too complicated, and I just didn’t want to deal with it.” While McKenzie (2003a) found that the ‘risk’ discourse frequently associated with high risk pregnancies potentially undermined the authority of experiential knowledge, women navigating the menopause transition align more closely with those struggling with chronic disease, a population which is likely to use experiential knowledge to justify treatment choices (Oliphant 2009). Yvonne, one of the interviewed HPs provides support for this finding: “I think what [women navigating menopause] tend to believe most is probably what they hear from somebody else [laughs]. So you know, a friend or a family member that’s gone through it.”

5.2.3 Interpersonal sources and making sense of health information

In addition to the knowledge (both biomedical and experiential) which participants gained from interpersonal sources, women viewed interaction with interpersonal information sources as an opportunity to make sense of information about menopause management. Naomi explained: “We do talk about [menopause] at work, and we do have those conversations, and people have come up with different solutions and other people have tried them. Or they recommend one product over another product and I think that that is very, very helpful for everybody. . . . sometimes you have to talk quite a bit about it before like you can wrap your head around certain things.” Cherri also alluded to the constructive nature of information exchanges with personal contacts: “I would listen to what someone else says – depending on their particular knowledge level and education and investigation. . . often it – triggers thoughts and so I’ll go off in one trail or another.” And Jill said, “I think there is a lot of wisdom and a lot of knowledge that can be taken from people going through that. . . . And yes everybody’s different but then collectively you take that little bit of information and then you can make your own little – ah, book I guess about what – you know and even that doesn’t guarantee anything.” As demonstrated by these examples, for many participants knowledge was not viewed as a static object; rather, women “construct versions of reality . . . and that knowledge is something [women] do together” (Tuominen and Savolainen 1997, 83). Thus, women’s reflections suggest that interaction with interpersonal information sources is more than a simple matter of transferring packages of information, it is a process of interaction that “constructs and produces events and states of things” (Tuominen and Savolainen 1997, 92).

5.2.4 Mothers: Their influence on women’s experiences of uncertainty

A salient theme which emerged from the data was the striking role which mothers played, either indirectly or directly, in women’s approaches to the uncertainties of menopause management. With only a few exceptions, participants mentioned or talked about their mothers' experiences and related those experiences to their own. Some women spoke of how childhood observations of their mothers framed adult perceptions: "I wasn't looking forward to menopause. . . . given what I thought my mother was going through" (Nicole). Others, when they encountered challenges at this life stage, directly sought information about menopause from their mothers: "I wanted to find out if she experienced [excessive bleeding]" (Hazel). And others related how their mothers' management of menopause shaped their own decision making: "It seemed like every article you read had a different take on it. And my mom was on estrogen only. And had been for quite a long time. But I didn't think that was the right way to go now. I thought that probably the combination was the best way" (Muriel). The most common theme expressed by participants was the expectation that their experiences would be similar to their mothers' experiences. This theme was expressed is a variety of ways. Some women felt that their own knowledge of menopause was compromised because their mothers did not or would not talk about their experiences during menopause. Camille's recollections were representative of this experience: "My mom didn't talk to me about it. They just didn't. So I didn't know that getting hot flashes – I just didn't know anything." Other participants attributed their lack of knowledge in part to the fact that their experience of this transition was very different from their mothers: "I was told that whatever your mother went through, you kind of followed that path. Well, my mother breezed through it and didn't really even know she had it. . . . My sister and I both suffered like quite badly" (Sue).

Other women assessed risk and made treatment decisions, particularly with respect to HT, based on their mothers' experiences. Sylvia's comment exemplified findings with respect to this theme: "For me the risk factor's pretty minimal because we have no cancer in our family. . . . My mother was on hormone replacement therapy. She had a hysterectomy in her 40s and she was on it till she was 65. She has no health issues as a result of it." At the time of the interview Sylvia was very specifically considering the age her mother stopped using HT as a marker for her own cessation of the HT. One of the HPs also noted the importance of mothers as an information source for women experiencing menopause: “I think that people value my opinion but I think it’s probably an opinion among many. They might value their mother’s opinion as much as mine” (Clare). The finding that women’s experiences during menopause are defined and shaped by perceptions of their mothers’ experiences has received limited attention in the literature (Dillaway 2007); it suggests that social contexts for menopause warrant further exploration.

5.3 Intrapersonal information sources

A particularly salient theme which became evident within the first three interviews and remained prominent throughout was the profound impact of intrapersonal knowledge. For many women, this internal source of information influenced all dimensions of the menopause experience as well as serving as a type of filter for information from other sources. Although receiving limited attention in the research literature (see section 2.3.2), women in this study presented intrapersonal knowledge as an information source which substantively influenced how they made sense of information related to the menopause transition.

Research has explored different ways in which women come to ‘know’ the world around them (Belenky et al. 1986) and how *ways of knowing* are used by women to interpret symptoms and make decisions about treatment (Turris 2009). Furthermore, studies have noted the important role of feelings, beliefs or attitudes for women making decisions about menopause management (Ekstrom 2005; Stephens, Carryer, and Budge 2004; Wathen 2006b). In this study, however, women used a variety of words and phrases (for example, “common sense,” “intuition,” “my gut,” “gut feeling,” “instinct,” “own judgement,” or “inner spirit”) which, upon closer questioning, all appeared to identify an explicit, intrapersonal source of knowledge which informed women in a similar way to formal or interpersonal sources. Therefore, in an attempt to reflect the ways in which women in the current study talked about these internally residing knowledge sources, I have chosen to identify them with the phrase *intrapersonal information sources*.

During the interviews many participants spontaneously referred to intrapersonal information sources; "my gut" and "common sense" were the most frequently used euphemisms. As the theme became apparent I began asking women to describe with more detail what they meant by these phrases. While some women used similarly vague descriptions – Cherri's response provides a typical example, "I think you have to listen to yourself" – other women explained this information source as a deeply personal integration of information sources and life experience. Lisa's comments exemplify this perspective: "It's hard to explain. My gut feeling; I listen to that. My instinct; I listen to that. Um – ah, just again, all the things that I've read, seen, heard, talked to, all that information that I've picked up along the way – does it fit in with that?" Participants' explanations ranged from the philosophical and spiritual to the practical, with Faye, Vicky and Lillian providing exemplars of these perspectives. Faye presented a particularly introspective description of what she meant when she spoke of her "intuition":

> I don't worry about am I looking – am I praying about this? Where's my intuition coming from? But that kind of just trying to get quiet and find the right answer not just by scientific data but by taking it all in and kind of breathing deeply about it for awhile is just – I figure the decision will come to me sometime when I'm bicycling or out doing something.

Vicky's expanded on her phrase "gut feeling" and explained, "I'd like to say that it's that element of common sense. I believe it has elements of God speaking to us, absolutely." And Lillian, who reported that she was guided by "common sense," demonstrated a utilitarian perspective when she explained, "when I get information and it comes that side and that side, I try to find the happy medium. I use my common sense." Lillian further illustrated this approach by noting that since some studies suggest drinking red wine and others suggest "you shouldn't," she resolved this dilemma by drinking half a glass of wine. This practical expression of intrapersonal knowledge was also used on occasion when Lillian was uncomfortable with prescribed medication.

Intrapersonal knowledge had instrumental value for women – it played a substantial role in guiding actions. “That’s the one thing that I’ve really learned is that, when my gut somehow is telling me that something’s a bit off, then I really need to stop and examine that” (Nicole). Dana was particularly adamant about the role of this information source in guiding her choices. When she described her online information searching, for example, she explained that she decided the relevance of information based on “my gut.” She noted that the source of the web page “makes no difference to me because, you know, if it is something that I already believe, it doesn’t matter to me. I’m looking for something that agrees with what I believe. And if it doesn’t, I just scrap it.”

Other women indicated that intrapersonal knowledge guided the evaluation of other information and information sources. When confronted by conflicting media coverage of a health issue, for example, many women turned to internal information sources for guidance. Anita and Sylvia both stated that they would rely on intrapersonal information sources and would potentially act on information which “makes sense to me.” Jill expressively described how she would develop and draw on her internal information sources in order to make sense of the contrasting information presented in the elicitation articles:

> There’s also stuff that if you care to listen around, listen to your own body and your children, and making your own assessment in here too. I think you gain a little bit of a – knowledge, you know, to make a wise decision about [a] headline like this and know, ‘OK this is good information. This is obviously not very in-depth or hasn’t been really studied.’ Right? . . . . Because it doesn’t bring trust to me even with the headline.

The notion that women draw on intrapersonal information sources as they navigate information about menopause management was strongly supported by interviews with HPs. Gail observed, “When we’re talking about what treatment, we have to consider what your personal beliefs and values are.” And Sonya noted, “It takes such a skilled practitioner to allow that – that patient value preference to dominate and not get frustrated. . . . but if a patient doesn’t own it, it won’t happen.” HPs manner of dealing with the authority of intrapersonal knowledge, however, varied. Some accepted the influence of this knowledge source but perceived the authority as misplaced if it conflicted with biomedical authority.

Gail for example, acknowledged the influence of personal beliefs and values, but added "It also is, if they've got a misconception or information, it's straightening that out." Francis also exemplifies this perspective: "If she strongly believes in something, I'm not going to change her. To change her belief. Except – except tell her – telling her my point of view. In other words, I say what – this is what I've learned in medicine and this is what the researcher's telling me." Other HPs were non-judgmental in accepting the authority of intrapersonal information sources. Denise exemplifies this perspective: "There is that art of being able to know your patient, interpret what they say in the context of their whole life and their set of values. And what may be the best treatment for them may not be the best treatment for patient B with the same basic medical problem." One HP discussed how beliefs influence both patients and HPs:

> Sometimes education doesn't change [women's] values and beliefs. Like they still have those with that. So I think the balance is that, like I know I have to have some beliefs myself and I understand that that's my belief. . . . It's all belief even though when you look at evidence. You're putting your own belief into that evidence, right? . . . . It's my interpretation of that evidence. I still believe that, right? And somebody else could say it in a different way and believe it in a different way. Right? . . . And so that's why I still think I'm – even in providing that information, I'm still providing in my belief. (Yvonne)

Findings related to participants' perceptions and use of intrapersonal information sources can be supported by pockets of literature in a range of disciplines. For example, intuition as a source of authoritative knowledge for midwives is described as "emerg[ing] out of [midwives'] own inner connectedness to the deepest bodily and spiritual aspects of their being, as well as out of their physical and psychic connections" (DavisFloyd and Davis 1996, 260). And, an exploration based on Aristotle's theory of virtue describes character as being related to personal enduring traits: "the attitudes, sensibilities and beliefs that affect how a person sees, acts and indeed lives" (Sherman 1991, 1). The only article which, to my knowledge, directly discusses intrapersonal knowledge focuses on the types of knowledge accessed by exemplary teachers. Intrapersonal knowledge is described as consisting of "reflections, ethics and dispositions" (Collinson 1996, 1). When participants in this current study were questioned about the meaning of intrapersonal information sources, their answers reflected something of the inner connectedness described by midwives, the enduring traits emerging from Aritotle’s theory of virtue, and the characteristics brought forward by Collinson (1996) – all of which influenced how participants viewed uncertain health information, and how they made decisions about health management. Furthermore, these intrapersonal information sources facilitated the construction of individual authority (McKenzie 2003a). Based on information drawn consciously or unconsciously from their own beliefs, values, life-long and bodily experiences, dispositions and reflections, participants constructed themselves as cognitive authorities and in many cases used that authority to challenge biomedical authority.

5.4 The internet

As noted previously (section 4.2.2) every woman in the study identified the internet as an important source of health information. This finding is supported by researchers who have identified women between the ages of 30 and 65 as being the demographic most likely to look to the internet for health information (Fox and Rainie 2002) Although its importance varied, participants presented online information searching as part of a continuum of information gathering which was situated within their everyday life contexts. A few women inserted caveats in their discussion of online health information behaviour. Jane provided a typical example of this small group when she acknowledged that she used the internet for health information seeking, but also said, “I am not 100% comfortable or confident with the internet as a source of information.” For the vast majority of participants online heath information seeking was an unremarkable part of information seeking which was inextricably linked with their offline health IB and their everyday experience of health. Table 4.3, for example, provides a glimpse into women’s reported strategies for seeking information about a health concern and it demonstrates the seamless integration of the internet with other information sources. Roslyn exemplifies the seamless integration of information sources, including the internet: “I had magazines, books, the internet, listened to other people, what they had gone through, what they’d tried to help themselves at that point.” Use of the internet was pervasive and fulfilled a range of purposes for participants. It provided initial introductory information, facilitated deeper exploration of health topics, confirmed information provided by other sources, provided alternative strategies for health management, and allowed women to explore health information at their own pace and to the level of detail which they desired.

Furthermore, women explicitly valued the internet as a source of health information. Some women enjoyed the access to information and the ability to explore health topics which were of general interest: “I just like to know sort of the ins and outs of things, [that] is why I would look things up [on the internet]” (Pat). Consistent with Im et al.’s (2007) findings, access to information provided by the internet was also valued by the many participants who perceived that they were receiving inadequate information from HPs. Thea provided an exemplary example of comments from these participants: “And that’s when I started to research stuff on the computer because I didn’t think I was getting medical help.” Women also valued this source because they found it easy to use and available at their moment of need: “I find it’s usually just easy. Something will trigger something and it’s ‘oh, I’ll just quickly [check the internet]’ – you know” (Dale). A further reason for valuing the internet was the perception that it provides current information: “I like to search for things and stuff and the internet is always constantly being updated. . . . I definitely think that it’s [medical knowledge] always kind of evolving, Yeah. And that’s why I think the internet is the easiest place to go that has the latest” (Camille).

The internet emerged not only as a hybrid information source in the sense of containing both formal (for example, information about menopause posted on the Mayo Clinic website) and informal (for example, interactive discussion lists) health information (Warner and Procaccino 2004), but participants drew attention to other hybrid qualities of this source. Quantitative evaluation of information sources used by women when seeking information about menopause frequently separates sources along artificially distinct lines. For example, Warner and Procaccino (2004) asked women to identify, from a provided list, the ways in which they were likely to find information about health care (this list included websites, newspapers, books, magazines, people with the same health concerns, and group discussions). Participants in the current study, however, did not necessarily see the distinctions between these sources. Dana, for example, talked about extensive “reading” as a means of gathering health information. She included in this category information she gathered from libraries, book stores and the internet. This notion of juxtaposing information seeking from books and from the internet was expressed by other women. Beverly provided a typical comment: “I usually either go to books or the internet to find out information.” In addition, the interactive nature of the internet merged internet and interpersonal sources. Gwen, for example, noted that she occasionally received emails which contained heath information and Paula looked online for personal information in the form of “testimonials from individuals that have been impacted by that medication or by that herb that they’re using.”

In this study, the internet emerged as an everyday and normal part of health information seeking. Findings therefore support a recent assertion that exploration of online information seeking “must be anchored within the everyday and offline context of individual’s health” (Kivits 2009, 685). In the following paragraphs, three themes which emerged from the data will be briefly highlighted: the influence of online heath information, the value women placed on the credibility of online information, and typical searching strategies reported by participants. This will be followed by discussion of HPs’ perceptions of women’s online health information seeking.

5.4.1 The influence of online health information

Information derived from online sources had a very real influence on participants: it added to women’s knowledge and influenced their approaches to health management. As discussed in previous sections, for many women the internet was a means of normalizing their experiences (see section 4.3.1.3), or addressing uncertainties about menopause as a life stage (see section 4.4.1). For many participants, the internet became a diagnostic tool. Camille's reported approach was representative: "I would just plug in my symptoms or whatever and, you know, kind of self-diagnose." And Laura provided a more detailed account of this approach: "So then I go, and on the internet it says what the symptoms are. And I'm thinking 'Oh, I have a few of those.' And then I go to [my doctor], and I say 'Well, I either have irritable bowel syndrome or I have colon cancer, or I have – celiac disease.'" During a discussion of women's internet use, one of the interviewed HPs confirmed that this approach to online information seeking has recently become evident: "Whereas people might have formerly presented with a symptom like 'I'm having headaches.' Now they'll come and say, 'I think I have a brain tumor'" (Clare). Online information seeking also influenced women's approach to treatment decisions. Jane described agreeing to a particular treatment regime because it was confirmed by information she found online, and Sue provided the most decisive example of influence. Sue was concerned about a prescribed medication. Exploration of online sources suggested that there "wasn't a lot of positive things about [the medication]"; consequently, and without consultation with her physician, Sue discontinued the medication. While this latter action was, in Sue's specific situation, deemed imprudent at a later point in time, a report from the Center for Studying Health System Change found, "Consumers who actively researched health concerns widely reported positive impacts: More than half said the information changed their overall approach to maintaining their health, and four in five said that the information helped them to better understand how to treat an illness or condition" (Tu and Cohen 2008, 1).

Prior to the early publication of WHI results, a 'poor compliance' discourse was evident in the medical literature – medical publications emphasized that women's poor continuance with HT (both uptake and adherence to therapy) was a major barrier in the medical management of menopause (Genuis 2004b). Following the WHI, a discourse shift towards the empowerment of women and shared decision making (SDM) in the face of uncertainty became evident in the medical literature (*cf*. Légaré and Brouillette 2009; Salkovskis and Rees 2004). It is relevant to note that this shift coincided with a time during which the number of internet users grew and broadband connections became a normal fixture in North American homes (Fox 2006). Findings from the current study indeed demonstrate that the vast majority of this sample of women from one urban North American setting viewed the internet as an everyday routine source of heath information. The 'normalness' of this information source and the presumption that women are independently seeking health information and thus felt empowered as partners in SDM is demonstrated by the comments of interviewed HPs. For example, Wanda observed: "[Women] are pretty well informed. The odd one will come in and not know anything but that's not the norm. Most people are more educated, I find today, as opposed to say 20 years ago – 20 to 25 years ago. In a way education seems to be out there more, so it could be partly the internet that there's so much information available to people today." And Erin observed that women who come to her on self-initiated health management regimes found guiding information "mostly off the internet."

5.4.2 Credibility and online information

Although consumer health literacy has been raised as a concern in the literature (for example, (Hanif et al. 2009), findings demonstrated that the vast majority of women in this sample were aware that websites presented different perspectives, and that the *credibility* of online sources varies. Dale, for example, explained, "I know that Mayo Clinic had a lot of information on different topics. I try and go for – I don't know if they're the most reputable but I've heard of them. . . . I don't just go with 'Martha's Witchcraft' and stuff like that. I try and go with what I feel are reliable sources." In fact, the majority of women identified some assessment criteria which they applied when searching for online health information. Some participants explicitly expressed a preference for information from the hospital websites, professional organizations or consumer health associations (for example Christy, Faye, and Jane), and most women associated authority with known origins or authorship. Nicole’s comment exemplifies this theme: “I just tend to try to find out who is making the website? What is their agenda? Is this a pharmaceutical company?” Nicole’s questions draw attention to an additional theme which was evident in the data: women tended to reject online sources where ties to industry or commercial interests were evident. Laura, for example, indicated that if she came across a website which was “just advertisements for drugs,” she would move on to another site. And Muriel similarly commented, “A lot of the things you get up on Google are sponsored by ones that have an interest, I guess. Yeah, like companies or something that might have an interest, and you’re looking at that site. [I] tend to avoid those sites.” This theme supports earlier findings. Wikgren (2001), for example, found that online discussion group participants rejected commercially oriented sites as these sites were perceived to lack credibility; and Ginman et al. (2003) found that even when diabetics were unaware of existing quality criteria for online health information, they unconsciously applied quality assessment criteria related to document authorship, age and information presentation style.

For some participants the uncertain authority of internet information produced ambiguous responses. Pat’s comments illustrated this phenomenon. Early in her interview Pat said that she tended to rely on formal sources for health information and she stated, “I don’t trust much of the information on the net because it’s – there’s so much there and it’s easy to put there – that to me, it’s not really a reliable resource.” Later in the interview, however, Pat related that she used the internet to confirm information from her physician: “I will look [my medication] up on the internet and see, you know, check several sources to make sure I’m getting kind of reasonable information.”

It must be noted that credibility assessment is related to the type of knowledge which is desired and, therefore, to the relevance of posted material to the individual information seeker. Interview data revealed that a small proportion of participants sought access to experiential knowledge via the internet. “I also read all the people that, you know, write in the comments there. That have some – you know from the two year old to 11, to 24, to a gentleman who was 78. Like, what were some of their main symptoms?" (Jill). Participants in this study primarily reported using the internet for gathering orienting or factual information as opposed to networking; they were more likely to report gathering experiential knowledge from interpersonal information sources.

Jill's preceding quotation draws attention to the issue of *relevance*. While concerns about health information literacy tend to focus on quality and reliability of online health information (*cf*. Hanif et al. 2009; Pérez-López and Pérez Roncero 2006), little attention is given to the relevance of information (Marton 2003). This concept is closely related to the context of the individual information seeker (Saracevic 2007) and places value on women's perceptions of information usefulness. For example, Lisa explained, "If I find it very very interesting, I'll keep drilling down. Until I've exhausted what I think are most avenues. You never get them all. But most – that I've satisfied my answer that I'm looking for." The pervasive and ongoing use of the internet by participants and the satisfaction with retrieved information suggests that health information found online was relevant to the needs of women seeking information about the menopause transition.

5.4.3 Online searching strategies

Participants mentioned a range of approaches to online searching. While some women favoured specific websites (Irene, for example, relied on the Mayo Clinic website – it was recommended by a trusted HP and she was very satisfied with retrieved information), search strategy for the vast majority of participants focused on utilizing the Google search engine. Representative quotations include: "I am just a Google doer" (Camille), and "I Googled it" (Lillian). Only one participant indirectly acknowledged other search engines. In response to a question about the specifics of online searching, Beverly responded, "Google. A search engine of some sort." This ubiquitous use of the Google search engine is consistent with the overall use of Google by the general population at the time interviews were being conducted (SearchEngineWatch staff 2009).

Consistent with studies focusing on search strategy (Fox 2006; Renahy and Chauvin 2006), women tended to explore the first few links provided by the search engine and to then use hyperlinks from those websites to explore other online sources. Exemplar comments by study participants include the following: Hazel explained that she looked at the top one or two results from a Google search, “The one, the top two that I go to. Those are the internet ones I go [to];” Beverly focused on the abbreviated captions provided by the Google search, “As far as opening up, what do I open? Totally random, like what strikes me in the little caption right there;” and Thea said, “If I Google something. . . then there might be another subject or topic [tangential to the original topic] that hey, that’s sort of like what I’m looking for.” In the same way that women habitually gathered health information from multiple sources (see section 4.2.2), participants tended to gather and compare information from multiple websites: “I tend to use several and collect that information and then sometimes I print it out and compare them and have a look” (Muriel); and “I spent hours on the computer reading them all and sifting through the information and finding common denominators that this was a symptom and this could possibly be a symptom of menopause, right?” (Roslyn). Findings from this study support Renahy and Chauvin’s (2006) observation: “Consumers also seem to appreciate the possibility of checking and comparing information on different websites” (267).

5.4.4 HPs perceptions of women’s online health information seeking

Interviewed HPs confirmed that the internet was a pervasive source of health information for women experiencing the menopause transition. HPs tended, however, to express concern about the ‘noise’ created by the mix of health information available online: “I know a lot of people will explore a lot of things on the internet. And I think – I mean, they get good information. They get bad information on the internet. So that’s a challenge for us as physicians or as healthcare providers” (Clare); and “People are consulting the internet a lot and like they don’t seem to go into an encyclopaedia, like the Home Encyclopaedia of

Medicine. They generally seem to go to the internet. Which is in some ways unfortunate because sometimes they get really off track. Whereas if they'd stuck with the medical book for home use, sometimes they wouldn't get so far out in left field" (Mark). Many HPs favoured the use of hospital or association websites (for example Gail). Although HPs did not necessarily have personal familiarity with these websites, they appeared to view these sources as 'safe' because of their 'branding.' Renee's comments exemplify this prevalent perspective: "I try to get [women] to stick to really orthodox sources – like anything that has got 'org' or dot 'edu.' You know, for the American sources. Because I am – there's so much nutty stuff out there that it's – I really would prefer people not to use them. I refer people to the Canadian Medical Association website and to Mayo Clinic." Although HPs working in menopause clinics provided women with a handout listing suggested websites, Renee, like many of the community based HPs, did not address internet use for health information seeking unless it was brought up by patients. Two HPs said that they had occasionally gone online to check the information their patients were bringing to them (Mark and Denise). However, consistent with Hanif et al.'s (2009) findings, a number of the HPs explicitly noted that they were reluctant to recommend internet resources because of their own lack of familiarity with this medium (for example Wanda and Clare). Although HPs tended to view the internet as a source of potentially distracting or conflicting information, the literature suggests that online health information seeking has the potential to facilitate patient engagement in health management and health promotion, and thus "contribute positively to health outcomes" (Hong 2008, 587).

5.5 The media as an information source

Findings from this current study supported previous research suggesting that the mass media is an important source of information for women in the menopause transition (see section 2.1.3). Furthermore, findings provided a glimpse of how women experienced media information related to the menopause transition, and how those experiences influence their information behaviour. Although the internet was a prominent source for participants who were *actively* searching for information related to menopause, women were more likely to gather health information from the media (including television, radio, and printed magazines and newspapers) through incidental information encounters or when scanning or monitoring media as a part of everyday routine media use. These latter approaches were not surprising given that in these mediums users cannot effectively limit content to their personal interests. Monica, for example, noted, "I stumble across them [media 'shows' related to health]. I don't search them out." And Beverly said she picked up health information when "reading the odd thing in a magazine at the doctor's office. . . . A little bit in the paper. We don't get that [the newspaper] a lot either. And the odd thing you see in the news." Women who monitored the media on a regular basis (for example, newspaper reading or television news watching) reported that they would likely notice health information. In fact, women presumed that they would hear about new health breakthroughs or discoveries through the media. Christy's comment exemplifies this view: "Let's presume that there was a change in diabetes information that suddenly appeared. I would probably hear about that through the media."

Primary themes which emerged from the data follow: participants valued the media as a means of providing access to health information; however, women also expressed concerns about media dissemination of health information. Furthermore, participants expressed concern about media creditability and some demonstrated familiarity with issues related to health and media literacy. Finally, discussion by HPs and women of the dissemination of menopause information by Oprah on her television show will be used to highlight the divergent views of media-mediated health information which are held by HPs and women.

5.5.1 Media as a means of facilitating awareness

While some participants talked about their experiences with media-mediated health information in the narrative portion of the interviews, all of the women discussed media supplied health information within the context of the elicitation articles. Data revealed that women viewed the media as an important *awareness tool*. In other words, women did not view the media as a means of in-depth exploration of health topics; rather, media was valued because it provided an overview of new or timely information and because it empowered women by making them aware of potentially useful information (Powell, Collins, and Martinez 2009). Cherri's reflections during the elicitation portion of the interview exemplify the perspective of many participants who viewed the media as an awareness tool. "I think it's a good thing [health information in the media]. People who want to know have the choice to look at whatever is available." Thea's view also exemplified the perspective of media as an awareness tool:

> People can choose to read it or not read it depending upon their own situation. So I'm thinking it's the person himself. Is this going to help you today? Or is this going to help me? Is this going to help someone else? It probably would help one of us. One out of the 10 that read it will read it and get something. The rest of us may not even read it that day. It's still there. . . . I think information on any level should be out there. Whether or not we choose to grab it that day is all about what's going on with your body.

Other observations included: "It's good because people were aware, right? And at least then you're putting the ball in – so this just puts the ball in my court" (Joyce); and "I think it brings your attention to the subject" (Sue).

In addition to the theme of media as an awareness tool, many women noted that media-communicated health information served as a 'springboard' for further information seeking. Quotations illustrating this theme were evident in women's responses to elicitation articles: "It [the elicitation article] would be a jumping off point. . . . I would probably go and read the original article" (Christy); and, "I would take it seriously. I would either start taking – I might even go out and buy Vitamin D at this point. . . . if I had a doctor's appointment coming up soon, I might raise that or check in on that or see if there's any contrasting information (Faye)."

The media was also viewed as a means of removing barriers to health information. Gwen, for example, suggested that without the media, people may not have learned about the dangers of thalidomide: “Years ago they had thalidomide. You know? That’s a really big one and if that hadn’t come out in the media, would people have known about it? Might have been hidden. . . . So research is important. The findings, I believe, need to be publicized.” Whether Gwen’s specific knowledge of this medical tragedy was correct or not, the story she related demonstrated that she viewed the media as a means of revealing potentially “hidden” health information which, Gwen suggested, should be available to the consumer. Nicole also alluded to the media as a means of ensuring that health information is not privileged information: “Information is supposed to be freely available. So I mean to start then, honing in and saying, ‘No, only the elite, only those qualified. . . will have a look at this. And if they deem it necessary for you to know, you will be informed.’ Doesn’t sit well with me.” Vicky experienced the media as an information source which broke barriers of ignorance and made people aware of choices: “It’s forcing people to look at their lifestyle choices. . . . It’s forcing us to be aware that there’s alternative sources of information.” Similarly, Paula referred to the media as a means of bringing information to large numbers of people who might otherwise be uninformed: “Because the power of the media, you can reach more people. You can give them the information. . . . You can bring it out to millions of people by using the media.”

The notion that the media, in its role as an awareness tool, educates consumers and facilitates access to information which might otherwise be privileged was prominent in the data. This notion is supported by published studies which suggest that the media (including the internet) allows consumers to be more active participants in health decision making (Klein-Fedyshin 2002; Macias, Lewis, and Shankar 2004; Warner and Procaccino 2004), involvement which the current participants took for granted. Lisa, for example, said, “I believe the information should be put out there but I do believe that people have to take it upon themselves to research that information and learn who is behind it, why it was put out there, and . . . be more responsible for their health care rather than just going to a doctor and trusting them.” Lisa’s comments draw attention to an additional theme which emerged from the data: women’s responsibility for exploring beyond media-provided health information in order to effectively use that information for decision making. Anita’s assertion is typical of participants’ observations about responsibility following media-facilitated awareness: “It’s a good thing. Then you have to do your homework.” Faye likewise noted, “I think it’s good that there’s more out there because I think I want people to have to sort through it for themselves. . . . I don’t want somebody else sorting through it for me and saying, ‘Read this but don’t read this.’ Feels a little bit totalitarian.” Women’s comments focused primarily on consumer responsibility for exploring information initially encountered in the media; however, media accountability when reporting health information emerged as a minor theme: “These headlines grab people. So I think it’s really – they just have to be careful how they do it” (Joyce); and, “Maybe the people that are doing the reporting are going to have to be much more disciplined. I don’t know, we can’t control them. I mean we don’t want to have censorship or anything” (Jane).

5.5.2 Concerns about media dissemination of health information

Despite the value women placed on the media as an awareness tool, concerns about media-mediated health information emerged as women talked about their experience with this information source. Participants were likely, however, to position their concerns as something which might impact *other* people. Three examples of this positioning follow:

> *Pat*: “I think it [the media] has its dark side though and there’s a lot of, I don’t know lots, some people I’m sure, who take it [health information in the media] too seriously and apply it too broadly. Perhaps, to themselves and those around them.”
> *Nicole*: “Because I think you’re going to get an awful lot of people who are going to go and – I was going to say, “Go off the deep end’ – but, go into almost cult like camps and follow various media star physicians etcetera. Or naturopaths, or health gurus of any kind, size, shape and description, off into areas that may be very detrimental for them. And how that gets regulated or what gets dealt with – I don’t know.”
> *Dale*: “There’s a lot of people that don’t seek medical help unless they’re dying. You know, they’re not proactive in their health care. They’re

> reactive. So this [health information in the media] might be the only way some people get any kind of information."

As with internet information sources, a primary theme was participants' concern with respect to the credibility of the information they read or heard in the media. This was particularly evident during the elicitation portion of the interview. Although some women accepted the articles used in the elicitation exercise as information from the news source itself (this was demonstrated by discussion of the information in the articles without reference to origins beyond the media source), many women wondered where health information in the media originated and whether there were hidden motivations behind published information. Lillian, for example, noted with surprise that despite the conflicting information, the elicitation articles all originated from the Canadian Broadcasting Corporation (CBC): "Now this is CBC and this is – also CBC [surprised tone of voice when noting that the dissenting article was also CBC in origin]. But the news, who puts the information into the news? . . . You want to find out who disseminates the information." And Cherri's concern about the "agenda" of media communications was also representative of concerns expressed by participants: "I always take what I read in the newspaper with a grain of salt. Sometimes they have an agenda that they are promoting. . . . And then you have to find out who's funding the TV show. Is it being funded by a pharmaceutical company? And are they pushing their product? That's a question I would have – also, perhaps magazines" (Cherri).

Although women expressed concerns about health information in the media, analysis suggests that the majority of participants appreciated the critical importance of health and media literacy skills, including the ability to read, understand and apply health information to one's own situation (Ad Hoc Committee on Health Literacy 1999) and the ability to analyse and evaluate media-mediated information (Livingstone 2004). This appreciation was demonstrated by women as they read and sought to make sense of the elicitation articles: "I'm looking and I'm thinking, 'Okay. Funny. Randomized, double blind placebo controlled study, 36 *thousand* women compared to 50. I would end up taking a little closer look" (Vicky); "I'm trying to decide on like what group of people are the? How many people" (Laura); and "I'd probably look . . . decide if, you know, if the objects of the study were the same. If they were truly studying the same thing. Or is this just a little excerpt that somebody pulled out of, you know, out of context" (Pat). Although the women did not necessarily know how to apply the information to their own situations, their comments demonstrated that they understood the importance of correctly interpreting study details in order to effectively use the information communicated in the media.

5.5.3 Perspectives on media influence: Oprah as illustration

While women viewed the media as a valuable awareness tool and, at the same time, expressed concerns about this medium as a source of health information, HPs primarily expressed concern about media-communicated health information and about the influence of this information on women. Only a few HPs made minor reference to the role of the media as an awareness tool. Representative observations from HPs include the following: "I think it's great that we have all this access to information the last 10 years in the media with – in regards to our own health. But I think sometimes . . . we hear what we want to hear too, right?" (Connie); and, "Certainly more women are coming forward and looking for help with symptoms because they're aware that it's not all in their head" (Amy). The majority of comments about media-mediated menopause information, however, expressed concern about this medium as a source of health information. Renee, for example, highlighted the "climate of fear" created by the media: "It scares people half to death. Mostly they [the media] report negative things because that makes news." And Francis expressed the view that consumers should be protected from the confusion sometimes caused by media publication of new research findings:

> They've gone a little bit too far. And especially when they talk about the new research. Quite often that research they're talking about it – it may be the first phase. . . . Of course, they say, 'Well, but the public should know.' But, the public should know? Wait until you have a more and more

> valid reason to publish it. It's not 'The public should know and just period.' . . . If you are going to do that, and you are really – you have the heart of these people that you want to help them, everybody and give them optimism, etcetera etcetera, for heaven's sake, wait until you actually, for sure, have a valid reason to do that.

In this quotation, Francis directly challenged the notion that the media has a valid role to play in raising awareness about medical issues and suggested that (1) women should be sheltered from information which may be unsettling, and (2) there should be a "valid reason" beyond informing when publishing medical information in the media. While these comments might be considered outdated in light of the realities of the internet age, they also reflect the view that medical information is privileged information which should be optimally communicated by biomedical authorities.

The struggle to maintain biomedical authority in a time of pervasive information availability both via the internet and the media was typified in this data by reports related to Oprah's menopause-related television feature. In January 2009, this celebrity talk show host featured discussion of menopause, HT, and bioidentical HT (Kosova 2009). While the WHI has been viewed as the pivotal event in the history of HT prescribing (Peterson et al. 2004), the dissemination of health information by Oprah on her television show was noted by HPs in this current study as having a greater impact on women: "There weren't as many phone calls, so that was 2002 around that, as there has been since the Oprah show. . . . Like her show aired on January 15th. On the 16th we started to get a flood of calls and we didn't know this show had happened, right?" (Sonya). Exploration of comments and reflections on Oprah highlight the divergent views on media-communicated health information which were expressed by women and HPs

Women's discussion of Oprah and her influence was limited to approximately one third of study participants, with some women positioning Oprah as a valuable source of menopause information and other women expressing disinterest or concern about Oprah's influence. A common theme for women who valued Oprah's information on menopause was the personal connection with the experiences of other women which the show fostered: “I just felt a little bit better in knowing that the women that were on that show went through the same thing I did where they weren’t getting information and they had a long wait to get any” (Thea). Anita’s comments also exemplified this theme:

> I don’t watch much television, unfortunately, but I remember watching it sometimes, what is there, the Oprah show. When they talk about women, menopause, and things like that. . . . when I saw a woman that was – has been treated, but it was like a testimony from her before the treatment and after. And you know, I feel so much like her, I have been through that. So and I think that tons of people going through the same thing, so it makes you feel better. You’re not alone. You’re not crazy. You can get help if you want. You have different options. It is so important.

Women also noted personal connection with Oprah: “[Oprah] was obviously is going through it so she decided to kind of make it her mission, I guess, to talk to women about it, because no one was talking about it. So I found that really helpful” (Camille). This personal connection highlighted by participants is supported by the research literature (Marshall and Pienaar 2008). These scholars note that Oprah’s profound influence as a talk show host is fostered by her ability to move beyond voyeuristic displays to the communication of the message, “you are not alone” (527). This notion of a personal connection formed with Oprah or her guests on the show was supported by one of the interviewed HPs who sought to explain Oprah’s influence. “It’s woman to woman. So I think this whole sort of interest in bioidenticals is Oprah: one woman talking to another woman. Even though it’s an audience of 30 million or whatever. But that’s just how health information flows to women, right? So that peer-to-peer, those sort of face-to-face conversations” (Sonya).

Women did not, however, universally identify with Oprah. Representative remarks include: “Oprah’s not somebody that I would [laughs]. . . you know, reliable. . . . Oprah’s a charming person but I’ve never watched her show. Talk shows are not where I go” (Faye); and “You choose someone you trust. You choose Oprah. . . in this case you take somebody who is in a sense is packaged to look trustworthy” (Nicole).

HPs' reaction to Oprah's influence exemplifies the general reaction to media-mediated health information expressed by HPs in this study. Three quarters of the interviewed HPs commented on Oprah, with the majority expressing some surprise at Oprah's pervasive influence. Sonya and Renee's observations exemplified this perspective. "It's the Oprah influence. Yeah. Her mentioning things or sanctioning just – I had no idea how she impacts the world" (Sonya). And, "The Oprah thing was huge. I got, I don't know how many – maybe a hundred women that asked me about – 'What about this Oprah stuff? Can I get that?' . . . . It's a very rare woman, I find, that doesn't know something about it [bioidentical HT] because of Oprah" (Renee). Striking concern was also expressed by HPs about the influence of Oprah's show on women experiencing the menopause transition and the degree of empowerment which Oprah appeared to impart to women. Representative examples of these concerns include: "When [women] talk about Oprah, right? Oprah is God, I don't know. . . . The power that she has. And that she uses it and that she's empowered these women to come. And some of them are *demanding* the bioidentical hormone business" (Gail); and "I find the women are even having stronger opinions. But maybe because of things like Oprah, there's certain things that are out there that are really selling and those books that are selling. And they're very strong statements that are being made. More so than before. Really strong" (Yvonne).

While most of the HPs viewed Oprah's presentations as a challenge to biomedical authority and were concerned about the competing influence of media-mediated health information, Denise pointed out shortcomings imposed by traditional biomedical authorities:

> It's hard when you haven't seen the show. And I'm not a big Oprah watcher. . . . It's hard because we try and stick to . . . the more formal Western medicine – SOCG and our recommendations are that we're supposed to follow – sometimes those seem very, very behind. And that's not even the right description of – they're good sources of information but quite often they don't address the issues that we're getting from the media and from television.

Denise's observation is supported by scholars who have noted that women seek information from a range of information sources when they perceive that their needs are not being met through traditional, formal sources of health information (Macias, Lewis, and Shankar 2004; Wathen 2006a). While noting the pervasive influence of Oprah (see comment in previous paragraph), Renee's enthusiasm for women's information seeking beyond the traditional boundaries of medical knowledge was representative of a very small number of the interviewed HPs: "Patients are becoming more willing to find out stuff for themselves. And it's not always the right stuff. But just taking the step to be involved in figuring their own health care out, I find it really good. . . . And people find some information that sometimes I don't know about. And then they bring it to me and I always find it very interesting." While information seeking in the post-WHI environment has clearly encompassed both formal and informal information sources, Oprah's influence on management of the menopause transition and particularly on the bioidentical HT debate, as demonstrated by findings from this study, provides support for the view that "information and opinions obtained from the media have become major determinants in the patterns of drug use" (Pines 2005, 364).

5.6 Libraries and books as sources of information

Findings from this study suggest that even in the current environment of fast access to consumer health information via the internet and ubiquitous exposure via popular media, libraries and books were valuable and frequently mentioned information sources for participants. Four women mentioned neither libraries nor books as they described sources of health information. One participant specifically noted that she did not read very much ("I don't like to read a lot of stuff. I'm a terrible reader. It's got to be in little point form and then I can understand it"). Although this point was not noted by the participant herself, and she was completely proficient with spoken English, this woman was one of the participants who had an accent, which suggested that English was not her first language. Another participant reported using books for health information behaviour, but specifically noted, "I rarely go to a library. Small town, so I find that – yeah. Google and whatever." All of the remaining 22 participants mentioned utilizing a library and/or books in their quests for health information. Half of these specifically mentioned utilizing resources at a library. While none of these participants specifically reported going to the library to use online resources, a number spoke specifically of using the books at the libraries. Hazel’s comments exemplified this coupling: “Then I got a book. . . . from the library.”

While some scholars have raised questions about the relevance of libraries and paper documents in an internet age (*cf*. D'Elia et al. 2002; Gyeszly 2001), a primary theme which emerged from this data was the value participants placed on the library as a trusted starting point for information exploration. Naomi specifically identified the library as a place to begin exploring health information: “I used to go and visit Dr. [W], and after we were finished, I would go to the library there [a hospital library]. Right. And they have a lot of good information that I would call starting information.” Muriel and Joyce’s use of the library also exemplified this theme. When her doctor was “quite sure” that she was not having menopause symptoms, Muriel convinced her doctor to the contrary after she “went to the library and looked it up” and brought that information back to her doctor. Similarly, when Joyce was told she needed biopsies she went to the library to explore information about breast cancer. While women noted or discussed the pros and cons of other information sources (including HPs, interpersonal sources, internet, and media), libraries were included in women’s lists of information sources as a presumed ‘good.’ That is, not a single participant either justified her use of the library as legitimate, nor did any participant discuss the ‘cons’ of using this information source.

In the same way, books appeared to represent a ‘good’ information source for women. While some participants noted particular books which were influential as they navigated menopause-related information (Naomi, for example, noted the classic book *Our Bodies, Ourselves*) or highlighted their identify as readers (for example,“I read a lot of books” (Irene), and “I’m a real book person” (Sue)), other women listed books as simply one of their common information sources. As noted previously (see section 5.4), books were commonly coupled with online information seeking. Anita’s reflection exemplifies this coupling:

"For me it's just gathering all the information that I can through books or the internet." In her interview Anita notes the pros and cons of online health information, but issues such as the credibility, authorship, or currency of health information derived from books did not draw any comments. Beyond the implied 'good' of using books as information sources, three reasons for specifically preferring books were noted by participants. (1) When asked about the ideal or most helpful way in which she would like to learn about menopause, Beverly responded, "I do find something written down is helpful to me. You can always go back to it. Either online or in book form, whatever." (2) Anita responded to this same question by saying, "I think reading about it myself. Because it gives me more time to think about things." And (3) Joyce provided a reason for utilizing information from the book *Our bodies, Ourselves*: "I used that book a lot because it was written by women who'd done a lot of thinking and talking."

Although women appeared to accept books as a valid source of health information, HPs were more discriminating. Yvonne's comments exemplified the concerns of many of the interviewed HPs:

> But before that [Oprah's show in February 2009], it was about books. [Women] picked up a book and some of them, if they've been along menopause for a little bit longer, they might have picked up a number of books. So they'll come in with their books. Suzanne Somers, for example, has had a number of books that they'll come in [with]. I remember the first time that she had the first book out. They came in with their book, and would highlight, you know, things in the book. So there's always been some book. It just changes, the name. . . . So you know, people who sell books or do whatever or kind of promote and market their product the right way, that often will – women will listen to that, too. And sometimes it's hard to change opinions when they've already been made with those – that impression of that resource. Especially if it's in print, I think.

Joyce also related an incident where a physician questioned her use of books as a source of health information: "[The doctor] said, 'Where did you come up with all these questions?' And I said, 'Well, I went to the library and I got out some books.' And he said, 'Oh, lay books! Oh, God!' . . . . I said, 'This is the only way I know to find information.' I said, 'I'm not stupid. I didn't pick up a book from 1921." In this latter case, the HP questioned the authority of "lay books" and

Joyce countered, not by discussing the authority of consumer health books, but by offering currency as a measure of source credibility.

5.7 Source consistency as a heuristic measure for accuracy and credibility

As discussed in section 4.2.2 and demonstrated in this current chapter women gathered and placed value on information from multiple sources. Although sources have been explored as separate entities in this chapter and in many cases participants did differentiate between sources, women also demonstrated that construction and making sense of uncertain health information related to the menopause transition involved an integration of information from different sources. Women expressed appreciation for the relationships between information which were established when sources directly or indirectly pointed to one another (see section 4.2.2.2), and tended to view varying sources not as competing, but as enriching knowledge and understanding. Participants valued multiple sources not only for the different perspectives they offered (this was made evident by the use of different sources as a means of addressing or fulfilling different information needs), but data analysis reveals that participants make sense of information from multiple sources by comparing and compiling information across sources. Muriel, for example, said that she based her evaluation of health information on “cumulative information.” This draws attention to a prominent theme which emerged from interviews with women: consistency between sources was used as a heuristic which confirmed information accuracy and credibility.

Source consistency was highlighted by women who looked for multiple instances of similar information within a single type of source and by those who noted similar information as they moved from source to source. Lisa, for example, equated consistency in the information she received from interpersonal sources with reliable, trustworthy information about health management: “One of [my acquaintances] said that they tried this for that, to another [acquaintance]. And then they go and try it, come back [and say], ‘[Lisa], that worked.’. . So there’s two verifications right there and I’m the third because I did it and it worked. That’s pretty good. Pretty – then I can trust that.” Seeking source consistency was particularly prominent when seeking online information about this life transition. Nicole exemplifies those who looked for consistency in the information presented on different websites:

> I will look at a variety of sites. So I will look at – you know university based sites, or Mayo clinic sites, things such as that. And look at them with a great deal of care and try and see if all of them are in agreement. Because sometimes they aren’t. Sometimes their information is somewhat different. Or sometimes it’s the same information but there’s a slight twist in the interpretation. So that’s one thing I would look at.

Faye specifically highlighted her search for “overlapping” information sources, noting not only external formal and informal sources, but also intra-personal sources (“what makes sense”). This participant’s narrative is representative of those who spoke of consistency across a range of sources:

> I don’t just go to the Mayo Clinic site, for example, I go to the library, I look at self help books. I go to Audrey’s Bookstore, I get sort of lay people books as well as Mayo Clinic or professional journal articles. And I talk to friends. And then I figure out where things are overlapping and what makes sense. . . . Mostly I try to read when I’m sort of figuring out – like in my early fifties, figuring out how I was going to deal with menopause – read really broadly until I figure out – until I started to see overlaps of information, and then I can start saying, ‘Okay, here’s the reliable stuff and here’s just the stuff that everybody’s saying.’

Specific response to information consistency varied; however, source consistency was predominantly viewed by interviewed women as a sign of credibility. Based on this perceived credibility women were more likely to feel like they had achieved a reasonable basis for decision making. Both Gwen and Sue exemplify this theme, although in Gwen’s case consistency confirmed current health practices, while Sue was motivated to discontinue a current management strategy. Gwen stated: “[My doctor] said, ‘Take calcium magnesium with Vitamin D. And that’s what I’ve been doing. So this would reinforce. . . it’s one more bit of information that can reinforce the good reason why we should be taking it.” Greater consistency in “negative” online information, on the other hand, convinced Sue to discontinue a prescribed medication, even prior to consultation with her physician: “I had gone on the internet and read about [my medication] and there wasn’t a lot of positive things about it. There seemed to be more negative than positive. So I went off of it.”

Data analyses suggest that, for this group of participants, information inconsistency served as an indication for continued information seeking. Dale illustrates this finding: “I try and definitely cover more than one source so I can compare information as well. One might contradict another; [then I] try and find another to see what they say.” Jane, provides another example of inconsistency as a motivation for ongoing information seeking. This participant encountered inconsistent formal information from HPs. This led to online information seeking, the discovery of information which Jane found to be consistent with information from one of the HPs, and Jane’s decision to follow one of the advocated treatment strategies: “I went to her on Thursday and I said, ‘I finally accept that this is what it is.’”

Interviewed HPs confirmed that information consistency was likely to facilitate information use and decision making. Amy, for example, noted, “What we have found on many occasions is that it’s helpful for the patient to hear a message from more than one person [more than one HP], and that it takes hearing it from more than one person before [women] kind of, you know, decide, ‘Oh, okay, here’s what’s happening and it probably would be beneficial.” This theme is also supported in the literature. Brasher (2001), for example, notes that although information can decrease uncertainty by facilitating meaning making, “information does not need to be ‘correct’ to reduce uncertainty. . . but at some level it needs to create perceptions of coherence” (483).

This finding draws attention to the notion of *parallel evidence*, as it relates to Bradford Hill’s revised guidelines for appraising evidence (Howick, Glasziou and Aronson 2009). Just as similar (though not identical) studies may reveal parallel evidence which improves the strength of evidence for a given conclusion, women viewed parallel information as enhancing the ‘strength’ of both formal and informal menopause-related information. Furthermore, Lankes (2008), in an exploration of online information seekers’ understanding of *credibility* notes, "users are shifting from more traditional "authority" methods of credibility determination, where users cede determinations to trusted third parties, to a "reliability" approach where users seek commonalities and coherence among multiple information sources" (667). He observes: "If an authority approach was as simple as believing that a given news anchor will give a credible answer, then switching from news station to news station looking for commonalities in the same story is a reliability approach" (680). To my knowledge, the notion that source consistency confirms information accuracy and credibility has not previously been identified within the studied population; however, it has been identified by scholars exploring students' IB (Dubicki 2010; Julien and Barker 2009). This study, therefore, is in itself an example of parallel evidence as described by Howick, Glasziou and Aronson (2009).

While interviewed women reported the wide and fluid use of information sources, these findings confirm Lankes' (2008) observation that the proliferation of sources, particularly the internet, has led to a "culture of information self-sufficiency" (680) where data consistency has become a measure for credibility. For participants navigating uncertain information about the menopause transition, source consistency became a heuristic which facilitated the construction of uncertain health information as credible and thus a basis for information use.

5.8 Conclusion

This chapter has illuminated the varied information sources which women access as they strive to make sense of uncertain information about the menopause transition. Investigation focused on women's responses to evolving health information as presented by HPs, inter- and intrapersonal sources, the internet, media, books, and libraries. And finally, the notion of source consistency as a heuristic measure of accuracy and credibility was brought forward and discussed. In Chapter 6, the third research question is explored as findings related to women's self-positioning with respect to information sources are presented and discussed.

CHAPTER 6

RESULTS AND DISCUSSION: SOCIAL POSITIONING AND DECISION MAKING

While health information behaviour research has commonly treated accounts of information seeking as “relatively unambiguous pathway[s] to actions, beliefs and actual events” (Potter and Wetherell 2001, 200), discourse analysis suggests that language is a “medium for interaction (Potter 1997, 146) and that participants’ accounts “produce and build their experience, emotions, identities and social worlds through dialogue and discourses” (Tuominen, Talja, and Savolainen 2005, 328-9). Scholars note that discursive practices have constitutive force through which identities are developed and different subject positions are generated (*cf*. Davies and Harré 2001; Given 2002; McKenzie 2002). Furthermore, it is these views of self, generated by changing discourses, which provide the contexts within which people exercise agency by making choices between contradictory influences (Davies and Harré 2001) and by adopting and/or discarding components of various social positions (Given 2002). In this chapter discourse analysis is used to explore “how people tell stories about themselves and how they present themselves in talk” (Wetherell 2001, 186). Social positioning theory (Davies and Harré 1990; Van Langenhove and Harré 1994) provides a lens for exploring the ways in which participants position themselves when encountering, seeking or exchanging health information, and how that positioning influences health IB. Cognitive authority, the notion that cognitive strategies are used to determine and justify information sources as authoritative for a given individual (Wilson 1983), has been used in the literature as a framework for exploring the influence of a wide range of sources including the internet, media and public bioethics committees (Rieh 2002; Savolainen 2007b; Kelly 2003). McKenzie (2003a) extended this notion by exploring how pregnant women used positioning to construct biomedical, experiential and individual authority. This chapter focuses on the ways in which participants positioned themselves and formal information sources, and how they ascribed cognitive authority as they described their navigation of uncertain information about management of the menopause transition.

Data analysis suggests that women positioned themselves as autonomous, collaborative and/or dependent information seekers and decision makers as they navigated uncertain information about the menopause life transition. For the vast majority of participants, social positioning was dynamic. It changed fluidly during the interview and was influenced by multiple factors. It is important to note not only that positioning was dynamic, but that these positions were nuanced. For example, while some who positioned themselves as responsible for their own health management viewed input from HPs as undesirable, others who similarly positioned themselves actively solicited information from HPs as a part of their decision making process. Interview data indicates that these nuances and the ways in which women positioned themselves when encountering, seeking or exchanging information were profoundly influenced by belief structures with respect to biomedical knowledge. Jill and Cherri's narratives exemplify the influence of biomedical beliefs on the way positioning was expressed in action. Jill tended to distrust HPs and she positioned herself as autonomous based on her underlying belief that medical intervention was 'unnatural': "I will go more towards the natural stuff and try to read and – inform myself a little bit more about some of the stuff here, versus going over there [to see a physician] where they prescribe something that damages my body quite a bit more." Cherri, on the other hand, established autonomous positioning ("I'm responsible for managing my health. No one else will do it for me. I have to do it for myself"), but explicitly sought biomedical information as part of her information gathering strategy: "I would probably see one or two specialists and get their best information, and ask them if they can point me to clinical research studies. So I would read them up, read them myself."

In this chapter, each of the positions which emerged from the data (autonomous, collaborative, and dependent) are explored; this is followed by an examination of factors associated with the dynamic positioning of participants and by exploration of the dynamic positioning demonstrated by one of the participants

(Muriel). This more detailed representation of dynamic positioning provides insight into and exemplifies the fluid positioning of participants over the long term and throughout the menopause transition - a more cohesive picture of positioning and changing cognitive authority than can be provided when exploring positioning practices in isolation. The influences of evolving socio-cultural discourses on participants as well as implications for shared decision making (SDM) are also explored.

6.1 Autonomous positioning

A primary theme emerging from the data was that many women presumed that they were autonomous and self-directed information seekers and decision makers with respect to the management of the menopause transition. This positioning was expressed in a number of different ways by participants. Women adopted biomedical language and used metaphors to position themselves, they conjured notions of accountability and control by presenting themselves as ‘responsible’ for their own health management, and they recounted specific situations where they actively and assertively directed health management or medical investigation and treatment. Monica and Dana illustrate positioning which was established by drawing on biomedical imagery: “I’m the one who’s taking care of me. . . . I’m the primary caregiver” (Monica), and “I’m probably my own general practitioner” (Dana). Personal responsibility is exemplified by Christy’s statement: “As far as I’m concerned, I’m responsible for my health.” And other participants asserted autonomy by describing how they directed their own health management when they were interacting with HPs. Camille and Hazel’s comments were representative of this perspective: “So that’s what I did. I *told her* [the doctor] what I wanted to do” (Camille), and “That’s when I insisted, ‘You have to give me an ultrasound because I feel it’s not going away and I am concerned” (Hazel). It is interesting to note that following the 2002 publication of WHI findings the medical literature also indicated a discursive shift in tone towards women’s empowerment and SDM (*cf.* Légaré and Brouillette 2009;

Salkovskis and Rees 2004), a change which, perhaps not incidentally, coincided with significant growth of internet users (Fox 2006).

While some women consistently positioned themselves as autonomous, the narrative portions of interviews demonstrated that almost all of the participants who primarily positioned themselves as collaborative or dependent, intermittently adopted autonomous positioning. For example, a subset of women expressed autonomous positioning by using or experimenting with over-the-counter products and/or alternative therapies without consulting or telling a HP. With no overt declaration of autonomy and without any covert overtones, these women demonstrated complete comfort with taking control of their health management in these circumstances. For instance, Jane and Irene expressed preference for and reliance on biomedical authority; however, both went to alternative practitioners as a part of their investigations with respect to health management. In addition, many women who relied on HPs for information about the menopause transition related that they concurrently experimented with non-prescription health products (for example, Lillian and Gwen). Indirect autonomous positioning was also exemplified by Sylvia, a participant who also demonstrated dependent positioning. For example, when explicitly asked how she viewed her role in managing her health she responded: “I guess – I can bring my issues up to my doctor and have a discussion with him.” However, Sylvia expressed concern about her own ongoing use of HT and related that shortly before the interview, and without consulting her physician, she had decreased the frequency with which she took prescribed HT and had begun experimenting with an exercise regime which she hoped would control her severe hot flashes.

Consistent with the literature (Davies and Harré 2001), participants were largely unaware of their positioning practices; however, data analysis revealed that when participants were explicitly asked about their role in personal health management, almost every participant expressly positioned herself as an autonomous decision maker. This explicit positioning occurred even when narratives clearly suggested collaborative or dependent positioning. Pat and Gwen’s statements were representative of this finding. When asked about primary responsibility for personal health, Pat quickly answered, “Oh, me.” This response contrasted markedly with Pat’s discussion of information seeking and decision making earlier in the interview. For example, Pat had related that if she was wondering if a health concern warranted a visit to a HP, she talked to her doctor’s receptionist and “they decide if I should come in.” When Gwen was directly asked how she viewed her role in personal health management, she responded: “To be responsible. To find out the information I need.” This assertion contrasted with Gwen’s previous statements in which she primarily positioned herself as being the subject of action on the part of HPs: “They’re all about making you more self aware. . . they’re educating you.” This participant had also noted, “I’m depending a lot on what my doctor advises.”

A small group of women felt that they were pressured into assuming autonomous positioning and directing their own health management. Unlike Henwood et al.’s (2003) study where “many patients [did] not want to take responsibility or seek out information for themselves” (604), these women engaged in information seeking and in part positioned themselves as autonomous, but they also demonstrated ambivalence towards that positioning. Sue, whose positioning changed as she dealt with different stages of the menopause transition, exemplifies this ambivalence. For most of her interview this participant positioned herself as an autonomous information seeker and decision maker (“From the beginning of my menopause, I kind of was my own doctor”). However, when she was asked how she might ideally like to learn about health information, Sue responded:

> I wish that it was given *to* us when you reach a certain age. . . . What I have done to kind of look at my own self – I have gone through a lot of different research, different angles. I think it’s a hard thing. And I don’t think a lot of women have that time or that effort so that’s why I think having – why should all women go through that? Why not have [a women’s health centre]? A great facility for us to go to and then have – be looked after?

And Thea, who stated, “I can’t wait for someone else to come and help me – I think it’s just get’er done. Fix it yourself because nobody else is going to fix it,” yearned for more explicit advice when it came to treatment options: “It’s a long choice after they do tests and they sort of give you, 'Well, we could do this. We could do this. We could do this. This is the risk. Here's the risk for this one. This is the risk for this one.' Well, jeez, you know, you're still thinking, 'I don't like any of those risks, okay? What do you think I should do?'"

Women primarily drew on individual authority when positioning themselves as autonomous information seekers and decision makers. That is, they "relied on themselves as cognitive authorities, using their own reasoning, bodies, or experience as evidence against which to test the authority of another sources" (McKenzie 2003a, 281-2). A prominent theme in this study was that women based their autonomous positioning on individual authority derived from their position as unique interpreters of their own bodies and physical experiences: "No one knows your body better than you do" (Dale). Joyce drew on intimate knowledge of her body and her own reasoning when, after having her concerns dismissed by HPs for many years, she finally asserted autonomy and insisted on specific thyroid assessment: "I said, 'Look, I have all this weight, I should be hot all the time. I should not be cold with this weight.'. . . So finally when I was almost 40 I went to the doctor and I said, 'Look. I want a test. I know you can test for thyroid function.' I said, 'I want this test.'" Paula also exemplifies this perspective. This participant related her dissatisfaction with information from HPs in the context of two very personal experiences with cancer. She then justified her autonomous positioning by stating, "If I'm the least bit sceptical, I'm going to pursue it. It's my body. It's my health." Women's reliance on intrapersonal information sources (see section 5.3) for evaluating information might also be viewed as a means of asserting individual authority and supporting autonomous positioning. In the following quotation, for example, Nicole drew on individual authority based both on her physical body and her "gut." She also uses biomedical authority to support her position of autonomy.

> I brought [the doctor] the book. I said, 'And you know, it's written by so-and-so.' And I mean this guy is editor of you know, major major journals. So we're not talking about Joe Farmer Brown who decided he's going to have an interest in this area and write a book. And, and [the doctor] was actually a bit taken a back that I had had that. And I mean he didn't put up too much of a fight. But my thing was, okay, I sense that this man is

> coming from, you know, a reasonable motivation. But I – this is my health and I have to protect it in the way that I feel is important. And that's the one thing that I've really learned is that, when my gut somehow is telling me that something's a bit off, then I really need to stop and examine that.

'Positioning' is a reciprocal concept (Davies and Harré 2001) and by constructing a position of autonomy for themselves, participants inevitably constructed a position for HPs. In this study, autonomous positioning with respect to information behaviour during the menopause transition resulted in the construction of HPs as either 'trusted guides' or 'hired consultants.' As Faye, for example, related her experiences during the menopause transition and her exploration of HT as a means of managing symptoms during this transition, she positioned her physician as a trusted guide: "She. . . was very helpful for me as a person. She said, 'This is the information. It's completely your choice.'. . . So I felt like I was engaged with somebody who would really be patient with my own decision making process and yet was able to kind of stand up to that still and say, 'But here are the things that you might gain from [HT].'" Christy's statement also exemplified this perspective by positioning the HP as an expert who should have provided valuable information: "It's entirely my responsibility to know, that includes querying the physician who should be the expert on the subject." The notion that HPs were hired consultants was explicitly represented by Lisa, Dana, and Nicole: "The doctor is someone that I pay to help me" (Lisa); "I contract things out – to different doctors that I trust" (Dana); and, "He [a physician] and I are no longer in a consultant relationship, *but*, he served a purpose" (Nicole). In this latter statement, Nicole alludes to another theme which emerged from the data: participants who positioned themselves as autonomous (and in some cases, who positioned themselves as collaborative) tended to view HPs as dispensable and replaceable. Comments made early in Nicole's interview illuminated this perspective: "I will easily find another physician if we can't establish a rapport so that I can feel like I can actually trust the person and the information that's coming from them." Monica's comment with respect to a physician who did not appear to value her input during medical appointments exemplifies this theme: "I dropped him like a hot potato."

Some of the HPs reinforced the notion that, for some women, they acted as consultants when providing information to women in the menopause transition. Mark, for example, observed, “I think [women are] basically looking for information. Yeah, they’re consulting me as far as what’s best for them.” And Clare noted, “There’s some women who have it all figured out and ask you for hormones or whatever.” While there was a tendency for HPs to “try to help put things in perspective” for women (Amy), a perspective primarily based on biomedical authority (see section 6.2), interviews with some of the HPs supported women’s autonomous positioning. Yvonne, for example, explained that she saw her role as trying to “balance” her own beliefs while giving women information and trying to understand their beliefs. By striving to find “common ground,” Yvonne suggested that women would then “make the most informed decision for themselves. Because I don’t know what that is. I couldn’t tell you what is best for you.” Mark noted that his approach to autonomy would be influenced by women’s symptoms:

> There’s no hard and fast answer, you know. If [women are] really distressed and depressed and you know – like I said before – then you might have to say, you might have to be more aggressive as far as your treatments go. But for basically women who are looking for something for symptom relief and being uncomfortable, basically, I think just give them the options and let them make the final say.

While many of the women’s narratives presumed autonomous positioning, Sonya highlighted a challenge which autonomous positioning presented to HPs: “It takes such a skilled practitioner to allow that – that patient preference to dominate, and not get frustrated.”

6.2 Collaborative positioning

Although there was a strong tendency for women to explicitly position themselves as autonomous, a second important theme emerging from the data was that many women positioned themselves as collaborative information seekers and decision makers, with HPs taking reciprocal roles as co-collaborators. This is in keeping with previous research, which demonstrates that women seek information sharing and active involvement in decision making (Brown et al. 2002), and with findings discussed in earlier chapters (for example, in section 4.2.2.2 it was noted that women appreciated when HPs acknowledged their involvement in information seeking by referring them to information sources). Collaborative positioning incorporated varying degrees of personal versus HP involvement; however, key elements of collaborative positioning included (1) two-way sharing between women and HPs, and (2) appreciation for different types of knowledge and cognitive authority. This stands in contrast to the 'informed patient discourse' which is prevalent in consumer health literature (Henwood et al. 2003) and which predominantly adopts a knowledge transfer model of one-way communication, focuses on 'patient education,' and is dominated by biomedical knowledge (Dixon-Woods 2001).

Participants positioned their information behaviour as collaborative by using words such as "equal" (Monica) or "partnership" (Lisa) to describe their relationships with HPs. For example, after Monica stopped seeing a HP who did not listen to or act on her input, she "finally found someone who treated me like an equal." Collaborative positioning was supported by notions of two-way communication between women and HPs. This was demonstrated by women who looked to HPs for biomedical expertise but also spoke of their own critical contribution, which focused on the communication of personal experiences and contexts. Joyce, for example noted that she had a responsibility to keep track of how she was feeling, "because [the doctor] has no way of knowing how I feel." And Roslyn said that she wanted to understand the medical aspect of health management, but that she also had a role to play in dealing with lifestyle factors. A number of women described the two-way of exchange between women and HPs as a "conversation." Anita exemplified this perspective when she described her relationship with HPs at a menopause clinic: "That conversational thing, yeah, that is important to me. . . . It's not a receptor only. You have to be part, getting involved and do something – participate." Later in the interview Anita added, "You have to be an active participant in the process. Otherwise it's not going to work." Although Lisa tended to position herself as autonomous with respect to information seeking and decision making, collaborative positioning was evident when she talked about her two-way interaction with alternative health practitioners:

> I don't have to do 'I'm the boss' with them. . . it's a – you're having a conversation with, we're trading information and ideas. They're using my information to help them with a, get a cause [for symptoms]; and I'm using their information to say, 'Yeah, I've tried that and this is what happened.'. . . It's a back and forth constantly. It's not an, 'I'm the doctor you *listen*.' It's an, 'Okay, well, let's work together on this.'

When Lisa did seek a traditional physician for health care, she positioned the desired relationship as collaborative: "When I'm going to a new doctor, I'm interviewing them as much as they're interviewing me. Right? To see if we're a good fit for each other." By stating the need for "a good fit for each other," Lisa asserts the reciprocal nature of collaborative positioning.

Participants who positioned themselves as collaborators perceived that HPs valued not only biomedical authority but were willing to listen to their patients and were open to hearing about other sources of information. Vicky, for example, valued a HP who was respectful of a range of approaches to health management: "I don't want somebody who will discard the fact that I want to use supplements and that I believe that we have to monitor what else is in our systems." And Joyce highlighted a collaborative relationship with a physician who was willing to listen to and act on personal concerns derived from lived experience:

> When I was concerned about blood pressure, she said, 'No, it's not a problem.' I said, 'But I'm concerned.' And she said, 'Okay, I have a nurse practitioner. Let me make you an appointment. What she does is she comes in and she does three readings. . . I can set that up if you like.' She said, 'I'm not concerned. But if you're concerned, let's follow up.' *Bingo*. That's what I want because she's honouring my concern.

Naomi valued the input of HPs and positioned herself as collaborative by defining an ideal partnership as one in which HPs provide information and respect women's individual authority as a basis for decision making:

> I think that they should be in partnership with you. They're not there to judge you. They're there to – that has to be taken right out of the equation. They have to remain unbiased, right? And they have to provide you with

> all the information that they have so that you can make the best decision for yourself. And that’s when it becomes a real partnership.

Not only were perceptions of two-way communication and respect for different forms of knowledge key features of collaborative positioning, women were also more likely to position themselves as collaborative information seekers and decision makers if they perceived that HPs were also positioning them as collaborators. Roslyn exemplified this when she was asked how she viewed her responsibility and role with respect to health management. She responded, “I guess I see myself as – or not me, I see the two of us [herself and a HP] like partners. And I mean, that’s the first time I’d ever had that experience. . . . They [two specific HPs] understood what was going on and they were willing to let me take part in what was going on. To be an active participant in it.” The notion that women were more likely to position themselves as collaborative if they perceived that HPs likewise positioned them as collaborators was supported by an incident reported by one of the HPs. This HP criticized celebrity-mediated health information, thus openly devaluing the contribution of the patient (which had been derived from an Oprah show). It appeared that, as a result, the patient was not open to the information presented by the HP. This HP observed, “I’m going to learn from that and I’m not going to be so critical, then. I’ll just take out of it the positive aspects and go from there so that women will remain open when they’re listening to what [I] have to say.”

When participants encountered HPs who did not foster two-way information exchange, who did not appear to listen to or value experiential or personal knowledge, or who did not view the clinical encounter as a collaborative endeavour, women were less likely to value the biomedical expertise of the HP. Lillian exemplified this finding when she related her experiences with one HP. This participant was reluctant to begin taking prescribed medication and instead was using a natural remedy: “I said, ‘Well, I’m taking Red Yeast Rice.’ And [the doctor] said, ‘Well, that needs more study. We need the facts.’ I said, ‘The facts are that my cholesterol came down from 9 to 5.2.’” In this situation, the HP asserted that Lillian’s actions were not based on “facts,” thus drawing on knowledge entitlement (Tuominen and Savolainen 1997) and asserting biomedical authority. Lillian responded by asserting individual authority based on her own experience, and by drawing on biomedical authority offered by cholesterol figures. While the HP's concern for Lillian's choice may be reasonable, his comments devalued Lillian's personal knowledge, precluded two-way information exchange, and contradicted the prevalent 'patient empowerment' discourse (Cagle 2002). In light of this HP's subsequent assertion that Lillian was "strong minded," it was not surprising that Lillian disregarded the biomedical expertise which the HP might have offered and maintained autonomous positioning with respect to her decision to avoid prescribed medication. Subsequently this participant found a HP who fostered two-way communication and appeared to view the clinical encounter as a collaborative endeavour; Lillian positioned herself as collaborative when she discussed this latter relationship.

Interviewed HPs acknowledged the importance of collaborative relationships with women: "I try to be there to guide people, facilitate people" (Wanda), and "Women buy into their treatment a lot more if it's a partnership approach" (Connie). While women perceived that experiential and personal knowledge was an important contribution in collaborative relationships, many HPs positioned themselves as authorities who "enlighten" women (Clare) or "set them straight" (Gail) with respect to health management. Some HPs explicitly positioned themselves as authorities; however, analysis also revealed that many HPs in this sample positioned themselves as collaborative but drew on biomedical knowledge to establish authority. This was demonstrated in interviews by the use of knowledge entitlement (Tuominen and Savolainen 1997). HPs, for example, used the term "evidence" as a warrant for the factual nature of the information they were communicating: "I'll give [women] information as far as what supplements kind of have backing and what ones really don't have the evidence to show that they're beneficial" (Erin); and, "Our practice is based on evidence based guidelines from the Society of Obstetricians and Gynaecologists" (Connie). In this latter example, Connie's reference to the Society of Obstetricians and Gynaecologists of Canada also illustrates the use of category entitlement (Potter

1996), the notion that practice is trustworthy because it is based on guidelines from a medical society. There were a few HPs, however, who did appear to share women's view of collaboration and noted the challenge of blending what both HPs and women brought to the decision making process: "There's still a definite art to what we do and that is the melding of your experience and patient expectation. You can't make everything in medicine follow a cookie cutter mould. There is that art of being able to know your patient, interpret what they say in the context of their whole life and their set of values" (Denise).

6.3 Dependent positioning

Consistent with findings related to pregnant women (McKenzie 2002), most participants positioned themselves as active information seekers within their accounts of navigating changing health information related to the menopause transition. While the majority of women positioned themselves as autonomous or collaborative information seekers and decision makers, a small number of accounts positioned women as 'patients,' in other words, as dependent on HPs for health information. Some participants deferred to biomedical authority and clearly positioned themselves as dependent. Beverly exemplified this positioning: "When I get [information] from someone whose specialty is that, I have much more faith in that. It's not my area of expertise. It may be my area of interest but that doesn't make me trained in how to assess and how to analyze, like whether it's, like, how do you know?" Pat also exemplified this positioning when she described the circumstances of her bone density test: "I guess it might have been related to menopause. I don't know. He just sent me for a bone density, I'm not sure why." Similarly Gwen stated, "I take two of those because my doctor said." In the latter two examples the women positioned themselves based on the category entitlement of their physicians and did not express a desire to understand or seek further information. The majority of women who discursively positioned themselves as dependent demonstrated this by relating accounts in which they were passive objects of action on the part of HPs: "I feel very confident that *she's* watching my health” (Joyce). Jane’s statement is particularly noteworthy: “My doctor definitely said – I was – we were going to stop it immediately.” First using “I” and then “we,” Jane emphasizes the HP’s involvement in making decisions *for* her. However, women in this sample rarely looked exclusively to HP for health information; dependent positioning tended to be evident at specific moments within participants’ accounts. Dana and Roslyn exemplified the participants who, for a specific reason or period of time assumed a dependent position with respect to HPs: “I had decided to put my hands, my life in his hands basically and I thought, Okay, I’ll go with that” (Dana); and “At that point I decided to put my faith in that doctor” (Roslyn). Both of these participants were deliberate in explaining the temporal nature of their dependent positioning.

Positioning occurred on a spectrum and rarely did women assume one position consistently throughout the interviews. As noted in section 5.1.1, half of the women said that they would talk to their doctors in order to make sense of the conflicting health information (this was illuminated by the elicitation portion of the interview). This suggests that women were more likely to privilege biomedical knowledge in situations where health information was uncertain or evolving and where sense making is immediately sought after. Laura exemplified this positioning when she was asked how she would explore information she encountered within the context of her everyday life. She responded, “I would go ask to the doctor. . . . I usually go ask her.” Analysis of current study results which indicated that women who were confronted with conflicting health information were likely to seek information from HPs is supported by the scholarly literature which suggests that the SDM model is particularly appropriate in situations of medical uncertainty (Müller-Engelmann et al. 2010).

Dependent positioning in this study tended to reciprocally position HPs as prescribers (“My gynaecologist put me onto a replacement patch” (Christy)) or information providers (“She [HP] should be able to give me that kind of information” (Hazel)). A few women specifically expressed a desire for HPs to become primary decision makers. Thea’s comments are representative of this finding: “And we discussed risk again and I said, ‘You know what? I don’t know what other people are doing, but I need some sort of recommendation." Interviews with HPs supported the notion that some women seek explicit direction from HPs: "There's some women who want to be told what to do still. There are some who given the options they say, 'Well, you pick.' Or, '*You* tell me what you think is best or which one is the best one and you tell me what to do and I'll do it'" (Amy). Although the majority of HPs positioned themselves as collaborators, a focus on biomedical authority and providing 'factual' information to women inadvertently positioned women as dependent on HPs for accurate information. Connie and Gail provided representative comments: "And then some of those myths that are out there. I think we sort of dispel that" (Connie); and "If [women have] a misconception or information, it's straightening that out too, so that they – so education is key" (Gail). Yvonne explicitly acknowledged the potential positioning produced by biomedical authority. This HP observed that guidelines from medical associations tend to project the view, "Why don't people understand that this is the right [information]." Overt positioning of HPs as primary decision makers was demonstrated by two HPs. Francis, commenting on personal experience, presumed women's dependent positioning: "I sensed something and I know exactly what this patient – even if she wrote something different, I know exactly why she came." Renee, on the other hand, made a more overarching observation about women's dependence and lack of power with respect to research and development of HT:

> Well, I hate to say it - because - like and the way I would have thought even probably 10 years ago was 'nutty conspiracy theory.' But I actually think it's because men were in charge of using hormones. Developing hormones and telling women what's good for them. It wasn't women developing hormone therapy. And you know, men right now, they're starting to use testosterone therapy quite a bit more now. And they didn't settle for any nonhuman - from the get-go - they want human testosterone.

6.4 Factors associated with the dynamic nature of positioning

Although women positioned themselves as autonomous, collaborative, or dependent as they gathered and made sense of information about the menopause transition, positioning was dynamic and participants fluidly moved between positions as they talked about their information behaviour. This finding is consistent with van Langenhove and Harré's (1999) assertion that it is not fixed roles but fluid positionings which are utilized as people seek to cope with situations of everyday life. Close reading of interview data revealed two primary themes related to dynamic positioning: changes in positioning occurred in association with (1) the perceived nature and quality of interactions with HPs; and (2) personal context – particularly the experience of symptoms.

6.4.1 Influence of interaction with HPs on women's positioning

A salient theme which emerged from the data was that the nature of interaction with HPs influenced women's positioning. While some women identified a specific interaction which precipitated a change in positioning, participants' narratives also gave strong support for this theme. Beverly, who consistently maintained dependent positioning through most of her interview, exemplified participants who explicitly identified an incident which impacted their positioning. This participant related an interaction in which she moved away from dependent positioning and adopted an autonomous decision making stance: "My doctor was talking about putting me on medication; I wasn't fond of that idea. So, I'm kind of a non-compliant patient. So I thought, 'hmmm, okay, there's gotta be another way.'. . . I suppose that was probably the catalyst – that [the doctor] wanted to put me on something." Beverly's tendency towards dependent positioning was demonstrated in this quotation by her adoption of the words "non-compliant," a construction which is used in the medical literature to suggest that a patient is not acting in accordance with instructions from a HP (Aronson 2007). In this situation her reluctance to 'comply' with a recommended long-term medication led her to position herself autonomously and seek another physician. Having found a physician she felt comfortable with, Beverly once again assumed dependent positioning.

Analysis of participant narratives provided many examples of the influence of HPs on women's positioning. Faye, for example, positioned herself as an autonomous information seeker: "I interview a bunch of people and visit a bunch of people before I choose a doctor." However, when she engaged with a physician who focused on information provision and who she felt "would really be patient with my own decision making process," Faye then positioned herself as collaborative. Lillian, who readily positioned herself as autonomous when confronted by a HP who did not foster two-way communication (see section 6.2), positioned herself as collaborative when working with a physician who fulfilled her information needs:

> This is the reason that I like Dr. [Q]: because he gives you information. He's open with you. . . . He shows you the lab results. Other doctors, they just – like I went to the doctor here in the medical centre, Dr. [R], and he checked my blood pressure. I said, 'How high is it?' 'Oh, it's okay.'. . . I appreciate the professional – whoever they are, in whichever field they are – if they honestly give you information.

A final example is provided by Dale who exercised autonomy and rejected a HP who dismissed her concerns by saying, "Well that just happens." However she positioned herself as a partner with HPs who listened to her concerns and who communicated, "Let's examine [this] if there's areas of concern [for you]."

While some women moved from autonomy to collaboration when they encountered HPs who fostered two-way communication, many women positioned themselves as autonomous information seekers because they did not perceive that they could depend on HPs for information. Hazel exemplifies this finding. She repeatedly looked for "the answer" to her challenges with menopause symptoms; however, after being told that treatment choices were "up to you" and on another occasion that she was "asking me too many questions," she reported that she was "left wondering and no one to answer [my] question." As a result, Hazel described assuming a more assertive, autonomous role in her health care. She reported, "Basically I insisted, 'You have to give me an ultrasound,'" and during the interview she talked about her plans to procure a referral to a menopause clinic as her family doctor had refused to give her one.

Although scholars recognize that people’s preferences with respect to HPs’ roles in decision making may vary between individuals and that clinicians should assess the preference of individual patients (*cf*. Arora, Ayanian, and Guadagnoli 2005; Rodriguez-Osorio and Dominguez-Cherit 2008), interviewed HPs did not necessarily appreciate their own role in the positioning exhibited by women. For example Francis, in keeping with much of the published literature, presented women’s positions as static: “It is difficult to say how they make decisions because you can hear from women saying, ‘Well, I want to hear from you, doctor, that’s why I came to see you.’ And [others] say, ‘By the way, I’m not going to take any medications because I believe in –.’” Renee, on the other hand, positioned herself as a collaborator and, as her narrative demonstrated, her patients responded by positioning themselves reciprocally:

> I don’t see myself as much as, ‘The doctor with all the knowledge and I’m going to tell you what to do.’ Maybe I did at one point. But right now it’s more, ‘Okay, here’s some information - let’s work through it together. I don’t have all the answers. We’re going to figure out the answers together.’ And people find some information that sometimes I don’t know about. And then they bring it to me and I always find it very interesting.

6.4.2 Influence of personal context on women’s positioning

A second theme which emerged from the data was that women’s contexts, particularly their experience with menopause symptoms, influenced positioning. This theme was manifested both by women who moved from autonomous positioning towards more dependent positioning, and by women who became more autonomous as a result of their experiences. In other words, personal contexts, including challenges with respect to alleviating menopause symptoms, influenced but were not predictive of positioning. The notion that women’s contexts influence positioning is supported by Talja (1999) who noted that individuals do not have a static set of attitudes, values or knowledge structures; rather, in different social contexts individuals move between discourses.

Cherri provided an example of a participant who positioned herself as an autonomous information seeker and decision maker through most of her interview; however, when challenged by ongoing and life disrupting menopause symptoms, this participant adopted dependent positioning: “I went to a gynaecologist and I told him, ‘This is what’s happening, what do you suggest?’ And he said, ‘Well, you could try hormone replacement.’ So he put me on hormone replacement.” Unlike other accounts provided in Cherri’s interview, this narrative does not demonstrate information gathering from multiple sources, information checking, or her involvement in decision making; rather, in this situation Cherri positioned herself as the passive object of the HPs actions. This participant, however, also provided context for this positioning:

> If my youngest child was 15 or 12 at the time, and I didn’t have more responsibility for younger children, I could have coped with [menopause symptoms]. But I took on raising my grandson . . . I went back to getting up at night. Getting – changing his diaper, bottles at night, and the full care of the kind of thing I was used to doing in my 20s . . . that made me realize that I didn’t have the energy or the strength to look after a super active toddler.

Cherri’s narrative demonstrates the dynamic nature of women’s positioning and, in particular, the influence of personal context and the experience of symptoms on that positioning.

Both Jane and Roslyn provide examples of personal circumstances which influenced movement towards more autonomous positioning. Jane’s interview revealed that although she had “tended to go with my doctor pretty well,” a situation in which physical challenges were not alleviated by traditional therapies resulted first in internal questions, then in frustration, and finally in an abrupt lifestyle change and independent pursuit of a resolution for health challenges. Similarly, Roslyn had been relatively passive about health management prior to midlife when she began encountering life disrupting symptoms which her regular physician had “dismissed.” From this participant’s perspective, she “couldn’t function anymore,” and consequently she repositioned herself: “I guess I reached a point in my life where it was time for changes. And health was just one of the things that needed to be dealt with. And it was probably a point where I just felt that everything was really shitty in my life and the only person that could fix it was me.” Roslyn’s positioning, however, remained dynamic. After a period of time she was seen at a menopause clinic and in that context she positioned herself as a collaborator (see section 6.2) and even as dependent: “I decided to put my faith in that doctor.”

As discussed in Chapter 4 (section 4.3.2) the symptom experience emerged as a central theme related to women’s experiences as they responded to, made sense of, and used evolving health information about the menopause transition. Exploration of themes using discourse analysis also brought forward the experience of symptoms as a prominent influence on the ways in which women positioned themselves with respect to HPs. While women came to this life transition with existing internal frameworks and experiences, the experience of symptoms not only influenced information needs (Suter et al. 2007), but, as demonstrated in this current section, these physical symptoms influenced the ways in which women ascribed cognitive authority. For example, Jane, who had tended to rely on biomedical authority (see previous paragraph), stated, “I guess I would still ask [the doctor’s] opinion . . . [but] part of it has to be your own hunch I think, your own – its got to make sense to you too.” While in this statement the participant reluctantly affirmed biomedical authority, her experience with physical symptoms caused her to turn to herself as a cognitive authority (McKenzie 2003a). Jane viewed this positioning as a departure from her previous approach to health management and appeared to remain somewhat amazed by her new approach (“this is crazy”) and the physical relief she was finding through unexpected channels.

6.4.3 A case example of dynamic positioning: Muriel

Although previous sections demonstrate women’s fluid movement between autonomous, collaborative and dependent positioning, Muriel’s narrative provides insight into the dynamic nature of positioning over the long term and throughout the menopause transition. Speaking in a factual, evaluative manner, this participant systematically related her story, which began in the mid-1990s before the publication of WHI results and extended to the time of the interview.

Muriel began experiencing menopause symptoms when she was in her late 40s; however, despite this being within the average age range that women begin to experience menopause symptoms (NAMS 2006), her physician "was quite sure that I couldn't be having menopause symptoms and that I probably just needed to get a job at McDonald's pouring coffee because I was bored." Later in the interview further details were added: "His message was, 'Suck it up. You know, if you are in menopause, this happens to everybody. . . I have lots of patients and they just get used to this.'" Muriel described the course of events following the physician's dismissive comments:

> So I went to the library and looked it up and got whatever articles I could from the library and read [them] over. And decided that I was having menopause symptoms, and what I needed to do was ask my doctor to do the hormone testing thing so that he could see whether or not – what my body was producing. And that would be – tell him that I was having menopause symptoms. And then I decided that the best route was to take the combination of the two hormones. And so I went with that information, and I said to him, 'Do these tests. 'And when we got the results, I said, 'This is the hormone I want to be on or this is the way I want to do it,' and 'Will you give me these?' And he said, 'Yeah, looks like you are in menopause. I guess you're right about that.' And so, 'Okay. Do you have in mind the kind of dosage?' And I said, 'Yeah, we'll start with the lower dose and see what happens.'

In this initial scenario Muriel related an account of a physician who disregarded her experiential knowledge, and, using knowledge entitlement based on his experience with "lots of patients," positioned her as ignorant both in terms of lived experience and in terms of biomedical knowledge. At this point in the narrative, second order positioning (van Langenhove and Harré 1999) occurred: Muriel described seeking information from an authoritative source ("the library"), in a reputable form and likely of a biomedical nature ("articles"), thus presenting a story which repositioned her as a knowledgeable information seeker who drew on biomedical authority to support experiential knowledge. Through this account, Muriel positioned herself as not only an autonomous information seeker, but also as a biomedical authority, a domain which was previously presumed by the doctor. In this passage the HP also repositioned himself by acknowledging Muriel's authority with respect to treatment decisions.

Muriel commenced HT and, drawing on the experiential authority provided by her mother’s positive experience with HT (“it was like night and day when she started taking hormones”) and individual authority arising from her own experience, this participant continued therapy, even when she encountered conflicting information about HT from a range of HPs. In one case she explained, “I guess I just got stubborn and just decided that even though [the doctor] would prefer I wasn’t on it, I felt better when I was.” Despite autonomous positioning, Muriel experienced ambivalence about taking HT after some years had passed. She explained, “I’m kind of against taking pills. This is something that really bothers me so I wanted to take the minimum that I could.” In order to deal with her ambivalence Muriel sought further advice. At this point Muriel found a “great” doctor, positioned herself as dependent, and relied on the options provided by the HP: “[The doctor] had all different options that we tried. . . . Now all of a sudden we have, yeah, we’re starting to solve some problems.” At this point in the interview Muriel used plural pronouns and positioned herself as the recipient of information rather than as an initiator of information seeking.

Some time later, however, this participant encountered friends who related their experiences discontinuing HT. Based on this information, Muriel decided to discontinue therapy: “I just thought that maybe it was time and I wanted to give it a try.” At her next medical appointment, however, her physician responded angrily and Muriel reported that she was told, “Well, we’re done here. . . now you can go back to your own family doctor.” Despite noting that she was “still kind of getting over it,” this participant was introspective about the distressing encounter: “It was like I turned [decision making] over to the doctor and then decided to take it back. And that wasn’t a good thing. You know, just from the way that she reacted to that. And really, I guess I didn’t even – when I decided to go off [HT], I didn’t even think, ‘What would the doctor think about this?’ I thought it was okay making my own decision about that.” In this passage Muriel recognized that when she positioned herself as dependent, she had inadvertently but reciprocally positioned the HP as the primary decision maker. When she made the decision to discontinue HT, she once again positioned herself as autonomous and positioned the HP as a consultant. The physician, however, did not accept this positioning and asserted her biomedical authority by providing an unsolicited prescription: “She actually *gave me* a prescription in case I couldn’t make it, ‘So you can go back on these, so here’s a prescription for when that happens.’” As Muriel reflected on her experiences during menopause and her views of HPs’ roles in heath management, she observed, “I come from a generation where I find it difficult to disagree with the doctor.” Nevertheless, she stated: “I am feeling more and more that I need to advocate for myself. I need to be in charge of my health.”

Muriel’s menopause story, as told in her interview, is what van Langenhove and Harré (1999) call “rhetorical redescription” (21). Muriel did not reiterate everything that was said or occurred; rather, she created a story within the context of the interview. Positions were influenced by encounters with HPs and Muriel’s personal context – her symptom experience, the number of years she was on HT, and information incidentally encountered through interpersonal contacts. While she expressed hesitation about her autonomous positioning (“I find it difficult to disagree with the doctor”), her story illustrated the fluid positioning that many women in the study assumed as they navigated evolving information and health management during the menopause transition.

6.5 Menopause as a socio-cultural construction

Because individuals are embedded in culturally and institutionally bound discourses (Given 2002; Talja 1997), interview data cannot be considered in isolation from the socio-cultural discourses which shape women’s perceptions of menopause and of their own roles as information seekers and decision makers. Participants positioned themselves, consciously and unconsciously, with respect to HPs and health information, and these positionings were both enabled and restricted by social processes and social information (Fuchs 2002). Talja (1999) notes, “Discourses are not individuals’ creation: they have taken their shape with the passage of time, they reflect the whole history of the societal form, and they have effects that no one has consciously intended” (169). Societal discourse has also been described as an “all enveloping . . . fluid shifting medium in which meaning is created and contested” (Taylor 2001, 9). From this perspective, “the language user is not a detached communicator, sending out and receiving information, but is always located, immersed in this medium and struggling to take her or his own social and cultural positioning into account” (Taylor 2001, 9). It is therefore valuable to briefly consider the development of societal discourses related to the menopause transition and to consider the ways in which women in the current study participated in these discourses.

As discussed in section 2.1.1, menopause management has been shaped by uncertainty and change (Bell 1987; Oudshoorn 1990). With the potential to prescribe exogenous hormones, menopause was firmly positioned within a biomedical framework as a endocrine deficiency disease (Bell 1987). This positioning was exploited by Wilson (1966), who introduced the notion that women’s femininity was doomed by the onset of menopause. Biomedical positioning was further established “through a shift towards a discourse of [disease] prevention, and later, a discourse of choice” (Murtagh and Hepworth 2003, 188). Accompanying notions of ‘choice,’ language adopted from the women’s movement, was the presumption that women were “empowered by the doctor” (Murtagh and Hepworth 2003, 196) – a presumption which ironically positioned women as decision makers while HPs retained the biomedical authority required for decision making. While women in the current study experienced menopause against the backdrop of these discourses, the unexpected publication of WHI results dramatically repositioned the menopause transition. Two discourses, which were influenced by the WHI, and which were evident in study participants’ narratives, were discourses related to prevention and discourses related to menopause as a natural life transition (NLT).

Although not all participants were familiar with the WHI, most were familiar with concerns about long-term use of HT (for example, cancer risk) and with the controversial nature of HT. Participants carefully considered their decisions before commencing HT (see section 4.4.2.2) and, consistent with the literature, the decision to commence HT was viewed as a means of temporary relief from symptoms rather than a long-term solution for disease (Hyde et al. 2010a). In other words, interview data illustrated that the discourse of prevention has been transformed from one pertaining to life-long deterrence of diseases such as osteoporosis or heart disease, to one of short-term symptoms control (Kelly et al. 2005; Taylor, MacLennan, and Avery 2006). Furthermore, this newly evolving discourse of *symptom* prevention was juxtaposed with notions of risk – in particular cancer risk. Despite the relatively short time span between the 2002 publication of WHI results and data collection for this current study (2009), interviews demonstrated that the vast majority of women had adopted this new discourse of prevention: almost all discussed HT within the context of short-term symptom relief. In fact, only one participant (Jane) discussed long-term disease prevention and, even for this participant, concern about the detrimental impact of long-term HT use eventually took precedence over concerns about osteoporosis. The almost exclusive focus by participants on HT as short-term symptom control was highlighted by concerns expressed about the duration and dosage of HT. Quotations in section 4.4.2.2 illustrate these particular concerns and demonstrate women's participation in this new discourse of symptom prevention.

With the WHI's repositioning of HT as a short-term symptom management strategy and with the accompanying 'HT as risk' discourse, a 'menopause as NLT' discourse emerged in consumer and medical publications (Genuis 2004a). Although the notion that menopause "is part of everyday life" (Hunter, O'Dea, and Britten 1997, 1546) was highlighted in pre-WHI qualitative studies, the post-WHI NLT discourse, coupled with on-going concerns about symptom management, has been associated with increased attention to complementary and alternative approaches to menopause management (see literature review, section 2.1.2). This was reflected by participants' positioning and attribution of cognitive authority. Section 4.3.2.1, for example, notes that many women concurrently sought information about symptom management from health food stores or alternative practitioners and from HPs; and section 6.1 highlights participants' comfort with initiating the use of over-the-counter and alternative therapies without discussing the decision with HPs. Fuelled by the information revolution, in particular the internet, and post-WHI discourses which focused on HT as risk and menopause as a NLT, participants explicitly positioned themselves as ‘responsible’ for their own health management and ascribed cognitive authority to a range of sources, including HPs.

These findings were supported by interviews with HPs. Sonya’s comments, for example, echoed the current prevention discourse and exemplified the interviewed HPs’ approach to menopause and HT: “[Menopause is] not a disease. . . . We’re potentially treating a symptom. It’s not an illness. It’s not life threatening in a major way.” HPs also reflected the ‘menopause as NLT’ discourse, and their interviews supported the notion that women were ascribing cognitive authority to a range of sources (see chapter 5). Amy’s observation exemplified this latter point: “There are probably very few that come in really not knowing much of anything, you know. I think most have done some of their own research or certainly listened to other women at work and things like that.”

An interesting observation made independently by two HPs suggested that a reconfiguration of the original ‘HT as prevention’ discourse may be emerging: ‘HT as *aging* prevention.’ These HPs noted that some of the bioidentical HT promotion related to a “longevity or aging-well perspective” (Sonya). Denise explained this further: “There’s an element of women going to [bioidentical hormone therapy] and it has nothing to do with being perimenopausal or postmenopausal [i.e. having symptoms]. It’s got everything to do with anti-aging. And that’s a different – different subset. . . . it’s almost like the eyelid, tummy-tuck, Botox group that’s moving into this.” Connie, another HP working with women in the menopause transition, also alluded to this ‘new’ prevention discourse when she observed, “[Women have] heard about bioidentical hormones. And they’ve seen Dr. Phil and they’ve seen Suzanne Somers and this is how they dealt with it, and don’t they look great, and that’s how I want to look and feel and everything else.” It must be noted that the opinions of HPs were mixed with respect to bioidentical HT. While Denise observed this “different subset” of women who were using bioidentical HT, she also noted that this type of therapy met the symptom management needs of some patients. And Renee said, “When I first started practice, we used pork insulin and it was a big deal when we switched to human insulin. It's like wonderful, now we have human insulin! Well, why the heck - my idea was, well, why are we using nonhuman identical - it's the only field of medicine or endocrinology where you don't use human hormones." Other HPs, however, expressed significant concern about bioidentical HT. Yvonne's comments demonstrated both the adversarial positioning which some HPs experienced and the concerns of HPs: "We're really fighting like every day. . . with every patient, I'm talking about what is bioidentical, like what it means, and what we know, what we don't know."

While bioidentical HT may be a new iteration of HT, the potential association between HT and an "aging-well perspective" raises the spectre of Wilson's 1966 assertion that estrogen is the antidote to the "living decay" endured by the post-menopausal woman (43), and is reminiscent of the accompanying notion that, without the benefits of HT, post-menopausal women are not fully women (or 'feminine'). Notions of HT and 'anti-aging' were not raised by women in this sample, although issues related to sexuality were brought forward by a subset of women (for example Anita and Laura) and highlighted as a neglected but needed area of discussion. The discursive construction of 'menopause as a symbol of aging' was seen as a barrier to this discussion: "No one wants to talk about – like sexual health. . . I just think we have to open the closet and start talking about it" (Naomi). Women in the sample did demonstrate ambivalence towards aging (they referenced menopause as a symbol of aging but did not identify with this discursive construction, see section 4.3.1.2). Nicole's comments highlighted this ambivalence. This participant noted the impact of aging ("there are just some days and I look at my face and I feel like I look really old and I don't like what I see in the mirror. And there are other days when that's not an issue"), but focused on the developmental aspects of menopause and compared this life stage to adolescence:

> And what I liken [menopause] to is a second adolescence in one sense. Because, like in teenagerhood, your body isn't behaving the way it used to and it's not under your control. Like you're having to learn to listen and adapt, but there are all kinds of things that are just way out of sync. And

> that's just the way it's going to be. Your roles in society are all shifting and changing. . . . For me this has just been a huge invitation.

The majority of women in the sample, however, focused on health as a holistic endeavour and positioned themselves as proactive managers of the aging process. Cherri's comments were representative: "I remembered that you lose a certain percentage [of muscular strength] every year after that age of 30. I can't remember what the percentage is. And I decided I want to reverse that. So that's why I'm doing this fitness program" (Cherri).

While social positioning theory provided a lens for exploring the ways in which women navigated changing information about the menopause transition, exploration of socio-cultural discourses provides a view of the broader context which shaped women's perceptions of menopause and of their own roles as information seekers and decision makers. This broader perspective illuminates the influence of the WHI on individuals' health information behaviour and on the ways in which women exercised personal agency when navigating uncertain health information.

6.6 Implications for shared decision making

Exploration of participants' autonomous, collaborative and dependent positioning, and of the socio-cultural discourses which shaped women's positions, suggests that findings from this study have implications for SDM. Concerns about the balance of power between HPs and patients during the clinical decision making process have been extensively discussed in the health care literature and SDM has emerged as a widely used phrase which carries with it the connotation of active involvement by both HPs and patients in the decision making process. While a systematic review of the literature indicates that the definition and use of this phrase remains a critical problem (Moumjid et al. 2007), SDM has come to represent a mid point between *paternalistic* and *informed choice* models of decision making (Elwyn, Edwards, and Kinnersley 1999). In the former, patients provide consent for treatments advocated by physicians; whereas in the latter, information is transferred from the HP to the patient, thus enabling independent decision making (Charles, Gafni, and Whelan 1997; Elwyn, Edwards, and Kinnersley 1999). SDM, on the other hand, is characterized by a patient and HP who are "involved in the process of treatment decision making; they share all relevant information and both agree with the final decision" (Müller-Engelmann et al. 2010, n.p.).

The prevalent trend towards SDM between HPs and patients has been shaped by societal discourses related to human 'rights'– particularly women's rights, patients' rights, and consumer rights (Rothman 2001; Tomes 2007). While discussions of women's rights have had particular impact in the areas of obstetrics and gynecology, increasing awareness of patients' and consumers' rights have discursively constructed notions of autonomy and control as they relate to relationships between HPs and patients (Charles, Gafni, and Whelan 1997). As a result, SDM has become embedded in notions of a *patient-centred care* (Elwyn, Edwards, and Kinnersley 1999), a construct which has, very recently, been identified by the Canadian Medical Association (CMA) as one of five pillars of their 2010 'Health Care Transformation Plan.' In this document, the "essential principle" of patient-centred care is defined as health care services which "are provided in a manner that works best for patients" (CMA 2010, 8). Later in this CMA document, this principle is interpreted in a manner similar to SDM's presentation in the literature (*cf*. Charles, Gafni, and Whelan 1997; Moumjid et al. 2007), that is, decision making is described as follows: "patients participate actively with providers in decisions about their medical care and treatment" (CMA 2010, 9). In addition to this general endorsement of SDM, this model has been identified as being particularly suitable within contexts of chronic illness, and within contexts of uncertainty (*cf*. Müller-Engelmann et al. 2010; Salkovskis and Rees 2004), such as the management of menopause (Légaré and Brouillette 2009; Murtagh and Hepworth 2003).

In the current study, women's discursive constructions of autonomy, collaboration, and dependence occurred within the context of information behaviours, including health decision making. Parallels can be drawn between these positions and the range of decision making models discussed in the previous paragraphs (see table 6.1).

Table 6.1 Positioning and decision making models

Positions identified by women	**Decision making models**
Autonomous ……………………..	Informed choice decision making
Collaborative ……………........	Shared decision making
Dependent ………………………..	Paternalistic decision making

Women who positioned themselves as autonomous decision makers presumed personal responsibility and viewed HPs as consultants or guides who provided formal health information, which participants then utilized in the decision making process (section 6.1). Most participants valued the information provided by HPs, but situated this formal health information within a complex information world which included intra- and inter-personal information, information from internet sources and information gathered from or encountered in the media (see chapter 5). While Henwood et al. (2003) note that the ‘informed patient discourse’ can be limited because consumer health information constitutes one-way information provision from HPs to patients, findings from this study suggest that women who positioned themselves as autonomous information seekers and decision makers tended to utilize information from multiple sources (see section 4.2.2). Not only did women move fluidly between information sources, but they did not necessarily differentiate between formal and informal sources. They were thus empowered not just by information from HPs, but by a plethora of information sources, perhaps most significantly by the internet. Paula, for example, regularly gathered information from her physician but sought further input from the internet or library before making a decision about health management. Furthermore, this participant used both established consumer health information websites and “testimonials from individuals that have been impacted by that medication or by that herb that they’re using.” While women who positioned themselves as autonomous decision makers had a range of experiences with HPs (some only consulted HPs occasionally, while others sought and valued information provided by HPs), these participants viewed themselves as active information gatherers who were responsible for health decision making in the area of menopause management.

Collaborative positioning was most similar to SDM. Although resembling autonomous positioning in its appreciation for different types of knowledge, collaborative decision making highlighted two-way sharing between women and HPs (see section 6.2). Similar to SDM as described in the literature (Moumjid et al. 2007), participants who positioned themselves as collaborative decision makers frequently viewed their own contribution as being related to personal experience, characteristics and context, and they looked to HPs for biomedical expertise. In contrast to discussions of SDM in the literature, discussions which focused on “transferring technical information, making sure patients understand this information, [and] helping patients base their preference on the best evidence” (Légaré and Brouillette 2009, 170), participants who positioned themselves as collaborators in this study emphasized the importance of HPs who were willing to listen to their patients, who engaged in conversation as opposed to focusing exclusively on biomedical authority, and who were open to hearing about other sources of information.

Only a small number of participants positioned themselves as dependent information seekers and decision makers, thus adopting what has been called a ‘paternalistic’ decision making model (Elwyn, Edwards, and Kinnersley 1999). This positioning was most commonly made evident by indirect positioning or was adopted for a finite period of time (see section 6.3). For most women who explicitly adopted a decision making structure wherein they provided consent for treatments advocated by HPs, this dependent positioning was based on trust (see section 5.1.1) which women established with particular HPs.

Just as socio-cultural discourses have shaped the trend towards SDM, these same discourses have discredited dependent positioning and paternalistic decision making in health care. The discursive construction of patients’ rights has brought issues of patient choice to the foreground of medical encounters and the “former paternalistic way of doctors deciding what was best for their patients” has been replaced by the discursive construction of the HP as an enabler of patient choice (Hvas and Gannik 2008b, 190). The notion that paternalistic decision making is outdated was demonstrated by the CMA's recent and very public focus on patient-centred care (CMA 2010). This notion was also supported by interviewed health professionals who, in their explicit discussion of decision making, distanced themselves from paternalistic models focused on the notion of enabling women's choices. Sonya, for example, stated, "It's really about the options, so that [women] understand that there's a range of options [they] can choose." Despite the overt movement away from paternalistic decision making models and the focus on patient choice, HPs in the sample primarily focused on options which were provided within the context of a patient – HP interaction and were leery of the influence of the informal and media information sources on women's decision making. Clare, for example, stated, "I try to caution people and say, 'the newspapers aren't necessarily interested in providing health information. They're interested in selling their newspaper and in catchy stories.'" And Amy noted that when women gathered information about treatment options prior to consulting HPs, "Then we have to sort of try to take things a step back and sort of re-explain and maybe sort of help them to see the truth in some of the messages but some of the things maybe that aren't where we're coming from." These quotations highlight a dilemma which Charles, Gafni and Whelan (1997) noted in their often quoted paper on SDM: while shared participation in decision making may be an important goal, "the specifics of what this really means in terms of input by both physician and patient is left unclear" (686).

Consideration of participants' positioning through the lens of decision making models described in the health literature suggested that although women tended to position themselves as autonomous decision makers, many not only valued information from HPs, but at some point during their information search they specifically sought information from formal information sources. And, despite women explicitly positioning themselves as responsible for decision making, data demonstrated that HPs were valued sources of information for most women and were specifically appreciated in certain contexts – for example, women tended to refer to HPs when confronted with conflicting health information during the elicitation portion of the interview (see section 5.1.1). While these findings draw attention to a SDM approach, women in the current study engaged in information behaviours which extended well beyond the patient – HP relationship. They were informed and empowered by a wide range of sources and drew on both biomedical and NLT interpretive repertoires as they constructed their experiences of the menopause transition (see section 4.3.2.1) and made decisions about menopause management. Furthermore, Rothman aptly noted in 2001 that although consumers had achieved significant involvement in treatment decisions by the 1990s, the influence of consumers over health management would be critically extended by the "extraordinary information revolution which we are now experiencing" (259). He noted that the balance of power between HPs and women has shifted "not so much because of lawyers, but because of webmasters" (260). Analysis of data demonstrated that this was the case: every woman in the study identified the internet as an important source of health information (see section 4.2.2), and online information sources made rich contributions to women's knowledge of their health management and influenced their decision making (see section 5.4.1).

Interview data therefore suggested that although women moved between positions and between decision making models, their preferred approach fell between SDM, a model which proposes that HPs and women "reach a common agreement on the decision to implement" (Moumjid et al. 2007, 541), and the informed choice model. Most participants valued information from, advice given, and two-information exchange with HPs; however, they also valued information from other sources and perceived that they were making their own decisions with respect to navigating menopause information and managing this life transition. Dale's comment exemplified this decision making stance: "I was in control of the plan. . . they provided the options, the information, the tools I needed. The kit. And I was the one that manipulated the tools." While the informed choice model is represented in the literature as a knowledge transfer model where information is 'downloaded' from the HP to the patient "who then has the knowledge and preference necessary to make a decision" (Moumjid et al. 2007, 541), data from this study suggested that this was a more complex process. Women not only gathered information from multiple formal and informal sources, they also integrated and interpreted their multifaceted information worlds within the context of intra-personal knowledge and personal contexts in order to make decisions about menopause management - a model which is more similar to knowledge translation than to knowledge transfer.

6.7 Conclusion

This chapter explored how interviewed women positioned themselves when encountering, seeking and exchanging health information related to the menopause transition. Social positioning theory provided a lens for exploring these dynamic aspects of information encounters and revealed that interviewed women tended to assume three positions as information seekers and/or decision makers: autonomous, collaborative or dependent. Positioning was dynamic and was influenced by the nature and quality of interactions with HPs, and women's personal contexts. In the next chapter attention turns to the fourth and final research question as women's construction of uncertain health information related to the menopause transition is investigated.

CHAPTER 7

WOMEN'S CONSTRUCTION OF EVOLVING HEALTH INFORMATION

The translation of knowledge into practice has been identified as an active process in which understanding is constructed from encountered information, research knowledge, existing knowledge structures, personal experience, reflection, negotiation of meaning and sociocultural environments (Gherardi 2006; Talja, Tuominen, and Savolainen 2005). The notion of knowledge translation (KT) as a process moves beyond more static notions of evidence-based practice (EBP) (see section 2.4) and provides a framework for exploring information behaviours (IBs) in situations of evolving health information. Informed by the view that health knowledge is a 'work in progress' which is provisional, emergent and incomplete (Upshur 2001), and by research suggesting that principles of shared decision making (SDM) are particularly applicable in situations of medical uncertainty (Légaré and Brouillette 2009; Müller-Engelmann et al. 2010), it is valuable to seek deeper, more contextualized insight into the construction of evolving health information by women who are navigating changing information about the management of the menopause transition.

In this chapter participants' responses to health information as provisional and to encounters with uncertain health information are illuminated through exploration of perceptions of health information as a circular phenomenon, responses to changing health information, and the relationship between uncertainty and personal health management. Women's responses to the elicitation articles are explored, as well as participants' experiences and understanding of 'evidence.' Finally, consideration is given to how women make sense of and potentially use uncertain health information. This final section focuses on women's 'postures' as they make sense of uncertain and sometimes conflicting health information, source complementarity, social contexts for learning, and making sense through narrative accounts.

7.1 Health information as a provisional, emergent and incomplete

Given the explicit recruitment goals of this qualitative study (to interview women who had been or were navigating changing information about the menopause transition), as well as the guiding questions used in interviews, it is not surprising that study participants explicitly acknowledged, reflected on, and discussed the evolving and uncertain nature of menopause-related health information. Furthermore, interview transcripts confirm that ongoing media coverage of both controversies and developments related to menopause management, partnered with participants' personal experiences of this life transition, heightened women's familiarity with the notion of health information as uncertain and incomplete. Three prominent themes related to the provisional nature of health information emerged from analyses of interview transcripts. (1) Uncertainty provoked a view of health information as a circular as opposed to emergent phenomenon. (2) Evolving health information generated feelings of uncertainty and scepticism with respect to medical information, but encouraged women to adopt a range of responses to uncertain health information. And, (3) the lack of certainty with respect to menopause information galvanized women to take responsibility for making sense of evolving health information, including the evaluation of health information and risk assessment.

7.1.1 Health information: A circular phenomenon

Analyses of interview data revealed that whereas researchers may view evolving health knowledge as forward moving or emergent, women tended to view recommendations arising from medical research as somewhat circular, arbitrary, and potentially contradictory. Women spontaneously compared the HT debate to other health 'stories' in the popular press and drew on these everyday information encounters as well as on their personal experience in order to chronicle 'flip flops' of expert opinion. Jane, for example, explained, "Like cholesterol and oat bran, and butter and margarine. What's good one day is poor the next. You know – highly recommended poison." Later in the interview Jane noted the consequence of this perception: "For some people they would just do it like cholesterol. It's come and it's gone, and it's come again. You know it's – I think you tend to just disregard all that." Other women also pointed to examples of 'flip flops' emerging from medical research. Sylvia was not alone in noting changing recommendations with respect to both red wine and butter: "Okay, for a while there, a glass of red wine was good. Now they're saying maybe not. . . . Don't eat butter. Now they're saying, 'Nothing wrong with butter.' So it's just like – ahhhh." And Paula noted changes related to milk consumption: "It's like how milk was good for all of us. Now all of a sudden too much milk is not good."

The perception that there is a capricious quality to health information led participants to assign responsibility for potential unreliability to either the media or to sources of formal health information. Nicole's observations illustrate the notion that responsibility rests with the media:

> I mean, this is typical of science and media's relation to science. That's what I would say. Because every time some scientist somewhere says something, the media pounces on it and it's the next best thing. And then whenever somebody else discounts, disproves, calls it into question – the media pounces on it and tells everybody, 'Whoops! Go the other way.' And it just keeps going back and forth.

While research suggests that conflicting information in the media leads to a lack of confidence in and even suspicion towards media-relayed information (Cozzens and Contractor 1987), participants were also likely to view formal sources of medical knowledge, such as health research itself, as arbitrary. Sue's comments exemplify this scepticism: "It's like, is coffee good for you or bad for you? You know, yeah yeah, and you get a study done and then you get a study against it." Other participants assigned responsibility for change and upheaval in treatment approaches to HPs: Gwen noted a perceived about-face in education about fruit consumption for diabetics, "There's been a shift in the thinking in two years." And Cherri noted, "They've almost reversed the protocol for treating asthma in crisis."

The perception of health information as a "back and forth"(Naomi) rather than forward moving phenomenon is demonstrated not only by the narrative accounts of women, it is reinforced by respected lay publications such as *Consumer Reports*. For example, an article titled “New research overturns 10 health ‘truths’” highlights a number of widely accepted ‘truths’ within conventional medical practice and then notes, “Every one of those beliefs and practices turned out to be wrong. Other medical treatments, once equally discredited, proved useful after all” (2006, 2). While it might be argued that the mandate of consumer publications is to respond to and report on current events and recent developments, thus perhaps inevitably reinforcing perceptions of circular rather than evolutionary progress, some HPs also represented changes in practice related to menopause management as a “pendulum kind of going back and forth” (Denise). Sonya noted that ever since the first results of the Women’s Health Initiative study (WHI) were published in 2002 practice has begun moving back towards some pre-WHI prescribing practices, for example, the prescribing of HT for more than the currently recommended 5 year maximum. “Research is really coming out sort of validating that the cardiovascular risks aren’t as great if you’re using it within ten years of your last [menstrual period].” Sonya did, however, view the WHI as having progressive elements; she reported that prior to the WHI menopausal women were likely being over-treated with HT, whereas “understanding has really evolved” subsequent to the publication of WHI results. The majority of HPs did, in fact, view health information as provisional and medical research as a vehicle for moving medical knowledge forward. Mark, for example, noted the forward momentum of medical knowledge: “The assumptions that we made for a long time were just not right.” Interviewed HPs also noted that notions of health information as provisional and emergent had personal application. Renee said, “I’m evolving too. I mean, right now I have my certain way of doing it and I’m pretty sure that a year from now it will be slightly different.”

7.1.2 Women’s responses to changing health information

Women participating in this study tended to view changing health information as a source of uncertainty. “Because everything is good one day; it’s not so good the next day. So yeah, it’s confusing that way” (Hazel). Participants used a range of words and phrases to describe their experiences with changing health information. Examples include, “frustrating” (Laura), and “It would put a question mark in your mind. Definitely” (Gwen). Jill expanded on this theme:

> It’s sad, because it throws the consumer – into a non-trust kind of mode. They say, ‘Hey, they don’t know nothing.’ So therefore they tend to go in[to] nonchalant behaviour about their health. Like, ‘Oh yeah, everything leads to cancer.’. . . . And also I can see where people would go not-trusting and therefore sometimes [don’t] take care of their health as much as they should.

For many women, the view that health information is cyclic and even contradictory provoked scepticism. Naomi, for example, commented, “There have been so many studies that have gone circular and they’ll come back and find the first study was inaccurate that I’m very sceptical.” And Paula noted, “Depending on the research that’s been done, things may have changed, but it makes me more sceptical the first time around.”

While uncertainty and scepticism about evolving health information as it is presented to consumers was a predominant theme, women noted specific strategies which they used when making choices in identified areas of uncertainty. Some women spoke of ignoring conflicting information: “I guess maybe if we hear too much of the conflicting whatever, we just kind of put the blinders on and say, ‘Enough’” (Camille). While others suggested a ‘wait and see’ approach: “I’ve seen – read so many things that have come full circle, I’m not one to go in and jump on it” (Naomi). Jane articulated a very specific and cautious strategy: “Well, I’ll stay the course and give it a year. Cause that’s sort of a technique, to not be the first to change but don’t be the last to change.” For some participants, however, conflicting health information suggested possibilities for change and provided hope in the face of inadequately resolved symptoms. Both Camille and Anita, for example, were struggling to find appropriate treatment for severe symptoms. Camille commented, “There’s always the capacity for things to change. Like there could be a study being done right now and the results come out tomorrow.” And after taking part in the elicitation portion of the interview, Anita observed, “I think that there will always be conflicting results when they are researching something. And that doesn’t necessarily mean that there’s no answers, there’s nothing to – maybe not now, but we will have something in the future, I hope.” It is interesting to note, however, that after Anita’s caveat, “I hope,” she went on to demonstrate her lack of confidence in the health information she based her decision on: “I’m not sure [Vitamin D is] really helping me. I don’t know. I just pray not to get breast cancer.”

While confusion following the 2002 publication of WHI results has been documented in the literature (see section 2.1.4), findings from this study indicate that uncertainty experienced as a result of evolving health information was ongoing at the time of data collection. This was confirmed by the interviewed HPs. “The problem is that another book will have conflicting information. So there’s a lot of different information out there. And really, it’s quite confusing” (Wanda). Furthermore, HPs acknowledged that evolving information about the management of the menopause transition is confusing not only to women, but to HPs as well. Yvonne highlighted the uncertainty experienced by HPs in the immediate wake of the WHI: “There was nothing directing [i.e. not practice standards]. What are you supposed to do?” And Mark’s comments, made seven years after the first publication of WHI results, demonstrate ongoing astonishment about the challenge this study presented to HPs: “It was so drastically *different* from what we thought and [how] we were trained. . . . It’s pretty shocking information. It’s just completely against all of our previous thoughts about hormone replacement.”

7.1.3 Uncertainty and personal responsibility for health management

As discussed in section 4.4.1.4, participants were active information seekers in response to uncertainty about menopause as a life stage, and this information seeking represented the beginning of an ongoing process as women explored information about the menopause management, including the use of HT (section 4.4.2). A particularly prominent theme, which became apparent as women expressed their reactions to overtly changing health information, was that actual or perceived upheavals in conventional medical knowledge increased women's feelings of responsibility not only for their own health and well-being, but also for making sense of uncertain and/or conflicting health information. The following two quotations exemplify this theme: "[Conflicting health information] encourages me to keep looking to find additional information and maybe clarify the information" (Dale); and, "There's always new information coming about everything. There's pros and cons. . . . So it's hard to believe everything that's out there. So I would certainly explore it more before I would fully trust it" (Hazel). While uncertainty increased participants' feeling of responsibility for making sense of changing health information, it should be noted that for some participants feelings of responsibility were accompanied by ambivalence: autonomous positioning was accompanied by a wish for more explicit guidance from health professionals (see section 6.1).

The notion of consumer responsibility in situations of uncertainty was confirmed by HPs. Denise noted that, particularly following the WHI, women took responsibility for their decisions: "What was fascinating – there was a lot of that [which] was driven by the public. Like, first time in my practice where they came in saying, 'I *don't* want to be on anything right now.' And that was really interesting because some of those women, I think, were not on a bad balance of HRT." Gail's comments, which emphasize women's responsibilities in the current situation of uncertainty with respect to symptom management, were representative of other interviewed HPs: "[Women] really have to understand that whatever they choose is trial and error." The literature also supports the notion that in situations of medical uncertainty, HPs are more likely to expect consumers to take active responsibility within the context of SDM (Salkovskis and Rees 2004). And Archer (2007) even goes so far as to suggest, "The dynamics of the marketplace in 2006 indicate that many physicians would prefer that the consumer make the final decision as to what is appropriate in terms of hormone therapy" (30).

7.2 Response to elicitation articles

Elicitation techniques have not received significant attention in the literature. Although this may be because they are left unidentified or differently identified (Vardeman and Aldoory 2008), this study suggests that presentation of specific material which "seeks to elicit further or to reelicit properties, features, or reactions that are directly and /or indirectly relevant to the content area" (Johnson and Weller, 2002, 495) is a useful technique for revealing women's understandings of uncertain health information presented in the popular press. The use of articles, which presented contrasting perspectives, allowed data analyses based on women's in-the-moment experience of uncertainty, thus generating data which augmented participants' narrative accounts.

When confronted by conflicting health information in the form of media published articles, women primarily viewed the articles as a part of bigger world of health knowledge communication, and women drew on their multifaceted information worlds as they responded to the presented information. The majority of women did not, within the context of the interviews, come to specific conclusions about the elicitation material; however, they situated their uncertainty within the larger world of health information through their consideration of possible source material for the articles, including questions about funding for the studies. They furthermore sought to bridge perceived information gaps by discussing potential or theoretical behavioural intentions with respect to the content of the articles.

A small number of women discussed the elicitation articles without reference to the origins of the information (i.e. the source research studies which were identified within the articles); however most women demonstrated through their observations and comments that they were aware that the information in the articles was presented by, but did not originate from, the media. Cherri, for example, observed that the information in the first articles sounded “reasonable” based on the fact that identifying information was provided (for example, the name of the researcher), which would allow her to “look at the study and read it myself.” And Pat explicitly noted that the “CBC is a news reporting agency, not a study evaluator.” This participant concluded that, in fact, one could not be certain that all relevant details of the study had been reported. Participants also noted potential commercial influences associated with information creation and distribution, thus alluding to the larger context of media-mediated health information and the challenges individuals face when making sense of that information. This is exemplified by the following quotations: “Probably my first question would be who sponsored the study” (Beverly); “What are the politics behind this [the publication of contrasting study results]?” (Lisa); and Muriel wondered if the information was being promoted in the media because “we want you all to run out and buy Vitamin D.”

By situating published health information within a larger context, responses to the elicitation articles draws attention to the complex information worlds women inhabit and access as they make sense of uncertain health information. While section 5.1.1 highlights participants’ tendency to look to HPs as authorities who might play a role in helping them make sense of uncertain medical information encountered in elicitation articles, close reading of interview transcripts demonstrates that women construct ‘sense’ by seeking to clarify conflicting information through interaction with a range of other sources as well. Hazel, for example, stated: “I would have to find out more about it before I would trust the study. . . .probably Google and see. Check out more what others have to say.” Women described consultation with a variety of sources, including intra-personal sources. The following statements provide examples of the sources women noted: “I’d do more checking on this. I’d go to the internet. I’d talk to my doctor” (Paula); “I’d probably talk to my mom about it” (Camille); Jill suggested that it was important to “listen to your own body”; and Sylvia said that she would alter her intake of Vitamin D “if it makes sense to me.” While these comments do not speak to the credibility or influence of the media on behaviour, they support the notion of the media as an awareness tool (see section 5.5.1) and demonstrate that for these participants, the construction of uncertain health information is situated within the context of a multifaceted information world.

Analyses suggest that women's experience with evolving menopause information may have provided context which influenced participants' subsequent construction of uncertain health information. Roslyn, for example, noted that prior to her experience during the menopause transition she would not have paid attention to or read articles such as those presented during the elicitation portion of the interview. Her experience with menopause, however, altered her approach to health information: "I would read it really carefully and try to pull out what's important and what they're actually saying. . . .I tend to look at things like this differently now because the Women's Health Initiative." Sue also explicitly acknowledged the influence of the WHI on her approach to media-mediated health information:

> Because when the study came out in the early part of – the 2002 – the HRT studies, they said, 'Linked to breast cancer, heart, all that.' I didn't question it. I didn't question it at all and I took it at face value. So that's when I stopped [HT] and everything. And then when I went to the Menopause Clinic and I talked to the doctor, like my main thing was HRT. Question mark. Exclamation point. Like what is this? Tell me about it. And then when she told me what the studies . . . .like there was more to it than what you heard. That – after that, I started questioning studies because I thought, well, maybe we're not getting all the information. Or maybe there's more to this.

7.3 Women's experience with and understanding of 'evidence'

Since the 'birth' of EBP with its emphasis on the 'hierarchy of evidence' (see section 2.4.1) and Sackett et al.'s refining of EBP as "the integration of best research evidence with clinical expertise and patient values" (2000, 1), much thought has been given to the complexity of 'evidence.' The field of KT and particularly the PARIHS framework takes notions of evidence another step forward by drawing attention to an evidence spectrum which incorporates research, experiential, social and tacit aspects of evidence (see section 2.5.1).

Given the complex and sometimes contested nature of this construct within the health literature, it is not surprising that interviews with women and HPs suggest a nuanced and varied understanding of evidence.

It is valuable to briefly consider a generic definition for *evidence* before considering notions of evidence which emerged from interview data. The Oxford English Dictionary provides the following definitions for evidence: “Testimony or facts tending to prove or disprove any conclusion,” and, “Information, whether in the form of personal testimony, the language of documents, or the production of material objects, that is given in a legal investigation, to establish the fact or point in question” (OED Online 2010). These definitions suggests that evidence is a core concept when establishing factual substance, that evidence may be used to support or dispute contentions brought forward by various representatives, and that it is something which may be held in contention. Moreover, this definition suggests that evidence is something which is *constructed* from a range of inputs, for example, witnesses, documents, or objects. This view varies from the perspective commonly put forward within health fields, where evidence is frequently associated with a positivistic entity which can be empirically documented and which can then be used to guide the messy real-world business of practice.

While interviewed women rarely used the word ‘evidence,’ their construction of uncertain health information (i.e. how they made sense of and potentially used uncertain and evolving information related to the menopause transition) was integrally related to how they identified and assigned value to notions of evidence. Data suggest that women’s construction and understanding of menopause-related information was influenced by their construction of evidence as research, as material object, as negotiated belief or opinion, and as lived experience.

7.3.1 Evidence as research

Evidence is commonly conceived by HPs and other professionals as emerging from empirical research, expressed in peer-review published articles, compiled in and strengthened by systematic reviews, and interpreted for practitioners in documents such as practice guidelines. Although understanding of empirical research varied among interviewed women, the majority were aware that research studies have potentially important implications for health management and decision making. (This notion was specifically made available for discussion through the introduction of the elicitation articles, which indicated empirical origins within the texts.) Perhaps not surprisingly, given the context of the interviews, analysis of transcripts indicates that a primary theme emerging from women's discussions is the notion of research studies as contested ground. Participants focused on the quality of research studies, including problems related to research application and potential conflicts of interest, and the reporting of research results.

As women talked about health information, discussed research relevant to the menopause transition, and interacted with the elicitation articles, many raised questions related to research quality. Although a few participants were positive in their discussions of research-derived evidence (Faye, for example, carefully perused one of the elicitation articles and noted, "It seems like a pretty reliable study, and well defined and put together. I would take it seriously;" and Cherri related that in a situation of uncertainty she would ask a HP to "point me to clinical research studies. So I would read them up, read them myself"), most of the participants focused on questions with respect to the reliability of research evidence and used their questions to distance themselves from immediate application of findings. Muriel exemplified this perspective:

> I have to say that I'm very, very sceptical about the latest new study showing this or showing that, because, I know from [my previous employment]. And just the numbers of people that you need to have a study with any kind of weight at all. So when I see an article that says they have a study and they don't tell you all that information or they say, 'We

> interviewed a thousand women.’ And I’m going, ‘That’s a drop in the bucket. You really haven’t got any information there.’”

The size of a given study stimulated many comments from women: “It does say over here it was a small study to begin with. So they would have to do more research to be sure of that” (Hazel); and Vicky noted, “Thirty-six *thousand* women compared to 50. I would end up taking a little closer look. But again, I don’t see how my calcium and Vitamin C hurt me while I was taking them, because I was taking them from natural sources.” While the latter two quotations were contrasting in that Hazel drew attention to the study being “small” and Vicky was astonished by the large size of one study, in both cases the women followed their observations by distancing themselves from consideration of how the information might influence personal health management. In addition to exhibiting qualified response to research on the basis of research quality, information attributed to studies was also contested based on its application to individual women. Jane’s comment exemplified this concern: “You kind of look at [studies published in the newspaper] and you go, ‘Well. Is that true for her or is it not?’ From what I know about evidence based, it’s gotta be – the population they’re talking about has got to match who you’re talking to.”

A second theme, which is related to research quality, was concern about potential conflicts of interest. The following quotations demonstrate this theme: “Like how do I know who wrote these articles? Like are they doctors?” (Gwen); “You look who does the study. If it’s the drug companies then I’m thinking [makes hand gesture indicating uncertainty]” (Joyce); and, “Yeah, this double blind, placebo controlled blah blah blah – Okay, who did the test? Who sponsored it?” (Lisa). Although potential divergence between the goals of medicine and the goals of industry is an ongoing topic of interest in the medical literature, studies related to consumer perception and concern with respect to this potential conflict are limited. A recent Australian study, however, found that consumers value information about the interactions between pharmaceutical manufacturers and physicians and report that they would use that information to choose health providers and guide decision making (Edwards and Ballantyne 2009). Findings from this study suggest that participants who were navigating information related to the menopause transition were aware of and concerned about the potential influence of industry. Awareness may have been heightened by participants' specific interest in menopause information and the extensive media coverage of conflicting studies about this life transition. As was the case with concern about research quality, however, participants' concerns about potential conflicts of interest provided a discursive means of qualifying responses to the research studies encountered within the context of everyday life.

Another prominent theme emerging from the data was women's concerns about the reporting of research findings. Roslyn, for example, said, "I also realize that how things are reported is important too. . . . So yeah, I would read it really carefully and try to pull out what's important and what they're actually saying." Pat expressed concern that news articles reporting on research might represent "just a little excerpt that somebody pulled out of, you know, out of context." Pat explained that if she was interested in a given topic she might carefully examine the media articles in order to determine is if sources were appropriately cross referenced and if the "objects of the study" were accurately represented. In both of these examples, the participants expressed responsibility for close examination in order to make sense of the media articles. Nicole drew on her educational background when she stated, "I think I know, perhaps more than many readers, about how science really works. . . . And that a lot of stuff isn't as definitive as the newspapers would like to make it."

Although concerns about research quality, conflicts of interest, and the reporting of research findings emerged as prominent themes, expressions of concern were vague and were primarily constructed by participants as justification for distancing themselves from presented information. Despite the fact that this group of women were on average better educated than the typical Canadian woman (as indicated by 2006 census data) (E-Stat 2006), findings do raise questions about participants' abilities to process and use research evidence which is represented in the consumer press. Concern about media-representation of scientific research has, in fact, been discussed in the scientific literature (*cf.*

Marin, Delgado, and Tironi 2010; Woloshin, Schwartz, and Kramer 2009). Scholars note the shortcomings of media communicated health information, the media’s positive potential for consumer health education, and the ways in which the medical community “should take more responsibility to help make straightforward medical reporting a reality” (Schwartz and Woloshin 2004, 227). Women’s tendency to distance themselves from the research evidence is perhaps understandable given that the research most commonly discussed by participants was provided through the media (it was, in many cases, the elicitation materials that provoked discussion of the media and research presentation). As demonstrated by women’s reactions to the elicitation articles (see section 7.2), however, women also responded to contested research evidence by seeking further information.

Research evidence which was presented by HPs was valued, although women did not necessarily identify this information as research (within the context of the interviews I could only assume that material provided by HPs was research based). For example, Laura noted that her physician gave her “written material to read. . . .I would say it’s not pamphlets. A lot of it is like – just loose-leaf papers that she’s printed off herself I think.” And Thea related, “Some of [the HPs] were giving me more information than I got ever. Giving me information that has been researched.” A few women (for example, Christy and Naomi) explicitly referred to occasions when HPs directed them towards research evidence in the form of medical journals or articles. In these cases, women were appreciative of the HP recommendation of research evidence. Nicole, for example, related that when her physician provided her with information from a medical text she thought, “‘Okay. This is somebody I relate to, this is somebody I have respect for.” This suggests that women are more likely to appreciate research evidence when HPs act as facilitators for that evidence (see also section 4.2.2.2). These findings also suggest that women would be empowered by a basic understanding of research methods as it would allow them to interact constructively with both media-mediated health information and health information from HPs.

Although HPs’ understanding of health information as provisional (see section 7.1.1) alludes to the potentially contested nature of research evidence, interviews with this sample of professionals primarily support the notion of evidence as research. HPs tended use the notion of research evidence as a warrant for the factual nature of formal health information (see section 6.2). Erin, for example, explained: “I’ll give information as far as what supplements kind of have some backing and what ones really don’t have the evidence to show that they’re beneficial.” And Francis described a encounter with a patient: “I say [to the patient], ‘This is what I learned in medicine and this is what the research is telling me. . .the evidence-based medicine. So that obviously is very much different from your belief.’” By juxtaposing “evidence” derived from medical education and the patient’s “belief,” evidence is clearly positioned as factual, while doubt is cast on the patient’s perspective.

7.3.2 Evidence as material object

While evidence in health fields is frequently conceived as *research* evidence, the dictionary definition provided in section 7.3 notes that evidence may also consist of proof provided through “material objects.” This idea is supported by an article published in *Communication and Medicine*, which introduces the idea that evidence may be medical representations (e.g. test results) or artifacts (e.g. x-rays). These material objects take meaning as “practical evidence” through a process of discursive construction by practitioners (Maseide 2006, 44). This notion is supported by Gherardi (2006) who contends that knowledge is a constructed process that is based on research and experiential evidence as well as on reflection, negotiation of meaning, situational factors, and material artifacts.

Although material objects were not primary sources of evidence for interviewed women, it is worth noting that manifestations or evidence of physical reality was important to women, particularly because of uncertainties associated with the course of menopause (see section 4.4.1) and the experience of menopause symptoms (see section 4.3.2.1). For participants, the use of medical representations (for example, hormone level testing or bone density tests) was not just a question of reading the results; rather, meaning and practical use was based on the individual, their circumstances, and the construction of their needs. Meaning was created from the objects by women and between women and others (primarily HPs) as they talked about the material object. Lillian relates an incident which exemplifies this form of evidence: [The HP] said, ‘You have to take Lipitor for the rest of your life.’ You know, just like that, as if he were god. I know he isn’t. And I said, ‘Well, I’m taking Red Yeast Rice.’ And he said, ‘Well, that needs more study. We need the facts.’ I said, ‘The facts are that my cholesterol came down from 9 to 5.2.’” In this situation Lillian was objecting not only to the notion of life-long medication, but also to the manner of the HP. She used a concrete test result (her cholesterol level) to reposition herself as someone in possession of the ‘facts,’ and therefore as someone with the right and capacity to choose her own treatment – in this case she was trying a product from a trusted health food store.

A more common type of material evidence for interviewed women was provided by hormone level testing. Muriel used the results of hormone testing to establish the validity of her menopause symptoms, and, moreover, to discursively re-situate herself as a biomedical authority, a position which her physician previously presumed (see section 6.4.3). Dana also referred to hormone testing as a form of material evidence: “I did play that game of going to health food stores and taking different things and stuff like that. . . . But I guess I prefer having been tested and knowing exactly what my levels are. And I really have a lot of relief in not playing that guessing game any more.” And Sue, who had engaged in a long personal search for appropriate menopause management, suggested that appropriate concrete evidence in the form of comprehensive hormone testing would provide an environment where women could develop trust for medical information and for HPs:

> I think if they would have said they would have done all the tests and see[n] where all my hormones were, not just estrogen and progesterone, but every other hormone that you have, and what levels they’re at, what

> this is doing, what this isn’t doing because you need to up this one to bring you to a certain level – I would probably have put my confidence in a facility like that.

7.3.3 Evidence as negotiated belief or opinion

As participants talked about research studies or formal health information within the context of their experiences with menopause-related information and the elicitation articles, they tended to situate these representations of evidence as negotiable opinion or belief. In other words, the notion of an empirical basis for understanding health information or making decisions about health management was apparent; however, determining the validity of the information was based on determining what or who to believe among the possible available options. Cherri, for example, questioned contrasting empirical findings and rhetorically asked: “Who do you believe? Who to believe? I don’t know.” Muriel comments are also representative: “This [article] comes out saying that this study has been done and that this is the case. This [article] says this study has been done but it’s not conclusive, and probably it’s not the case. So now it’s up to you to make the choice again.” In both of these cases considerations are not focused on the evidence itself; focus is directed towards evidence as a negotiated belief or opinion. Vicky further illustrates this perspective: “I’m going to just keep living my life and they [indicates the elicitation articles] can sort out what they believe and don’t believe.” Evidence was thus presented not as a positivistic entity, but as a negotiated belief.

Interviewed HPs provided support for the finding that women situated evidence within the context of negotiable belief. For example, Connie noted: “There’s a little bit of different information that’s being given at different clinics as well, so – you know, I’ve had women that have said, ‘Well, they say this here and they say this here, and so what do I believe?” One of the interviewed HPs insightfully described the challenge of differentiating between empirically derived evidence and evidence which is open to discussion and thus situated as negotiable. This individual noted that “as much as possible” she tries to follow the recommendations and consensus statements of governing bodies, however, "we do taint it with our own belief. . . we have to understand that we're bringing in that too." She explained in more detail:

> Because it's all belief even though you look at evidence. You're putting your own belief into that evidence, right? So you say the quality is not good. You know, that they had too small samples, they didn't randomize patients, and they didn't – or there's no study to support it so it doesn't work. Or it's not safe or, you know, whatever. Because I'm still putting my own belief in it. It's my interpretation of that evidence. I still believe that, right? And somebody else could say it in a different way and believe it in a different ways.

This HP's assertion, "I'm still putting my own belief in it. It's my interpretation of that evidence," is supported in the literature. Scholars exploring changing approaches to menopause management note that underlying practitioner beliefs, preferences and cognitive frameworks as well as publicity influence treatment decisions and the understanding of evidence (Allen and Mansfield 2004; Chase and Youngkin 2004). Furthermore, application of population derived medical evidence to individuals an ongoing challenge which requires clinician judgement (Griffiths, Green, and Bendelow 2006), and research demonstrates that even when looking at the same evidence with respect to HT, reputable medical groups come to different conclusions and consequently make variant recommendations with respect to management of the menopause transition (Ettinger et al. 2006).

7.3.4 Evidence as lived experience

While the evidence-based movement seeks to elucidate knowledge which is formal, explicit, derived from scholarship and which can be applied in practice, another form of evidence is that which is derived experientially. In the published literature this has been identified in a variety of ways including as tacit evidence (Ferlie 2005), clinical experience (Rycroft-Malone, Seers et al. 2004) or practical evidence (Maseide 2006). Furthermore, a clear link is made between this type of evidence and lived experience: "The gaining of tacit knowledge, in contrast to the route learning of facts, is experiential and typical of apprenticeships" (Sturmberg and Martin 2008, 768). In addition, qualitative exploration has demonstrated that clinical practice is primarily guided by this experientially derived evidence. Gabbay and le May (2004) describe this evidence as "'mindlines' – collectively reinforced, internalized, tacit guidelines" which are informed by multifaceted information sources including personal and peer experiences, and interaction with formal and informal information sources (1013). While scholars have recognized that clinical experience is central to EBP (*cf*. Hay et al. 2008; Sackett et al. 2000), the lived experience of patients has also been identified as an important aspect of the evidence spectrum (Rycroft-Malone, Seers et al. 2004).

A prominent theme in the interviews with women was the identification of lived experience as an important source of evidence, which played a noteworthy role with respect to decisions about managing health and wellness. Jill exemplified those participants who looked to lived experience as an important source of evidence. After looking at the elicitation articles she said, "I have no medical background whatsoever, except for what I've lived or what I've experienced." This participant questioned the information in the articles, thus positioning her lived experience as a sufficient basis for questioning the validity of the articles and the studies on which they were based. Monica provides an additional example of decision making which was based on evidence derived from lived experiences. This participant reported that because of her mother's experience as a nurse ("she looked at health food stories and chiropractors and things as sort of voodoo"), she herself was sceptical of alternative approaches to health management. Nonetheless, based on the lived experience of interpersonal contacts and without her characteristic exploration of multiple information sources, Monica reported that at one point she experimented with an over-the-counter estrogen cream. In this case, her more common tendency to avoid alternative products as well as her decision to use the cream was based on the lived experience of others; and her decision to discontinue the supplement was based on her own lived experience, "I didn't think it did much."

Women's evaluation of risk provides an example of lived experience constructed as evidence. A primary concern for women who were considering HT during the menopause transition was cancer risk. Women who had used or were contemplating HT use all described some level of risk assessment with respect to this therapy. Some focused on reason-oriented risk assessment, while a predominant theme was the influence of experiential evidence. Christy exemplified a reason-oriented approach when she described assessing information which was published in an article related to the 2002 publication of WHI results. She concluded: “They gave this whole list [of complications and confounding factors related to the study] and I didn’t have any of those. . . . So I kind of looked at it and said to myself, ‘Well, this is something I’ll ask about the next time I go in, but it doesn’t look to me like I should [stop taking HT] today.’” This approach suggests “behavior mediated by conscious appraisal of events” (Slovic et al. 2004, 313). This analytic approach to risk assessment was reflected by the interviewed HPs. Amy, for example, exemplified this perspective: “I talk a lot about weighing risks and benefits and sort of looking at the big picture; and try to explain the difference between relative and absolute risk because that’s a big thing that creates a lot of confusion.” This approach also tends to garner attention in the literature: concerns about the representation of health information in the media frequently focus on the inclusion of study limitations and indications of scientific uncertainty (Jensen 2008), or the appropriate communication of relative vs. absolute risk figures (Schwartz and Woloshin 2004).

While some focused on analytic risk assessment, a predominant theme emerging from the data was the influence of the “experiential system,” a “quicker, easier, and more efficient way to navigate in a complex, uncertain, and sometimes dangerous world” (Slovic et al. 2004, 313). Reliance on this experiential approach draws attention to the notion of evidence as lived experience and was demonstrated by relationships between cancer-related experiences and considerations of HT use. The following examples exemplify those whose lived experience did *not* include cancer: “I wasn’t worried about uterus cancer, and I wasn’t particularly worried about breast cancer because it’s not in our family” (Jane); and “[The doctor] said, ‘Well, quality of life is more important than maybe the risk factor.’ And for me the risk factor’s pretty minimal because we have no cancer in our family” (Sylvia). These women put aside analytic consideration of a potential cancer-HT relationship on the assumption that family history made this consideration unnecessary. For women who had lived experience with cancer in their families, concern with respect to cancer risk played a significant role in their consideration of HT: “My mom died of breast cancer and I’d had a few lumps in my breast and I just made up my mind that anything with hormones was bad for me. I’d never read a single article, didn’t know anything about hormone therapy. I was totally uninformed but I was determined that I was not using hormone therapy” (Roslyn). The threat of cancer and its relationship with HT was a prominent theme for interviewed women and lived experience of this dilemma also occurred vicariously:

> The other thing that happened is my closest friend lost her mother from breast cancer, lost her grandmother from breast cancer, lost her mother’s sister from breast cancer. . . . And she said that her doctor had at one point talked about HRT and she basically said, ‘Well, what choices can I have, you know. On the one hand I can get this, and on the one hand I can get that.’ . . . .And, I think having witnessed that dilemma with her, that also just turned me off HRT. I just felt it was too much of a quagmire and too complicated, and I just didn’t want to deal with it. (Nicole)

Although the relationship between women’s concern about cancer and the decision to use or not use HT has been documented in the literature (Genazzani et al. 2006), for some women the lived experience of symptoms provided sufficient evidence for choosing to use HT, even when there was family or personal experience with cancer. Naomi, who had lived with resistant and severe menopause related symptoms, explained that her lived experience provided sufficient evidence for her use of HT: “It’s controversial in the sense that I have this history of cancer and I’m using HRT. . . .And there’s a lot of people that don’t understand for me, it’s about quality of life. It really is.” This is particularly demonstrated by Thea, whose story of her menopause experience was laced with references to a family member whose suffering and perhaps even death was attributed by family members to hormone supplementation. When Thea sought help for seriously disruptive menopause symptoms her consideration of risk was based on both lived experience with her relative and the experience of her own symptoms. Her first prescription for HT “sat on the counter for about two weeks” because she had “heard horror stories about them. I mean, I’m older. I might be at risk. All these things came in my brain.” After more extensive consultation with a second HP, Thea decided to try using HT: “You go, ‘Okay, well what’s the risk on this level here and well, there’s still a risk. . . breast cancer and all sorts of stroke issues were brought up and you know, you really don’t – you want to do something to get your quality of life back.” At the time of the interview Thea’s personal lived experience had provided compelling evidence to support HT: “because you get so sick of being sick. . . . I was driven in trying to solve those symptoms, for sure. Mine were really taking over my whole enjoyment factor in life.”

The influence of lived experience as a source of evidence which women rely on or consider in conjunction with other forms of evidence highlights the importance of personal context for women who are navigating information related to the menopause transition. Information sources cannot be considered in isolation from the evidence women derive from their lived experiences. In the examples provided, focus was given to the influence of lived experience with cancer and with menopause symptoms; however women also looked to interpersonal sources of information in order to draw on the lived experience of others (see section 5.2.2). Although Rycroft, Seers et al. (2004) note, “in reality little is known about the role that individuals play or the contribution their experience makes” to EBP (85), this data suggests that women’s experiences provide information that they construct as valid evidence and which influences risk assessment and decisions about menopause management.

7.4 Making sense of changing and uncertain health information

Given the complex array of sources which participants interacted with as they navigated uncertain information related to the menopause transition (see chapter 5), it is valuable to move beyond interaction with specific types of sources, how women position themselves with respect to health information (chapter 6), and the construction of evidence (see section 7.3) and consider how women integrate and make sense of the complex information worlds they inhabit. While integration has been discussed within the context of previous chapters, this section focuses specifically on themes which illuminate women's personal experiences of knowledge translation as this occurs within their everyday lives. The following themes which emerged from data analyses and which relate to women's construction of uncertain health information will be examined: women's 'postures' as they make sense of uncertain and sometimes conflicting health information, source complementarity, social contexts for learning, and making sense through narratives.

7.4.1 Analytic and experiential 'postures'

Theorists from the field of psychology have explored the notion of two interacting modes of information processing (a rational and an experiential system) which are activated by varying circumstances and stimuli (Epstein 1994). Data analyses from this study demonstrate that although participants used rational processes to make sense of uncertain health information, they also made sense of information through a more experiential approach which incorporated intuition and affect. Within the context of this exploration I have chosen to use the term *posture*, which is defined as "a stance, an attitude" (OED Online 2010), as a descriptive term that reflects women's conscious and unconscious dispositions as they made sense of uncertain health information. In this study, women's varying postures as they experienced, made sense of, and used (or did not use) health information reflected analytic/logical and experiential/intuitive positioning. It is important to note that women's postures were not static and, furthermore, interviews demonstrated that they were not mutually exclusive.

Women's analytic posture with respect to health information was demonstrated by characteristics described by Slovic et al. (2004): women focused on logical connections as they explored uncertain information mediated by a range of sources; their actions were based on conscious consideration of information and events; and they used logic and different forms of evidence in order to justify their use (or non-use) of information. Camille exemplified this posture as she struggled to reconcile use of HT with her fears of cancer: “It made sense that, yes, I should at my young age, I should still have those hormones in me. And what we’re doing is just replacing what I don’t have. So it made sense to me.” In this case Camille adopted an analytic posture in response to a discussion with her physician. The same analytic posture is demonstrated in the following conversation:

> Camille (C): Basically what I would do is build up a sleep debt after about three nights and then I’d take a sleeping pill. Because I didn’t want to be doing that every night, right? So that’s what I would do, if I went on without a good sleep for two, three nights, a third night I’d take a pill.
> Interviewer (I): Did someone tell you to do that or did you
> C: No. That’s just what I thought. I mean, because I realize that if I take a pill every night then I’m [going to] need one to get to sleep. So I would just kind of accrue this debt and then poof.
> I: Then how did you decide to do that?
> C: I don’t know. I just did. I just thought about it and thought, ‘Well, that’s the part that makes the most sense.’ And my doctor said be careful to not – or he said, ‘Try not to take this more than two or three times a week.’ I mean, I had a friend who was taking two a night. Every night. So, and I don’t like to take a lot of medication.

In this situation, Camille considered her struggles with insomnia, the instructions from her physician, her knowledge of a friend’s experience, and her own disposition towards medication. On the basis of this conscious appraisal, she found a way to make sense of information about sleeping medication, and she found a way to use that knowledge in the context of her own life.

An analytic posture was also adopted as women sought to understand information mediated by informal sources. Sylvia, for example, explained:

> On the internet, when I wanted to look up gallbladders and hormone replacement therapy and what I did find is that hormone replacement therapy concentrates the bile. And I was not eating a lot of fat. So I thought, ‘I’m going to start eating a tablespoon of peanut butter every morning and see what happens.’ Sure enough. I haven’t had any of those symptoms again. Soon as I forget, it comes back.

By taking information from the internet and applying her own understanding of nutrition based on some background in the health field, Sylvia made logical connections and, like Camille, found a way to apply the information to her management of the menopause transition. These exemplars highlight the range of information which women integrate as they make sense of encounters with formal and informal health information, and the varying types of evidence which are incorporated as women find ways to make sense of that information.

Analyses demonstrate that women also adopted experiential postures, which incorporated intuition and affect, as they processed uncertain heath information. This posture was demonstrated by women who utilized information that made sense according to their experiences (“experiencing is believing”), was based on intra-personal information sources, and was on a very general level oriented towards “more rapid processing” (Slovic et al. 2004, 313). Jill, for example, was explicit about assuming an experiential posture. Although acknowledging that information from books might be “good,” she wondered aloud whether some of her friends’ experiences of menopause symptoms were ‘self-fulfilling prophecies’ based on material they had read about the menopause transition. She asserted, “Menopause’s going to be what I experience, not from what I read from a book. . . . I’m not even going to give my mind a chance to even excuse certain behaviour [because of] what I read there.” Nicole also assumed an experiential posture after relating the experience of a friend who gathered so much information through a formal literature search that she was unable to translate the findings into useable information: “I think that’s probably one of the reasons I just turned off on the HRT stuff. There was just *So. Much. Stuff.* And, I was, as I said, satisfied with where I was going, with where my body was going. I think more than anything, I was satisfied with where my body was going.” Immediately after explaining why she chose to focus on her own embodied experience, Nicole reinforced this posture by relating the experience of a friend who lost loved ones to cancer: “The other thing that happened is my closest friend lost her mother from breast cancer, lost her grandmother from breast cancer, lost her mother’s sister from breast cancer” (see full quotation in section 7.3.4). Dana illustrates an experiential posture which draws more explicitly on the intuitive elements of experience. Dana was asked in the interview if she looked at the author or origin of websites she explored. This participant responded, “Makes no difference to me because, you know, if it is something that I already want to believe, it doesn’t matter to me. I’m looking for something that agrees with what I believe. And if it doesn’t, I just scrap it.” This participant continued, “I didn’t always have that confidence. . . but now I sit and see how it feels first.”

Although interviews thematically support the notion that making sense of uncertain health information is facilitated by women’s analytic and experiential postures, women’s perceptions of their own experiences and their construction of those experiences within the context of the interviews highlight the inherently inseparable nature of these two approaches. This is exemplified by exploring Christy and Faye’s narratives. Christy assumed analytic and experiential postures in the course of her interview, and, rather than being contradictory, each represented an approach which made sense to Christy in the specific context she was describing. When trying to verify information she had heard from a girlfriend, she unsuccessfully consulted HPs (“it was a very ‘shut it down’ kind of discussion”) and then conducted her own search for information online where she discovered both “old wives tales” and citations to studies in the medical literature. By assuming an analytic posture with respect the information she found, and in light of her own knowledge of physiology, Christy developed a rationale for the practical information which had been recommended by her friend. Later on in Christy’s narrative, however, she encountered information about the WHI. While first assuming an analytic posture, (she spoke of considering “complications” and “confounding factors”), she almost immediately related that she became “even more concerned over time about the impact of this stuff that I – what I was *feeling* [great emphasis on the word ‘feeling’], right? . . . So, I went back again [to her doctor] and I said, ‘You know what, I think this is causing me these problems.’” In this instance, and based on experiential evidence, Christy assumed an experiential posture when she spoke to her physician. Christy also demonstrated this posture at another point in her narrative when she emphasized her own responsibility of health management: “The stuff that I got [from HPs], I’m kind of going ‘Na, I don’t think so’. . . it might be right in theory and it might be right if you generalize it out to the population but you're not talking about me. . . I know that what you're saying is not right for me." In this latter example Christy, who overall tended to demonstrate an analytic disposition towards heath information, exhibited an experiential and almost intuitive stance by positioning herself as the unique interpreter of her own body and physical experience, "I know that what you're saying is not right for me" (see also section 6.1).

Faye is also representative of the inseparability of the analytic and experiential postures as demonstrated by interviewed women. Faye described her approach to health information seeking as "intentional and thorough, maybe even academic" and discussed her tendency to consult a wide range of sources when she was "sort of figuring out" health challenges. She noted that she "liked the idea of the [menopause clinic]. That it was sort of more comprehensive and more thorough," and when asked by a HP if she was interested in a referral to the clinic, she reported that her response had been: "I'd be interested to talk to somebody. I think I know what there is to know but I'm happy to go see if I'm wrong." While these examples demonstrate Faye's analytic stance with respect to health information, she also clearly articulated the influence of an experiential posture:

> Maybe a part that I emphasized less in emphasizing my scientific approach to trying to get comprehensive information is that I do also feel like I evaluate things on very much on how they feel. . . . So I do all this reading and then I try to make a wise, intuitive decision with, 'Am I comfortable with this? Am I ready to do this?' But also, 'How does it feel physically?'. . . . I sort of get myself intuitively to the point where I'm ready to make a decision. But that takes – you know, this information gathering is part of it, but then just letting it sort of feel it out. Am I ready to – am I really ready to go there?

Although scholars suggest that "health information for consumers has been designed, almost exclusively, to evoke analytic processing (Hibbard and Peters 2003, 428), these findings suggest that women adopt both analytic and experiential postures when seeking and making sense of health information. Just as recent research on health promoting media messages suggests the importance of messages which provoked cognitive and experiential response (Dunlop, Wakefield, and Kashima 2010), findings from this study suggest that further understanding of both of these approaches to processing information will increase understanding of women's IB and decision making during the menopause transition, and assist HPs and information professionals as they seek to facilitate health information literacy.

7.4.2 Source complementarity

Discourse with respect to health information sources and health evidence is frequently conceptualized as a dialectic, a competition between information sources or types of evidence for the limited time or allegiance of the information seeker. Following the publication of WHI results in 2002, for example, many surveys were conducted seeking to identify women's primary sources of information with respect to HT risk and/or HT discontinuance or continuance (*cf*. Genazzani et al. 2006; Heitmann, Greiser, and Dörin 2005; McIntosh and Blalock 2005). In contrast to the notion that information sources compete for attention, or that the influence of one information source (for example, the media) may come to displace the influence of another (for example, the HP), findings from this study demonstrated that women who were seeking information about management of the menopause transition tended to seek, scan and monitor information on this topic across mediums. This suggests that, for these participants who were navigating uncertain health information, a predominant feature of health IB was *complementarity*, not competition or displacement. The notion of complementary use of information sources suggests that an individual looking in traditional media for information about, for example, a health concern, would also be likely to look online for information related to the same content area (Dutta-Bergman 2004). The primary features of this perspective are that enduring interest in a specific subject area motivates IBs across mediums, and that "information seeking behavior through the different media complement each other in fulfilling the individual's information needs" (Dutta-Bergman 2006b, 89). Data from the current study suggest that for interviewed women, complementarity played an important role as they sought to make sense of and use uncertain health information about the menopause transition.

As discussed in Chapter 4, participants described gathering information from multiple sources and viewed sources as complementary to one another. In fact, the view of information sources complementing one another was reinforced by the value women placed on sources which directly or indirectly pointed to other information sources (see section 4.2.2). Complementarity was also demonstrated by participants' use of a range of information sources in order to fulfil a variety of information needs, and by the finding that women tended to focus on interest areas (specifically, health concerns relevant to themselves or family members) as they gathered health information across mediums (see section 4.2.3). In Chapter 5, complementarity was evident as discussion focused on the complex array of sources women used as they navigated uncertain information related to the menopause transition. A few examples which have been discussed in Chapter 5 include the following: women frequently consulted HPs subsequent to personal exploration of a range of information sources, and conversely, when encountering health information in the media, many women subsequently sought information from HPs (see section 5.1). Other primary themes emerging from the data and which demonstrated complementarity were the seamless integration of online information seeking with other information sources (see section 5.4); and, media-mediated health information as an awareness tool and a 'springboard' for information seeking via other mediums (see section 5.5). Quotations supporting complementarity can be found in the sections which specifically discuss these examples. In addition to the numerous examples of complementarity evident in Chapters 4 and 5, and given that the literature on this topic is, to my knowledge, limited to secondary analysis of quantitative data (*cf*. Dutta-Bergman 2004; Nguyen and Western 2006; Tian and Robinson 2008), two specific illustrations of complementarity found in this data are described in the following paragraphs.

The elicitation portion of the interview provided numerous examples of complementarity as women were confronted with conflicting reports on Vitamin D research and were asked to explain how they would make sense of the media stories. Participants brought a range of options forward. These included discussion of the articles with HPs (for example, Irene) or other people (for example, Cherri), as well as engaging in personal exploration of a range of information sources (for example, Jane). Paula's comments as she read and considered one of the elicitation articles are representative of complementarity: "OK, who is this guy? [Referring to the author of the research study that was discussed in the news article.] He's a researcher. I would Google him. I'd be like, 'OK, that's nice. Who is this guy?' – then I would do a – find out some information about him to see, is he somebody that is a world renowned research expert on Vitamin D and the study of cancer?" A number of women also demonstrated an integration of intrapersonal information sources. In reaction to the elicitation articles Jill suggested both listening to other people and "listen[ing] to your own body"; and Dana stated, "I would go back to my gut."

Although many HPs expressed grave concerns about the competing influence of media-mediated health information, the reaction of women to Oprah's foray into issues related to menopause also provides an illustration of complementarity. Camille, for example, highlighted a relationship between the television show and interpersonal information gathering among women: "It kind of opened up the dialogue and stuff. Because we'd say, 'Oh, did you see that Oprah?" Amy, one of the HPs, also provided support for complementarity between the Oprah show and other information sources: "I guess the good thing is that it does get the conversations started, you know. Like certainly more women are coming forward and looking for help." Despite that fact that celebrity-mediated health information presented significant challenges to HPs, the most compelling demonstration of complementarity was illuminated by Gail, one of the HPs who worked at a menopause clinic:

> I can't believe the influx of calls we've had from that Oprah show. I really can't. The power that she has. And that she uses it and that she's empowered these women to come. . . .We've over 200 women waiting to see us now. And we're booking into – whereas before our wait list, before the Oprah show, was about – we were down to about – you know, maybe 40 or 50 at our peak times of people waiting. Now we have over 200 women waiting to be seen.

While the interviewed HPs were unenthusiastic about Oprah as a purveyor of health information, Gail's comments clearly illustrate complementarity between media-mediated health information and formal health information. Many women who were interested in the information provided by Oprah were motivated to also seek information about the menopause transition from other sources, including from HPs.

Findings from this study are both supported by the research literature and extend considerations of complementarity between information sources. First established as a feature of news consumption across traditional and new media (Dutta-Bergman 2004), complementarity has been established between interpersonal crisis communication via telephone and the internet (Dutta-Bergman 2006a), and between mass media and visits to a HP (Tian and Robinson 2008). Results from this study provide insight into the way women think about and experience complementarity, and its integral constructive role as women navigate a wide range of informal and formal information sources in their quest to make sense of and use changing and uncertain health information.

7.4.3 Social contexts for learning and for knowledge construction

Data analyses reveal a third prominent theme with respect to women's construction of uncertain health information: the notion that social contexts play an important role for women as they make sense of uncertain information about management of the menopause transition. Close reading of the data demonstrates that women find interactive contexts in a variety of ways; these social contexts serve a range of purposes as they facilitate knowledge construction; and, women themselves identify social contexts as important for learning and for the translation of knowledge for personal understanding and use.

Women encounter or seek social contexts through a variety of mediums. The most apparent interactive contexts were created by interpersonal information sharing between women and their family, friends, or colleagues: "I really just talked to some girlfriends. . . 'This is what I'm feeling.' And they would say, 'Maybe you should check about menopause because it sounds like you've got the symptoms'" (Camille); "I have this ladies' club that I've been in for about 13 or

14 years now, and there’s like eight of us that still meet and we meet once a month. . . .We do talk about [menopause]. . . .It really comes up in conversations naturally” (Sue); and, “Like at work, in the lunchroom, you’d hear all of us. . .talking about how are you doing with your hot flashes or night sweats or memory or aches and pains and you know, drying up, and all this sort of information. Everybody is just telling what worked for them. You know, it’s been very interesting as well. It’s been really open, honest dialogue” (Naomi). While these examples demonstrate the constructive potential of face-to-face social contexts, women also found online social contexts which facilitated interaction and understanding of menopause management.

> Like I went into the site, I looked at the causes, the symptoms, all of this and then I went and scrolled down into some of the comments [of] the people that lived through that. And to me that’s a big source right there too. Talk to people that *lived* through that. . . . Nobody knows better than the person that has gone through it. How it is affecting and I think there is a lot of wisdom and a lot of knowledge that can be taken from people going through that. (Jill)

Although none of the participants described active involvement in online communities, a number of women, like Jill, expressed appreciation for the interactive elements and learning provided by online personal commentaries or blogs. Social context was also provided vicariously through the media. Sonya, one of the interviewed HPs, specifically noted the vicarious experience of media-mediated social contexts: “It’s woman to woman, so I think this whole sort of interest in bioidentical is Oprah. One woman talking to another woman. Even though it’s an audience of 30 million or whatever. But that’s just how health information flows to women, right? So that peer to peer, those sort of face-to-face conversations.” While section 5.2.3 describes and demonstrates the contribution of interpersonal knowledge sources to knowledge construction, consideration of the diverse ways in which women experience social interaction and social contexts draws attention to sociocultural environments as a potentially diverse yet central component of knowledge construction (Talja, Tuominen, and Savolainen 2005).

Data analyses suggest that social interaction facilitates uncertainty management and knowledge construction in a number of different ways. For example, while participants gathered information from a range of sources in order to prepare for encounters with HPs or to supplement information (see section 4.2.3.2 and 4.2.3.4), social interaction appears to play a key role in encouraging women to make sense of and use information. Hazel, for example, reported, "[I] talked some more with some friends and they said, 'Okay, go back to you doctor and say this is what you want.'" After this exchange Hazel engaged in further information seeking and then approached her HP with information about her preferred treatment strategy. A further example is provided by Christy who, after visiting her physician, sought supplementary information through interpersonal source: "it was much more expansion, confirmation – looking for practical application and dealing with it." Lisa was particularly descriptive as she spoke of the construction of knowledge which occurred between people as they exchanged information about their lived experience:

> When you're talking and discussing with someone, the words are flowing back and forth, you're both getting something from those words. And maybe you can both help each other – *help each other* with your words. . . .We're trading information and ideas. They're using my information to help them . . .and I'm using their information to say 'Yeah I've trying that and this is what happened; and I tried this and this is what happened; and I tried this, this is what happened'. . . .It's a back and forth constantly.

The notion that social contexts serve a range of purposes as they support knowledge construction is supported in the literature. Brasher (2001), for example, found that "supportive others act upon uncertainty management processes by providing direct or indirect assistance as sources of information, collaborators in information gathering, evaluators of information, or buffers against information" (485). And other scholars have noted that in the face of frustration with uncertain information provided by physicians and contradictory media articles, women in this life transition who were at risk for hereditary breast and ovarian cancers used an online discussion group to "built their own social structure by engaging in reciprocal and multi-participant conversations over time" (Kenen et al. 2007, 769). Furthermore, it was found that the "sense of trust and community. . . appeared to enable these women to make the unpleasant choices they faced with a degree of confidence they otherwise might not have felt on their own" (Kenen et al. 2007, 769).

This qualitative study is framed from a social constructionist theoretical perspective which views knowledge as "a communicative construct which is produced in a social context" (Tuominen and Savolainen 1997, 89), and yet an unexpected finding was that participants themselves explicitly valued and specifically identified a preference for social contexts for learning about and constructing knowledge about menopause management. In fact, analyses demonstrated that over half of the women identified information exchange within social contexts as a preferred way of learning about menopause. When Paula was asked what she might envision as an ideal way for women in this life transition to learn about health, she responded,

> Women's health centre. . .a place that women could share. Like, maybe there are menopause support groups. I don't know, 'cause I never went to one, but by women sharing with each other and having that common thread. . .knowing that you're not alone. Whether it's menopause, cholesterol, or whatever it may be. I seriously believe that it's important for women to share that information.

And Dale said:

> I would like to see, this might sound odd, a support group. Not an Alcoholics Anonymous. Like – I'm a big advocate of having female friends. . . .Because I think it's a team effort. And I know it's difficult to have healthcare teams like at the Mature Women's Clinic but I think groups like that could get discussions started and at least show people a few different directions or avenues that they can branch out on to start seeking information.

While acknowledging a need for biomedical knowledge, women recognized that research-based evidence was only one part of decision making (this is also recognized in the knowledge translation literature; see, for instance, Rycroft-Malone et al. 2002) and their notions of ideal learning situations emphasized the learning that occurs between women in social contexts. Consistent with notions of complementarity, findings suggest that interviewed women did not view social contexts for learning and encounters with HPs as conflicting or competitive. Rather, they saw interactive contexts as opportunities which empowered them to make sense of uncertain health information, integrate formal and informal information, and deal more effectively with personal health management.

7.4.4 Making sense through narrative

When EBP was introduced in the early 1990s, expertise was subordinated to external evidence and HPs were urged to look beyond experiential knowledge to the research literature for appropriate evidence on which to base practice. This approach was modified by Sackett et al.'s (2000) definition of EBP, which advocated the integration of research evidence with clinical experience and patient values (see section 2.4.1). Despite this expanded conceptualization, "even proponents [of EBP] agree that they have a poorer handle on how to factor in clinical judgment and patients' circumstances than they do how to judge the hierarchies of evidence" (Charon and Wyer 2008, 297). In order to improve understanding of patient values and circumstances the attention of some scholars has focused on patients' stories: "only by listening to the stories that patients tell can clinicians understand their patient's values" (Lockwood 2004, 1035). A relatively recent editorial in the prestigious journal, *The Lancet*, takes this idea further and proposes that "illness unfolds in stories" and that it is through an understanding of patient narratives that understanding of "the final step in the pathway that leads from research idea to improved patients' outcomes, namely, patients' own decision to accept and execute offered interventions" can be achieved (Charon and Wyer 2008, 297). *Narrative evidence-based medicine* thus seeks to situate patients within their own stories in order to help the HP "make sense of a patient's complicated and often unordered disease account" (Goyal et al. 2008, 737). Goyal et al. (2008) continue in their discussion of narrative medicine: "It is only when that string of amino acids is configured into a *shape* that the protein can do work. . . .So, too, for the configuration of plot, which enables an otherwise flaccid string of events to *do* something, that is, to achieve meaning” (737). The notion of narrative as a means of understanding patient accounts is consistent with literature related to qualitative interviewing. Becker (1997), for example, notes that it is through stories that people “organize, display, and work through their experiences” (25).

While scholars seek to incorporate the notion of narrative within medical practice in order to help HPs ‘make sense’ of patient values and circumstances, findings from this current study suggest that women themselves make sense of uncertain health information through the telling of their own narratives and by listening to the stories of other women navigating this transition. This is made evident by findings related to interpersonal information sources and experiential evidence (see sections 5.2.2. and 7.3.4). Furthermore, while the focus in section 7.4.3 is on social contexts as a means of making sense of uncertain health information, it is also apparent that it is, in part, the narratives available within social contexts which facilitate women’s understanding and use of uncertain health information.

Interview data demonstrate that interviewed women constructed sense as they told the stories of their experiences. Section 4.3.2.1, for example, explores the contribution that women’s narratives make to a deeper understanding of the symptom experience. Discussion focused on how women’s stories provide insight into the influence of personal context on the symptom experience, the challenge women experience because of the difficulties in defining menopause symptoms, and women’s construction of the symptom experience based on common interpretive repertoires. Muriel also exemplifies the value of narratives as a tool for making sense of uncertain health information. This participant told the story of her experience with menopause management (see section 6.4.3) and, within the context of her narrative, she began to construct understanding. She explained that whereas her daughter would feel free to disagree with a HP, she came “from a generation where I find it difficult to disagree with the doctor.” A short while later in response to a question about responsibility for health management (“Where do you see your role in all that?”), this participant reflected again on a particularly negative encounter with a HP and then concluded, “And yet I think that I am feeling more and more that I need to advocate for myself. I need to be in charge of my health. Yeah."

Thea exemplified the many participants who sought understanding through the narratives of other women. This participant noted that after initially engaging with a small group of women in a teaching session at a menopause clinic she attended, her interaction was solely with HPs. Although she appreciated these latter interactions, she was focused in her desire to hear the continuing stories of the women she initially interacted with.

> I'd like to see, 'What have you tried?' 'What have *you* tried?' But that information isn't available to me. After you get that initial set-up then the doctors and the pharmacist and everything else sort of hone in on me alone, on my own sessions. But it doesn't give me any background to, 'Hey, what worked for you?' You know what I mean? I don't have any contact with those ladies anymore. And I'd like to [have contact with the original group of women] because I'd like to say, 'Well, this is what I tried and I got to this point. What have you tried?' And, 'Did you think that was risky?' And then she could ask me if I – you know what I mean? I think that would be helpful. But that isn't the case. . . so I'm just stumbling through trying to make myself better. . . . I would like to go back and revisit the ladies that I was in the session with and see where they're at.

Despite acknowledged input from HPs, Thea's narrative reveals deep uncertainty about the course of her own treatment as well as a sense of being alone in her attempts to find an appropriate treatment strategy. Thea commented at a number of points during the interview that she'd like to meet again with the original group of women and hear the stories of their experiences managing this life transition. Through these stories, Thea hoped to make sense of her own experience: "I'd like to know these things because we don't really know as people if we're doing the right thing and [the HPs] don't really tell you if you're doing the right thing, either."

Interviews provided women with the opportunity to bring together multiple facets of their menopause experiences, including their histories with health management, their physical experiences, and their interactions with formal and informal information sources. The telling of stories within the qualitative interviews facilitated a view of knowledge not only as a *thing*, but as *flow* (Snowden 2002); in other words, the generation of knowledge was focused on "*context* and *narrative*, rather than content alone" (Sturmberg and Martin 2008, 768). Furthermore, narratives allowed information interactions or encounters to be "seen as one chapter in an individual's ongoing engagement with, and construction of, their life-world" (Olsson 2005, n.p.). Irene exemplifies the integration of stories within the interview narrative. This participant related her childhood experience with the terminal illness of a parent. She described helping to count out different colors of pills, visiting her parent in hospital, and admiration for the resilience which was modeled. She then told the story of her own fight for life-saving intervention for a child, as well as her own search for relevant information with respect to menopause-related challenges. This participant concluded, "I learned that you have to fight and like they say, the early bird gets the worm or whatever, the screamer gets the – I don't know. It just kind of clicked then and since then I did a lot of fighting." Close reading of the interview brings forward the stories of a child's experience with parental illness, a mother's experience with a very ill infant, and a woman's ongoing health challenges related to the menopause transition. Taken as a narrative, these stories construct the experiences of a woman with close ties to the medical community and yet a woman who independently and without hesitation engages with information seeking in order to make sense of uncertain health information: "I would tend to listen more to the doctor. But after a while if it doesn't help. . . [I'd] dig into this."

At the same time as these examples corroborate qualitative interviews as "occasion(s) for constructing" (Holstein and Gubrium 1997, 120), one of the interviewed HPs confirmed the importance of women's stories as sites of construction:

> Just the chance to finally tell their story and sort of get through all that. You know, there's signs up in some offices now that say you can only talk to [the doctor] about one thing per visit. So, do I go in and talk about the hot flashes or is it more about the sleep or – because I'm not sleeping well, then I'm not thinking clearly at work, is that my one issue? Like can you imagine having to sort of put a priority to – they're all connected. It's a big snowball effect, right? . . . I'm hot and bothered and tired and thin skin and my husband wants to have sex. Do I want to follow through with that? Someone – like [women] just feel relieved to be able to sort of put all that out there. (Sonya)

In this passage, Sonya emphasizes that in fact the menopause experience cannot be separated into factual accounts of individual symptoms. Women's menopause symptoms are interrelated with one another and, furthermore, relate to work and home life. It is in the opportunity to relate stories that women's menopause experience can be understood.

In addition to confirming people's tendency to seek easily accessible and interpersonal information sources (Case 2007; Harris and Dewdney 1994), analyses of interview data demonstrate that women make sense of their menopause experiences and uncertain health information through narratives. These narratives included previous personal and health-related experiences, current physical realities of the menopause transition, and interactions with formal and informal information sources. While evidence is frequently conceptualized in the health literature as empirically derived, Rycroft-Malone, Seers et al. (2004) confirm that the production and, perhaps more importantly, the *use* of health evidence is a "social as well as scientific process" (84). Findings from this study suggest that narratives not only facilitate women's understanding and use of uncertain health information, they also illuminate patient perspective, thus bridging the gap between the metaphorical research bench and bedside.

7.5 Conclusion

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Interviews with women who had been or were navigating uncertain information about the menopause transition revealed themes which illuminate women's experiences making sense of and using uncertain health information. Data analyses reveal that in response to uncertain and evolving health information participants assumed personal responsibility both for seeking information and for constructing sense from the information available to them. While evidence is frequently conceptualized as being exclusively derived from empirical inquiry, interviews demonstrate a more nuanced view of evidence which includes evidence as research, as material object, as a negotiated belief, and as lived experience. As women constructed sense from uncertain information about the menopause transition, they tended to adopt analytic and experiential ‘postures,’ they viewed information sources and different types of evidence as complementary, and they valued social contexts for learning and for making sense of conflicting health information. Finally, the findings illuminate the central place of narratives within holistic EBP which seeks to understand and truly incorporate patient values and perspective.

CHAPTER 8
CONCLUSION

This dissertation has explored sense-making and information behaviours (IBs) elicited by uncertain and evolving health information mediated by formal and informal health information sources. Exploration focused on the experiences of women as they responded to, made sense of, and used uncertain information about the menopause transition. In this final chapter major findings of this qualitative study are briefly summarized. Findings are organized according to the four research questions posed in the first chapter of the dissertation; this corresponds to chapters 4 through 7 which sequentially addressed each of the research questions. Following this summary, other interesting findings related to the knowledge translation (KT) in everyday life and elicitation techniques are presented; theoretical contributions are discussed; and implications for practice in health fields and Information Science are examined. This latter section focuses on implications for health literacy and for shared decision making (SDM). In conclusion, consideration is given to future research direction.

8.1 Summary of major findings

8.1.1 Experiences of women

Findings from this study illuminated the first research question: ‘What are the experiences of women as they respond to, make sense of, and use uncertain and/or evolving information about HT and menopause?’ Women participating in this qualitative study engaged in a range of IBs as they explored concerns about health and wellness, particularly related to the menopause transition. Data analyses demonstrate that participants were active information agents who portrayed their information seeking as a sequential, familiar series of interlinked exploratory steps involving multiple sources. While consistent with previous theory which asserts that people follow habitual information seeking patterns, this study demonstrates seamless integration of the internet into searching strategies and the fluid movement between informal and formal information sources. Previous studies suggest that women frequently begin information gathering by consulting interpersonal sources; however, findings from this study suggest that, perhaps as a result of readily available online information, participants were most likely to begin with personal, autonomous exploration of a range of sources, most notably, the internet. This was followed by information gathering via informal interpersonal sources or formal sources such as health professionals (HPs). While women consulted a wide range of information sources, data demonstrate that participants were aware of the varying perspectives provided, and viewed the spectrum of available information as enriching and complementing elements of the search process. This was supported by data demonstrating that referral from one source to a second source built trust and reinforced the notion that sources were complementary.

Furthermore, participants gathered health information for a variety of purposes, each of which contributed to empowering women as primary stakeholders in their own health and wellness. Interviews strongly supported previous studies which note that women commonly seek health information for themselves and others, particularly family members. Participants also gathered health information out of general interest and as a part of everyday life information scanning; their interest was attracted by information which evoked personal identification, thus motivating further exploration; and women mentally and physically collected or ‘filed’ health information for potential future use by themselves or others. Women also frequently gathered information in order to evaluate and supplement health information encountered or gathered from other sources; online health information was the primary source for evaluative or supplementary health information. All of these activities served to improve participants’ control over their own health and to facilitate informed decision making. This was particularly demonstrated by participants’ tendency to gather information in preparation for formal encounters with HPs, frequently seeking information from HPs only after they had exhausted their own information finding capacities, when seeking information clarification, or when pursuing access to a specific medical service.

Findings provide important insight into women's self-perceptions as they navigate evolving information about the menopause transition. Data demonstrate that women positioned themselves as 'healthy' even when facing menopause-related challenges, thus, discursively supporting the notion of menopause as a natural life transition (NLT). Furthermore, in response to menopause symptoms, women sought information which aligned their experience with the 'normal' experience of others. This information, which offered women noteworthy comfort even prior to the ameliorating symptoms, was deliberately sought, indirectly gathered through interactions with other women, and encountered via the media. Confirmation that symptoms were 'normal,' served not only to affirm the reality of this physical embodiment of the menopause transition, it also empowered women to seek further information. Analyses also revealed the theme 'too young for menopause.' This indirectly reinforced the biomedical positioning of menopause as a deficiency disease. In addition to women's self-positioning as 'too young' (this was particularly evident in those who experienced menopause prior to 50 years of age), participants reported that this theme was also evident within the context of visits with physicians. While perhaps conceived as a complement, this occurrence reinforced culturally embedded notions of menopause as a negative representation of aging.

The 'symptom experience' and its relationship to IB emerged as an important finding of this study. Almost all of the interviewed women situated discussion of menopause symptoms prominently within their narratives and linked this experience closely with recognition of information need and subsequent information seeking. This association was confirmed by interviewed HPs. Findings also highlight the value of qualitative findings: interview narratives facilitated nuanced understanding of the symptom experience from women's perspectives. Findings reveal that women's personal contexts played an important role in their understanding and interpretation of this experience, as well as the urgency with which women sought information. Narratives highlighted the challenges women experienced when seeking to identify menopause symptoms and supported the notion that women draw on varying interpretive repertoires as they construct and make sense of their experiences of the menopause transition.

Given the stated topic of investigation, it is not surprising that uncertainty was central to the experience of women as they responded to and made sense of changing information about the menopause transition. Many women perceived a lack of available preparatory information about this life state, about perimenopause and about symptom management. Uncertainty was exacerbated by a perceived lack of information from HPs and, moreover, many women described situations in which their concerns about menopause were not addressed or mitigated by consultation with HPs. Findings also demonstrate that the uncertain and controversial nature of menopause information appeared to play a role in levelling the proverbial playing field between informal and formal health information: women moved easily and with little differentiation between information sources. While management of menopause symptoms emerged as a noteworthy source of uncertainty, an important finding is that women’s decision to use hormone therapy (HT) did not mark a resolution of uncertainty or a termination in information seeking; rather, it represented a provisional decision which was situated within a context of ongoing IBs related to the menopause transition. Despite highlighting deficiencies with respect to menopause information, participants were active information seekers in response to their uncertainty.

An important recommendation from interviewed women was that information about menopause should be a routine part of health care, beginning well before the anticipated onset of this life transition. In addition, consistent and frank communication by HPs and consumer health sources may help women feel comfortable with the inevitable uncertainties of this life stage and the challenges many women encounter when navigating changing information about this life transition.

8.1.2 Information sources and response to evolving health information

Participants interacted with a complex array of informal, formal and hybrid sources which were both encountered and deliberately sought as women navigated uncertain information about the menopause transition. This section addresses the second research question: ‘In what ways do information sources facilitate women’s varying responses to uncertain/evolving health knowledge? And what are the tensions experienced by women as they make sense of information that is facilitated in different ways by formal and informal information sources?’ The section begins with major findings related to traditional formal sources, moves to discussion of inter- and intra-personal sources, continues with discussion of the internet and media, and highlights findings related to books and libraries. Finally, major findings with respect to notions of source consistency are presented.

Data demonstrate that although independent health information seeking was a prominent strategy for interviewed women, the vast majority of participants did, at some point, look to HPs as authoritative sources of information about the menopause transition. While contacting a HP was an uncommon first response for women seeking health information in this context, findings also reveal that, when confronted with conflicting health information (as occurred in the elicitation portion of the interview), participants were likely to look to HPs as authorities who could play a role in helping them make sense of uncertain medical information. *Trust*, however, played a critical role in mediating women’s confidence in HP facilitated information. Without trust participants were less likely to integrate and use information provided by HPs and, furthermore, unsatisfactory interactions with HPs emerged as a noteworthy barrier to health information. Perhaps in response to the perception that HPs can impede the search for information, participants developed specific strategies (for example, targeted questioning) for drawing needed information from this source. A final prominent finding was that participants positioned female physicians as being more understanding and helpful than male physicians. Data analyses revealed, however, that participants used gender as a discursive signal which identified the information sharing, helpful HP vs. the HP who was unable or unwilling to address women's concerns. When participants identified gender, therefore, they were identifying qualities related to communication. The strongly expressed preference for female HPs as information sources has implications for all HPs who work with women in this life transition.

Results from this investigation confirm that women tend to seek easily accessible and interpersonal information sources. In particular, this investigation reveals that formal medical information was make more valuable when it was provided or interpreted by interpersonal contacts with biomedical qualifications; and that participants most frequently expressed their appreciation for the experiential knowledge gained from interpersonal sources. Women deliberately sought information from interpersonal sources in order to better understand and normalize their own experiences in this life transition and in order to gain insight into the lived experience of symptom management. Participant interviews suggest that those navigating the menopause transition are similar to those struggling with chronic disease in that experiential knowledge provides justification for treatment choices. Findings also demonstrate that interaction with interpersonal sources is more than a simple matter of information transfer; these interactions are an important part of the process of construction which occurs as women integrate and make use of uncertain health information mediated by a range of informal and formal sources (see section 8.1.4). Data also bring forward the striking influence of mothers on women's perspectives with respect to menopause management. Almost every participant related her mother's menopause experience to her own. This included childhood observations which framed adult perceptions; direct solicitation of information from mothers; attribution of knowledge deficit to a lack of communication with mothers; expectations that personal experiences will mirror mothers' experiences; and assessment of risk and treatment decisions, particularly with respect to HT, based on mothers' experiences. This insight, that women's experiences are defined and shaped by their mothers' menopause experiences, suggests that more nuanced investigation regarding the influence of women’s social contexts on their menopause experience and decisions is warranted.

A particularly salient finding was that women were substantively informed, influenced and guided by intrapersonal information sources. This source of information, which was identified by many women and supported by interviews with HPs, can be described as a deeply personal integration of information and life-long experiences (drawn consciously or unconsciously from beliefs, life-long and bodily experiences, dispositions and reflections) that coalesced into an explicit source similar to informal and formal information sources. Findings demonstrate that based on this information, study participants constructed themselves as cognitive authorities and in many cases used this authority to challenge biomedical authority.

The internet emerged from the data as an explicitly valued, everyday and normal part of health IB for interviewed women. It was an important source which served a range of purposes including as an accessible means for gathering introductory information about general or specific health concerns, for seeking information in preparation for or following interaction with a HP, or for learning about alternative strategies for health management. Participants were aware that the credibility of online sources varied and the majority of women identified some assessment criteria. While interviewed women primarily reported interest in orienting and factual information from this source, a small number of participants used the internet to access the lived experiences of other women. Findings clearly confirm that search strategy for the vast majority of participants focused on utilizing the Google search engine. An important finding was not only that women tended to gather, compare and integrate information from multiple websites, but also that online IBs were inextricably linked with offline health IB and the everyday experience of health. In other words, the internet was part of a continuum of information gathering which was situated within women’s everyday life contexts. While HPs confirmed that the internet was a pervasive source of health information for women experiencing the menopause transition, they tended to express concern about the ‘noise’ created by the mix of informal and formal information available online. Nonetheless, the pervasive and ongoing use of the internet by participants and the satisfaction with retrieved information suggests that health information found online was relevant to the needs of women seeking information about the menopause transition.

Findings from this study support research suggesting that the mass media is an important information source for women in the menopause transition. Although the internet emerged as a prominent source for women who were actively searching for menopause-related information, women were more likely to encounter media-mediated health information either incidentally or when scanning or monitoring as a part of everyday routine media use. Findings indicate that women viewed the media as an important awareness tool and as a 'springboard,' which encouraged further information seeking. Participants valued the media for its capacity to provide an overview of new or timely health information (as opposed to facilitating in-depth investigation), and for its capacity to empower women by making them aware of potentially useful information. The notion that the media played a role in educating consumers, removed barriers to health information, and facilitated access to information which might otherwise be privileged was prominent in the data. Interviews with HPs provided contrasting information. Concern about the influence of media-mediated health information was significant and some HPs expressed concern about biomedical authority in a time when health information is pervasive online and in the media.

Another important finding was the value participants placed on libraries and books as trusted starting points for exploring health concerns. Despite the value placed on fast and easy access via the internet, the vast majority of women mentioned utilizing libraries and/or books as a part of routine health IB. While women discussed the pros, cons and uncertainties of health information mediated by other informal and formal sources, libraries and books were presented by participants as a presumed 'good' source for health information.

A final major finding with respect to information sources and women's responses to evolving health information about the menopause transition was that consistency between information sources was used as a heuristic which confirmed information accuracy and credibility. Source consistency was determined by multiple instances of similar information within a single type of source, and by similar information discovered as women moved between source types. Analysis demonstrated that information inconsistency served as motivation for ongoing information seeking whereas consistency facilitated the construction of uncertain health information as credible, and thus as a basis for information use.

8.1.3 Positioning and uncertain health information

Interviews with participants yielded more than unambiguous accounts of IB in the face of uncertainty. Findings illuminated the third research question: ‘How do women position themselves when encountering/seeking/exchanging health information, and how does that positioning influence further health IB?’ Women’s narratives provided a means for exploring the ways in which participants positioned themselves and information sources, and how cognitive authority was ascribed as women made sense of uncertain information about the management of the menopause transition. This facilitated deeper understanding of how women navigate uncertain health information mediated by the wide range of informal and formal information sources encountered within the context of everyday life. Findings demonstrate that participants positioned themselves as autonomous, collaborative and/or dependent information seekers and decision makers.

A primary theme was that many women presumed that they were autonomous and self-directed information seekers and decision makers. Participants accomplished this positioning by adopting biomedical language and suggesting notions of accountability and control through the presentation of personal responsibility and the recounting of specific situations in which they actively directed their own health management. While some participants consistently positioned themselves as autonomous, almost all of the participants who primarily positioned themselves as collaborative or dependent intermittently adopted autonomous positioning. This occurred without overt declaration of autonomy or covert overtones, but simply as women freely and frequently concurrently (1) consulted a multiple of information sources and heath practitioners; and/or (2) used or experimented with over-the-counter and/or alternative therapies. Women were largely unaware of their positioning practices; however, when explicitly asked about their role in personal health management, almost every participant expressly positioned herself as an autonomous decision maker. A small group of women felt that they were pressured into assuming autonomous positioning and analysis suggests that these women experienced some ambivalence towards personal responsibility for health management. Women primarily drew on individual authority when positioning themselves as responsible for their own health and well-being during the menopause transition, a significant theme being that individual authority was derived from being the unique interpreters of their own bodies and physical experiences. For women who demonstrated this positioning, HPs were reciprocally positioned as ‘trusted guides’ or ‘hired consultants.’

Second, women positioned themselves as collaborative information seekers and decision makers, with HPs taking reciprocal roles as co-collaborators. This positioning incorporated varying degrees of personal vs. HP involvement. Key features of this positioning were two-way information sharing, and appreciation for different types of knowledge and cognitive authority. Participants were more likely to position themselves as collaborative if they perceived that HPs also positioned themselves as collaborative participants in information sharing and decision making, and if they perceived that HPs valued not only biomedical knowledge but were open to hearing about other sources of information. Furthermore, women were less likely to value the biomedical expertise of HPs who did not foster two-way information exchanges, who did not appear to listen to or value experiential or personal knowledge, or who did not view the clinical encounter as a collaborative endeavour. This finding stands in contrast to the ‘informed patient discourse’ prevalent in consumer health literature. This discourse adopts a one-way communication model as it focuses on ‘patient education’ through the communication of biomedical knowledge. While interviewed HPs acknowledge the importance of collaborative relationships with women and most positioned themselves as collaborators, HPs tended to use knowledge entitlement based on biomedical knowledge in order to establish authority, thus inadvertently positioning women as dependent on HPs for accurate information.

While the majority of interviewed women positioned themselves as autonomous or collaborative information seekers and decision makers, a small number of accounts demonstrated dependent positioning. These women deferred to biomedical authority and positioned themselves as ‘patients.’ While this positioning was demonstrated by some through the category entitlement of HPs, the majority of women discursively positioned themselves as dependent by relating accounts in which they were passive objects of action on the part of HPs. Nonetheless, interviewed women rarely looked exclusively to HPs for information about this life transition: dependent positioning was most commonly temporal and evident at specific moments within participants’ accounts. Positioning occurred on a spectrum and women rarely assumed one position consistently throughout interviews. Elicitation demonstrated that women were more likely to express a desire to consult HPs and specifically gather biomedical knowledge when confronted with uncertain or evolving health information, thus suggesting a tendency to privilege biomedical knowledge in situations where sense making of uncertain health information is immediately desired. Participants who assumed dependent positioning were likely to reciprocally position HPs as prescribers or as information providers.

Although analyses revealed three primary positions as women navigated uncertain information about health and wellness during the menopause transition, these positions were dynamic and changed fluidly during interviews. Furthermore, they were influenced by multiple factors, most particularly by the perceived nature and quality of interactions with HPs and by women’s personal contexts. Women’s narratives commonly included specific incidents which influenced positioning. While some women moved from autonomous positioning to collaboration when they encountered HPs who fostered two-way communication and respect for the knowledge women brought to the therapeutic interaction, many women positioned themselves as autonomous in response to a lack of information from and/or non-collaborative communication style of HPs. It is interesting to note that HPs showed limited appreciation for their own influence on the positioning of women. Women's contexts, particularly their experience with menopause symptoms, also emerged as an important influence on positioning. While not predictive of positioning (women both moved from autonomous to dependent positioning, and became increasingly autonomous because of their symptoms experience) the physical manifestations of menopause emerged as prominent influences on the ways in which women positioned themselves and ascribed cognitive authority.

The positions women demonstrated through their narratives were both enabled and restricted by the socio-cultural discourses which shaped women's perceptions of menopause and perceptions of their own roles as information seekers and decision makers. In addition, participants experienced menopause against the backdrop of historical discourses with respect to menopause management. Two discourses evident in women's narratives and influenced by the Women's Health Initiative study (WHI) were discourses related to prevention and to menopause as a NLT. Data revealed that consideration of HT was situated within a 'HT as risk' discourse and that the pre-WHI discourse of prevention was transformed from one pertaining to life-long disease deterrence to one of short-term symptom control. The focus on short-term use was highlighted by participants' prominent concerns about HT dosage and duration, and by the notion of 'menopause as a NLT.' An interesting observation emerging from interviews with HPs was that the 'HT as prevention' discourse may be undergoing an additional iteration, this time from symptom prevention to *aging* prevention. This was attributed to celebrity presentations which emphasized bioidentical hormone use as a strategy for maintaining youthful appearance. While the discursive construction of 'menopause as a symbol of aging' was seen by some participants as a barrier to the discussion of menopause (particularly issues related to sexuality), the majority of participants focused on health as a holistic endeavour and positioned themselves as proactive managers of the aging process.

Findings related to women's positioning as autonomous, collaborative and/or dependent information seekers and decision makers had important implications for SDM. These will be discussed in section 8.4.2.

8.1.4 Women's construction of uncertain health information

Finally, findings address the fourth research question: 'How does the construction of uncertain and/or evolving health information encountered via diverse mediums and within various contexts influence health IB, KT, and encounters with health professionals?'

The notion of KT as a personal process by which women make sense of and potentially use health information provides a lens for exploring IBs in situations where health knowledge is evolving. Given the aims of the study it was expected that participants would focus on and discuss the changing and hence uncertain nature of menopause information. Narratives confirm that ongoing media coverage of controversies and developments as well as personal experiences with health information and the menopause transition heightened women's familiarity with the notion of health information as a 'work in progress.' Analysis demonstrates, however, that whereas researchers may view health knowledge as emergent, participants tended to view it as circular, capricious, and potentially contradictory. This led women to assign responsibility for unreliability to either the media or to sources of formal health information, such as medical research itself. The view that health knowledge is cyclic provoked uncertainty and scepticism, and women identified specific strategies which they used when making choices in identified areas of uncertainty. These included both ignoring conflicting information and a 'wait and see' approach. For a small number of women, evolving information about menopause management provided hope for improved treatment options in the future. Analyses demonstrate that women were active information seekers in response to uncertain menopause information and these IBs represented the beginning of an ongoing process as women explored information about menopause management. A prominent theme was that actual or perceived uncertainty with respect to conventional medical knowledge increased women's feelings of responsibility not only for management of health and well-being during this transition, but also for making sense of uncertain and/or conflicting health information. This theme was confirmed by both HPs and the literature: in situations of medical uncertainty HPs are more likely to expect consumers to take active responsibility within the context of SDM.

The majority of women did not reach specific conclusions with respect to contrasting material presented during the elicitation portion of the interview; rather, participants situated articles within a larger world of health information and knowledge communication. Most women were aware that information was presented by, but did not originate from, the media sources and noted issues related to information ethics, such as the potential commercial influences associated with information creation and distribution. Analyses demonstrate that women construct 'sense' by seeking to clarify uncertain information about the menopause transition through interaction and consultation with a range of sources, including intra-personal sources. Findings support the notion that women valued media as an 'awareness tool' and suggest that women's experience with evolving menopause information may have provided context which influenced women's subsequent construction of the contrasting information in the elicitation articles. By situating media-mediated health information within a larger context, women drew attention to the multifaceted information worlds they inhabit and access as they make sense of uncertain health information.

Consistent with the PARIHS framework, interviews with women suggest a nuanced and varied understanding of *evidence*. Analyses demonstrate that women primarily constructed evidence as research, material object, negotiated belief or opinion, and lived experience. While most women were aware that research evidence has potentially important implications for menopause management, a primary theme emerging from women's narratives was the notion of research evidence as contested ground. Participants raised questions related to the quality of research, potential conflicts of interest, and the reporting of research evidence. These concerns provided women with a discursive means of qualifying response to research evidence. Although expressions of concern were frequently vague and suggest that women would be empowered by basic understanding of research methods, participants' questions served to distance women from immediate application of research findings and to encourage further information seeking. Data analyses, in fact, reveal that women were more likely to appreciate research evidence when HPs acted as facilitators for this form of evidence. Although not a primary form of evidence for participants, objective or physical evidence (e.g. hormone level testing) was important to women, perhaps particularly because of the uncertainties associated with the course of menopause and the experience of menopause symptoms. Meaning and practical use of material evidence was based on individual circumstances and the construction of need, and was, furthermore, constructed by and between women and others (primarily HPs) as they talked about the physical object. Evidence as research or as objective material object suggests an empirical basis for health decision making; however, interviews with women also brought forward the notion of evidence as negotiated belief. For participants, validity of information was based on determining what or who to believe among the available options. In other words, representations of research or material evidence were understood by women as negotiable opinion or belief. Finally, a prominent theme in the interviews was the identification of lived experience as a critical source of evidence. For many participants, this experientially acquired evidence provided sufficient basis for questioning the validity of other forms of evidence and was, at the very least, considered in conjunction with other forms of evidence. The notion of experientially derived evidence draws attention to women's personal contexts and suggests that women construct their experiences as valid evidence which influences the navigation of uncertain health information and decisions about menopause management.

Given the rich data provided by interviews, it is valuable to summarize major themes which illuminate how women constructed uncertain health information which they encountered via informal and formal information sources, and how this construction influenced IB, decision making, encounters with HPs, and KT. Prominent themes include: the ‘postures’ women assumed as they navigated uncertain menopause information, source complementarity, social contexts for learning, and the role of narratives when making sense of uncertainty.

Women demonstrated analytic/logical and experiential/intuitive postures as they experienced, made sense of and used (or did not use) health information. These postures reflected women’s conscious and unconscious dispositions as they processed changing health information. Analytic postures were demonstrated by a focus on logical connections as women explored uncertain information mediated by a range of sources, by the use of logic and different forms of evidence to explain the information use, and by the conscious appraisal of information and events in order to determine application of information within personal contexts. Women also adopted experiential postures and incorporated intuition, affect, intra-personal information sources and lived experience. Analyses demonstrate that these approaches were not mutually exclusive and in fact women adopted different postures as they made sense within specific contexts. Findings suggest that greater understanding of these postures will increase understanding of IB and decision making during life transitions and will assist HPs and information professionals as they strive to facilitate health information literacy.

Health education is frequently conceptualized as a competition between information sources for the limited attention of the consumer. Data from this study, however, suggest that women who were seeking information about menopause management exhibited enduring interest in the topic and fluidly incorporated multiple sources as they sought to fulfill their information needs. In other words, they exhibited source *complementarity*, not competition or displacement. Data presented throughout the ‘results and discussion’ chapters provide insight into how women experience source complementarity and demonstrate its integral constructive role as women made sense of and used informal and formal information about the menopause transition.

A third and prominent theme illuminated by interview data was the notion that social contexts play an important role as women make sense of health information related to menopause management. Analyses demonstrate that women find interactive contexts in a variety of ways including interpersonal information sharing, online personal commentaries or blogs, and/or social contexts provided vicariously through the media. Social interaction facilitated learning, uncertainty management and knowledge construction in a number of different ways (for example, it played a key role in encouraging women to persevere and make sense of confusing health information about the menopause transition). Furthermore, interviews revealed that women themselves valued and specifically identified a preference for social contexts for learning about and constructing knowledge about menopause management. These findings bring emphasis to notions of social constructionism and the idea that sense making is facilitated by learning that occurs between women and others. In keeping with findings related to complementarity, women did not view learning through more informal social contexts or via interactions with HPs as conflicting; rather, they were empowered by supportive contexts which facilitated information exchange.

Finally, interview data demonstrate that participants made sense of uncertain health information about the menopause transition through the telling of narratives and by listening to the stories told by other women navigating this transition. Interviews proved to be constructive opportunities in which women brought together multiple facets of their experiences with menopause and with menopause-related information. The contribution of narratives was particularly apparent as women related their experiences with menopause symptoms and their journeys as they sought to make sense of uncertain information about symptom management. Analyses suggest that it was in the opportunity to relate stories that participants came to a deeper understanding of changing health information, that sense was constructed from uncertainty, that women were able to translate knowledge into practice within the context of their everyday lives, and that patient perspective was illuminated for HPs. While evidence based practice (EBP) has urged practitioners to look to the research literature for appropriate evidence on which to base practice, narratives situate patients within their own contexts, thus facilitating truly patient-centred health care.

8.2 Other interesting findings

8.2.1 Knowledge translation in everyday life: PARIHS framework

While KT is typically identified as a task for professionals or institutions, this study supports the view that individuals may also engage in a process of KT as they respond to, make sense of and potentially use health information encountered within everyday life contexts. This individual, contextual and constructed view of KT is informed by the Promoting Action on Research Implementation in Health Services (PARIHS) framework. Although this framework is utilized most commonly for KT research at organizational levels, the notion that the ability to use information or change current practices is a function of the relationship between evidence in diverse forms, women's contexts, and the ways in which evidence is presented or promoted (facilitation) supplies a heuristic which thematically guided interviews and was evident in themes emerging from interview data.

Participants valued research evidence, but other forms of evidence (for example, experiential evidence) were equally valued and frequently used interchangeably and/or in concert with one another. Data analyses in fact suggest that relationships with HPs, formal information provision, and personal decision making were facilitated when women perceived that HPs accepted and valued different types of evidence. Findings not only confirmed the notion of an evidence spectrum but also that "the production of evidence is a social as well as scientific process (Rycroft-Malone, Seers et al. 2004, 84). Evidence was constructed between women and HPs as they discussed changes in research evidence and subsequent evolving HT prescribing practices, the application of population based research to individuals, women's individual quality of life and the experience of symptoms, and personal risk/benefit factors; it was constructed between women and in social contexts as they observed and discussed personal experiences, experiential knowledge, and their of understanding health information delivered by a range of mediums; and it was constructed within individual women as they evaluated the often contrasting types of evidence they encountered via informal and formal channels. Because of the evolving nature of health evidence with respect to menopause management, the implementation of research evidence was moderated by other forms of evidence, and information use or change in current practice can be attributed in part to the multifaceted manifestations of evidence.

Data analyses demonstrate that personal context played an important role in what evidence was valued and how it was incorporated within women's lives. Life requirements, (such as work and/or family responsibilities), as well as perceptions with respect to quality of life (for example, the experience of symptoms) were important contextual factors which influenced participants' translation of health evidence into potentially useable information. Because these factors were individually experienced and not necessarily transparent to HPs or to women themselves, narratives were important vehicles for illuminating context both during the interviews and in the construction of evidence between people. While the experience of menopause is on one level very individual, there is also a universal aspect to the experience. Findings suggest that the sociocultural context of menopause (for example issues related to gender and to aging) also played a role in women's individual experiences as they responded to, made sense of and acted (or chose not to act) on uncertain health information related to this life transition. While evidence is the most apparent input within the context of EBP, findings support the notion that context was a multidimensional and critical ingredient in the KT process of participants.

Findings support the notion that different information sources play facilitating roles in their communication of health information. The way in which evidence and its implementation was presented and promoted by both formal and informal sources influenced women's responses to and use of menopause information. Participants were, for example, much more likely to respond to evidence provided by HPs if women felt that there was a two-way exchange of information and respect for a range of different forms of evidence. This suggests that it is not the information alone which promoted information use; it was the way in which the information was enabled through effective communication by

HPs. A further example is provided by the lived experience carried in personal stories and sought by women in their interactions with others or gathered vicariously from the media and internet. These narratives carried evidence (for example, experiential evidence) and were thus a means of facilitation which effectively enabled information use as women struggled to sort out challenges such as the recognition of menopause symptoms, symptom management, and initiation or change of treatment approaches. While the PARIHS framework limits facilitation to the deliberate actions of an appointed facilitator who seeks to enable a specific practice (Harvey et al. 2002), results from this study support a broad view of facilitation. In situations of uncertainty where individuals are seeking to make sense of health information encountered in their everyday lives, it appeared that understanding of health evidence was enabled and made potentially actionable by a range of facilitating circumstances. While some of these were deliberate (for example, communication strategies used by HPs and in consumer health materials), others occurred as a result of the medium itself (for example, access to online communication of experiential evidence by others with a similar health concern) and others were a results of sociocultural influences (for example, the celebrity culture which influenced reception to health information provided by Oprah).

This study suggests that the PARIHS framework provides a useful heuristic for exploring participants' experiences, and their navigation and use of uncertain information about the menopause transition. It promotes consideration of the diverse factors which are required in order to achieve the translation of knowledge into practice in the lives of individual women. Attention to facilitation is a particularly useful aspect of this framework when applied as a heuristic for the exploration of KT on an individual level. Principles of EBP have brought important emphasis to the documentation and use of the best available evidence; this heuristic focuses attention on the way in which evidence is enabled. All three core elements of the PARIHS framework made important contribution to this study and have potential to contribute to the practical use of health knowledge by individuals who are making sense of uncertain health information. Research using this framework, however, remains primarily focused on organization level change. I believe that while evidence, context and facilitation are critical elements for the exploration of health information use and, when used in concert, provide a useful heuristic, this study also raises questions with respect to this framework's formal use for further study of the KT process undertaken by individuals.

8.2.2. Elicitation: Capturing subjective understanding

Elicitation techniques have not received significant attention in the literature. Although this may be because they are unidentified or differently identified in the published literature, this study suggests that presentation of specific material which "seeks to elicit further or to reelicit properties, features, or reactions that are directly and /or indirectly relevant to the content area" (Johnson and Weller 2002, 495) is a useful technique for revealing women's understandings of uncertain health information presented in the popular press.

Triangulation of research methods is not uncommon in qualitative research, however, the use of two approaches within the single interview proved to be an effective and efficient means of gathering a range of data about women's response to uncertain health information. I also observed that presentation of the articles stimulated the interest of participants and revealed more subjective reaction as they were confronted with a concrete example of contrasting media stories. While narratives brought the issue of menopause management forward in a reflective and perhaps retrospective manner as women recounted their experiences and stories, elicitation served to bring forward affective response to uncertainty. Furthermore, this approach facilitated concrete discussion of behavioural intent with respect to seeking clarifying information.

These findings suggest that while semi-structured interviews will potentially bring forward rich data related to participants' thoughts, experiences and reflections, elicitation techniques offer a unique opportunity to draw out affective response and reaction to the 'here and now' experience associated with a given subject area.

8.3 Theoretical contribution

This exploratory study used different theoretical perspectives, specifically human information behaviour theory, a social constructionist approach, the PARIHS framework, and positioning theory, to generate and illuminate findings. Use of multiple theories proved to be an effective means of generating rich data which facilitated the goals of this exploratory research project, furthered understanding of emerging themes, strengthened research credibility, and improved potential transferability of findings. While strong theoretical underpinning is important for all scholarly research, this study brings attention to the contribution of theory triangulation for exploratory research – research which entails “broad-ranging, intentional systematic data collection designed to maximize discovery of generalizations based on description and direct understanding” of a particular process or situation (Alan Stebbins 2008). This study demonstrates, for example, that whereas human information behaviour theory provided a foundation for investigation of information sources and IB, positioning theory brought focus to women’s roles in decision making and to sociocultural influences, and the PARIHS framework facilitated exploration of KT as a multifaceted, constructed process which is shaped not only by information itself, but by women’s contexts and the ways in which knowledge is presented.

Triangulation of theory (Patton 1999) was, furthermore, supplemented by other theoretical perspectives which were incorporated based on themes emerging from the data. Of particular note was the theory of complementarity (Dutta-Bergman 2004), and notions arising from the field of psychology and related to rational and experiential systems of information processing (Epstein 1994). These theories validated and extended research findings by rooting themes in previous research while at the same time demonstrating “theoretical elaboration in new contexts” (Vardeman and Aldoory 2008, 286). The notion of complementarity provides a particularly clear example of this. While originally proposed in the communication field as a means of understanding utilization of traditional and new media, this theory provided insight with respect to the complex information worlds which women in this study adeptly navigated and called on when making sense of uncertain health information. In addition, utilization of this lens brings attention to its application within other disciplines (for example, Library and Information Science (LIS) and Nursing).

It is important to note that multiple theories were not used as a means of comparing or evaluating theories against one another; rather, multiple theories illuminated and extended understanding, as well as "open[ing] up the possibility of dialogue across theories" (Varghese et al. 2005, 24). In fact, Varghese et al. (2005), who used three theoretical perspectives to explore teacher identity, note that "multiple theoretical approaches are absolutely essential if we are not to lose sight of the real-world complexity of our subject" (40). This study makes an important contribution by illustrating the use of multiple theories in the exploration of a complex, real-world situation: women's experiences as they responded to and made sense of evolving information about the menopause transition.

8.4 Implications for practice

Two primary implications for practice in health fields and LIS emerge from this dissertation: implications for health literacy and for SDM. These areas of inquiry have been discussed extensively in the biomedical literature and as well as in LIS literature. Focus in both of these areas, however, has tended to be on the provider rather than the consumer. In this study, attention is given to women's perspectives with respect to navigating uncertain or evolving information about the menopause transition. As a result, findings suggest that notions of both health literacy and SDM should be broadened to incorporate how women actually use information, and how women position themselves with respect to decision making in areas of non-crisis health management, such as the menopause transition. Focus on women's experiences navigating uncertain and changing health information also suggests explicit implications for information professionals working in health fields, and for HPs.

8.4.1 Health literacy

Health literacy has been widely defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Berkman, Davis, and McCormack 2010, 16). This definition draws attention to individual capacity and, by extension, to health literacy as a skill which can be enabled by the provision of appropriate materials or taught by assessing and ameliorating the deficits of the consumer. This latter activity has traditionally focused on writing and numeracy skills, but has more recently focused on outcomes, for example, the capacity to make health decisions and to understand and participate in communication within health care settings (*cf*. Berkman, Davis, and McCormack 2010; Parker 2005). While these capacities are important, findings from this study suggest that current focus does not incorporate the complex, everyday life information worlds which women inhabit, nor does it take into consideration information use – “how information is actually used and made valuable in people’s lives and made sense of in the context of their own experiences” (Souden et al. 2010). This study of women’s IB and the construction of uncertain health information related to the menopause transition suggests a range of implications for improving health literacy. These implications are important both for HPs who deal with women on a one-to-one basis as they discuss the individual woman’s physical realities, concerns and needs, and for information professionals who may be directly involved with the provision of health literacy education and resources.

- Results from this study demonstrate that independent exploration of health information is a pervasive strategy for women seeking to understand uncertain health information about the menopause transition. This is likely to occur prior to seeking information via formal channels as well as following and in conjunction with HP consultation. This, as well as participants' explicitly expressed preferences, suggests that education about this life transition should be appropriately integrated by HPs as a routine part of everyday health provision. Findings suggest that this integration, which should commence before the anticipated onset of the menopause transition and be communicated as an unremarkable part of information regarding women's lifespan health and well-being, will begin to address the sociocultural silence which surrounds menopause, thus potentially improving women's understanding of their experiences when they reach this life transition.

- Findings demonstrate that independent health information seeking is pervasive in this population, and yet concerns about research evidence were prominent (particularly concerns about research quality, conflicts of interest, and the reporting of research). Expressions of concern, however, were vague and primarily constructed by participants as justification for distancing themselves from the presented information. This suggests that women would be empowered by basic understanding of research methods and terminology. This knowledge would allow women to interact constructively with information about health research which is covered in the popular press, discussed online, and communicated by consumer health publications and/or HPs.
- This study revealed that the internet was a ubiquitous source of health information for participants and, furthermore, that women would not only benefit from, but would welcome health information literacy instruction which included generic assessment skills with respect to online information. Women demonstrated that they were aware of the varying authority and quality of websites. Differing views of relevance and different information needs, however, suggest that health literacy which focuses exclusively on promoting specific 'trustworthy' websites and discouraging the use of other websites would not meet the varying needs of participants. Women valued the internet in part because it gave them unfiltered access to alternative points of view, thus allowing them to read

material which they perceived as relevant to their needs (for example, their need for experiential evidence). On the other hand, participants valued HPs who pointed them to secondary sources of health information. This reinforced women's trust in both the HP and the suggested supplemental material. This finding suggests that in addition to generic skills which would facilitate assessment of the websites which women themselves discover and value, women would welcome website recommendations from HPs. This finding has implications for HPs. Many interviewed HPs did not maintain familiarity with online consumer health resources and felt unprepared to make recommendations to women.

- While health literacy instruction primarily focuses on *evidence* as an empirically derived construct, interviews with women suggested that women's information needs are contextually situated and, as a result, they valued, integrated and made use of different forms of evidence. For example, a theme which emerged from data analyses revealed that women specifically sought experiential evidence in order to determine that they are 'normal' in their experience of the menopause transition and/or to illuminate research evidence. This suggests that notions of health literacy must expand and begin to take into consideration the differing types of evidence which women find useful at particular moments of need. This is a challenging proposition as EBP (and by extension health literacy initiatives) has been steeped in suspicion of experiential knowledge. Health literacy education can begin to address this dilemma by moving beyond an emphasis on 'good' vs. 'bad' information sources and instead focus on helping women to understand that different forms of knowledge (or evidence) are valuable for different information needs. Women would thus be encouraged to differentiate between the type of information they were seeking, the suitable authority for that information, and appropriate use of different forms of evidence.
- Movement away from teaching 'good' vs. 'bad' information sources is particularly important because of the evolving nature of menopause

information. Perhaps because they were aware of ongoing uncertainty with respect to menopause management, women specifically valued the media as an awareness tool and they appreciated online access to a wide range of perspectives. These findings suggest that health literacy instruction which focuses on generic assessment skills and which clearly addresses the varying needs which different types of information sources meet, will help women navigate changing and uncertain health information.

- Finally, given findings with respect to complementarity, health literacy constructs need to begin to incorporate the multifaceted realities of women's information worlds and the complex ways in which women interact with and potentially use health information. Participants moved fluidly between informal and formal information sources and were, in fact, likely to scan, monitor and seek information across mediums as they constructed understanding from uncertain information about the menopause transition. Women not only valued varying sources for the range of information provided, they were also more likely to engage with HPs when they perceived that HPs were open to different types of knowledge. These findings suggest that health information providers and/or health information literacy educators should assume that women gather information from a wide range of sources and should provide positive guidance with respect to the strengths and the types of evidence or knowledge which can be obtained from different sources. Instead of ignoring or vilifying informal, media or other non-traditional sources of health information, communication of the information derived from these sources should be encouraged in order to better understand women's contexts and needs, and to have a voice in women's integrative sense making.

8.4.2 Shared decision making

In the health literature SDM is promoted as a desired decision making model and is characterized by communication from HPs to patients in order to help them understand treatment choices and come to an agreement based the best available medical evidence and the options provided by the HP. Although this represents an important step forward when compared with paternalistic styles of decision making, data analyses suggest that women tended to move between autonomous and collaborative positioning, and between the SDM and the informed choice model for decision making. These findings have important implications for HPs who are working with women to achieve optimal health and well-being during this life transition, and for information providers who seek to make available information which will support decision making in health care environments.

- This study revealed that women's views of SDM were nuanced and differed from typical conceptions in the medical literature. Women explicitly positioned themselves as autonomous information seekers and decision makers, and yet they valued input from HPs and findings suggest that participants were more likely to appreciate research evidence when HPs acted as facilitators for that evidence. Data demonstrate that women did not feel restricted to options provided by HPs, nor did they perceive that health management decisions should necessarily be decided by mutual agreement between women and their health providers. However, women sought out collaborative relationships with HPs who fostered two-way communication, who appeared to appreciate different types of knowledge and cognitive authority, and who supported them in their quests for information and decision making. These findings present a challenge for HPs as they strive to balance women's notions of autonomy and need for health expertise and HPs' own moral and potentially legal responsibility to provide what they perceive to be optimal patient care. Findings suggest that particularly in areas where health information is uncertain and emergent, SDM models should encompass two-way information sharing and consideration of knowledge and treatment options which may be introduced not only by HPs, but also by women. While HPs may not always be in agreement with the decisions women make, acknowledging the uncertain and emergent nature of biomedical knowledge will allow acceptance of provisional decisions based on women's current contexts and will leave the door open for further collaboration and ongoing revision of health decisions.

- Findings demonstrate that women gather information from a wide range of sources, and that the internet played in integral role in the IBs. Participants valued information sources according to the ways in which they fulfilled information needs and cognitive authority changed according to women's information needs. While data suggested that complementarity was a primary feature for women, HPs tended to differentiate between information sources and, in particular, they viewed information from interpersonal, internet and media sources as being in competition with formal health sources. These results, as well as complementarity theory itself, suggest that HPs should view women's IBs as a positive feature. Rather than posing a challenge to authority, IBs which incorporate informal sources are most commonly accompanied by IBs which involve formal information sources, thus empowering women to participate in SDM.
- Data further demonstrate that although women move fluidly between information sources and personal positioning, women were more likely to position themselves as collaborative (as opposed to autonomous) if they perceived that HPs were also positioning themselves as collaborators. This suggests that HPs can deliberately engage in behaviours which facilitate collaboration and SDM. These behaviours might include the following: focus on women's narratives in order to gain insight into contextual factors, engage in two-way information exchange rather than focusing exclusively on biomedical authority, and facilitate women's IBs. This

furthermore implies that for health information to be made actionable, consideration should be given not only to the delivery of high quality medical evidence, but also to women's contexts and the ways in which the information is enabled through effective communication by information providers.

- Women's active investment in information gathering and the fact that at some point in their information seeking the vast majority of participants looked to HPs as authoritative sources of health information suggests that HPs have a very real opportunity to facilitate decision making by fostering trust based relationships with women. Data analyses highlighted the critical role trust played in mediating women's confidence in information provided by HP. Active engagement not only as an information provider but also as a facilitator will help foster trusting relationships between women and HPs.
- Consumer health information has been almost exclusively designed to meet the needs of women exhibiting an analytic/logical posture as they strive to make sense of uncertain health information. Findings, however, demonstrate that women adopt both analytic and experiential postures when interacting with and integrating uncertain information about the menopause transition. This suggests that further understanding of these postures will increase understanding of women's IB and decision making during this life transition, and will facilitate the development of educational materials which incorporate diverse modes of information processing. It also highlights the importance of women's personal contexts and the ongoing importance of the relationships between women and their health providers.
- Finally, results from this study suggest that more attention should be directed to women's lifespan development and to dealing with negative stereotypes related to aging women and the menopause transition. Interviews suggest that these sociocultural constructions played a role in women's lack of preparation for this life stage, inhibited women from

seeking information about the menopause transition, and contributed to the disregard some women experienced when they approached HPs with concerns about this life transition. In order to facilitate collaborative decision making, findings suggest that health providers and information professionals must be prepared to deal with all stages of human development and take extraordinary care not to contribute to negative constructions of the aging process.

8.4.3 Implications for information professionals and HPs

Information professionals play a distinctive role in managing information, facilitating access to information resources, and guiding health information literacy of users. Greater understanding of women's experiences as they respond to, make sense of and potentially use information will allow health librarians to more effectively meet the needs of this population. This research makes theoretical contribution to LIS by demonstrating the role of IB theory, a social constructionist approach, and positioning theory in illuminating the intricate ways in which women interact with and integrate uncertain health information related to non-crisis health management. Investigation based on the heuristic provided by core elements of the PARIHS framework highlights the critical roles of context and facilitation in the translation of knowledge into practice within women's lives. These findings suggest that in order to enable use of health information, those working as health librarians or information professionals must equally focus on the contextual relevance of information and the way in which information is presented or promoted to women.

This study furthermore highlights the notion of complementarity. While EBP brings focus to the central role of empirically derived evidence, this study draws attention to the varying types of knowledge and forms of evidence that made critical contribution to participants' on-going construction of health information. This suggests that instead of focusing exclusively on empirically derived health information, information professionals working in health fields need to consider providing guidance and information literacy instruction which focuses on the best quality information which meets the specific information need of the patron. The theory of complementarity makes a particular contribution to information professionals working in health fields as it illuminates women's fluid movement and use of informal and formal health information. Participants' interaction with health research which is communicated in the popular press, on the internet, and by consumer health publications and HPs suggests that women will be empowered by health information literacy instruction which enables basic understanding of research methods and terminology. In addition to facilitating understanding of research evidence, data suggest that information professionals should also encourage the development of skills which will allow women to appropriate assess the sources which they discover and value within the context of their own lives.

Implications for HPs have been discussed previously (particularly in section 8.4.2); however, findings also suggest that training for HPs working with this population should include greater awareness of the diverse experiences of women navigating menopause, including enhanced awareness of range of onset and greater appreciation for the devastating realities of symptoms for some women. While acknowledging the universality of the menopause life transition and its place as an expected and normal transition, interviews with women suggest that HPs dealing with women on a day-to-day basis will benefit from greater appreciation for the individual experience of this life transition, and the varying need for therapeutic intervention both between different women and, for individuals, at different stages of the transition. Furthermore, greater consideration must be given to the nuances of SDM. While women's desire for autonomy varies both between and within individual women, findings from this study imply that collaborative decision making can be enhanced if women perceive that HPs position themselves as collaborators with their patients.

8.5 Future research directions

At the same time as exploring sense-making and information behaviours elicited by uncertain and/or evolving health information, this research project raises questions which suggest topics for future research. Primary areas of potential future investigation relate to uncertain health information, SDM and positioning, health literacy and consumer health materials, and complementarity.

This study explored women's interaction with and integration of informal and formal health information related to management of menopause transition. This topic, which received exhaustive coverage in the medical and consumer press following the premature cessation of the WHI in 2002, is widely recognized among both women and HPs as an area where health information is uncertain and evolving. Health information in many other areas is also explicitly emergent; furthermore, in all areas of health there is uncertainty as population based findings are translated into practice and applied within the contexts of individual lives, and as new discoveries are made. This study is a first step in the explicit exploration of how people translate uncertain health information into use within their lives. Future research should explore how other populations and those experiencing a range of non-crisis health conditions navigate health management in situations of uncertainty. Although in this study interviews with HPs focused on women's responses to uncertain health information, findings suggest that it would be valuable to explore how health professionals respond to, make sense of, communicate and use uncertain health information.

Decision making emerged as a complex task which entailed the integration of different forms of knowledge (for example, empirical and experiential) and a range of informal and formal sources. Further exploration of the nuances of decision making in situations of non-crisis health management and uncertain health information is warranted. In particular, further study could investigate the potential impact of deliberate HP actions which facilitate collaboration (for example, specific facilitation of women's IBs). A study such as this might explore how purposeful HP actions influence women’s positioning with respect to information sources and their health decision making.

Given the intricate ways in which women navigate the many information sources they encounter within the context of everyday life, specific exploration of health literacy instruction and its influence on the ways in which information is actually used and made sense of would make a valuable contribution both to health fields and within LIS. Study should incorporate investigation into how health information literacy instruction might address the different forms of evidence (for example, experiential) which women encounter, seek and make use of. In addition, HPs’ roles as facilitators of health information warrant further study (for example, exploration of the impact on IB of HP facilitated supplementary materials or referral to specific additional information sources).

An additional area of investigation suggested by this study is an examination of consumer health materials themselves (perhaps utilizing content or discourse analysis). Women draw on both analytic and experiential information processing modes as they make sense of uncertain health information, and yet the literature suggests that formal consumer materials focus almost exclusively on analytic processing (Hibbard and Peters 2003). Findings suggest that, given that women adopt and move between both analytic/logical and experiential/intuitive postures when engaged in IBs, further understanding of both of these approaches and of health messages which provoke both analytic and experiential responses will improve understanding of women’s IBs and assist HPs and information practitioners as they seek to facilitate health information literacy and use.

Finally, this study has extended notions of complementarity by exploring source complementarity as it relates to women’s use of informal and formal information sources encountered in the context of everyday life. This theory holds promise for illuminating further exploration of the multifaceted information worlds which women inhabit. In addition, investigation of the application of this theory in other populations of health consumers and potentially HPs would add both theoretically and practically to understanding of health related IBs.

8.6 Conclusion

This exploration of women’s experiences and IBs as they made sense of uncertain and evolving health information makes a valuable contribution to the research literature both in LIS and in health fields. While studies have quantitatively documented such things as the information sources favoured by women experiencing this life transition and changes in the use of HT since the early 2000s, this study demonstrates the importance of exploring how people make information valuable within the context of their own lives, the complex ways in which information is integrated, understood and make actionable, and how relationships between people influence decisions about personal health management. Limited qualitative work has been done in health fields and, although the literature has called for exploration of uncertainty, little work has been done which qualitatively illuminates how and why women choose to access and use information resources, how people navigate and make sense of the diverse information sources accessed, and how women manage tensions between informal and formal information as they manage personal health and wellness. Findings not only reveal the rich insights which were generously provided by interviewed women and HPs, they also demonstrate the critical contribution of qualitative investigation to our understanding of women’s experiences navigating uncertain menopause-related information, and how women actually make use of uncertain health knowledge within their everyday lives.

With the dissemination of research results, it is my sincere hope that professionals in LIS and in health fields will gain fresh insight into the everyday and yet complex information worlds which people navigate and must make sense of in order to make decisions about health and wellness, and a new sense of their own potential roles as facilitators of health information and decision making. I further hope that this study brings new recognition for the critical importance of fostering collaborative relationships which draw on a range of evidence and knowledge types, and a renewed appreciation for the significant influence of women’s individual contexts on their information needs and health management.

Both information professionals and HPs can play a critical role as they facilitate access to and understanding of health information, and translation of that knowledge into practical use.

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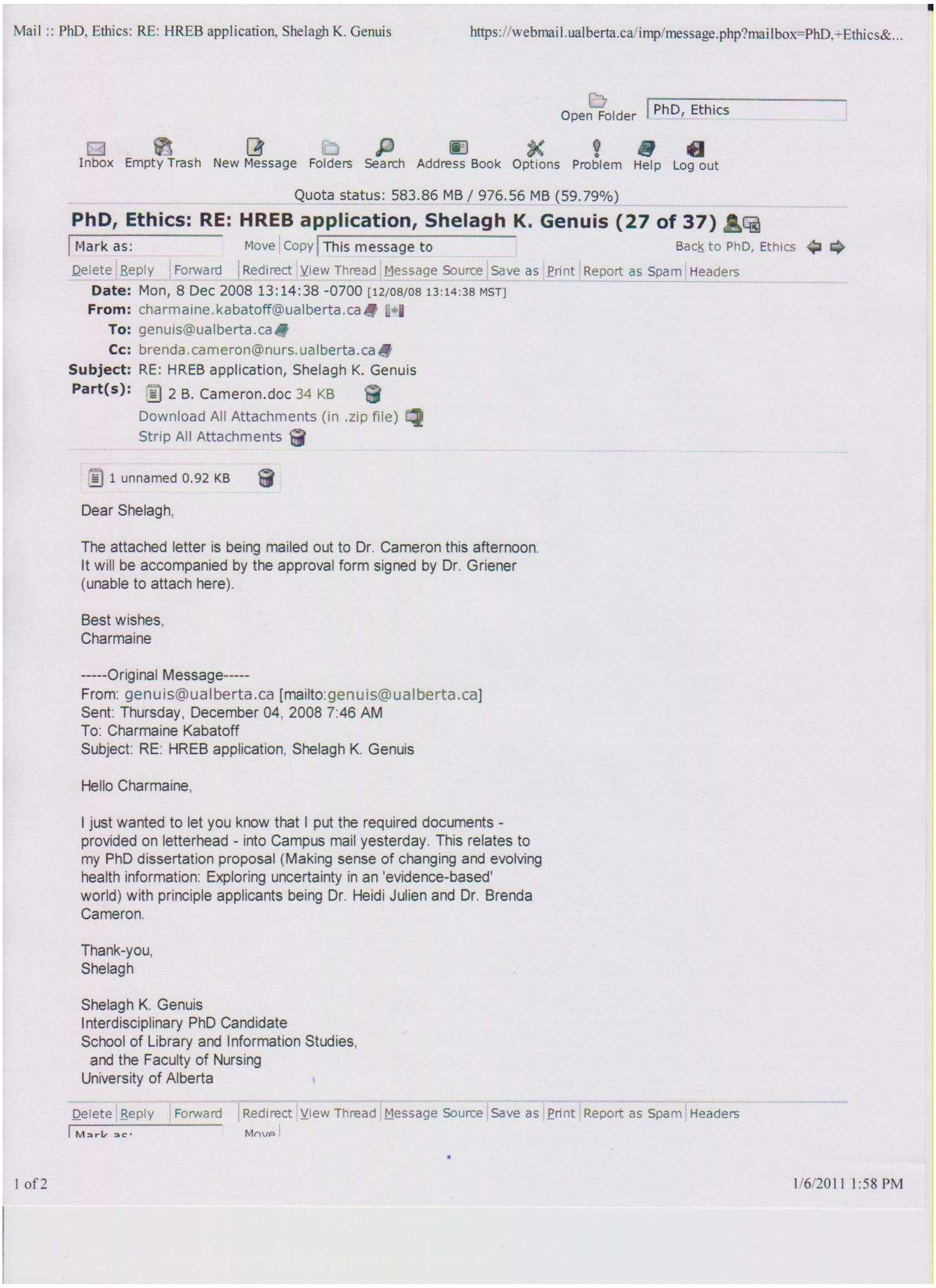
APPENDIX A
LIST OF ACRONYMS USED IN DISSERTATION

CBC	Canadian Broadcasting Corporation
CIHR	Canadian Institutes of Health Research
CMA	Canadian Medical Association
EBP	Evidence-based practice
ELIS	Everyday life information seeking
FDA	Food and Drug Administration
HP	Health professional
HT	Hormone therapy
IB	Information behaviour
KT	Knowledge translation
LIS	Library and Information Science
NAMS	North American Menopause Society
NLT	Natural life transition
NSERC	Natural Sciences and Engineering Research Council of Canada
PARIHS	Promoting Action on Research Implementation in Health Services
SDM	Shared decision making
SSHRC	Social Sciences and Humanities Research Council of Canada
SOCG	Society of Obstetricians and Gynaecologists of Canada
WHI	Women’s Health Initiative

APPENDIX B
ETHICS AND ADMINISTRATIVE APPROVAL DOCUMENTATION



Mail :: PhD, Ethics: RE: HREB application, Shelagh K. Genuis https://webmail.ualberta.ca/imp/message.php?mailbox=PhD,+Ethics&...

Quota status: 583.86 MB / 976.56 MB (59.79%)

PhD, Ethics: RE: HREB application, Shelagh K. Genuis (27 of 37)

Date: Mon, 8 Dec 2008 13:14:38 -0700 [12/08/08 13:14:38 MST]
From: charmaine.kabatoff@ualberta.ca
To: genuis@ualberta.ca
Cc: brenda.cameron@nurs.ualberta.ca
Subject: RE: HREB application, Shelagh K. Genuis
Part(s): 2 B. Cameron.doc 34 KB

1 unnamed 0.92 KB

Dear Shelagh,

The attached letter is being mailed out to Dr. Cameron this afternoon. It will be accompanied by the approval form signed by Dr. Griener (unable to attach here).

Best wishes,
Charmaine

-----Original Message-----
From: genuis@ualberta.ca [mailto:genuis@ualberta.ca]
Sent: Thursday, December 04, 2008 7:46 AM
To: Charmaine Kabatoff
Subject: RE: HREB application, Shelagh K. Genuis

Hello Charmaine,

I just wanted to let you know that I put the required documents - provided on letterhead - into Campus mail yesterday. This relates to my PhD dissertation proposal (Making sense of changing and evolving health information: Exploring uncertainty in an 'evidence-based' world) with principle applicants being Dr. Heidi Julien and Dr. Brenda Cameron.

Thank-you,
Shelagh

Shelagh K. Genuis
Interdisciplinary PhD Candidate
School of Library and Information Studies,
and the Faculty of Nursing
University of Alberta

1 of 2 1/6/2011 1:58 PM

(Letter attached to Charmaine Kabatoff's Dec 8, 2008 email)

December 8, 2008

Dr. Brenda Cameron
Nursing File#
B-321008
3rd Floor CSB

Re: Making Sense of Changing and Evolving Health Information: Exploring Uncertainty in an "Evidence-Based" World

Dear Dr. Cameron:

Thank you for Ms. Shelagh Genuis' correspondence dated December 4th, 2008, which addressed the requested revisions to the above-mentioned study. These changes have been reviewed and approved on behalf of the Research Ethics Board. Your approval letter is enclosed.

Next year, a few weeks prior to the expiration of your approval, a reminder will be sent to you via HERO. You will be required to complete the update online. If there have been no major changes in the protocol, your approval will be renewed for another year. All protocols may be subject to re-evaluation after three years.

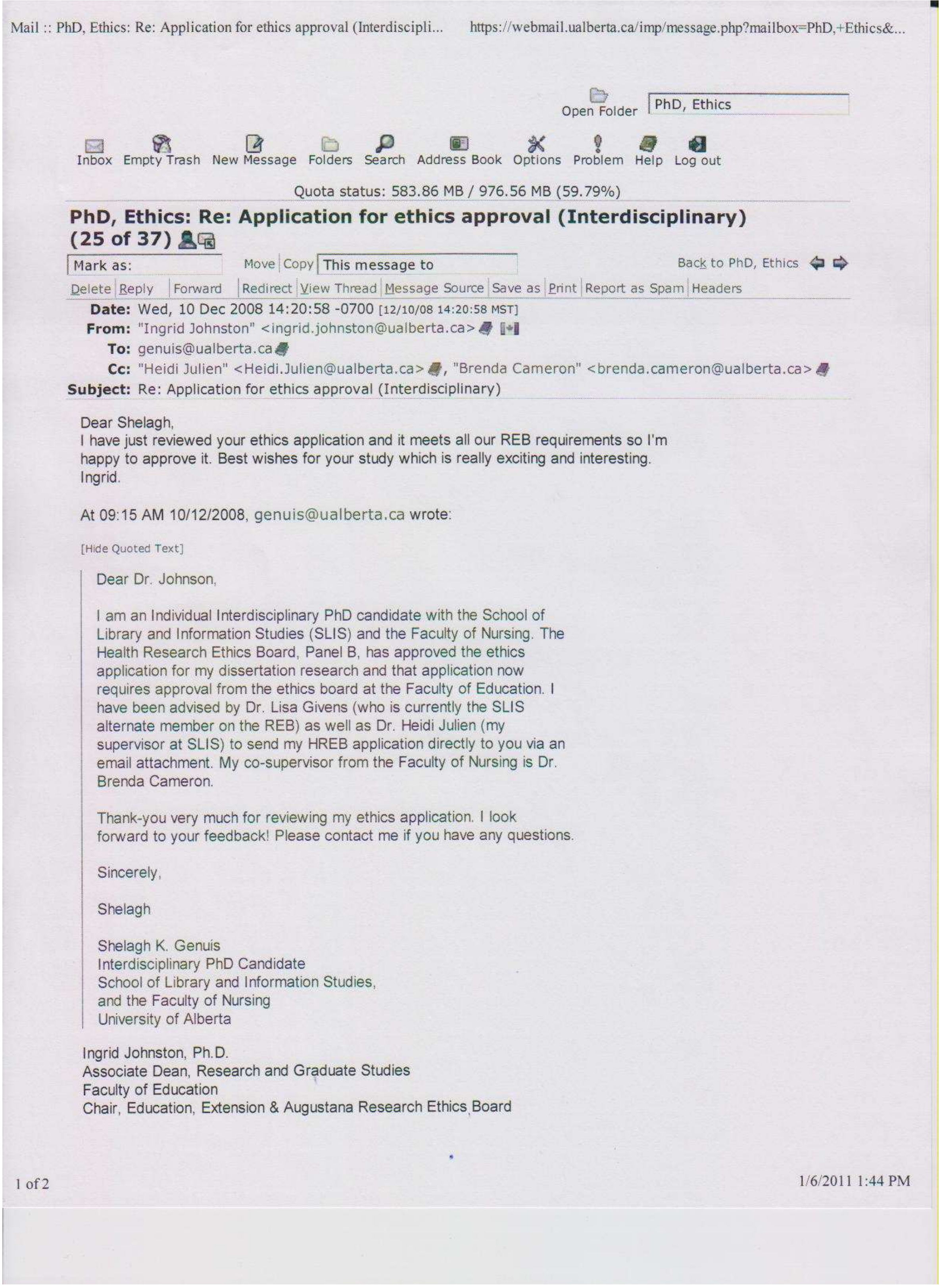
For studies where investigators must obtain informed consent, signed copies of the consent form must be retained, and be available on request. They should be kept for the duration of the project and for a minimum of seven years following its completion.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Capital Health or other local health care institutions for the purposes of research. Enquiries regarding Capital Health administrative approval, and operational approval for areas impacted by research, should be directed to the Capital Health Regional Research Administration office, #1800 College Plaza, phone 407-6041.

Sincerely,

Charmaine N. Kabatoff
Senior Administrator
Health Research Ethics Board (Panel B)

Education, Extension Augustana Research Ethics Board approval:



Mail :: PhD, Ethics: Re: Application for ethics approval (Interdiscipli... https://webmail.ualberta.ca/imp/message.php?mailbox=PhD,+Ethics&...

PhD, Ethics: Re: Application for ethics approval (Interdisciplinary) (25 of 37)

Date: Wed, 10 Dec 2008 14:20:58 -0700 [12/10/08 14:20:58 MST]
From: "Ingrid Johnston" <ingrid.johnston@ualberta.ca>
To: genuis@ualberta.ca
Cc: "Heidi Julien" <Heidi.Julien@ualberta.ca>, "Brenda Cameron" <brenda.cameron@ualberta.ca>
Subject: Re: Application for ethics approval (Interdisciplinary)

Dear Shelagh,
I have just reviewed your ethics application and it meets all our REB requirements so I'm happy to approve it. Best wishes for your study which is really exciting and interesting.
Ingrid.

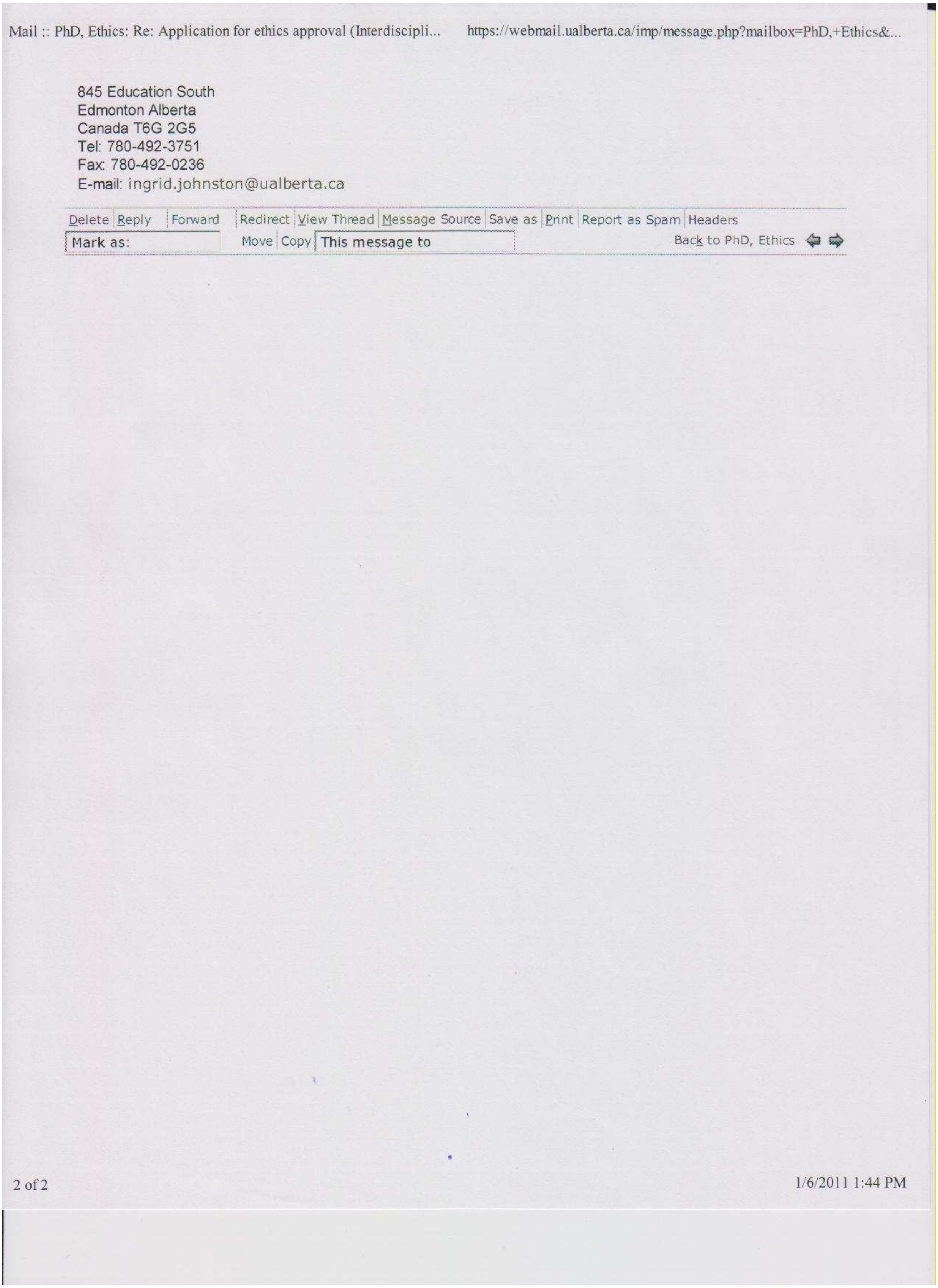
At 09:15 AM 10/12/2008, genuis@ualberta.ca wrote:

> Dear Dr. Johnson,
>
> I am an Individual Interdisciplinary PhD candidate with the School of Library and Information Studies (SLIS) and the Faculty of Nursing. The Health Research Ethics Board, Panel B, has approved the ethics application for my dissertation research and that application now requires approval from the ethics board at the Faculty of Education. I have been advised by Dr. Lisa Givens (who is currently the SLIS alternate member on the REB) as well as Dr. Heidi Julien (my supervisor at SLIS) to send my HREB application directly to you via an email attachment. My co-supervisor from the Faculty of Nursing is Dr. Brenda Cameron.
>
> Thank-you very much for reviewing my ethics application. I look forward to your feedback! Please contact me if you have any questions.
>
> Sincerely,
>
> Shelagh
>
> Shelagh K. Genuis
> Interdisciplinary PhD Candidate
> School of Library and Information Studies,
> and the Faculty of Nursing
> University of Alberta

Ingrid Johnston, Ph.D.
Associate Dean, Research and Graduate Studies
Faculty of Education
Chair, Education, Extension & Augustana Research Ethics Board

1 of 2

1/6/2011 1:44 PM



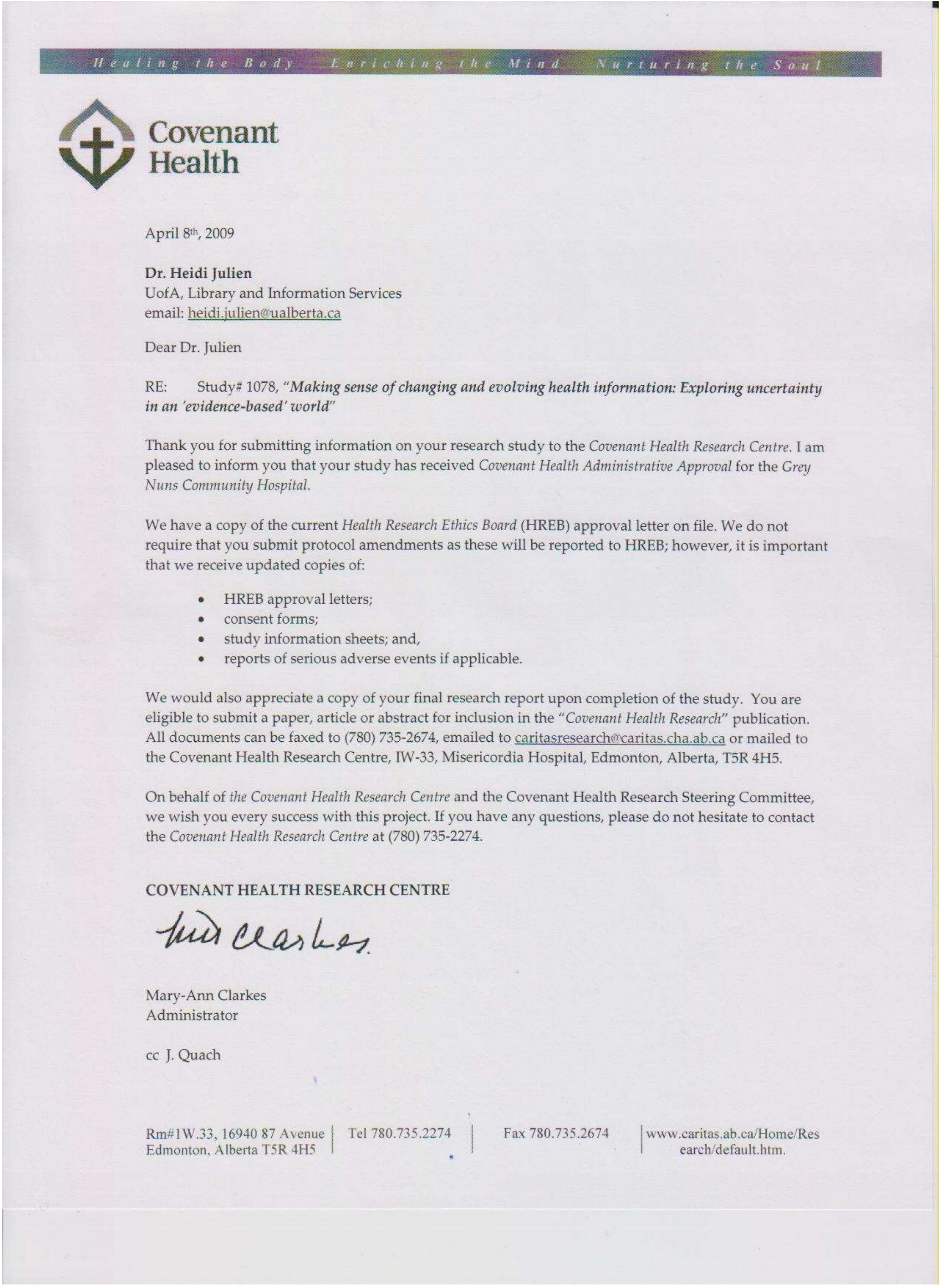
Mail :: PhD, Ethics: Re: Application for ethics approval (Interdiscipli... https://webmail.ualberta.ca/imp/message.php?mailbox=PhD,+Ethics&...

845 Education South
Edmonton Alberta
Canada T6G 2G5
Tel: 780-492-3751
Fax: 780-492-0236
E-mail: ingrid.johnston@ualberta.ca

2 of 2

1/6/2011 1:44 PM

Administrative approval from Covenant Health:



Healing the Body Enriching the Mind Nurturing the Soul

Covenant Health

April 8th, 2009

Dr. Heidi Julien
UofA, Library and Information Services
email: heidi.julien@ualberta.ca

Dear Dr. Julien

RE: Study# 1078, ***"Making sense of changing and evolving health information: Exploring uncertainty in an 'evidence-based' world"***

Thank you for submitting information on your research study to the *Covenant Health Research Centre*. I am pleased to inform you that your study has received *Covenant Health Administrative Approval* for the *Grey Nuns Community Hospital.*

We have a copy of the current *Health Research Ethics Board* (HREB) approval letter on file. We do not require that you submit protocol amendments as these will be reported to HREB; however, it is important that we receive updated copies of:

- HREB approval letters;
- consent forms;
- study information sheets; and,
- reports of serious adverse events if applicable.

We would also appreciate a copy of your final research report upon completion of the study. You are eligible to submit a paper, article or abstract for inclusion in the "*Covenant Health Research*" publication. All documents can be faxed to (780) 735-2674, emailed to caritasresearch@caritas.cha.ab.ca or mailed to the Covenant Health Research Centre, IW-33, Misericordia Hospital, Edmonton, Alberta, T5R 4H5.

On behalf of *the Covenant Health Research Centre* and the Covenant Health Research Steering Committee, we wish you every success with this project. If you have any questions, please do not hesitate to contact the *Covenant Health Research Centre* at (780) 735-2274.

COVENANT HEALTH RESEARCH CENTRE

Mary-Ann Clarkes
Administrator

cc J. Quach

Rm#1W.33, 16940 87 Avenue
Edmonton, Alberta T5R 4H5 | Tel 780.735.2274 | Fax 780.735.2674 | www.caritas.ab.ca/Home/Research/default.htm.

APPENDIX C
INFORMATION LETTER FOR PARTICIPANTS: WOMEN

Title of Study **Making sense of changing and evolving health information: Exploring uncertainty in an 'evidence-based' world**

Investigators

Heidi Julien, PhD
Associate Professor
School of Library and Information Studies, University of Alberta
Phone: 780 492 3934

Brenda L. Cameron, RN, PhD
Professor
Faculty of Nursing
University of Alberta
Phone: 780 492 6412

Shelagh K. Genuis, BScOT, MLIS
Interdisciplinary PhD student
School of Library and Information Studies, and the Faculty of Nursing,
University of Alberta
Phone: 780 467 6625

Background

Health information is changing all the time. New treatments are discovered and older health practices are discarded. It is a challenge for people to figure out what to do with all the new information they come across. People are also coming in contact with health information in popular media, on the internet, or at their local health food store. In this research study we are exploring how people make sense of health information that they run into in their everyday lives.

In 2002 new research was published about menopausal hormone therapy. This resulted in major changes in the way that hormone therapy is used. This research study caused a lot of debate. But it did open up discussion of menopause in the media. It also brought attention to the need for shared decision making between health professionals and women.

Purpose

The purpose of this study is to explore how women make sense of evolving information about menopause. We are interested in your experiences as you find and use (or do not use) menopause information. We are interested in what you think about the health information you bump into during your day. This might include information from television, newspapers or magazines, or the internet. It also includes health information you hear about and discuss with your friends or colleagues, doctors, nurses, or pharmacists. We would like to hear about information sources that are important to you when making health decisions. And we are interested in your experiences with health professionals as information sources.

The interview

If you agree to be a part of this study, you will participate in one audio-recorded interview. Only you and the researcher (Shelagh Genuis) will be take part in the interview. The interview will last about 45 minutes. It will take place at a location that works for both parties. It will be a casual, conversational interview. We are interested in your experiences and your perspective. There are no right or wrong answers!

At the interview we will review this information letter. The researcher will answer any questions you have. You will be asked to complete a simple consent form. The interview will then begin. It is important for you to know the following:

- Involvement in this study is voluntary.
- You may ask questions about the study at any time during your participation.
- Your privacy will be protected throughout the research project.
- No one besides the researcher conducting the interviews will have access to the audio-recorded interview.
- A nickname will be used to identify your interview and all related material.
- You may withdraw from the study at any point up until the time that your interview is transcribed and analysis has begun. If you withdraw, your interview recording will be destroyed. Your interview will not be included in research results.
- This project has received approval from the Health Research Ethics Board and the Education, Extension and Augustana Research Ethics Board at the University of Alberta.

Risks/Benefits

We are not aware of any risks related to this study. You do not need to talk about anything that makes you uncomfortable. We are interested in what you choose to share.

You may find it interesting to reflect on your experience with changing health information. The information you provide will add to understanding of women’s perspectives on health care and wellness.

Costs

This study involves no costs to you other than your time. You will be reimbursed for any parking expenses.

Confidentiality

Interview data will be kept for five years after the study is complete. Identifying data will be kept in a secure locked cabinet. It will not be attached to interview data. Your name will not be used in presentation of research results. Small samples of written dialogue may be included in presentation of data. But, all identifiers will be removed. Only members of the research team will have access to interview transcripts and notes.

All information will be held private except when legislation requires reporting.

Contact

Thank-you very much for your interest in this project. Your input is valuable and will add to the knowledge base of health professionals and information professionals. If you have any questions about this project please feel free to contact Shelagh Genuis at 780-xxx-xxxx.* Email: genuis@ualberta.ca

I look forward to hearing from you!

* I will get a cell phone for the duration of study recruitment.

APPENDIX D
INFORMATION LETTER FOR PARTICIPANTS: HEALTH PROFESSIONALS

Title of Study **Making sense of changing and evolving health information: Exploring uncertainty in an 'evidence-based' world**

Investigators

Heidi Julien, PhD
Associate Professor
School of Library and Information Studies, University of Alberta
Phone: 780 492 3934

Brenda L. Cameron, RN, PhD
Professor, Faculty of Nursing
University of Alberta
Phone: 780 492 6412

Shelagh K. Genuis, BScOT, MLIS
Interdisciplinary PhD student
School of Library and Information Studies, and the Faculty of Nursing,
University of Alberta
Phone: 780 467 6625

Background

Women are increasingly coming in contact with health information outside of health care contexts as medical research and treatments are discussed in popular media and on the internet. In a previous research project the role of medical and consumer publications in communicating changing information related to hormone therapy was investigated. This research study explores how women make sense of and use (or do not use) information about hormone therapy and menopause management. We are interested in your role as an information provider for women who are navigating evolving information about menopause. We are particularly interested in your perspective on the interaction between health professionals and women in light of the uncertainty introduced by the Women’s Health Initiative (WHI) era.

Purpose

The purpose of this part of the study is to explore health professionals’ view of women’s interaction with evolving health information. It is also to explore how health professionals facilitate knowledge translation for patients in non-crisis everyday situations. We are interested in hearing about how health information from television, newspapers or magazines, or the internet impacts the interaction between women and health professionals. This research touches on areas related to patient perspective, information acquisition in situations of uncertainty, knowledge translation (KT), and shared decision making. By focusing on information use within the context of evolving medical information, attention will be drawn to the many factors that influence health decision making and the use of health information in everyday life situations.

The interview

If you agree to be a part of this study, you will participate in one audio-recorded interview. Only you and the researcher (Shelagh Genuis) will be take part in the interview. The interview will last about 30 minutes. It will take place at a mutually agreeable location. It will be a casual, conversational interview. We are interested in your experiences and your perspective.

At the interview we will review this information letter. Any questions you have will be answered. You will be asked to complete a simple consent form. The interview will then begin. It is important for you to know the following:

- Involvement in this study is voluntary.
- You may ask questions about the study at any time during your participation.
- Your privacy will be protected throughout the research project.
- No one besides the researcher conducting the interviews will have access to the audio-recorded interview.
- A pseudonym will be used to identify your interview and all related material.
- You may withdraw from the study at any point up until the time that your interview is transcribed and analysis has begun. If you withdraw, your interview recording will be destroyed. Your interview will not be included in research results.
- This project has received approval from the Health Research Ethics Board (HREB) and the Education, Extension and Augustana Research Ethics Board (EEA REB) at the University of Alberta.

Risks/Benefits

We are not aware of any risks related to this study. You do not need to talk about anything that makes you uncomfortable. We are interested in what you choose to share.

The information you provide will add to understanding of how women make sense of evolving health information and how they translate it into everyday use. It will also add to understanding of how health professionals facilitate patient understanding of evolving health information.

Costs

This study involves no costs to you other than your time. You will be reimbursed for any parking expenses.

Confidentiality

Interview data will be kept for five years after the study is complete. Identifying data will be kept in a secure locked cabinet. It will not be attached to interview data. Your name will not be used in presentation of research results. Small samples of written dialogue may be included in presentation of data; all identifiers will be removed. Only members of the research team will have access to interview transcripts and any notes.

All information will be held private except when legislation requires reporting.

Contact

Thank-you very much for your interest in this project. Your input is valuable and will add to the knowledge base of health professionals and information professionals. If you have any questions about this project please feel free to contact Shelagh Genuis at 780-xxx-xxxx.* Email contact: genuis@ualberta.ca

* I will get a cell phone for the duration of study recruitment.

APPENDIX E
CONSENT FORM FOR PARTICIPANTS

Title of Study	**Making sense of changing and evolving health information: Exploring uncertainty in an 'evidence-based' world**	
Investigators	Heidi Julien, PhD Associate Professor School of Library and Information Studies, University of Alberta 780 492 3934	Brenda L. Cameron, RN, PhD Professor Faculty of Nursing University of Alberta Phone: 492-6412
	Shelagh K. Genuis, BScOT, MLIS Interdisciplinary PhD student School of Library and Information Studies, and the Faculty of Nursing, University of Alberta Phone: 780 467 6625	

Place a check under yes or no to the following questions:	**Yes**	**No**
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time up until the time that your interview is transcribed and analysis has begun? You do not have to give a reason.		
Has the issue of confidentiality been explained to you?		

Do you understand who will have access to any identifying information?		

Signatures:
This study was explained to me by:
____

I agree to take part in this study: YES ☐ NO ☐

Signature of Research Participant:
____

Printed Name: ____

Date: ____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Witness: __________________________________ Date: _________________

APPENDIX F
RECRUITMENT AIDS

Please note: formatting of recruitment aids altered by formatting of dissertation.

Recruitment aids for Women: Short notice and poster

VOLUNTEERS NEEDED FOR RESEARCH STUDY

Are you a woman with a personal interest in menopausal or post-menopausal issues? (e.g. health maintenance, hormone therapy, bone health, symptoms such as hot flashes, or other topics). Please consider volunteering for this study.

Title: Making sense of changing and evolving health information: Exploring uncertainty in an 'evidence-based' world

Health information is changing all the time. New treatments are discovered and older health practices are discarded. It is difficult for people to know what to do with all the new information they come across.

A research study is being conducted that explores the experiences of women as they hear about, read about, and try to make sense of changing health information about menopause. This might include information from television, the newspaper, the internet, or from health professionals. If you are willing to talk about your experiences **please contact Shelagh Genuis (780-xxx-xxxx or email genuis@ualberta.ca).** Feel free to call for more details. Please pass along this information women you know who might be interested. All phone calls, emails, and participation will be confidential.

This study has been approved by the Health Research Ethics Board, and the Education, Extension and Augustana Research Ethics Board at the University of Alberta. If you have any concerns about the study: please feel free to contact Dr. Christine Newburn-Cook, Associate Dean Research in the Faculty of Nursing University of Alberta, at (780) 492-6764. She is not connected with the study. [OR: If you have any concerns about the study: please feel free to contact the Patient Relations Office of Capital Health at 780-482-8080.]

Women & Health Information Study: Participants Needed

Who can participate in this study?

- **Women with a personal interest in menopausal or post-menopausal issues.** (For example: health maintenance, hormone therapy, bioidentical hormones, bone health, symptoms such as hot flashes, or other topics).

What is the purpose of this research?

- This research explores women's experiences as they try to make sense of health information about menopause and related issues.
- Health knowledge is changing all the time. New treatments are discovered and older health practices are discarded.
- It is challenging to make sense of all the health information presented on television, in newspapers, on the internet, and from health professionals.
- I am especially interested in how you make health decisions in situations where there is not one 'right' answer for everyone.

What is involved in being part of this project?

- I want to hear about YOUR experience from YOUR perspective.
- There are no right or wrong answers!
- You will participate in one, tape-recorded interview. It will last about 45 minutes.
- The interview will be set up at a location that works well for both of us.

Research Details:

- Your confidentiality will be completely protected throughout the project.
- The project has been approved by: The Health Research Ethics Board, and the Education, Extension and Augustana Research Ethics Board at the University of Alberta. (If you have any concerns about the study: please feel free to contact Dr. Christine Newburn-Cook, Associate Dean Research in the Faculty of Nursing University of Alberta, at (780) 492-6764. She is not connected with the study.)

Please contact me if you are interested or have questions!

Shelagh K. Genuis	
PhD Candidate, School of Library and Information Studies, and the Faculty of Nursing, University of Alberta	email: genuis@ualberta.ca Phone: 780-xxx-xxxx

Recruitment aids for health professionals: Short notice and poster

VOLUNTEERS NEEDED FOR RESEARCH STUDY

Are you a health professional providing care for or information to menopausal or postmenopausal women? Please consider volunteering for this study.

Title: Making sense of changing and evolving health information: Exploring uncertainty in an 'evidence-based' world

A research project is being conducted at the University of Alberta that explores health professionals' roles as information providers for women who are navigating changing information about menopause. We are particularly interested in your perspective on the experiences of women as they interact with formal and informal health information and make health related decisions; and your perspective on the interaction between health professionals and women in light of evolving health information related to menopause management.

If you are willing to talk about your experiences **please contact Shelagh Genuis (780-270-3065 or email at genuis@ualberta.ca)** for further details. Please pass along this information to anyone you know who might be interested. All phone calls, emails, and participation will be strictly confidential.

This study has been approved by the Health Research Ethics Board and the Education, Extension and Augustana Research Ethics Board at the University of Alberta. If you have any concerns about the study: please feel free to contact the Patient Relations Office of Capital Health at 780-482-8080.

Participants Needed: Research Study on Health Professional's Role as Information Providers

Who can participate in this study?

- Health professionals providing care or information to menopausal/postmenopausal women

What is the purpose of this research?

- Health knowledge is changing all the time. It is a challenge for women to make sense of health information available on television, in newspapers, on the internet, and from health professionals.
- The purpose of this project is to explore health professionals' roles as information providers for women who are navigating changing information about menopause.
- We are particularly interested in your perspective on the experiences of women as they navigate formal & informal health information and make health related decisions; and your perspective on the interaction between health professionals and women in light of evolving health information.

What is involved in being part of this project?

- You will participate in one, tape-recorded interview, approximately 20 minutes.
- The interview will be set up at a mutually agreeable location
- I want to hear about YOUR experience from YOUR perspective.

Research Details:

This project has been approval by the Health Research Ethics Board and the Education, Extension and Augustana Research Ethics Board at the University of Alberta. If you have any concerns about the study: please feel free to contact Dr. Christine Newburn-Cook, Associate Dean Research in the Faculty of Nursing University of Alberta, at (780) 492-6764. She is not connected with the study.

- Your confidentiality will be completely protected throughout the project.

Please contact me if you are interested or have further questions!

Shelagh K. Genuis	
PhD Candidate, School of Library and Information Studies, and the Faculty of Nursing, University of Alberta	email: genuis@ualberta.ca Phone: xxx-xxx-xxxx

APPENDIX G
SEMI-STRUCTURED, QUALITATIVE INTERVIEW GUIDE FOR WOMEN

Note: In keeping with principles of qualitative methodology, this is an interview guide. New questions or approaches to existing questions may emerge during the interview process (Marshall and Rossman 2006). Furthermore, questions may be adapted to the setting of the interview or the context of the participant.

Preliminary Procedures:

- Introductions, chat while setting up recording apparatus
- Adjust vocabulary of questions to participant's vocabulary
- Introduce project: review information letter; highlight interest in the personal experiences
- Ask if participant has any questions. Obtain informed consent.
- Turn on audio-recorder.

Background: Women are commonly coming in contact with medical information outside doctors' offices. It's now common to find in newspapers, magazines and on television, articles or stories about medical discoveries and new treatments, as well as alarming reports about problems with medical treatments. In a previous research project I explored how changes related to hormone therapy were discussed newspaper, magazine, and journal articles. What I'm interested in with this research project is how women actually make sense of and apply the health information that they come across in their day to day lives.

Health information behaviour: General

Purpose: To elicit reflection on evolving health information and information within the context of everyday life.

1. Given a specific health concern or something related to health and well-being, how would you go about exploring your concern?

2. Do you pay attention to health information encountered within the context of daily life? i.e. in newspapers, on television, in magazines etc.

3. Do you use the internet to find information about health or well-being? How is the internet used? Role of information found online?

Interpersonal information sources

Purpose: To explore the role of both informal and formal interpersonal information sources.

1. Can you tell me about people who you might talk to about health concerns?

2. What role might they play in helping you to figure out health related issues?

Menopause experience and information behaviour

Purpose: To learn about participants' experiences with changing information about menopausal hormone therapy and menopause management. To explore information sources that women use and prefer as they deal with changing information.

1. I wonder if you might share with me the story of your experience with and during the menopause transition. How have you learned what you know? How have you made decisions about personal health management in this area?

2. Aware of changes over past few years in the way that HT is being used during menopause? What do changes in information about menopause management mean to you?

3. What sources of information have been more useful/helpful for you?

4. Are you satisfied with the information you've learned/received about menopause?

5. How would you prefer to learn about this area?

6. Has the changing nature of information about health and well-being in this area of health influenced how you look at health information? Influenced your relationship with health professionals?

7. What do you see as your role in finding information about your health and well-being concerns?

8. Can you tell me how who you are as a person or your personal views or beliefs about health might influence your health decisions?

ELICITATION

Now I'd like to shift gears a bit. Because media is such an important player in bringing new health information to the public, I'd like to talk about some items that I have taken from the media over the last months.

Elicit reflection on evolving health information and health information encountered within the context of everyday life

1. How might you respond if you came across this item during your day-to-day activities?

2. Are there people you might talk to about media stories like these?

3. Would health information such as this have an impact on your decisions about personal health management?

4. Who or what other sources might you turn to in order to sort-out conflicting health info?

5. It is becoming more common that new discoveries in health care are being talked about on television or the radio, or written about in magazines and newspapers. What do you think about this? Does it influence your views or decisions about managing your own health?

Conclusion

Do you have any last comments about how health information from different sources has influenced your decisions about managing your own health? Last comments about how you use health information in your day-to-day life?

APPENDIX H
SEMI-STRUCTURED, QUALITATIVE INTERVIEW GUIDE FOR HEALTH PROFESSIONALS

Note: In keeping with principles of qualitative methodology, this is an interview guide. New questions or approaches to existing questions may emerge during the interview process (Marshall and Rossman 2006). Furthermore, questions may be adapted to the setting in which health professionals work (e.g. a menopause clinic, private office practice, or community setting).

Preliminary Procedures:

- Introductions, chat while setting up recording apparatus
- Introduce project: review information letter; highlight interest in the personal experience
- Ask if participant has any questions. Obtain informed consent
- Turn on audio-recorder

Background: Women are increasingly coming in contact with health information outside doctors' offices as medical research and treatments are discussed in newspapers, magazines and on television. In a previous research project I explored how changes related to hormone therapy were discussed newspaper, magazine, and journal articles. Today what I'm really interested in is your view of women's health information behaviour and your perspective on the interaction between health professionals and women in situations where health information may be uncertain because of evolving research (for example following the publication of results from the Women's Health Initiative).

Evidence and information sources

- What type of information sources primarily influence women making health decisions related to menopause in general or hormone therapy in particular?
  (Most important sources to the women you work with?)

- How informed are the women when bringing their concerns to a health professional? What info do they bring with them?

- It is becoming more common that health information is being introduced directly to women through the media or on the internet.
  I'm wondering what you think about this development?

- Impact of media/internet information sources on interactions with health professionals?

Facilitating role where health information is evolving

1. Can you tell me about how you approached or dealt with the uncertainty that came from the publication of WHI results?

2. Your role in facilitating women's understanding of changing information about hormone therapy or other menopausal concerns?
How do you think women view the role of health professionals in decision-making during the menopause transition?

3. Do you see health professionals as information providers? How do you accomplish this role? Do you make use of or refer women to sources of information in the community? (e.g. websites, consumer health groups)

<u>Role of patient context</u>

1. Three core elements have been identified for EBP: best research evidence, practitioner expertise, and patient values.
   How do you see women's values playing a role in EBP?

2. Does uncertain/evolving health information change the balance between HPs expertise and women's values?

3. In situations where information is evolving and uncertain, what do you see as the patient's role in decision-making?

4. Role of beliefs, who women are as individuals, ("my gut," "intuition," "common sense") in decision-making?

APPENDIX I
PARTICIPANT PROLIFES (WOMEN)

Anita began to experience menopausal symptoms soon after the birth of a child. She was in her mid-thirties at that time and did not realize that her symptoms might be related to menopause. There were many major challenges in her life at the same time, including a major relocation and cultural adaptation, and consequently she did not immediately attribute her physical experiences with the menopause transition: “It’s not all black and white. And those things are all – you know, acting together, affecting you at the same time.” However as symptoms persisted, she gathered information from a range of informal, formal, and media sources and determined that she was perimenopausal. Eventually Anita was seen at the menopause clinic and received HT. At the time of the interview Anita was perimenopausal and taking HT. Anita had an undergraduate degree from her country of origin and training from a technical college in Canada. She is married, has a child, and is currently seeking employment.

Beverly approached menopause as a natural life transition (“It’s just a natural progression of life and it’s not a big deal”) and related that she went through menopause at 53. She experienced “a few issues with hot flashes,” for which she takes “a little bit of hormonal supplement, natural supplement.” However, she was clearly disinclined towards HT: “I have never found that logical because that implies that the Lord made one big mistake coming in mid life, you know, which I don’t believe.” Beverly is currently postmenopausal, married, has adult children, and works part-time in her own home-based business.

Camille entered the menopause transition at 38 and has since experienced ongoing challenges with a range of symptoms. Although a patient at the menopause clinic and currently on HT, at the time of the interview she had not yet achieved a balance between symptoms exacerbated by HT itself (i.e. bleeding) and her severe symptoms associated with menopause. She was frustrated with the inability to find a satisfactory balance and described her medical care by stating, “we’re just kind of messing around trying to figure it out.” Camille has taken some post-secondary college courses, she is currently working at home and does occasional contract work.

Cherri entered perimenopause around 47 years of age. Although looking forward to menopause and the cessation of monthly periods, menopause symptoms and decreasing strength and stamina, coupled with significant family responsibilities, motivated Cherrie to seek help. “I recognized that I needed to do something about the menopausal symptoms, and so I went to a gynaecologist and I told him, ‘This is what’s happening, what do you suggest?’ And he said, ‘Well, you could try hormone replacement.’ So he put me on hormone replacement and it made a huge difference to the way I felt. So I’ve continued on it, but low dose.” Because her monthly periods have been maintained (although irregular and lighter) by HT, Cherrie noted that she did not know if she was postmenopausal or not. Cherrie has an undergraduate degree and is at home caring for a number of children. She is married and also has adult children.

Christy experienced premature menopause (< 40 years of age at onset) which began prior to having children; she was postmenopausal at the time of the interview. Although no longer taking HT, she had in the past used a variety of forms of HT because she was experiencing “all sorts of symptoms that were really very uncomfortable.” Because of a combination of concerning side-effects from HT (mental confusion) and the publication of WHI results in 2002, Christy and her physician elected to discontinue HT. At that point Christy “was far enough into menopause, I think that it didn’t matter.” Christy is married and has children. She has a graduate degree and works in the education field.

Dale began experiencing physical changes in her mid- 30s (alterations in her period, significant mood swings, and hot flashes) after her second child was born. She lived in a rural community where “my family doctor didn’t really take them seriously. The symptoms.” Furthermore she didn’t identify her symptoms as perimenopause: “I just thought, you know, we had had a baby….we had moved shortly after that, started a new job here, you know, a new city. I just thought stress or – .” Eventually a specialist, who Dale was seeing for another reason, referred her to the menopause clinic. Although she initially had “some hesitation because there’s been a lot of press out there about risk to stroke and blood clots and other things,” Dale appreciated the team approach of the menopause clinic and the notion that she could try treatments and evaluate how they worked and how she felt about them. At the time of the interview Dale was taking HT, “I feel more informed. I feel more aware. And you sort of have in the back of your mind when you have all these health issues and you’re not sure and you’re uncertain, it does weigh heavy on you.” Dale has an undergraduate degree and is employed by the government; she is married and has children.

Dana did not experience hot flashes or other classic menopause symptoms, however in her late 40s she had abnormal bleeding which she associated with menopause. Dana identified herself as perimenopausal. She had, however, been told by physicians that her bleeding was caused by a serious medical condition. Dana, relying on intra-personal information sources, believed her bleeding to be an indication of menopause. Dana relied on her own information gathering and “my gut,” and indicated that she did not like dealing with physicians (“I don’t like doctors. . . .They don’t think”). Not comfortable with traditional medical intervention, Dana also expressed discomfort with HT: “I don’t think, at a gut level, I again wouldn’t have opted for that. Same as I didn’t really like the Pill when I was younger.” Dana has high school education and did clerical work; she is currently financially independent and not working. She has adult children and is divorced.

Faye related that she likely began having menopause symptoms soon after a child was born in her mid-40s, however she began recognizing the onset of menopause symptoms when she was approximately 50: “recognizing that these were hot flashes and they were coming fairly regularly and my period was getting less regular.” She first managed her symptoms by making lifestyle changes, but when she experienced other disconcerting symptoms Faye began look more closely at treatment. Despite “a long bias against taking any kind of hormones,” and after independent investigation as well as input from trusted HPs, Faye elected to go on HT. At the time of the interview, Faye described herself as being at the end of perimenopause. In addition to her strategic, positivistic approach to information gathering, Faye also related that intrapersonal information sources strongly influenced her decision making: “I evaluate things on – very much on how they feel – I sort of get myself intuitively to the point where I’m ready to make a decision.” Faye has a graduate degree, works in the education field, is married and has children.

Gwen has been perimenopausal for a “couple of years” (since she was approximately 50) and currently has irregular periods. Although she has had significant unrelated health challenges over the past number of years, Gwen’s menopause symptoms have been limited to irregular bleeding and some mood swings. On the advice of an acquaintance, Gwen tried some over the counter “HRT…. an all natural vitamin thing,” however “I started experiencing side effects so for me it didn’t work.” She has never used prescribed HT. Gwen has some university education and is not employed outside her home. She is married and has adult children.

Hazel’s symptoms began approximately a year before I interviewed her and since that time she has struggled with significant symptoms and unsatisfying encounters with medical professionals. “I haven’t had a very satisfying experience with going to the doctor. They just give you brief information and tell you to see the specialist. And even the specialists don’t seem to have the time….So like you’re left wondering and no one to answer your questions.” On the advice of a friend Hazel specifically asked for a referral to the menopause clinic, however her family doctor was unwilling to refer her and told her that she was “nowhere close to [menopause].” At the time I interviewed Hazel, she was extremely uncertain how to proceed and very eager to find help. Hazel has high school education and works in social services; she is a single mother.

Irene had an extensive and complicated medical history which included a medically induced pseudo-menopause in preparation for an oblation procedure – something Irene felt had “just screwed my body from A to Z” – and a hysterectomy which did then render her postmenopausal. She had consulted many health professionals and naturopaths for various health challenges and, because of her history of cancer, had been refused HT. She attributed this refusal to gender bias: “that’s when I say the males of the world came out – the doctors that don’t give hormone replacement therapy to anybody. And that’s when I fell down through the cracks kind of thing because they wouldn’t give me anything.” At some point she was referred to the menopause clinic where she was prescribed HT. Irene continues to have significant health challenges: “I’m still trying to figure it because I’m still not 100 percent sure that that’s – they don’t know what’s the matter.” Irene has an undergraduate degree and works in the education field; she is married and has adult children.

Jane had a hysterectomy without removal of the ovaries when she was in her early 40s and, at the time, was aware of potential estrogen cessation. Jane was not experiencing menopause symptoms but was very concerned about osteoporosis and other potential sequelae of what she perceived as estrogen deficiency: “I didn’t go on all these replacements and stuff for hot flushes necessarily. I just was concerned about the fact that when my estrogen ran out, I wanted to keep it going, because of my. . . back then I was very firm on it.” After the WHI was published she stopped taking HT. At the time of the interview Jane had ongoing concerns about osteoporosis. Jane has an undergraduate degree and worked in health care until her recent retirement. She is married and has adult children.

Jill was in postmenopause, although still experiencing some menopausal symptoms, at the time of the interview. She had her last period when she was 44: “menopause crawled upon me and I was not aware that it was menopause until a few years after. Because I thought, ‘I’m *way* too young.” Jill was very active physically and believed “that carried me through a lot of this stuff.” When she realized that she was in menopause and began engaging in information seeking she found much of the information “depressing” and therefore “decided to discard that information because it was working on my psyche negatively too much.” Jill demonstrated a strong inclination towards a natural life transition approach and disinclination towards traditional medicine and medication. Although she described problematic symptoms, particularly night sweats and hot flashes, Jill stated, “It will take over your life and then you get consumed by this and then you will pay attention to all the little symptoms and then it works with that. And I've decided to not let that happen to me." Despite some disruptive symptoms, Jill described various lifestyle changes she had made in order to cope with and manage her symptoms (exercise, exposure to sunlight, diet). Jill has high school education and is at home; she is married and has children.

Joyce had a hysterectomy around 45 years of age and although one ovary was left, it "shut down" within a year of surgery, thus putting Joyce into menopause. At that point her physician put her on estrogen, "just because at that point they were sort of *into* hormone therapy." She was, however, sent for a mammogram and after the discovery of a lump "they yanked me off the estrogen patch." At that point any menopause symptoms that Joyce might have been experiencing were eclipsed by a severe depression: "I don't know in that year what kind of menopause symptoms I might or might not have had." Joyce was eventually diagnosed with a thyroid condition which she thought may have contributed to her illness. At the time of the interview Joyce was more than 20 year post-hysterectomy. Joyce had an undergraduate degree and had worked in the education field; she is married and does not work outside the home.

Laura experienced early menopause, beginning around 42 years of age, and subsequently suffered from "brutal" menopause symptoms including hot flashes, insomnia, mood alteration, and vaginal dryness. After two years of trying numerous herbal remedies, Laura went to her physician and asked for help: "I'm not functioning – I'm not sleeping. You know, I'm a basket case basically." After some experimentation, an adequate dose was established: "It's been really good ever since. I mean I still get the stuff, but at least I can function." Although Laura was not initially inclined to use medication, the use of HT made such a difference to her quality of life that she expressed great concern about the prospect of coming off HT at the recommended five year mark: "But I, like you kind of wonder, 'OK I've been on this stuff for, four years now. She only wants to have me on it till I'm 50.' But can I give up my little pills? I don't know." Laura has an undergraduate degree; she is married has not worked outside her home since she had children. At the time of the interview, some of her older teenage and young adult children lived at home.

Lillian had a hysterectomy with removal of her ovaries when she was 32 years old, after which she was put on high dose HT. She remained on that dosage for approximately 30 years. Concerns about breast cancer resulted in a lumpectomy: “it was cells that could later turn into cancer but it was fortunately not cancer.” Around that time a woman she encountered in the ultrasound clinic told Lillian she should go off HT. This was prior to publication of WHI results and Lillian related that she received different advice from different physicians: “Like one doctor told me, ‘You don’t need the hormones.’ And another doctor said, ‘Yeah, you take the hormones.’” At that point Lillian’s prescription was reduced and she independently also began to cut back on her dosage, “I gradually skimmed down.” Now in her 70s, Lillian still experiences some hot flashes but, under the care of a physician she is continuing to reduce her HT with the goal of stopping it completely. Lillian began her post-secondary education as an adult and over the years achieved a graduate degree. She never married and primarily worked overseas until her retirement.

Lisa was postmenopause at the time of the interview. She had experienced significant health challenges which, at 33 years of age, resulted in a tubal ligation. “Right after that, I started going into menopause. But I didn’t know that at the time.” Lisa began to experience mood swings and “really heavy and inconsistent” periods. After unsuccessfully seeking help through traditional medical channels, Lisa began exploring various lifestyle changes, particularly related to diet and exercise. In addition, she encountered information in a health food which led her to begin exploring vitamins and supplements, as well as herbal menopause remedies. Lisa engaged in considerable diet and lifestyle change and also found a herbal remedy which fulfilled her needs. Over the next years her periods gradually waned and stopped when she was about 43. She told me, “I never really had the symptoms as terrible as other people that I knew. Like you know, terrible hot flashes, night sweats, all these things.” Lisa has high school education and does clerical work in the alternative health field. She is in a common-law relationship.

Monica went through menopause when she was about 54. She provided few details about the perimenopause period except to say that she experienced some hot flashes in the evenings and “off and on at work.” Monica noted, “I just sort of let it flow. I mean, it’s not as if you decide one day, ‘Okay, now I’m going to have menopause.’” She viewed the menopause transition as an obviously “natural” process since no one (“except men”) was excluded; she added, “And that’s so nice not to have your period anymore. It *really* is nice. *Trust me, nice*. The hot flashes thing I can live without.” She had been disinclined to use HT, “I’d rather not be on any more pills;” however, based on discussions with a group of women she experimented with a natural hormone product. She did not find it effective. Monica has an undergraduate degree and works as a scientist in an area of public utilities. She is married and has adult children.

Muriel entered menopause when she was in her later 40s. She provided a detailed narrative of her menopause experiences beginning with the first time she unsuccessfully sought information from a HP. Muriel responded to the physician’s disinterest by doing her own research at the library. She took the information she found back to her doctor, requested testing, and subsequently commenced HT. Muriel described her experience as “frustrating . . . because the information at that time was so controversial. It seemed like every article you read had a different take on it.” Struggling with decisions about HT use, Muriel was eventually seen at a menopause clinic where she found solutions for some long term menopause symptoms. A short time prior to the interview, and after discussing HT discontinuation with some friends who were also in their early 60s, Muriel decided to stop HT. This choice did not garner approval from her physician; however, this participant concluded: “I think that I would rather be off it now than on it. I seem to be okay.” Muriel has an undergraduate degree and is retired. She is married and has adult children.

Naomi had a hysterectomy and one ovary removed when she was in her early 40s; her physician told her that HT was not necessary at that time. After surgery, however, Naomi immediately began experiencing severe symptoms (including vasomotor, memory problems, sexual dysfunction, and mood disturbance). “I hit menopause and hit the wall.” She was seen at a menopause clinic where she was diagnosed with a thyroid condition. This marked “the beginning of a very long journey for me in terms of health matters.” About four years later Naomi had her second ovary removed and once again experienced physical changes. At that point Naomi began using HT which she described as “controversial” (due to a family history which included cancer), but critical to her quality of life. Naomi noted, “I’m willing to take the risk.” When Naomi was interviewed she had been using HT for approximately seven years and felt that her symptoms were reasonably under control. Naomi has an undergraduate degree and works in health care. She is married and described her husband as “good support” through her many years of challenges associated with the menopause transition.

Nicole first became aware of being in the menopause transition when she was in her 40s and diagnosed with a related problem. She began using an external estrogen product as well as doing some reading and exploration with respect to natural products. Nicole had a number of symptoms related to menopause as well as related to “my many autoimmune diseases.” She saw a physician with a naturalistic practice for a period of time and briefly used a “bioidentical progesterone” cream. She also saw a conventional physician, received a prescription for a topical hormone cream, but did not choose to fill the prescription. The requirement for yearly mammograms as well as the breast cancer and death of a friend made Nicole uncomfortable with the progesterone cream and she independently stopped using it. “I just felt it was too much of a quagmire and too complicated, and I just didn’t want to deal with it.” At the time of the interview, Nicole was postmenopausal. This participant had a graduate degree, was retired, and was married.

Pat was postmenopausal at the time of the interview having gone through this transition at about 50 years of age. She paid little attention to the menopause transition and thought “Okay, it’s part of life, I’ll carry on with it.” She did not have any bothersome symptoms. Pat relied primarily on her physician for health information but she explained that she was moving from one city to another during that time and was without a doctor for a two or three years. As a result she was “through most of it” by the time she had a medical appointment. Pat has an undergraduate degree and works for the government. She is single.

Paula began going through menopause in her mid-40s and at the time of the interview she was postmenopausal. She experienced severe difficulty with changes in menstrual flow as well as hot flashes. Although Paula had a trusting and ongoing relationship with her physician and had a surgical procedure in an attempt to deal with menstrual flow, she was adamantly opposed to taking pills for what she viewed as “a natural thing.” After personal investigation of a wide range of information sources, Paula elected to use natural products and lifestyle changes to manage menopause symptoms. She also believed that acceptance was important: “acceptance that I’m a woman and that women go through menopause.” Paula had some post-secondary training and works for the government. She is single.

Roslyn commenced menopause around age 50 and at the same time was diagnosed with a thyroid condition. She had experienced severe menopause symptoms and described this as a “confusing time” of deteriorating health. After a discouraging encounter with her physician, followed by independent information seeking, Roslyn decided that she needed to find a doctor “who would be an advocate for me.” She was eventually referred to a menopause clinic. Although previously “dead against hormone therapy,” Roslyn agreed to try HT and gradually it brought her symptoms under control. Roslyn noted that “at that point I decided to put my faith in that doctor.” This participant had a high school education and owned her own business. She is divorced and has adult children.

Sue first began experiencing menopause symptoms at about 50 years of age, about 13 years prior to the interview. She reported that she still experienced problematic symptoms. Since first experiencing symptoms, Sue had investigated a wide range of information sources and had experimented with a range of natural products. Sue related that she had also tried HT but went off it when initial results from the WHI were published in 2002. She was, however, still suffering from menopause symptoms and went to a number of HPs looking for ways to manage her symptoms. Eventually she was referred to a menopause clinic which she found “very helpful.” She was taking what she identified as bioidentical hormones, although later in the interview she expressed some uncertainty about the term ‘bioidentical.’ Although the HT had appeared to be effective, Sue reported that she had recently been experiencing increased symptoms. Sue had been a manager at a utilities company before she retired. She is married.

Sylvia began experiencing menopause symptoms in her early 50s and immediately commenced HT. A number of years later, her doctor retired and her new physician would not renew her prescription. Sylvia reported that this new physician “yelled at me. She wouldn’t explain it. She just said ‘You’re at risk for breast cancer.’” Sylvia experienced “two very bad years of hot flashes” before finding another physician who renewed her prescription on the basis of ‘quality of life’ concerns. Sylvia explained the reasons why she felt that “for me the risk factor’s pretty minimal,” but she also related that, after approximately 10 years of HT use, she had been “cutting back a little bit in the last little while.” Sylvia related that she was also experimenting with physical activity as a therapeutic approach to hot flashes and that she hoped to decrease her use of HT over time. This participant had trained as a technician and worked in the health field; at the time of the interview she was self employed in a different field. She is married and has adult children.

Thea had been experiencing severe menopause symptoms for the past couple of years. Symptoms began around age 50 and included severe hot flashes, decreased libido, fatigue and mood swings. Thea’s long-time family doctor was not empathetic with respect to her distress and after some information seeking through interpersonal channels Thea heard about and received a referral to a menopause clinic. Based on a trial and error approach, Thea began trying a range of HT regimes. Although some symptoms were alleviated by hormone use, Thea was still suffering from symptoms and felt that further adjustments needed to be made. Thea is employed at a financial institution, is married, and has adult children.

Vicky was premenopause at the time of the interview. She related that she wanted “just some information” and to “do some pre-stuff so we have some reference points”; therefore she sought out a woman (likely an alternative practitioner) who specialized in talking to people about menopause. It was not apparent until the interview was underway that this participant was still premenopuasal; however, she was included on the basis that she was actively seeking information about this life transition. Vicky has an undergraduate degree and is involved in business with her husband. She has adult children.