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# The Self-directed Learning Actions of Women Regarding the Menopause Transition

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The Self-directed Learning Actions of Women Regarding the Menopause Transition

by

Jamie Johnson Cooper

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
in Curriculum and Instruction with an emphasis in Adult Education  
Department of Leadership, Counseling, Adult, Career, and Higher Education  
College of Education  
University of South Florida

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## Dedication

For all women at mid-life, past, present, and future.

### to my last period

*Lucille Clifton*

well, girl, goodbye,  
after thirty-eight years.  
thirty-eight years and you  
never arrived  
splendid in your red dress  
without trouble for me  
somewhere, somehow.

now it is done,  
and i feel just like the  
grandmothers who,  
after the hussy has gone,  
sit holding her photograph  
and sighing, *wasn't she beautiful? wasn't she beautiful?*

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*Kelly*, the yin to my yang, the “J” to my “P.”

*Nacho*, the very definition of friend.

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## Abstract

Research indicates that increased knowledge about the menopause transition positively impacts a woman's attitude about this stage in her life, and a more positive attitude leads to less distress during the transition. However, there has been no research regarding how women gain this knowledge about menopause, what factors in her environment may hinder or assist her, or how women's knowledge of menopause is leveraged by health care providers to help facilitate her menopause transition.

The purpose of this research was to explore the self-directed learning actions of women regarding their search for information about menopause, and to understand what factors, if any, may have helped or hindered her search.

A convenience sample of women 35-55 years of age was invited to participate in an online survey; a total of 227 usable responses were collected. Answers were analyzed by utilizing a simple frequency distribution to illustrate more and less common responses. Chi-square tests of independence were used to examine bivariate relationships, and content analysis was used to examine free response answers.

The results of this study indicated that most women did not seek information about menopause on their own. Women who sought information were primarily motivated by symptoms: what to expect, symptom relief, or validation that their experiences were normal. This study also indicated that the most utilized resource for

finding information was the Internet. It also found that women need more information from the health care community than they were receiving.

Findings from this study suggest a need to continue to connect adult education with health promotion. Additionally, women had a need for greater interpersonal support and beneficial interactions with the health care community. Finally, this study demonstrated that women may benefit from the normalization of menopause as a social construct. Perhaps this could best be achieved through education within larger conversations about human reproduction and about natural aging.

## Chapter 1

### Introduction

By the year 2013, some 50 million women in the U.S. alone had reached menopause (Menopause, 2013). Panay and Fenton (2016) assert that “As the global population continues to age, the impact of menopause on quality of life and long-term health become increasingly felt” (p. 214), having implications for individual women, but also society as a whole.

Prior to the mid-twentieth century, women “bred more and bled less’ (and) moved from last pregnancy and lactation to menopause” (Murtagh & Hepworth, 2005, p. 282). At that time, if a woman lived into her fifties, menopause was just one more part of life. In the 1940s, the American Food and Drug Administration (FDA) approved the use of estrogen therapy to treat the hot flashes that can accompany the menopause transition (Nelson, 2007), and menopause became a medical event.

Murtagh and Hepburn (2003) indicate that following the FDA approval of estrogen therapy, the predominant, medical construction of menopause in the West can be traced to the writings of Wilson (1966), who promised women they could be *feminine forever* by taking estrogen therapy (ET) once their menopausal journey had begun. Three decades later, Lee and Hopkins began publishing a *What Your Doctor May Not Tell You About . . .* book series, beginning with *What Your Doctor May Not Tell You About Menopause* (1996). Each book claimed to have answers to women’s mid-life

problems, answers that their doctors either did not know or would not share. Reflecting on the books' success, Hopkins writes on her co-author's official web page that the "sales of the 'Menopause' book were better than anyone at (the publishing house) ever dreamed, and by the fall of 1998 nearly half a million books had been sold" (2014, ¶11).

In sources such as Wilson's, Lee and Hopkins', and others, popular media told women that the *cure* for menopause could be found in hormone products such as estrogen or progesterone. However, in 2002 the Women's Health Initiative (WHI) released a report of findings from a study investigating the relationship of ET and cardiovascular disease. Instead of reducing the incidence of cardiovascular disease as physicians initially hypothesized, the WHI findings indicated that ET put women at a greater risk, not only for cardiovascular disease, stroke, and thromboembolism, but also breast cancer and gallbladder cancer. However, the study also found that the risk of osteoporosis and colorectal cancer was reduced (Grimes, 2003).

Women were confused about the efficacy and safety of the treatments they were receiving, and, in many cases, confusion led to a feeling of betrayal causing women to lose faith in their doctors (Schonberg, Davis, & Wee, 2005). McIntosh and Blalock (2005) examined the impact media coverage of the WHI report had on women's use of hormone replacement therapy (HRT) and their feelings of trust toward their physicians. More than half of the women in their study (53%) reported change in their use of HRT following the WHI report, and women who changed their use of HRT were also significantly less likely to trust further information provided by their physicians regarding hormone therapy.

The perception of menopause as a problem is perhaps greatest in Western culture, which overvalues youth and venerates women as sex objects (Astbury-Ward, 2003; Etaugh, 2008; & Dittmar, 2003; Sontag, 1979), because aside from being imbued with the idea that the physiological discomforts of menopause demonstrate an illness to be treated, menopause may also signal aging or being used up (Bowles, 1990; Brooks-Gunn, 1982).

Additionally, menopause is frequently a topic for comedic material. From the 1970s sitcom *All in the Family*, to the more recent *Sex and the City*, menopause has been a subject of ridicule and menopausal women have been the butt of jokes. In the eZine *Slate*, Thomas writes:

In the world of comedy, menopause is a more common plot device—because what could be funnier than men being grossed-out by the middle-aged female body (*That '70s Show*), or freaking out that middle-aged women are losing their minds (*All in the Family*), or watching women deny their age and head to Menopause Anonymous (*Absolutely Fabulous*)? (2013, ¶ 6)

### **Statement of the Problem**

Research indicates that increased knowledge about the menopause transition positively impacts a woman's attitude about this period in her life, and a more positive attitude leads to less distress during the transition (Buchanan, Villagran, & Ragan, 2002; Choi, 1993; Norton, Chilcot, & Hunger, 2014; Walter, 2008). However, a woman's understanding of menopause is complicated by cultural taboos, often leaving women unwilling to talk about it, even among friends, which may leave women uninformed and fearful (Nosek, Kennedy, Beyene, Taylor, Gilliss, & Lee, 2010; Sheehy, 1992).

Although research into women's health concerns in the last two decades of the twentieth-century increased dramatically, little research focused on women's health concerns at mid-life (Henrich, 2000, 2004). Since then, the initial wave of interest in women's health research has diminished. Existing research has established that increased knowledge about the menopause transition can decrease the distress experienced during this period (Choi & Park, 2008; Hunter & O'Dea, 1999; Mansfield & Voda, 1993); however, there has not been extensive research regarding how women gain this knowledge about menopause, what factors in her environment may hinder or assist her, or how women's knowledge of menopause is leveraged by health care providers to help facilitate her menopause transition. Additionally, in the health sciences, there has been extensive research regarding self-directed learning (SDL) for practitioners in the fields of medicine and nursing; however, there has been very little with regard to public health concerns.

### **Statement of the Purpose**

The purpose of this research was to explore the self-directed learning (SDL) actions of women regarding their search for information about menopause. Tough's (1971) study of SDL found that in addition to groups learning with a teacher, adults spent considerable time learning one-on-one with a teacher, in groups without a teacher, or even on their own. Additionally he found that the process adults undertake to develop their learning process is similar to the process classroom teachers take. Consequently, understanding the SDL actions women are taking at mid-life, where they are going for information, and what obstacles they encounter will allow those who



interact with them, health care providers (HCPs) and adult educators particularly, to think about ways to guide them on their journey, primarily with setting goals and with finding reliable resources.

### **Research Questions**

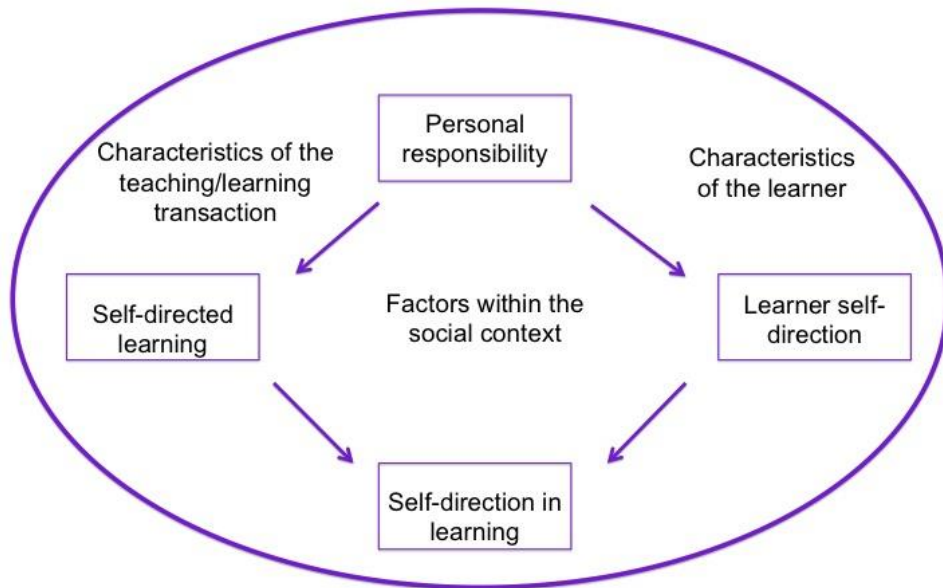
This study was guided by the following research questions:

1. To what extent are women between the ages of 35-55 engaging in self-directed learning about menopause?
2. What motivates women to seek information about menopause?
3. To what extent are there differences in identified resources and topics based on age, marital status, level of education, or race/ethnicity?
4. What are the socio-ecological factors that most influence women's self-directed learning actions in their search for information about menopause?

### **Theoretical Framework**

This research was conducted using the combined conceptual models of the Personal Responsibility Orientation (PRO) model of self-directedness in learning (Brockett & Hiemstra, 1991), and the Socio-ecological Model of Health Promotion (McLeroy, Bibeau, Steckler, & Glanz, 1988). Scholars have not arrived at a consensus regarding a *theory* of self-directed learning; therefore, “a coherent theory is not available” (Rothwell & Sensenig, 1991, p. 13). However, Brockett and Hiemstra (1991) describe the PRO *conceptual model* of self-directedness in learning as one in which both the instructional method of SDL and learner characteristics are considered to

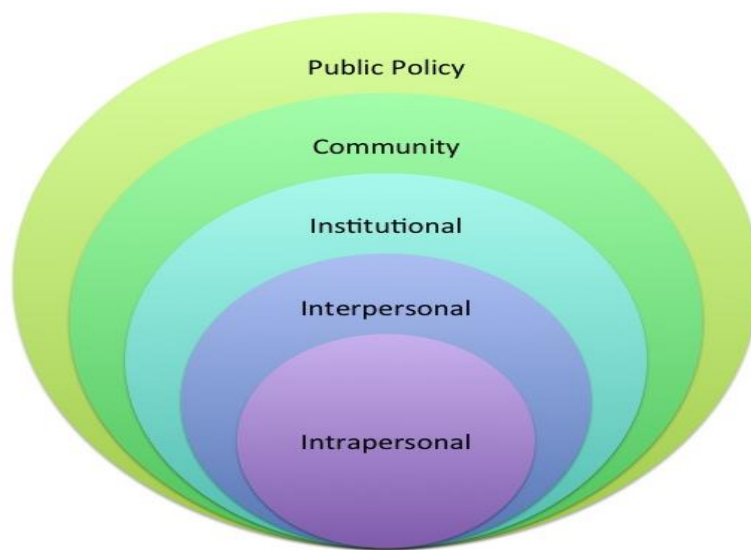
operate within the learner’s social context. Figure 1 illustrates this umbrella concept as adapted and illustrated in Stockdale and Brockett (2011).



*Figure 1.* The Personal Responsibility Orientation (PRO) Model of Self-directedness in Learning as conceptualized by R. G. Brockett and R. Hiemstra (1991) and adapted by S. L. Stockdale and R. G. Brockett in “Development of the PRO-SDLS: A Measure of Self-Direction in Learning Based on the Personal Responsibility Orientation Model,” *Adult Education Quarterly*, 61(2), p. 163. Copyright 2011 by SAGE Publications. Reprinted with permission (see Appendix G).

A sociological model is a form of systems thinking, understanding the whole by understanding the parts. In the mid-19<sup>th</sup> century, a German biologist by the name of Haeckel first used the term ecology “to refer to the totality of relationships of an organism with all other organisms with which it comes into contact” (van Lier, 2004, p. 3). Social ecology speaks to the dynamic interrelationship of the personal and the environment.

In 1988, McLeroy et al. discussed an ecological model of health promotion that reflects a range of levels of analysis available to plan health promotion interventions. This model focuses attention not only on the individual's behavior, but also the environmental determinants of behavior, as illustrated in Figure 2. English (2012) suggested that because an individual's health does not occur in isolation, but within the context of the larger community, health and well-being are reliant on and connected to societal structures. She asserts that one way to improve the health of the community, then, is through health education.



*Figure 2.* The Socio-ecological Model (SEM) of Health Promotion. This figure illustrates levels of environmental determinants of behavior and levels of analysis available for consideration in planning health promotion interventions.

This study utilized the SEM of health promotion within the PRO model of self-directedness in learning as what Brockett and Hiemstra labeled the *factors within the social context*. The combined models are illustrated in Figure 3.

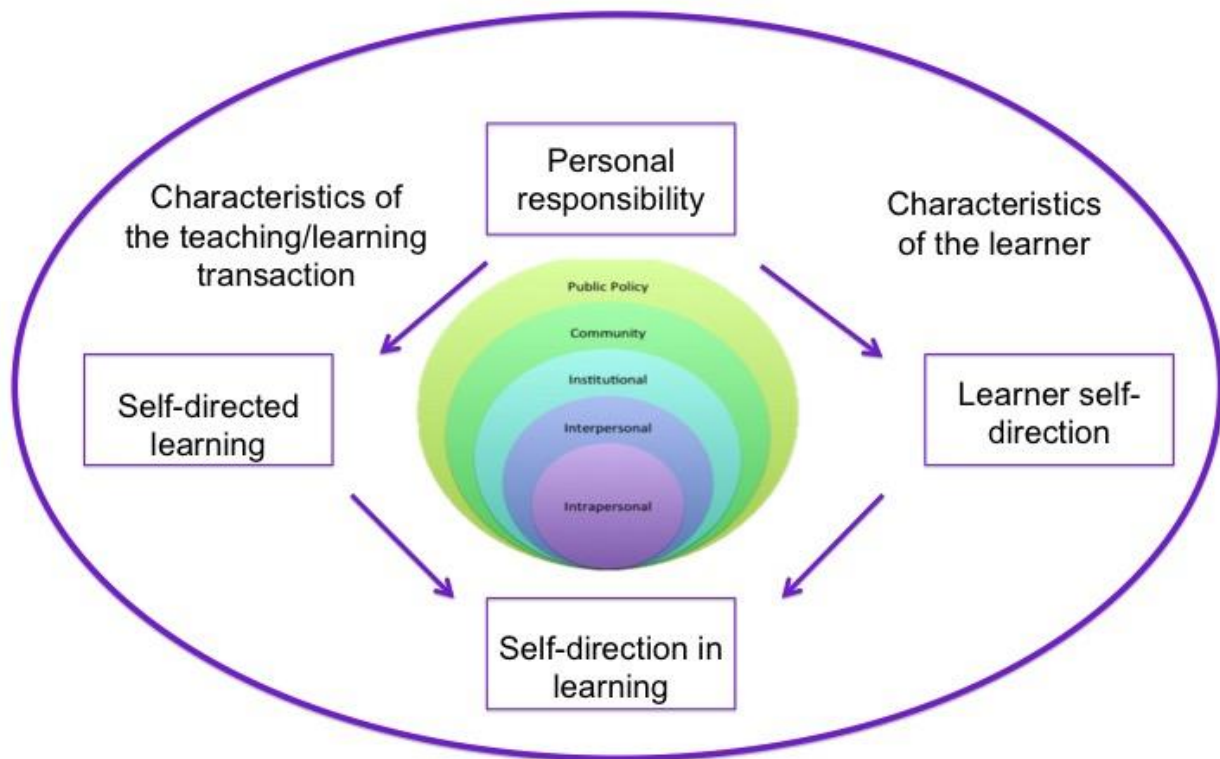


Figure 3. The Combined PRO and SEM Conceptual Models. This figure illustrates how the SEM of health promotion was utilized within the PRO model of self-directed learning.

SDL implies some level of learner autonomy; however, Knowles (1975), in his early discussions of adult learning, acknowledged that a learner's self-directedness was

likely to be situational rather than universal. Other scholars, in addition to Brockett and Hiemstra, express “that even those adults who can and want to be self-directed in their learning may choose not to exhibit or pursue this characteristic at certain times” (Merriam, Caffarella, & Baumgartner, 2007, p. 123). This sentiment relies on the learner’s *choice*, part of the intrapersonal level in the SEM. This study sought to explore environmental issues that may influence a woman’s choices, and perhaps other environmental issues that may impact a woman’s ability to be self-directed.

### **Significance of Study**

Research shows that a woman’s knowledge and attitudes about menopause can have a direct bearing on her perceived difficulty in the transition (Buchanan et al., 2002; Choi, 1993; Norton et al., 2014; Walter, 2000). Buchanan et al. (2002) assert that “A lack of communication about menopause affects women’s perceptions of their experience” (p. 100), leading to a negative perception of menopause as an illness. If foreknowledge positively impacts a woman’s menopause transition, understanding what women know, when and how they come to know, and why some women engage in self-directed learning while others do not will assist educators in “understanding the changes and transitions in adults’ lives [that will] enable [us] to anticipate learning needs” of the women with whom they work as well as “understand how life events facilitate or inhibit [their] learning ” (Knowles, Holton, & Swanson, 2011, p. 221).

### **Limitations**

While every effort was made to obtain as diverse a sample as possible, this study, by virtue of the fact that it utilized an internet administered instrument, did not

obtain responses from those without internet access. Because the instrument is branched, collection via hard copy without an in-person interview was not feasible.

As there is no one menopause experience, some women will experience a perimenopause transition that is negative, and some women will pass through the perimenopause transition with little to no disruption to their lives. Because participation in this study was voluntary and uncompensated, it is possible that women who experienced distress were more likely to respond.

### **Delimitations**

This study was conducted using a convenience sample. As a descriptive study, a convenience sample was sufficient to assess the possibility of additional studies with randomized samples.

Inclusion criteria were women who were between 35-55 years of age, who had not undergone induced menopause, who had computer access, who are able to read English, and who were willing to complete a survey questionnaire. The age range of 35-55 years included women of the average age from the time just before the onset of the perimenopausal period through shortly after the average age of menopause. This study sought the SDL actions of women who had not had induced menopause. Women anticipating surgical removal or chemotherapy/radiation ablation of their ovaries may engage in SDL actions; however, these actions would be for an event that they would be certain to take place and have most likely had conversations with their health care providers. It is a different preparatory process.

## Definition of Terms

Within this research, the following terms were used according to these definitions:

**Health care provider (HCP)** is an individual who provides health care services, either for medical problems or well care. This individual is usually a physician, but can also be a physician assistant or nurse practitioner (Vorvick, 2015). There are many kinds of HCPs for well care and common medical problems, such as internists, family practitioners, and OB/GYNs (obstetricians/gynecologists).

**Health promotion**, as defined by the University of Georgia College of Public Health, “draws from the biological, environmental, psychological, physical and medical sciences to promote health and prevent disease, disability and premature death through education-driven voluntary behavior change activities” (n.d., ¶ 1).

**Hormone replacement therapy or Hormone therapy (HRT or HT)** is the use of hormones prescribed by a physician to treat menopause symptoms. According to the North American Menopause Society (2014), the use of the term *hormone replacement therapy* (HRT) is no longer allowed by government regulators, who prefer simply the use of *hormone therapy* (HT) instead. Estrogen (ET) or estrogen and progesterone (EPT) can be prescribed as hormone therapy, the former being prescribed only to women without a uterus.

**Menopause** is the point in a woman’s life at which she has her last menstrual period. In natural menopause it is determined retrospectively after 12 consecutive months have passed without menses. For purposes of this study, menopause is meant

to indicate natural menopause, rather than menopause that occurs due to medical intervention.

**Menopause transition** refers to the period of perimenopause, which usually starts 8 to 10 years before menopause.

**Perimenopause** is the period during which a woman begins to naturally transition toward menopause as the body gradually produces less and less estrogen. Perimenopause usually begins when a woman is in her 40s, but can occur in her 30s.

**Self-directed learning (SDL)** is described as an individual determining one's own "learning needs, formulating learning goals, identifying human and material resources for learning, choosing and implementing appropriate learning strategies, and evaluating learning outcomes" (Knowles, 1975, p. 18).

**Self-directed learning actions**, for purposes of this study, are the activities a woman engages in, either when she autonomously perceives a need or when the idea has been suggested by another individual such as a HCP, to independently learn about the menopause journey. Such learning actions can include, but are not limited to, asking questions of other women, friends, or family; looking for information in electronic or print resources; taking a class; or initiating a conversation with her HCP.

### **Researcher's Perspective**

The researcher came to this study through her own lived experiences of the menopause transition. At 40-something, irregular periods first caused me a worry about pregnancy when menses was sporadic, then ovarian cancer when menses became extremely heavy. Eventually I also experienced hot flashes and mood swings. I knew



those were symptoms of perimenopause, but it really had not occurred to me to be thinking about menopause yet.

After suffering many seemingly unrelated little maladies, and being sent for a variety of tests by a list of physicians, I came across a website listing 34 symptoms of perimenopause (34-Menopause-Symptoms.com, n.d.). I realized I had experienced all but about six of these symptoms. Many of the little maladies I had experienced were right there on that list, yet none of the physicians I had seen had mentioned the word *menopause* to me.

As I began to do small research projects for other studies, I found that other women had similar experiences. I also found women who had not. As Mackey (2007) reports, the majority of Western women experience a non-problematic menopause. She also concludes that when women's experience of menopause is other than what she expected, it can be unfamiliar or unexplainable (and) may be linked to greater distress during menopause. That is, if the symptoms experienced at menopause have a sense of familiarity or can be explained or understood, they seem to be less disturbing and create less disruption in the life of the woman. I was among those whose experiences were unfamiliar and unexplainable; hence, my concern in this study was for women like me, those who needed or wanted information and were not receiving it.

### **Organization of Study**

This research is divided into five chapters. Chapter 1, the introduction, provides an overview of the study including the problem, purpose, research questions, theoretical framework, significance of the study, and definition of terms. Chapter 2 includes a

review of the literature relevant to this study. The review is presented in five sections including the conceptual models of menopause in Western culture; women's reported experience of menopause; self-directed learning; health promotion; self-directed learning, uncertainty management and health self-advocacy; and a summary of the chapter. Chapter 3 includes the population and sample, instrumentation, data collection, data analysis, ethics and a summary of the chapter. Chapter 4 provides a presentation of the findings including the demographic profile of the respondents, survey results, observations, and a summary of the chapter. Chapter 5 includes a summary of the study, as well as conclusions, implications, and recommendations.

## Chapter 2

### Review of the Literature

The purpose of this research was to explore the self-directed learning (SDL) actions of women regarding their search for information about menopause. This chapter presents a review of the literature that explores the research available regarding Western conceptual models of menopause; women's reported experience of menopause; self-directed learning; health promotion; and SDL, uncertainty management and health self-advocacy.

#### Conceptual Models of Menopause

Although menopause is a biological event, the social construct *menopause* is defined by individual understanding (Buchanan et al., 2002). It may seem that understanding menopause would be straightforward; however, there are many different conceptual models by which it may be viewed. Although there are others, five of the most common conceptual models are examined here. These models, or perspectives, include: medical, psychological, feminist, natural/holistic, and socio-historical,

**Medical.** A medical conceptual model views menopause as a deficiency disease requiring treatment. According to Conrad (2007), *medicalization* "describes a process by which non-medical problems become defined and treated as medical problems, usually in terms of illness and disorders" (p. 4). Interest in the process of the cessation of menses as a medical disorder grew as the professionalization of obstetrics and

gynecology (OB/GYN) as a field of medicine grew in the 18<sup>th</sup> century; at that time, the process of menopause was relatively misunderstood (Stolberg, 1999). The medicalization of menopause was cemented during the mid-20th century when the U. S. Food and Drug Administration (FDA) approved the use of synthetic estrogen for the treatment of menopause symptoms (Bell, 1987).

According to the medical model, as ovarian function diminishes, the female body becomes *deficient* in estrogen, androgen, and progesterone (Barile, 1997). The *Merck Manual of Gynecology* states that the “(d)agnosis is clinical” (Gass, 2016, ¶ 23) and *treatment* can require “lifestyle modification, complementary and alternative medicines, hormone therapy, (or) other neuroactive drugs” (Gass, 2016, ¶ 27) [emphasis added].

According to Dean (2005), the first American doctors to attempt to treat menopause symptoms in 1929 used a derivative from the amniotic fluid of cattle. In the 1940s, estrogen therapy (ET) was approved by the FDA for the treatment of hot flashes associated with menopause (Nelson, 2007). Because estrogen was effective in the relief of other symptoms, women began to expand their estrogen use even though there had not yet been any rigorous research to support its efficacy or safety (Women's Health Research Institute, 2013). The sentiment that menopausal women were deficient was promoted by a California psychiatrist in his best selling book, *Everything You Always Wanted to Know About Sex but Were Afraid to Ask* (Reuben, 1969). In this book Reuben maintained that:

As estrogen is shut off a woman comes as close as she can to being a man. Increased facial hair, deepened voice, obesity, and decline of breasts and female genitalia all contribute to masculine appearance. Not really a man, but no longer a functional woman, these individuals (menopausal women) live in a world of

intersex. Having outlived their ovaries, they have outlived their usefulness as human beings. The remaining years may be just marking time until they follow their glands into oblivion. (p. 287)

Three years earlier, in 1966, a practicing physician had told women that they could remain *Feminine Forever* and escape the deleterious effects of menopause by using ET (Wilson, 1966). The message seemed to be that to avoid being trapped in a world of intersex, women needed to keep their bodies pumping with estrogen. In 2002, one day after the release of the results of the Women's Health Initiative study, *The New York Times* reported that by 1975, Premarin, a trademark name for a preparation of conjugated estrogens made by Wyeth-Ayerst for the treatment of menopause, had become the fifth leading prescribed drug in the United States (Kolata & Peterson, 2002). The same 2002 *New York Times* article further reported that in 1975, at the same time that Premarin sales were skyrocketing, the *New England Journal of Medicine* published two major studies connecting estrogen to uterine cancer (Kolata & Peterson, 2002). Additionally, R. Wilson, the aforementioned Wilson's son, indicated that his father had been paid by Wyeth-Ayerst to write his book, *Feminine Forever* (Kolata & Peterson, 2002); however, there was no attribution to or acknowledgement of Wyeth-Ayerst anywhere in Wilson's book.

Goodman (1982) asserted that medical research into menopause such as Wilson's had been based on "the *least* powerful methodology" (p. 275) [original emphasis], clinical research. According to Goodman (1982), a primary failing of such research had been that only women who were symptomatic were studied; women who did not have particularly distressing symptoms had not sought treatment, thus creating a

perceptual bias. From this biased clinical research, an understanding of the distressed menopausal woman made its way “into vividly written medical textbooks” (Goodman, 1982, p. 276). This, Goodman continued, served to perpetuate the unbalanced image of menopausal women until “familiarity bred uncritical acceptance as well as clinical contempt” (Goodman, 1982, p. 276).

Similarly, Rostosky and Travis (2000) argued that the characterization of menopause as a condition of deficiency within medical and scientific discourse created an image of menopause as a problem. Niland and Lyons (2011) indicate that the medical view of menopause is still “the most dominant (and powerful) perspective” (p. 1238). Rostosky and Travis (2000) further contended that regarding menopause, “published medical literature is replete with negative biases. Furthermore, . . . scientific conclusions in established medical journals are often based on flawed theory and slipshod methodology” (p. 182).

According to Barile (1997), advantages of this model are that it attributes symptoms of menopause to biological causes and does not lay blame. Disadvantages, though, are that it encourages an overreliance on physicians, and reinforces the idea that women are different and inferior. According to Conrad (2007), “medicalization increases the amount of medical social control over human behavior” (p. 8). Mishra and Kuh (2006) indicate that women viewing menopause as a medical event may seek medical treatment for a “perceived condition rather than address the social and lifestyle issues that can occur concurrently” (p. 94).

**Psychological.** The psychological model ascribes negative experiences associated with menopause to psychological difficulties such as individual stress or underlying mental health issues. Additionally, it accounts only for psychological concerns, such as depression, but not physiological concerns (Barile, 1997). Although it is rarely contested that there are mid-life women who experience depression, there is uncertainty and controversy regarding the cause. A 1980 medical textbook taught young medical students that:

The empty nest is certainly a real phenomenon . . . . Most mothers recognize this bit of reality. However, they are often unprepared for the lack of responsibility and the relatively abrupt change in their life style which ensues from the loss of children in the home. Some women become depressed at this time . . . . It is infinitely more acceptable to attribute depression to menopause than it is to acknowledge that the loss of one's children is the major cause of the dysphoria. (Fink, 1980, p. 114)

Dennerstein and Soares (2008) stated that the cause of depression during menopause is unclear, "whether depressed mood is caused by psychological factors related to aging or whether [it is caused by] ovarian hormonal changes" (p. 137). They further indicated that "These observations suggest that the menopausal transition may be considered a 'window of vulnerability' during which women are at high risk for depressive symptoms," similar to other "vulnerability phases" such as the pre-menstrual or immediate post-partum periods; each of these periods in a woman's life may share an increased magnitude of hormonal turbulence (p. 138), and acknowledged that "Chaotic changes in hormone levels during the menopausal transition may be one of the major factors in increased risk of depression" (p. 139).

Mishrah and Kuh (2006) state that the research investigating how the menopause transition may affect a woman's psychological health and well being has not been as consistent as research investigating physiological health. Additionally, the results of the existing studies have yielded mixed results.

Dennerstein and Soares (2008) also discussed one sub-study of the Melbourne Women's Mid-Life Health Project that looked at the phenomenon of empty-nest syndrome and its correlation to women's mid-life depression, as well as another sub-study of the project which examined the consequences of physical, emotional, or sexual violence as possible causes other than menopause for depression in mid-life. To date, there is no consensus. "It's not clear how common depression is in menopause . . . . What is clear is that a history of depression does make menopausal women more susceptible to developing it" (Udesky, 2014, ¶ 17).

According to Barile (1997), an advantage to this conceptual model is that it implies a need for treatment and social support. A disadvantage may be that the blame for negative symptoms may be placed solely on psychological causes to the exclusion of other factors.

**Feminist.** The feminist conceptual model of menopause developed as a direct response to the medicalization of menopause of the mid-20<sup>th</sup> century. Feminists began to articulate objections to the medical model, accusing the male-dominated medical profession of "reflecting and perpetuating the social ideology of women as sex objects and reproductive organs" (McCrae, 1983, p. 111). In addition to rejecting the continued objectification of women into middle age, a feminist conceptual model of menopause is



concerned with the implication of patriarchal power when the view of menopause is that of a deficiency disease. The disease label is one that “decreases the status and autonomy of the patient while increasing the status and power of the physician” (McCrea, 1983, p. 113).

Murtagh and Hepworth (2005) stated that from the 1980s and 1990s came two major criticisms of the existing negative, medical constructions of menopause. First, the idea that menopause was “a monolithic physiological phenomenon which was invariably accompanied by devastating symptoms” (p. 279) does not hold up against the social, epidemiological, and anthropological studies of women’s experiences. Secondly, they write that the medicalization of menopause is exploitative and unethical. Therefore, a feminist conceptual model of menopause lies in direct opposition to the medical conceptual model. The feminist model instead asserts that menopause is “a natural developmental process, and an inevitable life transition” (Barile, 1997, p. 38).

In response to the disease framework offered by medicine, Murtagh and Hepworth (2005) presented three alternative ways the modernist feminist literature has called for women to respond: “resistance, revision, and informed choice” (p. 280). For example, Klein and Dumble (1994) called upon women to resist taking hormones and then not feel guilty for their choice.

Greer (1993) called for a poetic sort of resistance, one that leads to a revisioning: “If we are to be well, we must care for ourselves. We must not cast the old woman out, but become her more abundantly” (p. 359). Greer’s revisioning called on women to

reclaim their womaness and revise the negative perceptions of aging, including perceptions of menopause, into one that is not only positive, but powerful as well:

If we embrace the idea of witchhood, and turn it into a positive, aggressive, self-defining self-concept, we can exploit the proliferation of aversion imagery to our own advantage. It is after all no shame to know that lager louts find our presence inhibiting. Perhaps we do spoil things for all the boys together propping up the bar in the local pub or littering our highways and by-ways with their cans or bashing and knifing each other at football matches. So much the better. Why not wear a T-shirt that says, "A glance from my eye can make your beer turn rancid?" (p. 359)

Finally, with a history in the women's health movement of the late 1990s, the third response called for in the modernist feminist literature is that of informed choice. Worcester and Whatley (1992) suggested that most women make a choice about taking HT based on a "fear meter, asking themselves which diseases or discomforts they most dread" (p. 21). Murtagh and Hepworth (2005) added that making choices would be inevitable; however, they questioned the validity of making these choices based on a universal concept of menopause and biomedical science which is "questioned only in so far as the truth claims are provable or not. There is an assumption that it is possible to produce good (unbiased) information for women" (p. 281).

A post-modernist feminist conceptual framework, like the modernist framework, examines menopause from a social perspective; however, the post-modernist view is critical of both the medical and the modernist feminist perspective as providing an either/or construction (Harding, 1997; Leng, 1997). Leng (1997) concluded that as closed explanations, both frameworks fail to account for the wide variety of diverse menopause experiences. Therefore, Murtagh and Hepworth (2005) concluded, "Feminist writers have drawn attention to the deeply gendered construction of the body,

especially in relation to reproduction and sexuality. However, . . . feminist perspectives on menopause are not unitary” (p. 284).

**Natural/Holistic.** Natural and holistic conceptual frameworks, though similar, are not synonymous. Although the terms are frequently used interchangeably, a holistic framework is also used to describe yet another framework: integrative/complementary. Before the advent of HT, the approach to menopause was generally a natural one. In the 21<sup>st</sup> century, information on a natural conceptual framework of menopause is sparse in academic literature and also minimal in popular literature. A diligent search on the internet to find a discussion of menopause using terms other than *treatment, remedy, condition, abnormality, lack*, or other terms akin to treating an illness proved challenging as there was little available.

Morris-Gluth, founder of *Holistic Menopause*, speaks matter-of-factly on her web page as she seeks to encourage women to *embrace the change* (Morris-Gluth, 2015). *Holistic Menopause* does not sugarcoat concerns women may have during this time in their lives, using descriptive words such as *hormone imbalance, journey, and challenging*. However, indicative of the naturalistic approach, the web site also follows with words like *relief, freedom, and revitalized spirit*. It is in Morris-Gluth’s (2005) discussion of menopause that a working definition of the natural conceptual framework can be found:

Each phase of your transition requires that you stay in touch with your body. In perimenopause, your symptoms alert you to the areas of your life that need attention. Consider them a loud and clear “wake up call” to encourage positive change. The turbulent years of perimenopause give way to the “silent symptoms” of menopause and post menopause. Preventing age and hormone related health conditions like heart disease and osteoporosis require your

attention from this time forward . . . . Identify what you're experiencing as "normal" to regain a sense of control . . . . This natural transition is occurring precisely as intended and is preparing you for next chapter of your life. (¶ 3)

The second use of the term *holistic* in defining conceptual frameworks may also be referred to as an *integrative* or *complimentary* approach. Goodman (1982) states:

The most central flaw in previous menopause research is that it fragments a complex biosocial, biopsychological phenomenon. . . . The presumption that the menopause can be studied through one or several of its aspects to the exclusion of others has hindered the development of a general understanding of the scope and impact of the menopause experience. (p. 273)

The integrative conceptual framework is one, then, which seeks to rectify this fragmentation. Similar to the natural conceptual framework, the integrative approach refrains from defining menopause in biomedical terms of disease, but rather as a natural life transition (Carolan, 1994; Huffman & Myers, 1999). However, "denying the impact of biomedical factors ignores the reality of physiological change, possible disruptive symptomatology, and health risks" (Huffman & Myers, 1999, p. 263). Therefore, the integrative conceptual framework is informed by both the biomedical and behavioral sciences.

Liao and Hunter (1998) surmised that even at the clinical level, simply focusing on the biomedical aspects of menopause may not be useful. The authors further suggested that alternative therapies should be considered as part of the integrative framework, and health education be included as well. Comparing menopause health education to pre-childbirth classes, Liao and Hunter (1998) suggested that health education needs to take place before women actually need it, before perimenopause has begun.

According to Huffman and Myers (1999), an advantage of this paradigm is that it has the potential to empower women by returning control of their lives to them, encouraging them to become informed about the issues of menopause and the alternatives available to them.

**Socio-historical.** The socio-historical model contends that social factors influence a woman's experience of menopause (Barile, 1997). The menopause transition, like childbirth, is an experience that is exclusively woman's. "Reproduction and motherhood have been at the core of the feminist and women's movements ever since their emergence" (Neyer & Bernardi, 2011, p. 162). As the event that marks the end of woman's reproductive life, menopause is susceptible to all of the same socio-historical concerns that feminists have articulated throughout a woman's reproductive life. In this model, "Sociocultural attitudes toward women and aging are responsible for menopause symptoms" (Barile, 1997, p. 37).

Among the factors that contribute to the socio-historical model of menopause is the way women are viewed in Western culture overall. Therefore, not only is menopause viewed as a social construct, but cultural views of women in general—gender, sexuality, and aging—are social constructs as well. These are discussed further below.

**Gender.** Before engaging in a critical discussion of gender roles and womanhood in the oft-quoted publication *The Second Sex*, de Beauvoir (1953) first asks, *what is woman?* Her own answer examined such possibilities as: possessing a womb, functioning as a female, or being defined through the "eternal feminine" (p. 4).

Ultimately, though, de Beauvoir concluded that the social construct of woman is the *Other*:

Thus, humanity is male and man defines woman not in herself but as relative to him . . . . She is defined and differentiated with reference to man and not he with reference to her; she is the incidental, the inessential as opposed to the essential. He is the Subject, he is the Absolute—she is the Other. (p. 6)

De Beauvoir asserts that men and women are bound by a reciprocal need, but adds that “However equally compelling the need may be to them both, it always plays in favor of the oppressor over the oppressed” (p. 9). The need to which she refers is the need for sexual gratification and offspring; it is through her ability to provide these that woman is socially constructed, and that construction is not one of equality.

In a study of gender-role ideology of baby-boomer women (women born between the years 1946-1964), Lendon and Silverstein (2012) examined attitudes toward gender role egalitarianism today. Over a 34-year study period, the authors found that attitudes toward gender egalitarianism showed a sharp increase during the years of radical feminism, 1971-1985, followed by a stall or plateau. They attribute this pattern to a combination of two parallel ideas. First, the concept known as the *impressionable youth* posits that individuals take on the ideologies of the period in which they come of age. Baby-boomer women came of age during a period of time when feminists openly critiqued the subjugation of women and questioned the traditional role of women as wife and mother. The study also found that women’s gender role attitudes were later impacted by life events, such as experiences in the family and labor force. In this case, as these women faced the non-egalitarian reality of motherhood and the work force, attitudes toward gender role egalitarianism ceased to increase. Women’s attitudes

seemed to echo the attitudes of the greater social order. Faludi (1991) argued in her book *Backlash* that there existed a war against American women, driven by the media, that sought to turn back gains made by feminists of the 1970s. A reading of popular news in the early 21<sup>st</sup> century might indicate the backlash had been successful:

The sex industry is booming, the rape conviction rate is plummeting, women's bodies are picked over in the media, abortion rights are under serious threat and top business leaders say they don't want to employ women. It all adds up to one thing . . . an all-out assault on feminism. (Cochrane, 2008, ¶1)

And so, four decades after de Beauvoir, Tavis (1993) reiterated this idea of womanhood and Otherness:

In Western society today there are three competing versions of the mismeasure of woman . . . . One is that man is the norm and woman is opposite, lesser, deficient . . . . A second view is that man is the norm, and woman is opposite, but better . . . . The third view is that there is not a problem, because man is the norm, and woman is just like him. (p. 150)

De Beauvoir's construct of Otherness is not merely a statement declaring that women are different from men. Tavis (1993) clarified that:

In any domain of life in which men set the standard of normalcy, women will be considered abnormal, and society will debate her "place" and her "nature". . . . The study of "difference" is not the problem; of course people differ. The problem occurs when one group is considered the norm with others differing from it, thereby failing to "measure up." (p. 149-151)

With regard to menopause, being the Other, the human with a womb, the self that derives power from man's need for sexual gratification and progeny, Lorber and Moore (2002) state that "Since Western women's social status is so intertwined with their body and biology, menopause has been seen as virtually the end of womanhood" (p. 81). The authors go on to ask why, if menstruation is problematic, the cessation of

menses is more so. Referencing Golub (1992), they answer themselves: “Fear: fear of aging, fear of loss of sexuality, fear of getting depressed, fear of loss of health” (p. 236).

**Sexuality.** Rotosky and Travis (2000) asserted that “the notion of the body, and in association, one’s self-identity as a passive attractant, begins early and is carried throughout the life span” (p. 202). In her book addressing the historical fascination with feminine beauty, Wolf (1991) stated that in response to slumping sales in the 1960s, beauty magazines shifted their focus from fashion to women’s bodies, thus providing women monthly critiques by which to shape their body image. Calogero and Thompson (2010) define body image as “a multi-faceted construct that consists of self-perceptions, attitudes, beliefs, feelings, and behaviors related to one’s body” (p. 153), and “women are defined and treated more often as bodies than men” (p. 170).

Western society is inundated with sexualized images of women in every possible medium. The Health Promotion site for Brown University advises:

The media is a powerful conduit for transmission and reinforcement of cultural beliefs and values, and while it may not be exclusively responsible for determining the standards for physical attractiveness, it makes escaping frequent exposure to these images and attitudes almost impossible. (“Body Image”, n.d., ¶ 16)

As a result of being defined by a sexualized body, women internalize this standard of beauty (Stotland, 2002; Wolf, 1991). When a sexy, youthful body is one’s method of self-definition, mid-life can potentially be traumatic (Dillaway, 2005; Hvas, 2006; Niland & Lyons, 2011). Barrett (2005) maintained that woman’s social value is culturally linked to her sexual and reproductive potential. Mansfield and Voda (1993) stated, “As long as women are valued primarily for youthful attractiveness, they will fear



natural, even health-promoting body changes . . . as threats to their femininity and desirability” (p. 101).

Rotosky and Travis (2000) submitted that “Since American society links sexuality to youth, beauty, and vigor, sexual behavior among the elderly is treated in literature as a talking platypus phenomenon” (p. 187). The authors additionally express concern over a cultural emphasis on “*looking* sexy (passive and unrealistic) rather than *being* sexy (active and realistic)” (p. 184) [original emphasis], as well as concern regarding the extension of unrealistic beauty standards, once reserved for younger women, to increasingly older women. As an example, they cite a pictorial in a 1995 issue of *People* magazine that applauds women over 40 who continued to meet cultural standards of sexiness; that is to say, they looked 10 years younger than they actually were.

Therefore, a potential source of woman’s mid-life crisis is that if she has assimilated the understanding that her value lies in her youthful beauty, and menopause signals aging, which then implies the ending of her youth; thus, menopause may be seen as the harbinger of the end of her life as a valued human being and the beginning of becoming the old crone (Lorber & Moore, 2002). This may not have to be a conscious fear. Bartky (1990) stated:

In contemporary patriarchal culture, a panoptical male connoisseur resides within the consciousness of most women: They stand perpetually before his gaze and under his judgment. Woman lives her body as seen by another, by an anonymous patriarchal Other. (p. 72)

**Aging.** Although in the United States both men and women experience anxiety about aging (Rostosky & Travis, 2000), research indicates that women experience

greater aging anxiety (Abramson & Silverstein, 2006; Barrett & von Rohr, 2008; Cummings, Kropf, & DeWeaver, 2000; Lynch, 2000; McConatha, Schnell, Volkwein, Riley, & Leach, 2003). Men also seem to be less concerned about age-related changes in appearance (Halliwell & Dittmar, 2003). In 1999, Öberg and Tornstem investigated the attitudes of men and women about physical attractiveness. In investigating whether outward appearance was of equal importance to women and men, they found that “in all age groups, appearance is more important for women than men, and that this importance does not diminish with age” (Öberg & Tornstem, p. 640).

These findings were reflected in a 2012 survey about aging commissioned by the popular women’s magazine *Allure* and conducted by the marketing research firm Penn Schoen Berland. A Reuters analysis of the *Allure* survey (Reaney, 2013) found that most people believed women are under greater pressure than men to continue to look youthful, while men are considered to be old five years later than women. Women, more so than men, indicated that not only were they concerned about how looking old would impact their attractiveness, they were also concerned about how it would impact them on the job.

In a data analysis of a larger five-year longitudinal study, researchers found a correlation between women’s attitudes toward aging and their attitudes toward menopause; however, it was not a strong enough correlation to conclude they were measuring the same concept (Nosek, Kennedy, Beyene, Taylor, Gilliss, & Lee, 2010). Nevertheless, Hall et al. (2007) stated that “Grief about the loss of youth (and) beauty . . . are issues modern women are concerned about” (p. 111). Stotland (2002),

in discussing a Western culture hyper-focused on youth, stated that while “Images of beautiful young women are used to sell products,” and “Youth and beauty are synonymous . . . . The old woman is a marginalized, even demonized, figure in much of Western society” (p. 6). Rotosky and Travis (2000) have pointed out that images of old women in English literature are presented using descriptive terms such as *crone* and *hag*.

In regard to the correlation between aging and menopause, Van de Weil (2014) states, “As a nexus of fertility’s finitude and female midlife, menopause is a physical and cultural phenomenon through which the relation between the medicalization of the female reproductive cycle and normative attitudes toward aging become expressed” (p.74). Stotland (2002) added that:

The medical profession, in its zeal to adopt the use of hormones at menopause, has contributed significantly to the youth culture by advancing the concept that it is only through the miracles of modern medicine that women survive beyond menopause at all. (p. 6)

Additionally, Wilk and Kirk (1995) reported that most women who discussed menopause in psychotherapy associated it with getting old.

According to Barile (1997), one advantage of the socio-historical conceptual model is that it widens the view of menopause. A disadvantage, though, is that women may blame themselves for negative symptoms and feel inadequate. The medical and socio-historical perspectives often marry here, when “menopause is viewed as a negative sign of ageing, and HRT as a remedy to counter the bodily decay and the loss of sexual and physical attractiveness” (Niland & Lyons, 2011, p. 1239).

## **Women's Reported Experience of Menopause**

Menopause is a biological condition that every woman who has ovaries and lives through middle age will eventually experience, whether naturally, surgically, or chemically induced, as the ovaries begin to produce less estrogen. Women may experience their own menopause as a natural transition and a normal life phase, or something more negative, such as disease or dysfunction (Buchanan, et al., 2002). The transition to menopause, though inevitable, frequently does not foster open discussion, yet how a woman experiences menopause often “directly depends on the amount and types of information received” (Buchanan et al., 2002, p. 101).

Dillaway (2008) sought to examine how family and intimate interactions were influenced by menopause. This study revealed that often the medical perception of menopause was reaffirmed in intimate and family interactions. Although some women perceived their partners to be nurturing, others indicated that their partners felt they should be able to control their menopause experience. When they were not able to do so, “they were encouraged to define symptoms as problematic and seek medical treatment” (p. 47).

**Knowledge and attitudes about menopause.** There is a growing body of research on menopause that indicates a correlation between a woman's foreknowledge of the menopause transition, her attitudes toward menopause and aging, and the degree of distress she experiences during this time. Ayers, Forshaw, and Hunter (2010) conducted a systematic review of the research that has examined women's attitudes toward menopause and their symptom experience. That review found that all

12 studies reviewed mentioned a relationship between attitude and symptom experience, with a negative attitude correlating to symptom frequency.

Buchanan et al. (2002) found that women who held negative feelings toward menopause reported a higher number of emotional and physical symptoms when experiencing menopause. Mushra and Kuh (2009) reported that in “focusing on the adverse aspects, the resultant negative expectations of menopause may have become self-fulfilling” (p. 94). In two different qualitative studies, researchers found that when women’s experiences with menopause differed from their expectations, negativity and conflict often were the result (Choi, 1993; Walter, 2000). Choi (1993) stated, “When the disparity between one’s expectations and one’s actual body experience was great, the personal adaptation to menopause appeared to be affected” (p. 89). Mackey (2007) concludes that when women’s experience of menopause is other than what she expected, it can be unfamiliar or unexplainable (and) may be linked to greater distress at menopause. That is, if the symptoms experienced at menopause have a sense of familiarity or can be explained or understood, they seem to be less disturbing and create less disruption in the life of the woman.

As research indicates that attitude about menopause and symptoms during the menopause transition are frequently correlated, separately, additional studies indicate that knowledge of menopause leads to a more positive attitude. Buchanan et al. (2002) state that “it is important for communication researchers to explore the role of ambiguity and misinformation in women’s understanding of menopause” (p. 100). While Mansfield and Voda (1993) stated, “In turn, the meaning of menopause for any woman depends in

large part on the information available to her” (p. 89). Hunter and O’Dea (1999) asserted that “Women generally desire more information about the menopause than they receive. . . . Conversely, increased knowledge is likely to empower women and increase their sense of control or self-efficacy in relation to the menopause” (p. 249). A 2007 Korean study (Choi & Park, 2008) found that there is a need to develop an educational program about menopause due to a lack of women’s knowledge. A 2015 Iranian study found that “[A] health education intervention strategy is one of the alternative strategies for improving women's attitudes and coping with menopause symptoms” (Yazdkhasti, Simbar, & Abdi, 2015, p. 3).

A study of a psycho-educational intervention for healthy women 40–60 years of age (Rotem, Kushnir, Levine, & Ehrenfeld, 2005) found that women who participated in 10 weekly sessions experienced more positive attitudes toward menopause and a reduction in symptom severity. The authors indicated that one possible explanation for the success of the intervention may have been based on an integrative model which cannot separate “cognitive from emotional processes because of the reciprocal influence between emotions and cognition in learning processes, decision making, and attitude change” (p. 238). A health education, or psycho-education, intervention may provide information to women who do not have enough knowledge about the menopause transition to promote a positive menopause experience.

Another example of an educational intervention has been a course offered by the Couple-to-Couple League (CCL) of Northern Virginia as part of a series of courses called Natural Family Planning (NFP). In addition to courses dealing specifically with

family planning during the child-bearing years, they also offer a course in “Pre-menopause” for couples. Additionally, the Northern California Women’s Herbal Symposium has offered a course called “Demystifying Menopause,” taught by an MD, as just one of a number of courses on overall women’s health. Both of these courses present menopause as a normal life event.

**A positive menopause experience.** The history of menopause as a condition, as a topic of conversation, and as the subject of study, frequently revolves around pathological characteristics associated with this time in a woman’s life. However, Mackey (2007) asserts that the majority of Western women do not experience a problematic transition, but that unproblematic menopause has not been studied—because *wellness* as a subject of study is elusive. “It is elusive because it is a non-problematic state, thus difficult to mark out by measurement, events or experiences. In wellness, nothing stands out to notice, observe, or disrupt as it does in illness” (p. 39). Therefore, to investigate women’s experience of wellness and well-being at menopause, Mackey (2007) conducted a phenomenological study of post-menopausal women. In this study, she found that women’s response to symptoms at perimenopause correlated closely to their understanding of their symptoms as being normal or not normal aspects of menopause: “when women experienced changes they felt were normal for menopause, the changes were not perceived as disruptive” (p. 40).

In looking for a *typical* response to menopause, in a study of 24 Danish women, Hvas (2006) found that, rather than a typical response, women had a variety of responses to both menopause and aging, and these women did not seem to distinguish

between the two. All but one of the women were able to find positive aspects to this life stage, including having gained more freedom and possibilities for future personal development (aging) and no longer having to worry about menses (menopause). The few existing studies on non-problematic menopause, in conjunction with research that demonstrates a correlation between knowledge, attitudes, and distress at perimenopause, seem to point to a need for better education for women prior to the peri-menopause transition.

In a 2014 study, Cooper and McCarthy (2014a) conducted a focus group study with five post-menopausal women, followed by individual interviews, to learn about their perimenopause experience. In that small group, there was a clear continuum of experience, from one woman who had not suffered at all, to one who had reported tremendous disruption and a sense of social isolation. In this group of five, three of the women felt uninformed throughout the transition. Two of these women had a distressful transition. One indicated she had received misinformation from her physician who did not investigate perimenopause as a cause of her symptoms, because she was still menstruating; the other indicated she had not received much guidance from her HCP and had been too embarrassed to ask questions, even of her friends. The third did not feel as though she had experienced many symptoms, and certainly none that were disruptive. When something unexpected did come up, though, she was able to turn to her physician husband. The two remaining women were part of a very strong, longstanding network of friends on whom they relied for all of life's ups and downs. To them, perimenopause was just one more event. One of these two, at 61 years, had



been on HRT for two decades and, in the group, expressed feeling left out having never experienced a hot flash.

### **Self-directed Learning (SDL)**

Most scholars agree that SDL is universal, present in each person to one degree or another, and can take place in a wide variety of contexts: traditional, classroom experiences; alternative classrooms; or in the personal sphere (Guglielmino, 2012). However, for the process to begin, SDL must be activated “by the personal characteristics of the learner, combined with the given learning situation” (Guglielmino, 2012, p. 1). Although there is the capacity for SDL in each person, a consortium of scholars, including Houle, Knowles, Tough, and Guglielmino, advanced a list of characteristics that they considered the highly self-directed learner to possess. The list includes, among other characteristics, “acceptance of responsibility for one’s own learning” (Guglielmino, 2012, p. 1). However, accepting the responsibility for one’s own learning does not necessarily mean that there will, at least initially, be careful consideration of resources. Candy (1991) observed that

When someone sets out to learn something entirely new to them, it seems that they will make use of a variety of resources and, at the beginning at least, this is more likely to be on the basis of ready availability than any objective measure of their appropriateness. (p. 178)

SDL can be distinguished from formal learning in that self-directed learning is managed by the learner and can take place anywhere, whereas formal learning is an activity planned and carried out by an institution or other organization (Cross, 1981; Spear & Mocker, 1984; Tough, 1971). According to Merriam (2001),

Based on the pioneering research in self-directed learning of Houle, Tough, and Knowles, early research in self-directed learning was descriptive, verifying the widespread presence of self-directed learning among adults and documenting the process by which it occurred. (p. 8)

Although firmly established in adult learning theory, SDL is not a single theory, or model, or process. Research into SDL has illustrated that there are a multiplicity of understandings among scholars regarding its goals. Scholars such as Mezirow (1981) believed the focus of SDL to be on transformational learning and our role as educators to “assist adults to learn in a way that enhances their capability to function as self-directed learners” (p. 137).

Another understanding, held by scholars such as Brookfield (1993) and Collins (1996), views SDL as a tool for the promotion of emancipatory learning and social action. These scholars are critical of the potential for ignoring the social context in which learning takes place, and call for a more critical analysis.

The pioneers in SDL research seemed to hold a more humanistic philosophy, considering the focus of SDL to be on cultivating the learner’s ability to be self-directed. In addition to the theories of Houle (1961), Tough (1971), and Knowles (1975), Merriam (2001) contends that the model developed by Brockett and Hiemstra (1991), the Personal Responsibility Orientation model, is also grounded in this humanistic focus.

Among the voluminous scholarship in SDL, measures of self-directedness have been developed: a scale to show a learner’s readiness (Guglielmino, 1977), as well as a scale to show learner characteristics (Oddi, 1986). Additionally, scholars have developed a variety of models and processes illustrating how a learner works through a SDL experience. Knowles, in his early definition of SDL (1975), expresses a linear

process that many still view as the standard today: “learning needs, formulating learning goals, identifying human and material resources for learning, choosing and implementing appropriate learning strategies, and evaluating learning outcomes” (p. 18).

Research in the study of SDL tends to focus on either SDL as an instructional method, or on the characteristics of the individual learner allowing her to become self-directed. In the Personal Responsibility Orientation (PRO) model developed by Brockett and Hiemstra (1991), a framework is provided that comprises both. In the PRO model, in the instructional process component the learner assumes the responsibility for the planning, implementing, and evaluating her own learning process. This component speaks to the learners (perceived) level of control of the learning situation and her ability and/or willingness to direct the learning process, much like the definition for SDL put forth by Knowles. Stockdale and Brockett (2011) indicated a difference in the PRO model and Knowles’ definition. They contend that while Knowles focuses on learner *initiative*, the PRO model focuses on personal *responsibility* for this task. Stockdale and Brockett (2011) further explain that “Brockett and Hiemstra also emphasize the proactive nature of personal responsibility, which seems to point to a behavior very similar to initiative” (p. 165).

The personality characteristics component of the PRO model “centers on a learner’s desire or preference for assuming responsibility for learning” (Brockett & Hiemstra, 1991, p. 24) and “an individual’s beliefs and attitudes that predispose one toward taking primary responsibility for learning” (p. 29). In reviewing scholarship in

psychology, specifically work on self-determination theory and motivation, as well as literature in adult education theory, Stockdale and Brockett (2011) asserted that the learner characteristic component of the model can be viewed as “behaviors relating to (a) learner autonomous motivation and (b) perceived self-efficacy for self-direction in learning” (p. 167).

## **Health Promotion**

A study of the history of public health shows that the improvement of living conditions beginning in the 19<sup>th</sup> century led to the beginning of a decline in mortality. As people began to live longer, chronic disease, rather than infectious disease, grew as a primary public health concern (Coreil, 2010). *Health promotion* to combat many of the causes of chronic disease has become a contemporary focus of many public health efforts. The World Health Organization (WHO) defines Health Promotion as “the process of enabling people to increase control over, and to improve, their health. It moves beyond a focus on individual behaviour towards a wide range of social and environmental interventions” (2015, ¶ 1). In 1988, McLeroy et al. wrote that

During the past 20 years, there has been a dramatic increase in public, private, and professional interest in preventing disability and death in the United States through changes in individual behaviors . . . . Much of this interest in health promotion has been stimulated by the epidemiologic transition from infectious to chronic diseases as leading causes of death. (p. 351)

It was another two decades before the Centers for Disease Control and Prevention (CDC) looked beyond even the prevention of death and disease, to health related quality of life.

In 1979, the Surgeon General of the United States published a report which put forth a national agenda for public health by establishing five goals designed to improve the health of all Americans. Ten years later that report grew into a working plan, *Year 2000 Objectives for the Nation* (CDC, 1998). Since that time, there have been four iterations of the plan, updated by decades. Beginning with the second iteration, this set of national objectives has been known as *Healthy People: 2000, 2010*, and now, the most recent plan, *Healthy People 2020*. *Healthy People 2020*, a set of some 1200 objectives in 42 topic areas (CDC, 2013) is made up of four overarching goals and seeks to break new ground in “scope, outreach, and scientific underpinning of the initiative” (CDC, 2010, p. O-24). More than just seeking to address chronic disease, *Healthy People 2020* has among its goals to “promote quality of life, healthy development, and healthy behaviors across all life stages” (CDC, 2013, ¶ 2). At least three of the topic areas of *Healthy People 2020* are directly relevant to promoting good health in women at mid-life and to the issues under study in this project: Educational and Community Based Programs, Health Related Quality of Life, and Social Determinants of Health.

The University of Georgia College of Public Health (n.d.) asserts that health promotion is important because it “improves the health status of individuals, families, communities, states, and the nation” and “enhances the quality of life for all people” (¶ 4). In addition to identifying national health improvement priorities and engaging in critical research, one of the major components of *Healthy People 2020* is health promotion (CDC, 2013).

From a perspective of critical theory, English (2012) connects adult education and health promotion as a means to increase public participation in maintaining health in the community, reducing reliance on the medical community, and thus increasing individual control over one's own health. Additionally, English, in discussing the Canadian approach to the H1N1 crisis of 2009, indicated that:

Although health information was being given to the public through standard media outlets and through new social media sites and blogs, there was an ongoing need to raise the level of public participation and awareness of health and to continue to move it beyond consumption of facts and information. (p. 14)

Health promotion through education has the potential to have a favorable impact on women's experience during the menopause transition. In a study of 157 Australian women, Anderson, Seib, McGuire, and Porter-Steele (2015) found that an "intervention study documented reduced menopausal symptoms in midlife women that may be attributable to changes associated with the intervention" (p. 74). The authors speculate that one of the reasons the interventions were successful was that they occurred at a time when women were motivated and willing to make lifestyle changes.

Yazdkhasti et al. (2015) assert that the empowerment of women achieved through Educational and Community Based Programs has the potential to enhance a woman's "self-confidence, ability to achieve goals, sense of control over life and processes of change, and hope for the future" (p. 2). They further add that empowerment is especially needed because menopause has the potential to change a woman's lifestyle by impacting her physical, social, financial, and emotional quality of life.

To combat a lack of knowledge potentially exacerbated by contradictory information, the authors recommend empowerment-based education.

As Toral et al. (2014) wrote, “It is important to emphasise that menopause and postmenopause are complex physiological processes that are accompanied by the influences of ageing, sociocultural backgrounds, psychosocial factors and adjustment to new life roles” (p. 94), all elements that must be considered in health promotion efforts—in other words, a SEM approach.

### **SDL, Uncertainty Management, and Health Self-Advocacy**

Caffarella (1993) described SDL as a survival skill that people utilize in response to the rapid pace of change in modern society. In regard to self-health care, Valente (2011) states that “Self-care in health refers to a broad range of behaviors undertaken by individuals with the intention of maintaining or promoting health” (¶ 5). SDL is a valuable tool for individuals interested in practicing health self-care.

When an individual is suddenly faced with an unexpected or chronic illness, he or she is likely to experience uncertainty. Babrow, Kasch, & Ford (1998) indicated that uncertainty is “a central feature in illness experiences” (p. 1). According to Brashers (2001), “Uncertainty exists when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge” (p. 478). Royer (1995) tied uncertainty in illness directly to a lack of information, an inability to make predictions, and ambiguity. Rooks, Wiltshire, Elder, BeLue, & Gary (2012) state that “patients

reduce health care uncertainty by increasing their understanding of disease etiology or treatment options” (p. 176).

Professional health advocates, in addition to serving as ombudsmen and care managers, serve as educators and health information specialists to help patients increase their understanding (Hurst, n.d.). According to one advocacy firm, a professional health advocate serves a client or patient by *assisting with learning tasks*, identifying health risks, and managing and removing obstacles (SoCal Health Advocates, n.d.) [emphasis added]. A 2011 article in the journal *Academic Medicine* notes that the provisions of the 1997 *Jakarta Declaration on Health Promotion* makes social responsibility a priority moving into the 21<sup>st</sup> century (Dharamsi, Ho, Spadafora, & Woollard, 2011). The authors thus call upon physicians to act as health advocates by extending their responsibilities beyond the individual patient to the collective society. Health advocacy can be complex; it requires knowledge and effort.

According to Rager (2007), even as physicians are being called upon to become more responsible for communities, the incidence of individuals taking responsibility for becoming advocates for personal health care, health *self*-advocates, is increasing. Reasons for SDL actions in regard to health self-advocacy are many. From a study involving prostate cancer patients, Gray, Fitch, Phillips, Labrecque, Klotz, & Gray (1999) surmised that activities involving health-related SDL “seem to be the result of converging influences, including a growing distrust of medical authority, historical failures by the healthcare system to provide adequate information, and the ascension of a consumerist philosophy” (p. 134). Rager (2009) found that men and women turned to



SDL when facing medical issues, and in many cases “emotion served as a motivator for learning” (2009, p. 22). In other studies, Rager (2006, 2007) added the availability of information on the Internet as a reason for increased SDL activity regarding personal health.

In a study involving the SDL activities of older adults with known health conditions, Valente (2011) found six key factors related to how the study participants’ SDL activities were related to their health care. Key among those factors were that the participants “recognized a connection between aging and their overall health; [and] they understood the importance of managing their health and health care” (¶ 15).

Engaging in SDL activity to inform oneself about health concerns does not always imply learning in isolation. Another finding of import in Valente’s 2011 study is that it is often a health event that serves as the impetus for an individual’s SDL actions; however, once the learning process begins, participants engage in collaboration with a health care professional (HCP) to gain a better understanding of information found, or to gain additional information. Finally, even though an individual seeks to become a self-advocate, Valente also found that a participant’s personal management issues such as fear, procrastination, frustration, or anxiety can become barriers to SDL activities.

For health care issues in general, Rager (2009) indicates that “more and more *patients* are assuming the responsibility for conducting their own information searches and not relying purely [if at all] on the advice of health professionals” (p. 23) [emphasis added]. Middle-aged women are not, by virtue of their age, *patients*; however, given the correlation of knowledge, attitude, and distress at perimenopause, it may be reasonable

to consider menopause a health event. Nevertheless, Buchanan et al. (2002) found that “although women have access to a plethora of information about menstruation, conception, and obstetrics, they are generally uninformed about menopause or ‘the change’ until they either begin the experience or have completed it” (p. 101).

The research is mixed regarding the popularity of books versus Internet for learning new information. The Pew Research Center (2014) reported that in January 2014 only 76% of the American population reported reading at least one book, including e-books or audiobooks. However, for gaining health information, the Internet has made health and medical information readily available in a way that it was not before (Koch-Weser, Bradshaw, Gualtieri, & Gallagher, 2010). According to the Pew Research Center (2009), 61% of adults look online for health information.

Koch-Weser et al. (2010) cite five primary reasons why individuals might use the Internet for investigating health information:

social networking, participation, openness, collaboration among other users, and apomediation. Apomediation is the ability to go “directly to the source” of information rather than relying on a gatekeeper such as a doctor or other health professional. (p. 280)

In 1992, Sheehy shattered a cultural taboo by writing about menopause for the laywoman. Over 30 years later, Chrisler (2013) asserts that the topic remains taboo. An unwillingness to discuss menopause may contribute to a woman’s lack of understanding about the process. The Internet may allow women to increase willingness to seek information about menopause by allowing them to maintain control over their learning process.

## Summary

The research indicates that there are a multiplicity of lenses through which menopause may be viewed; the lens through which a woman views menopause may impact her experience of the menopause transition. The research also demonstrates that in addition to perception, foreknowledge may impact a woman's experiences during her menopausal transition. Additionally, self-directed learning has been examined as a health self-advocacy technique for health concerns such as prostate and breast cancer. Menopause is not an illness; however, it may be considered a health event. Thus, health self-advocacy by using SDL may allow women to maintain control of what they learn and how they learn it, often in the privacy of their own homes. These learning projects can enable women to understand the changes their bodies are undergoing and empower them to seek additional resources if necessary.

## Chapter 3

### Methods

The purpose of this research was to explore the self-directed learning (SDL) actions of women regarding their search for information about menopause. This chapter presents the methods and procedures that have been used to conduct this study. Specifically, the research design, population and sample, instrumentation, collection of data, data analysis procedures, ethics, and summary are described.

#### Research Design

Since this study was exploratory in nature, no formal hypotheses were developed. This survey study utilized a quantitative, descriptive research design. An online survey was conducted to understand the extent to which women inform themselves about menopause, a foreseeable life stage. Answers to the following research questions were sought:

1. To what extent are women between the ages of 35-55 engaging in self-directed learning about menopause?
2. What motivates women to seek information about menopause?
3. To what extent are there differences in identified resources and topics based on age, marital status, level of education, or race/ethnicity?

4. What are the socio-ecological factors that most influence women's self-directed learning actions in their search for information about menopause?

### **Population and Sample**

This study was conducted using a convenience sample of women. A snowball sampling component was also used, asking each participant to forward the survey information to at least three additional women to generate further participation.

Inclusion criteria were women who were between 35-55 years of age, who had not undergone induced menopause, who had computer access, who were able to read English, and who were willing to complete an online survey questionnaire. Initial invitations to participate in this study were presented by both a flyer and business card. See Appendix A for a copy of the flyer invitation and Appendix B for a copy of the business card invitation. Invitations were dispersed via online postings and dissemination in public spaces granting permission such as local businesses, hair and nail salons, universities, public schools, and women's centers and organizations, and through social media such as Facebook.

### **Instrumentation**

**Construction of questionnaire.** The questionnaire included two sections. The first section collected demographic information. Participants were asked to indicate: (a) age, (b) marital status, (c) level of education, and (d) race/ethnicity.

The second part of the questionnaire was branched to allow participants to see only questions that were relevant to them, thus keeping the questionnaire as short as possible and allowing the respondent to remain focused while helping to ensure

meaningful and relevant questions were answered. The purpose of this section was to obtain information about why and how participants have learned about menopause.

There were five parts to this section asking participants to indicate: (a) whether they had or had not researched menopause on their own; and if so, (b) the age at which they first decided to learn about menopause, (c) if their health care provider was influential in initiating the learning process, (d) what types of resources they used and which topics they explored, and (e) if they received outside assistance from others when seeking information about menopause. See Appendix C for a copy of the survey instrument.

In the Fall of 2013, Cooper and McCarthy (2014b) conducted a similar study, also utilizing an online survey questionnaire. The instrument, though similar, was revised for this study. The following changes were made:

In the previous study, the first section, which collected demographic information, asked participants to indicate household income and state of residence. In this study, household income was not a factor under consideration. Additionally, participants were not asked to indicate their state of residence.

The second section of the previous study was also adaptive and collected information about how and when participants learned about the menopause transition. The following five major parts to this section were included: (a) whether they had or had not researched menopause on their own; and if so, (b) the age at which they first began to learn about menopause, (c) if their health care provider was influential in initiating the learning process, (d) what types of resources they used and which topics they explored, and (e) if they received outside assistance from others when seeking information about

menopause. In this section of the current study, minor changes in wording were made to increase clarity and to reduce participant confusion.

In the prior study, an email script with a link to the electronic survey was sent to 10 key informants to disperse to potential participants. The informants were selected at the discretion of the researchers and represented both genders as well as a variety of ethnicities, income, and education levels. The informants were instructed to email a pre-written message, constructed by the researchers, that contained a link to the questionnaire, to any females who were 30 years of age or older. This dissemination method was utilized in an effort to obtain a varied sample of participants and to safeguard the anonymity of the participants; however, this method of dissemination was found to be inefficient and less than desirable in yielding the number of participants desired. In this study, the researcher solicited the participants directly, without a key informant as an intermediary.

**Measurement, validity, and reliability.** To gather evidence related to content validity, cognitive interviews were conducted to obtain the perceptions of five women regarding the content of the questionnaire. Following the model of the interview process utilized to develop and validate the Copenhagen Psychosocial Questionnaire (Berthelsen, Lonblad, Hakanen, Kristensen, Axtelius, Bjorner, & Westerlund, 2014), before the interview began, participants were instructed to “think aloud” while answering questions such as “How many windows do you have where you live?”

The interview began when each participant was confident with the process. Each participant was asked to begin the survey and read the questions aloud, as well

as articulate her thought process. Because speaking one's thoughts may not come naturally, the researcher encouraged participants to continue to vocalize their thoughts when they forgot.

Once cognitive interviews were complete, a small pilot study was conducted to explore instrument validity. To complete the pilot study, the following was accomplished in accordance with guidance published by Sociology, University of Surrey, UK (van Tiejlingen & Hundley, 2001). The questionnaire was administered to five women who met the survey inclusion criteria in the same way that the survey was administered in this study, electronically with written instructions. The amount of time taken to complete the survey was observed and participants were asked for feedback. The pilot study for this research led to one revision, moving the question: "Have you sought information regarding any health conditions?" from the end of the survey, to the beginning in the demographics section.

To test instrument reliability, once the questionnaire was complete, the survey was electronically administered to five women meeting the inclusion criteria, and then administered again one week later. Responses from the initial test were compared to the responses in the re-test by individual item response using the Pearson product-moment correlation coefficient (PPMCC). Forty-nine of 54 questions had a 100% correlation. However, in the test, one participant indicated she sought information from friends, but in the re-test indicated she did not, and one participant indicated she sought information from magazines, but in the re-test she did not. These changes impacted the correlation of follow-up questions regarding information satisfaction. Additionally, one



participant indicated she was not sure she was satisfied with regard to information she received from a family member, while in the re-test she indicated she was satisfied. An overall PPMCC score of 0.9074 was found.

### **Data Collection**

To obtain the information sought for this study, the validated survey questionnaire was utilized (see Appendix C). The landing page of the questionnaire contained the informed consent statement and eIRB number, inclusion criteria, and instructions for completing the questionnaire.

### **Data Analysis**

The primary, overarching question under study was research question one, to what extent have women engaged in self-directed learning activity to learn about menopause? To that end, the first research question was addressed in the survey questionnaire following the section capturing demographic information. Because the questionnaire was branched, question numbers could not be consistently applied. The first question was a yes/no question which asked: "Have you sought information about menopause?" For a table depicting the correspondence between research and survey questions, see Appendix D, Table D1. Responses were examined utilizing a relative frequency distribution to understand the proportions of these variables to the sample. Additionally, confidence intervals were computed around the sample proportions to estimate the population proportions. To put participant's research actions in context, the questionnaire also asked if participants had researched any other medical condition, and if so, what sorts of conditions they had researched.

The next survey question, “At what age did you first seek information about menopause?” expands on research question one. This question, which allowed an age-range answer choice, was analyzed utilizing descriptive statistics to illustrate when women begin to investigate menopause.

The remainder of the survey questions were, in fact, sub-questions and served to inform and describe learning activities, if any, such as what facilitated them, and/or what obstructed them. These questions were asked of women who answered question one in the affirmative, indicating that they had sought information about menopause. These questions were presented as a mixture of yes/no, free response and categorical multiple-choice items, and were examined utilizing the following methods of analysis.

Research question two, what motivates women to seek information about menopause, was addressed first by asking about conversations women had with their HCPs regarding menopause, asking directly what prompted her search, and also asking if she had been symptomatic. These responses were examined utilizing a relative frequency distribution to understand the proportions of these variables to the sample; confidence intervals were computed around the sample proportions. Additionally, free response answers were examined for patterns and common themes, as well as deviations from those themes.

Research question number three, understanding the types of resources women utilized when learning about menopause, was first examined in a series of yes/no questions. Each yes/no response was examined independently utilizing a simple frequency distribution to illustrate more and less common topics and resources.

Additionally, confidence intervals were computed around the sample proportions to estimate the population proportions.

The topics concerning menopause women most frequently sought information about were provided in free response format and were analyzed by utilizing a simple frequency distribution to illustrate more and less common topics and resources.

Additionally, confidence intervals were computed around the sample proportions to estimate the population proportions.

To consider relationships of the identified resources and topics, and respondent demographics (age, marital status, level of education, or race/ethnicity), data were examined using the chi-square test for independence and the demographic variables that were obtained in this study.

Answers to research question number four, which sought to learn about the socio-ecological factors that influenced women's search for information about menopause, came from questions scattered throughout the questionnaire rather than concentrated in a block or section. Returning to the types of resources women utilized when learning about menopause, in addition to the yes/no portion of the questions and the free response identifying the source, women were also asked to answer why they had or had not utilized each resource. These free response answers were examined for patterns and common themes, as well as deviations from those themes.

Additionally, women were asked in yes/no format if there was someone else assisting in their search, and were asked to provide in free response format, their relationship with that person when the answer was affirmative. Answers were analyzed

by utilizing a simple frequency distribution to illustrate more and less common sources of assistance. Additionally, confidence intervals were computed around the sample proportions to estimate the population proportions.

Women were also asked if there was information they were looking for that they could not find and, if so, what kind of information. Likewise, they were asked if they had continued their search after an initial investigation and, if not, why not. Answers were analyzed by utilizing a simple frequency distribution to illustrate more and less common sources of assistance. Additionally free response answers were examined for patterns and common themes, as well as deviations from those themes.

Finally, if women answered that they had not sought information about menopause, they were asked why not. These questions were presented as a mixture of yes/no and free response items. Free response answers were examined for patterns and common themes, as well as deviations from those themes.

**Power.** The minimum sample size sought was 131 completed surveys. The desired sample size was calculated using a power of 0.8 which Cohen (1992) considered high; an alpha level of .10; and an effect size of 0.3, which Cohen (1992) considered a medium effect size. The alpha level and effect size were appropriate since, as Cohen (1992) indicates, exploratory studies may hold a less rigorous standard for rejection.

### **Ethics**

Although no potential risks to the study participants were foreseen, this study was submitted to the Institutional Review Board (IRB) at the University of South Florida

to ensure the protection of the study participants. See Appendix E for a copy of the IRB letter.

**Description of the informed consent process.** The landing page of the questionnaire explained that participation in the study was voluntary and that no identifying information would be collected, enabling the researcher to maintain participant anonymity. This page also included the purpose of the study, the inclusion/exclusion criteria for the study, and the researcher's desire to publish the findings.

**Discussion of how privacy and confidentiality were maintained.** The data collected through Qualtrics were exported into an Excel spreadsheet. The spreadsheet and the analyzed data were encrypted and password protected on a flash drive. The survey for the study was deleted in Qualtrics within 60 days of the study close date. There were no identifiable characteristics collected that could be associated with the participants by name.

## **Summary**

The intent of this chapter was to present the research methods that were used to conduct this investigation into the self-directed learning actions of women regarding their menopause transition. The research design, population and sample, and instrumentation were provided, as were the data collection and analysis procedures, and ethics considerations.

## Chapter 4

### Findings

The purpose of this research was to explore the self-directed learning (SDL) actions of women regarding their search for information about menopause. This chapter presents findings of the study and includes (a) the demographic profile of the respondents, (b) survey results, (c) observations, and (d) summary.

#### Demographic Profile of Respondents

The demographic information collected during this study included age, level of education, marital status, and race/ethnicity. One of the inclusion criteria for this study was that women must be between 35-55 years of age. Eleven respondents outside this age range participated in the study. Those responses were removed before the data were analyzed. Additionally, women who had induced menopause due to chemotherapy or surgery were excluded. The questionnaire began by asking if the woman had entered menopause due to surgery, chemotherapy, or some other reason other than naturally. Women answering yes to this question were thanked for their participation and the survey ended. The number of usable responses totaled 227. See Table 1 for the demographic profile of the study participants.

Table 1

*Demographic Profile of Survey Respondents*

Variable	<i>n</i>	%*
<b>Age</b>		
35-39 years	47	21
40-44 years	50	22
45-49 years	53	23
50-55 years	77	34
<i>Total</i>	227	100
<b>Education Level</b>		
High school	12	5
Some college	34	15
2-year degree	18	8
4-year degree	58	26
Graduate degree	69	30
Professional degree	33	14
Other	3	2
<i>Total</i>	227	100
<b>Marital Status</b>		
Married	185	82
Single	18	8
Divorced	17	7
Widowed	1	1
Other	6	2
<i>Total</i>	227	100
<b>Race/Ethnicity</b>		
Asian	4	2
Black	13	6
Hispanic	15	7
White	191	84
Other	3	1
Not specified	1	<1
<i>Total</i>	227	100

*N* = 227 \*May not equal 100% due to rounding

Women aged 50-55 years were the largest group of respondents (34%,  $n = 77$ ). The age range of the remaining participants was fairly balanced, with participants in the age ranges 35-39 ( $n = 47$ ), 40-44 ( $n = 50$ ), and 45-49 ( $n = 53$ ) numbering between 21 and 23%.

The education level of the survey participants leaned toward those with college experience. Women with graduate degrees had the greatest representation in this study at 30% ( $n = 69$ ), followed closely by women with 4-year degrees at 26% ( $n = 58$ ).

The percentage of respondents with some college ( $n = 34$ ) and professional degrees ( $n = 33$ ), 15% and 14% respectively, were comparable, as were those with 2-year degrees ( $n = 18$ ) and high school ( $n = 12$ ), 8% and 5% respectively. Two women indicated they had vocational training, and one indicated she had a graduate certificate, but not a graduate degree.

The women who participated in this study were predominantly married (82%,  $n = 185$ ), while the number of women who were single ( $n = 18$ ) and divorced ( $n = 17$ ), 8% and 7% respectively, was comparable. One participant indicated that she was widowed, one woman was separated, and one woman indicated she was in a same sex relationship.

The respondents in this study were predominantly white (84%,  $n = 191$ ). Asian ( $n = 4$ ), Black ( $n = 13$ ), and Hispanic ( $n = 15$ ) women made up 2%, 6%, and 7% respectively. Three women indicated *Other*, but did not specify. One participant did not select any response. There were no participants in this study who identified themselves as either Pacific Islander or Native American.



## Survey Results

The questionnaire, administered through Qualtrics, collected 227 usable responses. The statistical software SAS, version 9.4 was used to conduct the computations. Chi-square tests of independence were used to examine bivariate relationships between demographic characteristics and women who had researched menopause, as well as between demographic characteristics and resources used and topics investigated by women who had sought information about menopause. Cross-tabulation processes and percentages were utilized to determine characteristics of the survey sample.

Content analysis was used to examine free response answers utilizing the Qualtrics Insight platform. Text responses were read and analyzed, then categorized and grouped by frequency and synonyms, then coded and clustered by theme.

The alpha level of 0.10 and effect size of 0.3, which Cohen (1992) considered a medium effect size, used in this study were appropriate since, as Cohen (1992) indicated, exploratory studies may hold a less rigorous standard for rejection.

**Research question number 1.** To what extent are women between the ages of 35-55 engaging in self-directed learning about menopause?

For purposes of this study, SDL activities are the activities a woman engages in, either when she autonomously perceives a need, or when the idea has been suggested by another individual, to independently learn about the menopause journey. To answer this question, the instrument asked women directly if they had engaged in a search for information about menopause, and if so, if anyone was assisting or guiding their search.

Fewer than half (48%) of the women ( $n = 109$ ) participating in this survey indicated that they had engaged in any kind of learning action regarding menopause. The majority (96%,  $n = 87$ ) of the women who had engaged in learning activities about menopause reported that no one else had assisted or guided their search. Of the 4% ( $n = 4$ ) who reported assistance, two women reported they were searching with friends, one was searching together with her husband, and one indicated she received guidance from “doctors and nurses.” Of the 109 women investigating menopause, 66 (61%) indicated they had received some information about menopause from their Health Care Providers (HCPs). Only 20% ( $n = 13$ ) of these women reported being encouraged to research menopause on their own by their HCP.

Chi-square tests used to examine bivariate relationships between demographic characteristics and women who had researched menopause demonstrate that the single most significant factor predicting a woman’s likelihood of engaging in research regarding menopause is her age,  $p = <.001$ , with a fairly large Cohen’s  $w$  effect size (0.43). Although the age range of survey participants overall was fairly balanced, that balance was not present in those who reported they had engaged in learning about menopause. There was a clear distinction between those above and those below the age of 45, with the women over 45 ( $n = 86$ , 66%) nearly three times more likely to investigate menopause than those under 45 ( $n = 23$ , 24%). See Table 2 for the demographic profile of study participants engaging in self-directed learning about menopause.

Table 2

*Distribution of Participants Researching Menopause by Demographic Profile*

Variable	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
<b>Age</b>					
35-39 years	9	19	38	81	11%, 30%
40-44 years	14	28	36	72	19%, 39%
45-49 years	32	60	21	40	49%, 70%
50-55 years	54	70	23	30	61%, 78%
<i>Total</i>	109		118		
$\chi^2 (3, N = 227) = 41.34, p = <0.001, w = 0.43$					
<b>Education Level</b>					
High school	8	67	4	33	43%, 84%
Some college	21	62	13	38	48%, 74%
2-year degree	10	56	8	44	37%, 73%
4-year degree	28	48	30	52	38%, 59%
Graduate degree	27	39	42	61	30%, 49%
Professional degree	13	39	20	61	26%, 53%
Other	2	67	1	33	26%, 92%
<i>Total</i>	109		118		
$\chi^2 (6, N = 227) = 8.24, p = 0.22, w = 0.19$					
<b>Marital Status</b>					
Married	89	48	96	52	42%, 54%
Single	7	39	11	61	23%, 58%
Divorced	8	47	9	53	29%, 66%
Widowed	1	100	0	0	27%, 100%
Other	4	67	2	33	35%, 88%
<i>Total</i>	109		118		
$\chi^2 (4, N = 227) = 2.53, p = 0.64, w = 0.11$					

Table continued on next page.

Table 2 (continued)

Variable	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
Race/Ethnicity					
Asian	0	0	4	100	0%, 40%
Black	5	38	8	62	20%, 60%
Hispanic	2	13	13	87	4%, 33%
White	99	52	92	48	46%, 58%
Other	2	67	1	33	20%, 94%
Not Specified	1	100	0	0	27%, 100%
$\chi^2$ (5, <i>N</i> = 227) = 14.01, <b><i>p</i> = 0.02</b> , <i>w</i> = 0.25					
Total	109		118		

Note: CI = confidence interval, Yes = researched menopause, No = did not research menopause, **bold** indicates significant values

This study demonstrated an inverse relationship between a woman's level of education and her self-directed learning actions in researching menopause. Of the women reporting a high school level of education, 67% (*n* = 8) had researched menopause. The numbers were similar for those reporting having obtained a 2-year degree (*n* = 10, 56%). The numbers move in the other direction, though, for participants reporting having obtained a level of education of a 4-year degree (*n* = 28, 48%), a graduate degree (*n* = 27, 39%), or professional degree (*n* = 13, 39%), although there was no statistical difference.

This study revealed that white women were more likely to research menopause than women who did not identify as white. The percentage of white women indicating they had researched menopause in this study (52%, *n* = 99) was higher than the

percentage of Black and Hispanic women combined (38% and 13%,  $n = 5$  and  $n = 2$  respectively). Zero women who identified as Asian had researched menopause, regardless of age, marital status, or level of education. Thus, the relationship between research actions and race/ethnicity were statistically significant ( $p = 0.02$ ); however, Cohen's  $w$  effect size (0.25) was somewhat less than the medium effect size sought (0.3). The remaining demographics were not statistically significant in this study: education level,  $p = 0.22$ , and marital status,  $p = 0.64$ .

The relationship between age and research actions was evident when women were asked at what age they had begun their search. Only 20 participants (18%) had researched menopause between the ages of 35-39; however, for women who began investigating menopause 10 years later, in the 45-49 age range, the number increased more than double, to 48 (44%), as illustrated in Table 3.

Table 3  
*Age at Which Research Began*

Age	$n$	%
20-24 years	2	2
25-29 years	2	2
30-34 years	6	6
35-39 years	20	18
40-44 years	25	23
45-49 years	48	44
50-55 years	6	6
$n = 109$		

*Note.* Percentage may not add up to 100% due to rounding.

To put these learning actions in context, the questionnaire also asked participants if they had researched any health condition, and if so, what health condition(s) they had they researched. Twice as many women reported seeking information about other health conditions as seeking information about menopause.

The questionnaire did not ask women who sought general health information whether that information was for themselves or someone else. However, three respondents were clear that the information sought was for children or other family members, not themselves. Table 4 provides the descriptive statistics of women seeking both information regarding any health condition and women seeking information regarding menopause.

Table 4  
*Frequency Distribution of Respondents' Health Information Seeking*

Condition for which information was sought	Yes		No	
	<i>n</i>	%	<i>n</i>	%
Any health condition	207	91	20	9
Menopause	109	48	118	52

*N* = 227

**Research question number 2.** What motivates women to seek information about menopause?

Answers to this question were sought by asking both directly and indirectly. The 109 respondents who answered that they had sought information about menopause were asked directly what prompted them to begin their search. Their answers were

provided in free response, open-ended format. Content analysis was used to analyze these data, listing responses, scanning for frequency of similar words or phrases, then coding and clustering by theme. Table 5 presents the most commonly stated motivations for researching menopause.

Of the 47 participants between the ages of 35-39 (see Table 1), the years immediately preceding the perimenopausal years, only nine (19%) had sought information about menopause (see Table 2). Of those nine, only two felt as though they *had* experienced any perimenopause symptoms.

Of the nine participants investigating menopause between the ages of 35-39, other than being symptomatic, two indicated that family had been a source of motivation, either by observing the experience of mothers or engaging in family discussion. One simply expressed curiosity and another indicated she had just *stumbled across* information online.

For the 28% of the women between the ages of 40-44 years ( $n = 14$ ) who researched menopause (see Table 2), experiencing symptoms was the primary motivator. Of the 14 who had researched menopause, only two *did not* indicate they had experienced symptoms, the inverse of those in the younger group.

It was not until women reached the age range of 45-49 years that the percentage of women investigating menopause ( $n = 62$ , 60%) was greater than the percentage of those who had not ( $n = 21$ , 40%). The numbers of women investigating menopause increased with age, yet nearly a third of the women between the ages of 50-55 ( $n = 23$ , 30%) had not investigated menopause at all (see Table 2).

Changes in menses and experiencing hot flashes were the two most common motivations reported. Following these two symptoms of perimenopause, women also noted symptoms such as mood swings, depression, lack of sex drive, being *itchy*, and adult acne. When all symptom-related reasons for researching menopause are combined, 44% of the respondents ( $n = 46$ ) were motivated, at least to some degree, by experiencing symptoms. Table 5 presents the most frequently occurring themes reported as motivation for researching menopause; a woman may have provided more than one answer.

Table 5  
*Commonly Stated Motivations for Women Seeking Information About Menopause*

Responses	<i>n</i>	%	90% CI
Experiencing symptoms other than hot flashes and change in menses	45	42	34%, 50%
Hot flashes	23	22	16%, 29%
Change in menses	22	21	15%, 28%
It was just time/the right age	7	7	4%, 12%
General curiosity	7	7	4%, 12%
Concern about mother's experience	6	6	3%, 11%
HCP suggested	2	2	0.6%, 6%

*Note.* CI = confidence interval

$n = 106$

For motivations other than being symptomatic, a few women indicated they felt as though they were just at the right age or were just curious ( $n = 7, 7%$ ); others were concerned because of their mother's experience ( $n = 6, 6%$ ). Some women just wanted



to know more ( $n = 5$ , 5%), some were motivated by their friends' experiences ( $n = 4$ , 4%), and two women (2%) just came across information and decided to read further.

A HCP is mentioned only twice as a motivation, and is noted here for its conspicuous lack of frequency. One participant who mentioned her physician as a motivator indicated that she was motivated because the physician provided a diagnosis of perimenopause, not that the physician actually suggested she conduct research.

Information regarding the HCP's involvement in how women learn and their influence on women's motivation to learn about menopause was explored further by asking women directly if they had spoken with their HCPs about menopause. More women than not had at least one discussion about menopause with her HCP ( $n = 66$ , 61%). However, those answering in the affirmative indicated overwhelmingly that they, themselves, had initiated the discussion ( $n = 54$ , 82%), as shown in Table 6.

Additionally, only 20% ( $n = 13$ ) of the women indicated that the HCP had suggested that the participant research menopause on her own after their initial conversation.

**Research question number 3.** To what extent are there differences in identified resources and topics based on age, marital status, race/ethnicity, or level of education? To learn how the 109 women who reported having investigated menopause informed themselves, the questionnaire presented 11 possible information sources and asked if they had used these, as well as allowing for an additional, free response answer for sources not presented. There were no responses indicated as a free response. The 11 sources presented and the reported utilization by demographics for women indicating they had researched menopause are described below.

Table 6

*Report of Women's Perceptions of Party Initiating Discussion about Menopause*

Initiator	<i>n</i>	%	90% CI
Woman asked questions first	54	82	73%, 88%
HCP brought it up	8	12	7%, 20%
Respondent not sure	4	6	3%, 13%

*Note.* CI = confidence interval

*n* = 66

**Resource utilization by age.** Although age was a factor in when women began SDL actions to find information about menopause (see Table 2), there was not a statistically significant relationship between age and the sources women used to conduct those actions. The most common type of resource by women of all ages were electronic media.

*Participants using a medical website by age.* The majority of participants in all age groups reported using a medical website to gain information about menopause. Women at opposite ends of the age spectrum, 35-39 and 50-55 years of age (*n* = 6 and *n* = 40, respectively), used medical websites the least, both still reporting a sizable number of users at 75%. Nearly all of the women between 40-44 years of age (*n* = 13, 93%) reported utilizing medical websites, while those between 45-49 years of age also reported a substantial number of users (*n* = 28, 88%). A chi-square test of independence indicated that there was no statistical relationship between age and

women choosing to use medical websites to find information about menopause ( $p = 0.33$ ) as presented in Table 7.

Table 7  
*Participants Using a Medical Website by Age*

Age	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
35-39 years	6	75	2	25	46%, 91%
40-44 years	13	93	1	7	73%, 98%
45-49 years	28	88	4	12	75%, 95%
50-55 years	40	75	13	25	64%, 83%
<i>Total n</i>	87	82	20	28	75%, 87%

*Note.* CI = confidence interval

$\chi^2 (3, n = 107) = 3.43, p = 0.33, w = 0.18$

*Participants using a non-medical website by age.* In addition to medical websites, participants were also interested in non-medical websites. In this study, non-medical websites were not utilized as frequently as medical websites, with about twice as many women choosing to forego this resource. Only one-third (33%) of the women between 35-39 years of age ( $n = 2$ ), and between 45-49 years of age ( $n = 10$ ) chose to use non-medical websites, followed closely by women between 50-55 years of age ( $n = 17, 31\%$ ). Women between the ages of 40-44, the women who utilized medical websites the most, utilized non-medical websites the least at only 15% ( $n = 2$ ).

There was no statistical difference by age for women using non-medical websites. The use of non-medical websites for menopause information by age is presented in Table 8.

Table 8  
*Participants Using a Non-medical Website by Age*

Age	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
35-39 years	2	33	5	67	12%, 63%
40-44 years	2	15	11	85	5%, 37%
45-49 years	10	33	20	67	21%, 48%
50-55 years	17	34	33	66	24%, 46%
<i>Total</i>	31	31	69	69	24%, 39%

Note. CI = confidence interval

$\chi^2 (3, n = 100) = 1.79, p = 0.62, w = 0.13$

*Participants using a book by age.* Very few women in this study turned to books, with virtually zero women between the ages of 35-39 choosing this resource. The use of books for women 40-44 years of age and women 45-49 years of age was comparable at 14% ( $n = 1$ ) and 13% ( $n = 4$ ) respectively. Women between 50-55 years of age used books the most frequently at 25% ( $n = 12$ ). There was no statistical difference by age for women using books to find information about menopause based on a chi-square test of independence. Table 9 presents the survey participants' use of books as a source of information about menopause.

Table 9

*Participants Using a Book by Age*

Age	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
35-39 years	0	0	7	100	0%, 28%
40-44 years	1	8	11	92	2%, 30%
45-49 years	4	11	26	87	5%, 24%
50-55 years	12	25	36	75	16%, 36%
<i>Total</i>	17	18	80	82	12%, 25%

Note. CI = confidence interval

$\chi^2 (3, n = 97) = 4.41, p = 0.22, w = .021$

*Participants using a magazine by age.* Few women chose to turn to a book as their first source of information, and fewer still chose a magazine. Only eight women (8%) found information in a magazine, one each between the ages of 35-39 (14%) and 45-49 (3%), and six between the ages of 50-55 (13%). No one in the 40-44 age range utilized a magazine.

There was no statistical difference by age for women using magazines to find information about menopause based on a chi-square test of independence. The use of magazines for menopause information by age is presented in Table 10.

*Participants consulting their friends by age.* The desire of the participants in this study to talk with friends about menopause was highest in the 35-39 age group ( $n = 5$ , 71%), then drops to the lowest (33%) in the next age group, 40-44 years of age ( $n = 4$ ), then slowly increases again to 57% in the 45-49 age group ( $n = 17$ ), and 69% in the 50-55 age group ( $n = 33$ ), comparable with the first group, 35-39 years of age.

Although many women chose to consult with their friends, there was no statistical difference by age based on a chi-square test of independence. Table 11 presents the use of friends as a source of menopause information by age.

Table 10  
*Participants Using a Magazine by Age*

Age	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
35-39 years	1	14	6	86	3%, 45%
40-44 years	0	0	12	100	0%, 18%
45-49 years	1	3	29	97	0%, 13%
50-55 years	6	13	41	87	7%, 23%
<i>Total</i>	8	8	88	92	5%, 14%

*Note.* CI = confidence interval

$\chi^2 (3, n = 96) = 3.61, p = 0.31, w = .019$

*Participants consulting their mothers by age.* In this study, many fewer participants turned to their mothers than their friends for information. And just as they turned to their friends, the women in the 35-39 age range were most likely to consult their mothers ( $n = 3, 43\%$ ), while those in the 40-44 age range were the least likely to do so ( $n = 2, 17\%$ ). Those in the 45-49 age range ( $n = 10$ ), and those in the 50-55 age range ( $n = 14$ ) were comparable at 34% and 30% respectively. There was no statistical difference by age for women consulting their mothers to find information about menopause based on a chi-square test of independence. Table 12 presents the number of women consulting their mothers for information about menopause by age.

Table 11

*Participants Consulting Their Friends by Age*

Age	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
35-39 years	5	71	2	29	4%, 90%
40-44 years	4	33	8	67	16%, 57%
45-49 years	17	57	13	43	42%, 71%
50-55 years	33	69	15	31	57%, 79%
<i>Total</i>	59	61	38	39	53%, 69%

Note. CI = confidence interval

$\chi^2 (3, n = 97) = 5.62, p = 0.13, w = 0.24$

Table 12

*Participants Consulting Their Mothers by Age*

Age	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
35-39 years	3	43	4	57	19%, 71%
40-44 years	2	17	10	83	6%, 40%
45-49 years	10	34	19	66	13%, 32%
50-55 years	14	30	33	70	20%, 42%
<i>Total</i>	29	31	66	69	24%, 39%

Note. CI = confidence interval

$\chi^2 (3, n = 95) = 1.81, p = 0.61, w = 0.14$

*Participants consulting other family members by age.* Very few of the participants in this study consulted with family members who were not their mothers.

Those who did consult with other family members reported primarily talking to sisters, although one woman reported consulting with her husband and children.

There was no statistical difference by age for women consulting family members based on a chi-square test of independence ( $p = 0.12$ ). Table 13 presents the use of other family members as a resource for finding information about menopause by age.

Table 13

*Participants Consulting Other Family Members by Age*

Age	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
35-39 years	1	14	6	86	3%, 45%
40-44 years	2	17	10	83	6%, 40%
45-49 years	2	7	26	93	2%, 19%
50-55 years	14	30	33	70	20%, 42%
<i>Total</i>	19	20	75	80	14%, 28%

*Note.* CI = confidence interval

$\chi^2 (3, n = 94) = 5.88, p = .12, w = 0.25$

*Participants using a talk show host by age.* Because of the prevalence of daytime talk shows offering medical advice, the researcher anticipated that a number of women would report that they had obtained information from these talk shows. However, only two participants (2%), both between the ages of 50-55, gained information about menopause from a talk show host.

*Participants using TV, film, or other media by age.* The questionnaire utilized in this study did not specify the meaning of TV, film, or other media. As such, two women indicated that their answers were in regard to the Internet. These responses should



have been considered with the earlier statistics for website usage; however, the nature of their Internet usage, whether medical or non-medical websites, was not provided. Altogether, only four participants (4%) gained information about menopause from TV, film, or other media, including the two who considered the Internet in this category: one in the 35-39 age group (14%), one in the 45-49 age group (4%), and two in the 50-55 age group (5%).

*Participants consulting a women's health center by age.* Although a woman's health center could be considered to provide services ranging from surgical abortion, to total women's reproductive health, to a place providing services that impact any area of women's lives, the questionnaire used in this study intentionally did not define what was or was not considered a woman's health center; instead, that definition was left to the individual participant's perception, allowing each woman her own perception. Fewer than one-third of the participants in each age group gained information about menopause from a women's health center, with three women referring specifically to their gynecologists. There was no statistical difference by age for women consulting a women's health center to find information about menopause based on a chi-square test of independence, as presented in Table 14.

*Participants using a class by age.* Although some participants commented that they thought the idea of a "menopause class" was silly, many others thought it would be a great resource, similar to classes offered at the beginning of menarche. However, zero participants in this study gained information about menopause from a class.

Table 14

*Participants Using a Women's Health Center by Age*

Age	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
35-39 years	2	29	5	71	10%, 60%
40-44 years	3	25	9	75	10%, 49%
45-49 years	6	21	23	79	11%, 36%
50-55 years	7	15	39	85	8%, 26%
<i>Total</i>	18	19	76	81	13%, 26%

Note. CI = confidence interval

$\chi^2 (3, n = 94) = 1.17, p = 0.76, w = 0.11$

**Resource utilization by level of education.** Women in this study with the highest levels of education were the least likely to research menopause. At 61%, the percentage of women with both graduate ( $n = 42$ ) and professional degrees ( $n = 20$ ) who had not researched menopause was considerably higher than those who had. The only other group that had more women not researching menopause was women with 4-year degrees; however, that number was more balanced with 52% ( $n = 30$ ) not researching menopause (see Table 2), though these results were not statistically significant.

*Participants using medical and non-medical websites by education level.* A vast majority of all survey respondents chose to utilize the Web to conduct their research. They favored medical to non-medical websites by significant margins at all education levels. Between 85% - 87% of the participants who reported having a high school education (87%,  $n = 7$ ), some college (86%,  $n = 18$ ), or a graduate degree (85%,  $n =$

23) reported using a medical website. The lowest usage of a medical website was by those with 4-year degrees, though still substantial at 74% ( $n = 20$ ). There was no educational level whose participants were more likely than not to use a non-medical website, though those with a 2-year degree used both equally ( $n = 5$ , 50%). Tables 15 and 16 illustrate there was not a significant relationship between education and choosing to use the Internet as a resource.

Table 15

*Participants Utilizing a Medical Website by Education Level*

Education level	Yes		No		90% CI	
	<i>n</i>	%	<i>n</i>	%		
High school	7	87	1	13	58%,	97%
Some college	18	86	3	14	69%,	94%
2-year degree	8	80	2	20	54%,	93%
4-year degree	20	74	7	26	58%,	85%
Graduate degree	23	85	4	15	71%,	93%
Professional degree	10	77	3	23	54%,	90%
Other	2	100	0	0	42%,	100%
<i>Total</i>	88	81	20	19	74%,	86%

Note. CI = confidence interval

$$\chi^2 (6, n = 108) = 2.32, p = .88, w = 0.15$$

*Participants utilizing a book or magazine by education level.* There was no substantial use of traditional print media overall by women participating in this study. However, there was the least use by women with the lowest and highest levels of education. Books were used more than twice as often as magazines, with a total of 17

(17%) women at all education levels using books, while only eight (8%) women overall reported magazine use, as presented in Table 17 and 18.

Table 16

*Participants Utilizing a Non-medical Website by Education Level*

Education level	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
High school	2	33	4	67	12%, 65%
Some college	8	40	12	60	24%, 58%
2-year degree	5	50	5	50	27%, 73%
4-year degree	6	24	19	76	13%, 40%
Graduate degree	7	28	18	72	16%, 44%
Professional degree	3	23	10	77	10%, 46%
Other	0	0	2	100	0%, 57%
<i>Total</i>	31	31	70	69	24%, 39%

*Note.* CI = confidence interval

$$\chi^2 (6, n = 101) = 4.44, p = 0.62, w = 0.21$$

No women with a high school education used either a book or magazine to find information about menopause. One of two women with vocational training used a book, but did not use magazines as an information source. Only one woman with some college used both books and magazines (5%).

On the opposite end of the education level scale, four women with graduate degrees also used both books and magazines (17%). Five women with 4-year degrees also used books (18%), and two (8%) used magazines. The greatest usage of books was by women with 2-year degrees, with 56% ( $n = 5$ ) using books as an information

source, but none of these women used magazines. A chi-square test of independence demonstrated statistical significance only for books.

Table 17  
*Participants Utilizing a Book by Education Level*

Education level	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
High school	0	0	6	100	0%, 31%
Some college	1	6	18	94	1%, 22%
2-year degree	5	56	4	44	31%, 79%
4-year degree	5	21	19	79	11%, 37%
Graduate degree	4	16	21	84	7%, 31%
Professional degree	1	8	12	92	2%, 29%
Other	1	50	1	50	7%, 93%
<i>Total</i>	17	17	81	83	12%, 24%

Note. CI = confidence interval, **bold** indicates significant values  
 $\chi^2 (6, n = 98) = 14.93, p = \mathbf{0.02}, w = 0.39$

*Participants consulting friends by education level.* Investigating menopause by consulting with friends was common for participants in this study. Women with professional degrees consulted with friends the least frequently at 47% ( $n = 6$ ). Those indicating *Other* were close, with 50% consulting friends ( $n = 1$ ), followed by 58% ( $n = 11$ ) of those with some college consulting friends, while 67% of those with high school educations ( $n = 4$ ) and those with 4-year degrees ( $n = 16$ ) turned to their friends. Women reporting having earned 2-year degrees turned to their friends most frequently

(78%,  $n = 7$ ). However, a chi-square test of independence did not demonstrate statistical significance, as presented in Table 19.

Table 18

*Participants Utilizing a Magazine by Education Level*

Education level	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
High school	0	0	6	100	0%, 31%
Some college	1	5	18	95	1%, 20%
2-year degree	0	0	9	100	0%, 23%
4-year degree	2	8	22	92	3%, 22%
Graduate degree	4	17	20	83	8%, 33%
Professional degree	1	8	12	92	2%, 29%
Other	0	0	2	100	0%, 57%
<i>Total</i>	8	8	89	92	5%, 14%

Note. CI = confidence interval

$\chi^2 (6, n = 97) = 4.00, p = 0.68, w = 0.20$

Table 19

*Participants Consulting their Friends by Education Level*

Education level	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
High school	4	67	2	33	35%, 88%
Some college	11	58	8	42	40%, 74%
2-year degree	7	78	2	22	51%, 92%
4-year degree	16	67	8	33	50%, 80%
Graduate degree	15	60	10	40	44%, 74%
Professional degree	6	47	7	54	27%, 68%
Other	1	50	1	50	12%, 88%
<i>Total</i>	60	61	38	39	42%, 58%

Note. CI = confidence interval,  $\chi^2 (6, n = 98) = 2.87, p = 0.83, w = 0.17$

*Participants consulting mothers and family by education level.* Only about one-third of the women researching menopause in this study (30%,  $n = 29$ ) spoke with their mothers first to learn about menopause, and only 20% ( $n = 19$ ) spoke with other family members. Women with professional degrees were the most likely to consult with their mothers (50%,  $n = 7$ ), and those with the least education, high school, were the least likely (25%,  $n = 1$ ). The relationship is inverse for those who chose to consult with family members other than their mothers. However, a chi-square test of independence did not show a statistically significant relationship for women consulting mothers or other family members as presented in Tables 20 and 21.

Table 20

*Participants Consulting their Mothers by Education Level*

Education level	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
High school	1	25	5	75	7%, 58%
Some college	8	40	11	60	24%, 59%
2-year degree	4	17	5	83	5%, 44%
4-year degree	6	27	18	73	15%, 44%
Graduate degree	3	13	20	87	5%, 28%
Professional degree	7	50	6	50	29%, 71%
Other	0	0	2	100	0%, 57%
<i>Total</i>	29	30	67	70	23%, 38%

*Note.* CI = confidence interval

$\chi^2 (6, n = 96) = 10.5, p = 0.11, w = 0.33$

*Participants using other sources by education level.* Only two respondents used a talk show host as an information source; one with a high school education and one with some college. Four women reported using TV, film or other media to obtain information, one each at the high school, some college, graduate, and professional degree levels. Seven women reported using a women's health center, fairly evenly distributed across educational levels, with no women reporting high school educations, 2-year degrees, or *Other* searching for information there.

Table 21

*Participants Consulting Other Family Members by Education Level*

Education level	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
High school	3	50	3	50	22%, 78%
Some college	4	21	15	79	10%, 39%
2-year degree	2	22	7	78	8%, 49%
4-year degree	5	21	19	79	11%, 37%
Graduate degree	4	18	18	82	8%, 35%
Professional degree	1	8	12	92	2%, 29%
Other	0	0	2	100	0%, 57%
<i>Total</i>	19	20	76	80	14%, 28%

Note. CI = confidence interval

$\chi^2 (6, n = 94) = 5.42, p = 0.5, w = 0.24$

**Resource utilization by marital status.** There was no statistically significant relationship or Cohen's *w* effect size between any of the resources utilized and marital



status. Women consulting non-medical websites had a Cohen's  $w$  effect size closest to the desired medium (0.25), but a  $p$  value of 0.19 as shown by Table 22.

**Resource utilization by race/ethnicity.** Race and ethnicity did not have much impact on women's SDL actions in their search for menopause except with the utilization of two sources. In those cases, the relationship was statistically significant. The first resource for which there was a relationship was race/ethnicity and the use of magazines. In this case, the most significant use of magazines to gain information about menopause was by black women (40%,  $n = 2$ ), presented in Table 23.

Table 22

*Participants Utilizing a Medical Website and a Non-medical Website by Marital Status*

Marital status	Yes		No		90% CI
	$n$	%	$n$	%	
Married	26	32	56	68	24%, 41%
Single	2	29	5	71	11%, 60%
Divorced	0	0	7	100	0%, 28%
Widowed	1	100	0	0	27%, 100%
Other	2	50	2	50	12%, 88%
<i>Total</i>	31	30	70	70	23%, 38%

Note. CI = confidence interval

$\chi^2 (4, n = 101) = 6.11, p = 0.19, w = 0.25$

Additionally, women not identifying as white reported a greater use of women's health centers for information than white women: 60% of Black women ( $n = 3$ ), 100% Hispanic women ( $n = 1$ ), and 100% of women identifying as Other ( $n = 1$ ), compared to

only 15% of white women ( $n = 13$ ). This relationship was significant with a  $p$  value of 0.002 and a medium Cohen  $w$  effect at 0.39, as presented in Table 24.

Table 23  
*Participants Using a Magazine by Race/Ethnicity*

Race/ethnicity	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
White	6	7	83	93	4%, 13%
Black	2	40	3	60	14%, 73%
Hispanic	0	0	1	100	0%, 73%
Other	0	0	1	100	0%, 73%
<i>Total</i>	8	8	88	92	5%, 14%

Note. CI = confidence interval

$\chi^2 (3, n = 96) = 7.04, p = 0.07, w = .0.2$

Table 24  
*Participants Using a Women's Health Center by Race/Ethnicity*

Race/ethnicity	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
White	13	15	74	85	10%, 22%
Black	3	60	2	40	27%, 86%
Hispanic	1	100	0	0	27%, 100%
Other	1	100	0	0	27%, 100%
<i>Total</i>	18	19	76	79	13%, 26%

Note. CI = confidence interval, **bold** indicates significant values

$\chi^2 (3, n = 96) = 14.83, p = 0.002, w = 0.39$

**Types of information women sought.** An analysis of the 259 responses given regarding types of information women sought across the 11 questions examining resource use, half sought information regarding symptoms ( $n = 130$ , 50%), as well as when they would begin ( $n = 37$ , 14%), or how long they would last ( $n = 16$ , 6%). One participant exclaimed, “Why do I feel like I do?” Women also wanted to know how to treat menopausal symptoms in general ( $n = 61$ , 24%), or specifically how to manage symptoms non-medically: “What exactly was changing in my body and how to deal with it naturally/because I did not want to go on any hormone replacement.”

Women sought to know what to expect ( $n = 20$ , 8%), and validation, seeking assurance that their experience was normal ( $n = 16$ , 6%). One woman wrote that she wanted to know, “If the things I was feeling was [sic] normal or if I was quite frankly, losing my mind!”

As with the numbers of women researching menopause, age was also a factor in the types of information sought, although women at every age level sought information about symptoms and symptom relief. Women in their mid-30s began by asking if their experiences were normal. Other than symptoms, many women under 40 sought anticipatory material, looking for information about what to expect, age of onset, and when to seek “treatment.” Women in this age range occasionally sought to compare their experiences with others. Once over the age of 40, the question changed from what to expect, to *how long will this last?* Women were more specific in their questions about symptoms; rather than asking about what menopause symptoms were in general,

they had questions about specific symptoms and how to “cope” with them. Women over 40 were also more likely to talk with their friends, seeking to compare experiences, gain advice, and give and receive comfort and encouragement.

Although women of all educational levels sought information about symptoms, symptom relief, and what to expect during the transition, only women with graduate and professional degrees indicated searching for information about memory loss or forgetfulness. Additionally, the same group of women, those with graduate and professional degrees, were the only ones who used the word *loss* in describing the information they sought: memory loss, weight loss, bone loss, loss of libido/sexual function, and loss of mental acuity.

There was not sufficient participation by women of differing backgrounds of race/ethnicity in this study to make any generalized statement about the types of information sought based on race/ethnicity.

**Research question number 4.** What are the socio-ecological factors that most influence women’s self-directed learning actions in their search for information about menopause?

The socio-ecological model (SEM) of health promotion utilized in this study explored five levels of social determinants of behavior and levels of analysis in examining environmental issues that may have impacted a woman’s ability to be self-directed: (a) intrapersonal, within the woman herself; (b) interpersonal, her relationships with others; (c) institutional, organizations; (d) community, social setting/cultural context; and (e) public policy, local, state, and federal. To answer this question, the instrument

asked women who had researched menopause to reflect on why they had or had not chosen particular resources and what types of information they sought; these answers were provided in a free response format. Women were also asked whether they had found the information they sought, and whether they were satisfied with the information they had found, answering *yes*, *no*, or *I'm not sure*. If they answered they had not utilized a source, they were asked why not. Additionally, women were asked if they had experienced any difficulties finding information, answering in a *yes* or *no* format. Women who answered in the affirmative were then asked what kinds of difficulties, which they answered in free response, open-ended format. Finally, they were asked if they had any final comments to share with other women, also answered in free response format.

***Satisfaction with information found using websites.*** More women utilized a medical website than any other resource (82%,  $n = 88$ ). These women most frequently cited reliability and accuracy as their primary reasons using words to describe their feelings about medical websites such as *reputable*, *truthful*, and *medical research*. Seventy of the respondents (73%) expressed that they had no concerns about the accuracy of the information they found. Of those having concern, three (13%) made no attempt to verify the accuracy of their information.

In looking for accurate information, one respondent said, "I couldn't get answers from actual doctors, so I was hoping MD websites would be the next best thing." Another shared that her doctor had told her she was imagining things so she felt she needed to find medical information on her own. In addition to their concern for medical

accuracy, however, women were also concerned with accessibility and privacy, and welcomed the speed and convenience of the Internet.

The medical websites women indicated they had used the most frequently were WebMD and the Mayo Clinic. One woman indicated she had searched the National Institute of Health (NIH) site. Most women utilizing a medical website to find information indicated they had found what they were looking for (67%,  $n = 54$ ) and were happy with the information they found (59%,  $n = 48$ ).

Women who used non-medical websites (31%,  $n = 31$ ) had different reasons for doing so than those using medical websites, although both appreciated the speed and convenience of the Internet. These women were very specifically looking for non-medical information, such as alternative therapies. Also, in using non-medical websites, several women were purposely looking for communities of women and voices of real experience. As one woman stated, “Because the medical sites provide clinical information but not much on how it feels to be going through menopause.”

Some women who sought information from both medical and non-medical websites indicated they were looking for balance, or a range of information, and some were just looking anywhere that might provide answers. As one woman shared, “Because I felt desperate and attempted to discover information wherever I could.”

Unlike with the medical websites, there was no one site that was prominent as a go-to resource; however, the type of site most frequently mentioned was a women’s blog: “(B)logs and sites run by women for women.” Most women utilizing a non-medical website to find information, similar to those using a medical website, found the

information they were looking for (71%,  $n = 20$ ) and were happy with the information they found (61%,  $n = 17$ ).

**Satisfaction with information found using books.** Very few women turned to a book as a first resource (17%,  $n = 17$ ). Of the women who utilized a book, many just considered themselves to be *book people* and considered books to have more in-depth information. One woman referred to the ability to keep the book as an ongoing resource as the need arose. Other women had been referred to specific books by friends or physicians. One woman indicated that she had found too much scary information on the Internet. She felt as though she was better able to control her learning with a book; to her, the book was safer. Table 25 presents the degree to which women were able to find the information they were looking for, as well as their satisfaction with the information found, utilizing different types of electronic and print media.

As with the Internet resources, women were primarily looking for information about menopausal symptoms, what they were and how to treat them. One woman read books just to learn about menopause in general. Another stated she was looking for “Alternative ways of looking after myself.” Most women reading books as an information source found what they were looking for ( $n = 13$ , 77%) and were happy with what they found ( $n = 11$ , 65%).

**Satisfaction with information found using magazines.** Very few women sought information from a magazine (8%,  $n = 8$ ); of these, ease and opportunity were the most cited reasons. One woman stated, “If I ran across an article about menopause I read it, [I was] hungry for the information.” In addition to the happenstance of coming

across a magazine article, women also appreciated a short, easy read. Finally, one woman indicated she subscribed to a magazine containing health content and would occasionally find articles about menopause there.

Table 25

*Satisfaction with Information Sought on Electronic and Print Media*

Information source	Yes		Not sure		No		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Information found on a medical website								
Found information sought	54	67	20	25	7	8	81	100
Satisfied with information found	48	59	18	22	15	19	81	100
Information found on a non-medical website								
Found information sought	20	72	4	14	4	14	28	100
Satisfied with information sought	17	56	6	22	5	22	28	100
Information found using books								
Found information sought	13	76	3	18	1	6	17	100
Satisfied with information sought	11	64	4	24	2	12	17	100
Information found using magazines								
Found information sought	3	37	4	50	1	13	8	100
Satisfied with information sought	4	50	3	37	1	13	8	100

As with the other resources, women read magazine articles because they wanted to know more about menopausal symptoms and symptom relief. One woman indicated



she wanted, “Information on my symptoms and any other information that might be helpful. You have to understand that at the moment I felt like I was losing it.” Another woman sought general information, and another still wanted to know about *lifestyle changes*. Only 38% ( $n = 3$ ) of the women who read magazine articles found the information they were looking for, and half (50%,  $n = 4$ ) were satisfied with what they read.

**Satisfaction with information found by consulting friends.** More than half (61%,  $n = 60$ ) of the participants researching menopause turned to their friends to talk about menopause. The most frequently cited reason for talking with friends was to learn from their experience ( $n = 39$ , 67%). Another similar, common reason was to gain a variety of perspectives ( $n = 16$ , 28%). Additionally, many women felt strongly that talking about menopause with friends provided valuable support ( $n = 12$ , 21%): “[T]o see if they had similar experiences, for support, to share as friends do about life.” The motivation for one woman to find support among her friends was not quite so positive, though, as she states that “Misery loves company.”

The information these women were frequently looking for, as the others, was information about menopausal symptoms and symptom management, what kinds of symptoms their friends experienced and how they relieved them. These women also sought to know what to expect and that their own experiences were *normal*. A majority of women turning to their friends found the information they were looking for (80%,  $n = 47$ ) and were satisfied with the information they received (70%,  $n = 41$ ). Table 26 presents the degree to which women were able to find the information they were looking

for, as well as their satisfaction with the information found, utilizing different types of personal resources.

Table 26

*Satisfaction With Information Sought from Personal Resources*

Information source	Yes		Not sure		No		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Information found consulting friends								
Found information sought	47	79	11	19	1	2	59	100
Satisfied with information found	41	70	12	20	6	10	59	100
Information found consulting mothers								
Found information sought	22	76	3	10	4	14	29	100
Satisfied with information found	21	72	2	7	6	21	29	100
Information found consulting other family members								
Found information sought	15	79	3	16	1	5	19	100
Satisfied with information found	14	74	4	21	1	5	19	100
Information found consulting a women's health center								
Found information sought	14	74	4	21	1	5	19	100
Satisfied with information found	11	58	3	16	5	26	19	100

**Satisfaction with information found by consulting mothers.** Almost a third of the participants (30%,  $n = 29$ ) who sought information about menopause turned to their mothers. Reasons for doing so included the value of her experience and family

history. Many women expressed a deep and abiding respect for their mothers. As one woman stated, “She is my ultimate teacher.” Some women thought this question was simplistic, with one woman responding, “The obvious choice, no?” Of the women who were able to discuss menopause with their mothers, they received the information they were looking for (76%,  $n = 22$ ), and were satisfied, for the most part, (72%,  $n = 21$ ) with the information they received.

***Satisfaction with information found by consulting other family members.***

Not nearly as many women turned to other family members (20%,  $n = 19$ ) as turned to their mothers, but those who did, did so for some of the same reasons, such as family history and similarity of experience. There was also a level of comfort expressed in speaking to someone with a familial bond: “I talked with everybody (in my family) I felt comfortable asking to see what they had done or were doing.” Most women indicated they had spoken to sisters or aunts. Only one woman, however, indicated that she had talked with her husband and children. She shared,

[My] husband and children gave me comfort and let me talk so they saw changes in me and that helped me too even though i wasnt [sic% all that open to accepting that they ALSO saw the changes (specifically moods). [Original emphasis.%

Nearly everyone wanted to know about menopausal symptoms, what they were, how long they lasted, how they alleviated them. One woman summed it up: “Did they take anything to alleviate symptoms? What were there [sic% symptoms? Did it effect [sic% their sex life? How did hot flashes change? Did they change? Do they ever stop?” The woman who spoke with her husband and children also found validation. Most of the women speaking with other family member received the information they

were looking for (79%,  $n = 15$ ) and were happy with the information they received (74%,  $n = 14$ ). One who spoke with family but was not satisfied with the information she found indicated: "I thought knowing what a family member went through may help me to know what I could expect, but I was wrong. My sisters and I have had very different experiences in menopause."

***Satisfaction with information found by consulting women's health centers.***

Six women indicated they used a women's health center as a resource, indicating that they believed they would receive reliable information from the health professionals there. As with other resources, these women sought information about menopausal symptoms and how to alleviate them. All but one of the women found the information they were looking for, though two of six expressed dissatisfaction with what they found, and one was not sure she was satisfied.

***Satisfaction with information found from other sources.*** Only two women acknowledged receiving information from a talk show host. One indicated that she was simply open to receiving information from all sources, and another indicated that it came at the right time. Both found the information they were looking for, but one was satisfied with the information while the other was not sure.

Four women indicated they had gained information from TV, film, or other media, but two of the four expressed confusion regarding what constituted *other media*, and thus determined the Internet to be media. The two remaining women seemed to gain the information casually and were primarily interested in the opinions others expressed about menopause. Of the women who utilized TV, film or other media, they were

evenly divided in whether or not they had found what they were looking for, but were nearly unanimous in that they were not satisfied with what they found.

**Reasons women did not choose resources.** Women had a variety of reasons for not choosing individual resources, including reasons that were very personal, involved money, or were a matter of convenience, among other reasons. Women who had not used a medical website indicated they had not done so for a variety of reasons. One indicated that she did not have reliable Internet, so she had not used the Web at all (5%). Nearly half of the 19 women sharing reasons ( $n = 9$ , 47%) for not using medical websites had instead turned to individuals, such as family, medical professionals, and even an acupuncturist. Four women, including one who owned a bookstore, read books (21%). One woman said, “I really thought, at first, my doctor would help me through it. I relied on him, and then changed doctors.”

Many of those who *did not use* non-medical websites did not for the same reasons they chose *to use* medical websites: they did not use non-medical websites because they wanted information that was *truthful, reliable, and accurate*, and did not want information that was *anecdotal, bogus, or misinformed*, as they felt non-medical websites would be ( $n = 34$ , 50%). One participant summed it up saying, “The logical thing to do seemed to be to go to a medical website with facts rather than blogs with opinions.” Some women ( $n = 14$ , 21%) indicated that the information they were looking for was medical in nature. Four women (6%) spoke to someone else first, one of whom spoke with her doctor. Additionally, women expressed concern about *wandering into inappropriate websites*, or being sold supplements.

Women who chose resources other than books indicated that they had not turned to books for a variety of reasons. Nearly half indicated that the Internet was just faster, easier, and more convenient ( $n = 38, 49\%$ ). However, there were also a number of women ( $n = 8, 10\%$ ) who indicated that the books were too expensive and they could not afford them. A small number ( $n = 3, 4\%$ ) were concerned that the books would be outdated, and others just did not like reading ( $n = 7, 9\%$ ). Two women ( $2\%$ ) indicated they would have been too embarrassed to conduct this research publicly.

Of the women who did not read magazine articles for information about menopause, 18 ( $22\%$ ) indicated that they just did not read magazines. Quite a few women indicated that the ease of the Internet made magazines seem cumbersome ( $n = 13, 16\%$ ). Another large group felt that women's magazines were not an appropriate source of medical information or were not trustworthy ( $n = 17, 21\%$ ), including one woman who felt that magazine content is heavily influenced by advertisers. Another simply exclaimed, "Who can believe that crap!" Some women cited that they did not have access to magazines or current magazine subscriptions ( $n = 8, 10\%$ ), and a few indicated that they could not afford magazines ( $n = 3, 4\%$ ).

Of the 36 women who shared why they did not consult their friends, more than half ( $n = 21, 58\%$ ) had not because either they or their friends were too young to worry about it yet. Seven women ( $17\%$ ) thought the topic was too personal or too embarrassing to discuss with friends, with one woman sharing that "I don't like people to know I am thinking about this." Another was not about to ask her friends questions about sex drive. Two women ( $6\%$ ) felt it was just easier to look online.

Although one woman felt that consulting her mother was an obvious choice, for some women, the choice was not so obvious. Many women indicated that their mothers were not an option as they had already passed away ( $n = 22, 34\%$ ) and a few mothers had dementia ( $n = 3, 5\%$ ). Other women ( $n = 11, 17\%$ ) did not have the close relationship with their mothers that would allow for a discussion that many women believed was deeply personal. One woman confided that “She thought I was ridiculous as I started to worry.” Another said, “My mom doesn't really talk about it and she doesn't have much to share about her experience.” Finally, many mothers could not share their experiences with their daughters because they had not experienced natural menopause, having had hysterectomies years before ( $n = 12, 19\%$ ).

Many of the women who did not speak with other family members indicated that they did not have *female* family members to speak with ( $n = 7, 10\%$ ), establishing gender as a definitive criteria for family information seeking. Some women indicated that they were not close to other family members ( $n = 15, 21\%$ ); some clarified closeness as geographical, some as personal, and some did not specify. Several women indicated that they did not wish to speak to family about personal health concerns, and one did not want anyone to even know she was seeking information ( $n = 5, 7\%$ ).

Of the many women who did not utilize a women's health center, the reasons were varied. Younger women expressed that there was no need yet ( $n = 5, 8\%$ ), and “Curiosity doesn't require a trip to the doctor.” Others indicated that the expense kept them away, that such a trip would either not be covered by insurance, or they did not

have insurance ( $n = 5$ , 8%). The majority indicated that they were not aware of a woman's health center in their area, and some felt the Internet or the advice from family was sufficient ( $n = 22$ , 33%). Several women ( $n = 11$ , 16%) indicated that if they were to seek medical advice, they would use their own doctors, although one woman was advised against visiting a women's center by her HCP: "The family PA I asked said I was too young at 34. So I stopped looking for answers."

Of the many women who did not gain information from a talk show host ( $n = 94$ , 98%), one woman indicated simply that she did not have cable to watch TV. Others indicated they were unaware of any talk shows where they could gain information about menopause. However, most of the women who did not utilize a talk show host stressed a lack of reliability and credibility from talk shows as a source. Some were discrete in their disapproval: "They are not a credible source." Others were much more candid in their disapproval: "Who can believe that crap!" and "Seriously?! I need real information from educated people."

Of the many women who did not gain information from TV, film, or other media, their reasons were much as those for a talk show host: "It wouldn't have occurred to me to look for menopause information from those sources," and "That's dumb."

**Continuing the search.** The majority of the respondents (65%,  $n = 62$ ) who had researched menopause at least once indicated that they continued to search for information after their first information seeking experience. Of the women who continued to look for information after their initial search, 23% ( $n = 21$ ) indicated that there was still information that they had been unable to find. In general, women



seemed to have found answers for most of their questions regarding symptom relief of common symptoms. The information that remained elusive was much more personal, frequently dealing with symptoms involving sexuality, such as a lack of libido or vaginal dryness. Others were also interested in finding more information on symptoms of a non-physical nature. One woman expressed that part of the menopause experience was a mystery when she exclaimed, "People talk about the hot flashes, lack of periods, bitchiness, but they don't always talk about the emotional distress, the anxiety, the hopeLESSness. . . . The hidden elements of menopause." Another woman simply wanted validation: "How to feel OK about myself without trying to turn back the clock."

***Why women did not research menopause.*** The 118 women in this study who had not researched menopause were asked to answer five *yes* or *no* questions suggesting some possible reasons why they had not, and then were provided an opportunity for free response to add additional reasons not offered.

The majority of women who had not researched menopause felt that they were too young (56%,  $n = 66$ ), and most had not given it any thought (67%,  $n = 78$ ). Of note, one participant over 50 felt she was too young to research menopause, and 13 women over 50 (56%) had not thought about it. A small number indicated that they were worried about what they would find out (11%,  $n = 13$ ) or were just too embarrassed to ask (4%,  $n = 5$ ); all but one of these women were between the age of 35-44 years. None of these reasons for not researching menopause had statistically significant relationships with demographics when analyzed using a chi-square test for independence except one: women who were too embarrassed to look were married,

$\chi^2 (3, n = 117) = 11.07, p = 0.01, w = 0.31$ . Table 27 presents the primary reasons women indicated they had not researched menopause based on their answers to yes/no questions. However, answers were slightly different when provided an opportunity for a free response, as presented in Table 28.

Table 27

*Reasons Women Chose Not to Research Menopause, Yes/No Answers*

Reason	Yes		No		90% CI
	<i>n</i>	%	<i>n</i>	%	
Too young	66	56	51	44	46%, 66%
Had not thought about it	78	67	39	33	58%, 75%
Not interested	37	32	80	68	21%, 45%
Afraid of what I'll find out	13	11	104	89	3%, 32%
Embarrassed	5	4	112	96	3%, 40%

*n = 118*

Content analysis was used to analyze the free response answers provided for not seeking information about menopause, listing the responses and clustering by theme. Five primary themes emerged: (a) it was too early; (b) it was not information they needed right now; (c) they were not concerned about the transition; (d) women were too busy/stressed with other life events; and (e) women were trying to ignore it.

Table 28

*Reasons Women Chose Not to Research Menopause, Free Response Answers*

Reason	<i>n</i>	%	90% CI
Too young	16	25	17%, 35%
Not information currently needed	8	13	8%, 22%
Not concerned about transition	7	11	6%, 19%
Too busy/stressed	4	6	3%, 13%
Trying to ignore it	4	6	3%, 13%

*n* = 63

In the free response answers, most commonly, women indicated that it was just too early (25%, *n* = 16). Some stated that their search was not urgent or that this was not information they currently needed (*n* = 8, 13%). A few women planned on taking a wait-and-see approach, indicating that they would research menopause if they felt the need arise, with one indicating that she was confident that there would be pharmaceutical or natural remedies available should she need them. One woman waited for her HCP to bring it up, though she concluded by saying, “No such luck.” Although a large portion of the participants had not looked for information because they felt they were too young, it did not seem to be because they were necessarily uninterested. They felt it was just not time for them to consider it.

Similarly, seven women (11%) did not feel concerned about the transition, indicating it just was not a priority. For some, they felt at ease based on family history, and others felt they had a good network of friends to help them through. Many

expressed that there were other things in their lives that were more important at this time.

Four women (6%) indicated that they were just too busy or too stressed out to think into the future. One woman commented that “Too much going on with life to research my someday in the future maybe problems.”

Additionally, four women (6%) stated quite frankly that they were trying to ignore the prospect of menopause, or avoid thinking about it. One woman said plainly, “I was trying to ignore it.” Another indicated, “There seem to be so many alternatives when it comes to treatment—I’m afraid I’ll be overwhelmed by what I find out.”

***Degree of difficulty finding information.*** When asked directly if they had experienced any difficulty finding the information they sought, most women indicated they had not (73%,  $n = 69$ ). However, a substantial 27% of women ( $n = 26$ ), indicated that they had. These women shared what types of difficulty they had experienced in free response, open-ended format. Content analysis was used to explore these answers, listing the responses and then clustering the responses by theme. From this analysis, two primary themes emerged: the availability of information and the philosophy of HCPs.

When asked what types of difficulties they experienced, 24 of the 26 women who said they had experienced difficulty expressed their concerns. Of those, 15 (63%) indicated that the information they sought just was not available, particularly if, as one participant said, a woman did not have a *cookie cutter experience*. Nearly half ( $n = 10$ , 42%) felt that there was a lot of information available regarding how to treat hot flashes,

particularly if HT was the primary treatment option. However, if a woman wanted to pursue another type of therapy, or if other health conditions made traditional HT unavailable, there were not many treatment options left. The same was true for women seeking information about their decreased libido. Another woman shared that though she had no difficulty finding information about physical symptoms, information about non-physical symptoms was not so readily available: “There should be much more about the memory loss and cognitive impairment.” And, “Everyone knows about hot flashes, but no one talks about so many of the other symptoms such as depression, anxiety, sleep. . . .”

Similarly, one participant felt that it was hard to discern *credible* information since “All [information providers] have an agenda.” Yet another woman felt that the information that was available was “behind a pay wall,” to subscribers who wished to pay for the information.

Additionally, some women ( $n = 5, 21\%$ ) felt as though they were not taken seriously or that discussions of menopause were restricted to comedic material. One woman complained that “It seems the data is [*sic*] limited and people just weren’t talking about it other than ‘hot flash’ jokes.” Women who indicated they struggled to communicate with HCPs expressed either not being taken seriously or being pushed toward hormone therapy or surgery. One woman stated that because her questions were not taken seriously and went unanswered, she eventually gave up: “I figured I was on my own to experience whatever may happen to my body with no help from any sources.” Another woman felt that her symptoms were not severe enough to warrant

attention, again using the words *taken seriously*. One respondent expressed difficulty in finding an HCP that shared her philosophy about menopause, one that allowed for a more natural transition: “It was difficult to find a doctor who had the same philosophy about menopause that I did. I did not want to go on birth control pills and I did not want to have a hysterectomy if I absolutely didn't have to have one.” Finally, one woman took the responsibility for not receiving adequate information from her HCP because she did not ask: “The problems are probably that I didn't ask for much information. So I didn't get a lot.”

Additionally, a participant expressed a concern regarding a lack of information, not in relation to her, but in relation to the way others understand menopause, specifically her colleagues at work:

I'm not sure there is a lot of information about how one is perceived in the workplace when their cognitive abilities, in my case, memory, some emotional impulse control, processing speed, and name recall, begin to decline, which I have associated, in part to menopause. As an executive, I have had individuals ascribe negative personal and moral motivations to subtle changes in cognitive function. This is ABSOLUTELY THE MOST SERIOUS UNEXPECTED EXPERIENCE for me, personally. [Original emphasis.]

**Anything else?** A concluding question presented to women who had researched menopause allowed women to provide any additional information in a free response format that they either thought would benefit the researcher, or they found to be intriguing, frustrating, helpful, or of interest to other women. About one-half of the women ( $n = 52$ , 47%) chose to comment. Content analysis was used to explore these data, listing the responses and clustering the responses by theme. Seven primary themes emerged, in rank order: (1) health care systems, (2) symptom management,

(3) all women are unique, (4) the value of foreknowledge and education, (5) support, (6) a need for more science, and (7) mental health and cognitive function. A summary of responses regarding final concerns or advice by theme is presented in Table 29 and discussed below; a woman may have provided more than one answer.

The most commonly recurring theme, with 19 of 52 responses (37%), involved HCPs and the health care system. In addition to a feeling that HCPs were not prepared to help them, some women felt they had either been betrayed by the health care system, or pre-menopausal women were concerned that it may not be responsive to their needs when the time came: "I felt like I was starting menopause early and my doctor just blatantly said that I wasn't experiencing menopause. Didn't even consider it. I felt she should have listened more and explored that option." In addition, women were also concerned about the costs of health care and insurance. Two women, however, had a positive health care experience and advised others to talk with their HCPs.

Closely following concerns regarding the health care system were concerns regarding symptom management ( $n = 18, 35\%$ ). Some women shared what worked for them, others were frustrated that they had not been able to find anything that worked: "What is frustrating is there doesn't seem to be any one thing that consistently helps."

And,

Friends can offer advice about what to watch out for in the future. Though my questions were not about vaginal dryness (didn't know it was a symptom), a friend offered the suggestion that if it happened in the future to try progesterone cream. Heads up info is always useful.

Table 29

*Final Concerns or Advice Women Offered to Other Women: A Summary of Responses by Theme*

Theme	<i>n</i>	%
HCPs/the health care system	19	37
Symptom management	18	35
Unique experience	10	19
Foreknowledge and education	9	17
Need for more science	7	13
Support	6	12
Mental health/cognitive function	6	12

*n* = 52

The next most recurring theme was an understanding that all women have a different, unique perimenopause experience ( $n = 10$ , 14%). Some women seemed to think that was okay. It allowed them to believe that though some women had experienced a negative menopause transition, since menopause is not universally negative, their experience may not be so bad. Others, however, were concerned that this individuality interfered with effective treatment; since there was no one-size-fits-all treatment, finding what works for individual women may be a challenge.

Another common theme was the need for appropriate foreknowledge and education ( $n = 9$ , 13%), particularly in regard to what women might expect during the perimenopause transition. In general, women were anxious for information to help them manage symptoms, and wished they had more information beforehand. Women expressed frustration that even though they had known about hot flashes, they were



surprised by symptoms such as cognitive impairment, memory loss, insomnia, and decreased libido.

The mood swings are few, but hot flashes are often and I thought they were a phase that would end. I understand they may occur for years to come, and so WHY didn't anyone TELL ME BEFORE?? I want to tell every young woman what she is in for, I have many women in my life and No One Told Me until I got old enough to start this???? [Original emphasis.]

Women were also concerned that the science behind treating menopause was inadequate ( $n = 6, 8\%$ ). For example, “I find it intriguing and frustrating that it still isn't clear if HRT is safe or not. It depends on who or what you read.” And, “There are not enough meaningful studies. Your doctor may not be up on best advice for your particular situation due to lack of studies and lack of your genetic info.”

Women frequently brought up the need for support ( $n = 6, 8\%$ ). Some women were grateful for the support of friends and family—“Women are friends to be treasured”—but most indicated they wished they had more support: “My husband has not been particularly helpful, not because he doesn't care about me, but he totally doesn't 'get it.’”

Finally, women expressed surprise and frustration by the mental health and/or cognitive functioning issues they experienced: “The raging anger is the worst for me.” And, “When you are in the thick of it prior to that last period I really thought I was going nuts. It was only after that last period did a lot of the symptoms and issues I was having make sense.”

Two women ( $n = 2, 3\%$ ) wanted to emphasize the positive aspects of menopause: “So far, at 50+, it's been no big deal for me. The women I know didn't have

any real problems either. I love not having a period every month.” See Appendix F for additional participant responses.

***Socio-ecological factors influencing SDL actions.*** There were socio-ecological factors that influenced women’s SDL actions at all levels of the socio-ecological model (SEM) of health promotion. These factors impacted where women went to find information, who they relied on for support, or if they even sought information at all. See Figure 4 for an overview of socio-ecological factors that influenced a woman’s SDL actions at all levels. These include (a) intrapersonal, (b) interpersonal, (c) institutional, (d) community, and (e) policy factors. These are environmental determinants of behavior that influenced women’s ability to be self-directed in their search for information about menopause.

*Intrapersonal factors.* Just as the majority of the women seeking information about menopause were symptomatic, information about symptoms was the most common type of information sought. The reasons for this varied, however. Many women certainly sought information about symptom relief. Others, though, sought validation; they wanted to know that what they were experiencing was normal. Without foreknowledge of the process of the menopause transition, some women were afraid they were “losing it.” One woman shared, “[I was looking for] information on my symptoms and any other information that might be helpful. You have to understand that at the moment I felt like I was losing it!” In their search for validation, women who used medical websites for factual information compared their symptoms to those given on the websites for a sense of normalization.

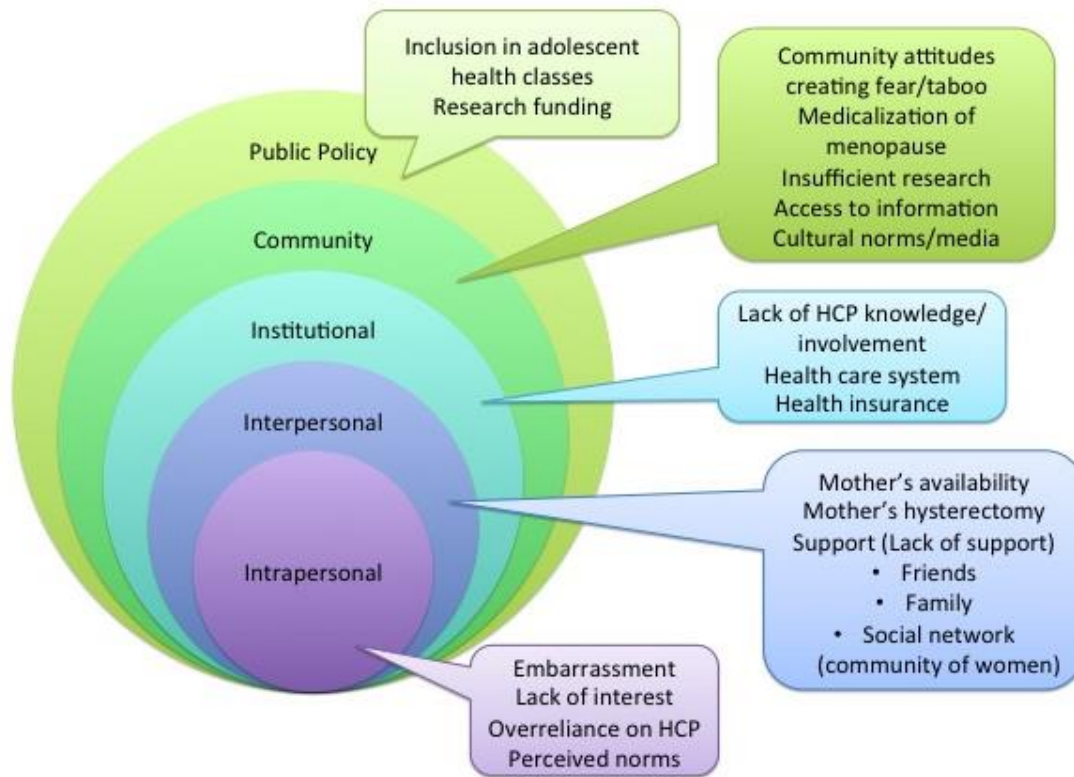


Figure 4. The socio-ecological factors influencing the SDL actions of women. This figure illustrates the levels of environmental determinants of behavior that influenced women's ability to be self-directed in their search for information about menopause.

The idea of *apomediation*—“the ability to go ‘directly to the source’ of information rather than relying on a gatekeeper such as a doctor or other health professional”— (Koch-Weser, 2010, p. 280) was certainly a reason for Internet use expressed by these participants. However, the idea of the anonymity of the web was also important. As buying a book or magazine, or visiting the library is a public act, a few women in this

study indicated that they would be too embarrassed to search publicly for information. When asked why she chose not to use a book, one woman replied, "I didn't want anyone to know I was seeking information about menopause." Another said, "[I] didn't want to search 'lack of sex drive' at the library." Economics were also a factor for a few women who indicated they were unable to afford books, magazines, or trips to a women's health center.

*Interpersonal factors.* Some women sought more interpersonal information; they were interested in other women's experience of the menopause transition. Some specifically sought positive experiences to balance all of the negative they had heard. To find the more personal information, one type of resource women frequently used was non-medical websites such as blogs where they could engage with a community of women. Additionally, women spoke to other individuals, primarily friends and family, to gain this personal information. Those they chose to speak with were almost exclusively other women. In general, women who talked to their friends did so for support. Women also spoke with family members for support, as well as seeking a way to view their own experiences as normal. The ability to connect with family was not always as successful as women would have liked. Although one woman expressed gratitude for the support of her husband and children, in general, women expressed that husbands "don't get it," and women wished men had a greater understanding of what they were going through.

It was hoped that in examining the information seeking behaviors of married women in this study in relation to those who were not married, the impact of marriage on women's understanding of the menopause transition could be examined. However,

because so few of the participants in this study were not married, it was difficult to obtain any meaningful data based on this demographic. The topics the few women who were not married stated they investigated were not qualitatively different than those married women investigated. However, married women who did not investigate menopause were the women who were too embarrassed to seek information at all.

As Dillaway (2007) reported, women tend to feel their menopause experience is normal if it mirrors their mothers' experience. Although most women who talked to their mothers sought that validation, many women in this study were unable to make that connection with their mothers. Among the primary reasons women were unable to consult their mothers were either the mother's unavailability due to death or dementia, or that the mother had a hysterectomy and had therefore not experienced natural menopause. There were, however, a few women who indicated that they did not have a close enough relationship with their mothers, or their mothers were unwilling to discuss a topic this personal in nature.

*Institutional factors.* There was ambivalence in the attitudes of many participants regarding the involvement of HCPs in their understanding and treatment of menopause. While some women were frustrated by what they perceived as a lack of medical knowledge about this transition, others resented and resisted what they saw as a movement to medicalize this normal, natural time in their lives. Some women were waiting for their HCP to tell them when they needed information, and sometimes that direction never came.

When attitudes about the health care community were expressed, women in this study, across age, race, and education boundaries were frustrated in all but a few cases. One woman complained,

Why is menopause still so unmanageable? Many doctors just can't answer questions and no one knows answers. Like you just have to have a support group to commiserate and celebrate. . . yeah, I jumped on the trampoline today and didn't pee my pants!

They were frustrated by a lack of knowledge about menopause in the medical community as a whole, and they were frustrated by a lack of support from their own HCPs. Women indicated that they needed much more from the health care community than they were receiving. They needed their HCPs to help them normalize the experience by understanding it themselves and then speaking to women early on. One woman even suggested conversations begin between women and HCPs as early as the teen years—not as a medical event, but as part of the reproductive process. They also needed HCPs to be informed about both pharmaceutical and natural methods of symptom relief, as many were still very concerned about taking hormones.

*Community factors.* There was minimal participation in the survey by women who did not identify as white, which aligns with existing research. In addition to a historical lack of participation by black women in medical research in general, the study by Im, Lee, and Chee (2010) found that black women did not want to discuss menopause to avoid embarrassment and negative comments. They also did not discuss menopause with white women, because they felt their symptom experiences and attitudes were very different.

Only a few of the respondents in this study who identified as Hispanic had conducted any investigation of menopause. The majority, across all age ranges and education levels, did not. This statistic aligns with existing research, such as the Im, Lim, Lee, Dormier, Chee, and Kresta study (2009) which found menopause to be viewed in Hispanic communities as simply *cambio de vida* (change of life), just part of life, and not a big deal. Perhaps even more relevant, the same study found that menopause was also viewed by participants as a very personal, body topic, and was therefore not discussed with others, even their mothers.

When asked if they had sought information about menopause from a class, many women expressed that the idea of such a course was silly; however, such courses do exist, such as the course offered by the Couple-to-Couple League (CCL) of Northern Virginia as part of a series of courses called Natural Family Planning (NFP). In addition to courses dealing specifically with family planning during the child-bearing years, they also offer a course in “Pre-menopause” for couples. Additionally, the Northern California Women’s Herbal Symposium has offered a course called “Demystifying Menopause,” taught by an MD, as just one of a number of courses on overall women’s health.

*Public policy factors.* Although very little regarding public policy emerged in the responses of women in this study, two points were clearly made. First, in regard to women’s understanding of menopause, a few women expressed a need for information early on regarding the perimenopause transition. It was even suggested that the end to menarche be taught alongside the beginning of menarche as simply part of the female

reproductive experience. The suggestion was made that this instruction become part of K-12 school policy regarding sex education. One woman stated,

The most important piece that is missing is education during childhood and teen years. We learned a lot about puberty and menses and birth control, but menopause and especially "perimenopause" is not talked about at all. That has been the most shocking thing to me. This is a real thing and no one ever said anything about it when I was growing up. It seems ridiculous that it was left out of all reproductive education. The only thing we ever learned was that eventually, sometime when you are older you will stop having your period.

More frequently, women expressed frustration at the lack of existing research regarding menopause and the perimenopause transition. A need for additional research funding was addressed.

### **Observations**

Receptivity to this study seemed to run hot or cold. Some women were extremely enthusiastic and happy someone was finally listening to them and were happy to share their experiences. Additionally, younger women commented that they became thoughtful about the menopause transition and the aging process after taking the survey; it had caused them to think.

On the other hand, the study was discussed both positively and negatively on a home school forum where the link had been posted. A few women were glad someone was interested in their experience, yet one woman felt that by suggesting that a woman may have concerns, the researcher was trying to "make it seem like menopause is bad."

Additionally, the researcher received an email from another woman who felt as though the survey asked too many repetitive questions. When it was explained to her that the repetitive nature was necessary for analysis, she accepted that explanation and



replied, “Good luck on your research! Fascinating study as I know there isn’t as much medical research on this as there should be!”

To invite women to the study, the researcher frequently approached women in a variety of public spaces, for example, the cashiers at the pet store or women visiting the library, verbally inviting them to participate in the study and offering them a flier with the survey information. Younger women, on occasion, were upset that they had been identified as being at least 35 years of age and some were not sure they wanted to participate in a study about menopause.

### **Summary**

The majority of women participating in this study indicated that they had not engaged in research to find information about menopause ( $n = 118, 52\%$ ). Of those not seeking information about menopause, most indicated they were too young to worry about it yet and/or had not given it any thought. Although fewer in number, some women indicated that they were too worried about what they would find out, or too embarrassed to seek information about menopause.

Defining self-directed learning (SDL) as an individual determining her own “learning needs, formulating learning goals, identifying human and material resources for learning, choosing and implementing appropriate learning strategies, and evaluating learning outcomes” (Knowles, 1975, p. 18), the women participating in this study who had researched menopause were engaged in SDL. Just as scholars of SDL have described, (Brockett & Hiemstra, 1991; Guglielmino 2012; Stockdale & Brockett, 2011), the women in this study took responsibility for their learning, sometimes in the face of a

lack of family support, or what they perceived to be neglect or misinformation by their health care providers (HCPs).

Guglielmino (2012) also stated that in order for the process to begin, SDL must be activated "by the personal characteristics of the learner, combined with the given learning situation" (p. 1). This study sought to understand what activated the SDL process to investigate menopause, and found that women in this study became concerned about menopause primarily after they were symptomatic. Additionally, a relationship between a woman's SDL actions to investigate menopause and her age was found.

The findings of this study confirmed earlier studies that indicated that there was no one-size-fits-all menopause experience. Each woman's experience was different, and each woman had different needs in treatment, support, and knowledge. As one woman advised, "It is a very personal and unique experience. Your experience will not necessarily be like another woman's, even close family members."

This study found that women over age 40 were more likely than younger women to research menopause. The age criteria for this study was selected based on the age that women are most likely closest to the perimenopause transition. Although the age at which women begin to notice symptoms of perimenopause varies, generally symptoms begin in one's 40s, but for some as early as their 30s. The age range of 35-39 years represents the years immediately preceding the perimenopausal years. At the other end of the transition, the average age of menopause in the United States is 51;

therefore, the age range of 50-55 years represents women who are likely to be just completing the transition and entering menopause.

Once women were motivated to begin learning about menopause, they were able to engage in SDL actions; however, the SDL actions of many of the women in this study demonstrated Candy's (1991) observation that often, at least initially, the resources chosen are the ones that are readily available moreso than "any objective measure of their appropriateness" (p. 178).

The majority of women who sought information on menopause did so using the Internet, and most Internet users indicated that they utilized medical websites. Just as other studies have found, participants indicated the ready availability of the Internet was a reason for using the Web for this information about their health, often citing ease of access as a primary reason for doing so. Some women had clear plans for both finding information and ensuring its accuracy; others were content to inform themselves with whatever information they found through a simple *Google* search.

Women who sought information about menopause were most interested in finding information about perimenopausal symptoms. They sought to learn not only what the symptoms were, but also how to treat them and how long they would last. However, only women with graduate and professional degrees indicated they looked for information about memory loss or forgetfulness. Additionally, the same group of women, those with graduate and professional degrees, were the only ones who used the word *loss* in describing the information they sought: memory loss, weight loss, bone loss, loss of libido/sexual function, and loss of mental acuity.

In regard to race/ethnicity, white women were much more likely than women who did not identify as white to seek information about menopause. The percentage of white women in this study who researched menopause was higher than the percentage of both the black and Hispanic women combined. The Asian women participating in this study did not research menopause.

There were six findings of statistical significance in this study. The first was that there was a strong relationship between age and when a woman begins to engage in SDL actions to investigate menopause. Second, this study found that white women were more likely to research menopause than women who did not identify as white, with the percentage of white women in this study who researched menopause higher than the percentage of both the black and Hispanic women combined. Third, there was a significant relationship between education and using books as a resource with the least book use being by women with the most and least education. Fourth, there was a significant relationship between being married and being too embarrassed to look for information about menopause. Fifth, black women were the most likely to use magazines as a resource, and finally, white women were the least likely to go to a woman's health center for information.

This study also found that women were primarily motivated to research menopause by symptoms, either to learn about specific symptoms or to find symptom relief. The majority of the women participating in this study indicated they wanted reliable, accurate, and accessible information; however, considerable numbers of

women were unable to find the information they felt they needed, and the majority were not concerned about the accuracy of the information they found.

Finally, many women were unsatisfied with the level of information and support provided by their HCPs; others felt their HCPs were un/misinformed. Further, a few felt that their HCPs did not listen to, or even trivialized, their individual concerns and were too eager to push hormone therapy or surgery.

## Chapter 5

### Summary, Conclusions, Implications and Recommendations

The purpose of this research was to explore the self-directed learning (SDL) actions of women regarding their search for information about menopause. The parts of this chapter include (a) a summary of the study, (b) conclusions, (c) implications for practice, and (d) recommendations for further research.

#### Summary of the Study

The purpose of this research was to explore the self-directed learning (SDL) actions of women regarding their search for information about menopause by answering the following questions:

1. To what extent are women between the ages of 35-55 engaging in self-directed learning about menopause?
2. What motivates women to seek information about menopause?
3. To what extent are there differences in identified resources and topics based on age, marital status, level of education, or race/ethnicity?
4. What are the socio-ecological factors that most influence women's self-directed learning actions in their search for information about menopause?

The population for this exploratory study included women between the ages of 35-55 who had not had induced menopause. The data were collected by an electronic questionnaire administered through Qualtrics software and were analyzed using SAS,

version 9.4. In addition, content analysis was utilized for answers to free response questions.

## **Conclusions**

Conclusions ascertained from this study follow.

Most women in this study did not investigate menopause on their own. Women who did, tended to have had a problematic transition or, in a few cases, anticipated a problematic transition.

Menopause was not a topic of concern for many women, in all age groups. In addition to not being concerned, younger women who did not research menopause did not because they felt they were too young, were worried about what they would find out, or felt too embarrassed to seek information.

Those who did investigate on their own took responsibility for their learning, even when they may have experienced a lack of family support, or what they perceived to be neglect or misinformation by their health care providers (HCPs).

Additionally, this study found each woman's experience to be different, and each woman had different needs in treatment, support, and knowledge. These findings confirm earlier studies that indicate that there is no one-size-fits-all menopause experience.

Women who did research menopause were largely symptom driven. Older women, particularly those who were symptomatic, searched for more information than younger or non-symptomatic women. In this study, the investigations of younger women were more casual, and less urgent. As women aged and their symptoms

increased, for many women the investigation took on more importance, indicating that there was a relationship between the age at which a woman began to notice symptoms of perimenopause and the age at which she began to seek information.

Other than being symptomatic, motivation for women in this study to seek information about menopause included curiosity, family history, or it just seemed like the right time in their lives.

Women frequently relied on their HCPs to inform them about menopause; however, that information was not always forthcoming. Additionally, there was very little involvement of the HCP in women initiating a search for information.

Once women were motivated to begin learning about menopause, they were able to engage in SDL actions; however, sources that were convenient and readily available, at least at the beginning of their search, were preferred. The Internet, primarily medical websites, was the favored source for the majority of women, largely for its ease of access, but also for its privacy as well. Sometimes ensuring the accuracy of information found was important, but most women were content to inform themselves with whatever information they found through a simple *Google* search.

Women who sought information about menopause were most interested in finding information about perimenopausal symptoms. They sought to learn not only what the symptoms were, but also how to treat them, how long they would last, and if their own experiences were normal.

Women in all demographic groups sought information about physiological symptoms such as hot flashes, and psychological symptoms, such as depression.



However, only women with graduate and professional degrees indicated they looked for information about memory loss or forgetfulness. Additionally, the same group of women, those with graduate and professional degrees, were the only ones who used the word *loss* in describing the information they sought: memory loss, weight loss, bone loss, loss of libido/sexual function, and loss of mental acuity.

Even though print media was not the most favored method of finding information about the menopause transition, books and magazines could not be completely discounted. Women still purchased books to keep on hand as a resource, and many appreciated the convenience of the short read of a magazine article.

In regard to race/ethnicity, white women were much more likely than women who did not identify as white to seek information about menopause. The Asian women participating in this study did not research menopause at all.

Factors at all levels of the socio-ecological model influenced women's SDL actions in regard to their search for information about menopause.

- At the intrapersonal level, women had internalized beliefs and attitudes that created barriers to finding timely, accurate information.
- At the interpersonal level, a lack of support, both active and passive, interfered with some women's motivation to research menopause, and drove others to learn what they perceived to be *wrong* with them.
- At the institutional level, the health care system both positively and negatively impacted a woman's search for understanding, though the positive experiences were the exception. In this study elements of the

health care system that influenced women's understanding primarily included which treatments were covered by insurance, and their HCP involvement.

- At the community level, community attitudes, social norms, and a woman's access to information interfered with women's understanding of her menopause experience, as did the medicalization of menopause in the health care community.
- At the public policy level, many women called for policy that would include information about the end of menses in school age discussions about the beginning of menses, as well as calling for funding for additional research about menopause in general.

### **Implications for Practice**

Implications for practice uncovered by this study are presented below.

The implications surmised from this study can be best understood as the need to connect adult education with health promotion, as education is known to be one of the key determinants of health, at every level of the socio-ecological model.

At the intrapersonal level, this study indicated that increased knowledge of the menopause transition—before perimenopause begins—has a positive impact on the menopause transition experience for many. Foreknowledge can empower women to make choices about their health from a place other than frustration or fear.

That women were embarrassed by menopause indicates a need for further education, not only for women, but cultural education as well.

Women have access to information about menopause from a variety of sources, though information availability was not sufficient for less common, more personal searches, such as for cognitive or sexual changes. Additionally, access to information is not enough. Women need access to reliable, complete, and accurate information. Community-based education projects, or information provided directly through HCPs or clinical practice groups are two realistic solutions.

In addition to knowledge, this study demonstrated that women have a need for greater support. Talking with others about health conditions is beneficial, allowing for individuals to gain information, find instrumental assistance, and/or emotional support. In this study, women spoke with friends and female family members to seek assistance and emotional support, as well as to gain information to normalize their own experiences. However, these women expressed that men also need to be brought into the conversation.

This study found that the women who were too embarrassed to seek information about menopause were young, married women. Women valued the information and emotional support gained from talking with friends; however, many also wished that their husbands were more understanding and would offer more support. Health education can assist more men in understanding the menopause transition and how they can support their partners, removing the stigma and taboo for both men and women alike.

One of the biggest concerns emerging from this study was the need for more beneficial interactions between women and the health care community, particularly their

HCPs. Women rely on their HCPs for timely, accurate information that is frequently not forthcoming. Additionally, women are frustrated when they feel their HCPs are not listening to their concerns, and either cannot or will not guide them toward non-pharmaceutical care as a first approach.

Therefore, at an institutional level it is first incumbent upon the medical community to more fully understand the menopause transition and the entire spectrum of treatment options. This gap in understanding should be addressed not only at the individual provider level, but also by professional and educational organizations, such as the American Medical Association (AMA), accrediting agencies that ensure the quality of medical education programs, such as the Liaison Committee on Medical Education (LCME), and similar institutions for other HCP fields such as the Physician Assistant (PA), and the Advanced Registered Nurse Practitioner (ARNP). Being able to hear the concerns of these women and treat them in the ways they are seeking equates to a practice of patient-based, culturally competent care.

It is also advisable for HCPs to become aware of what information is available online and proactively offer recommendations. Because the single most utilized source of health information, in this case menopause information, has been demonstrated to be the Internet, forward thinking HCPs can incorporate a woman's desire to know with her desire to use the Internet, and include practice-endorsed web information to women, including trusted sites to guide a woman's SDL investigation.

In order for an individual to be a partner in her own health, she needs to know how to achieve that. To that end, successful health education needs to be not just an

*individual* event, but also a *community* event. With this understanding, this study demonstrated the importance of the normalization of menopause as a social construct; that is to say, the way menopause is thought of, presented in media, anticipated, included and defined in the social process. Perhaps this can best be achieved through education within the larger conversation about human reproduction and about natural aging. Some women in this study encouraged beginning menopause education as part of early sex education courses, normalizing and demystifying the process and providing young girls with a complete picture of their reproductive lives, and then continuing that education as a woman approaches her child bearing years.

Menopause has the unique status of being both a part of a woman's reproductive life and also part of her aging process; healthy aging is a public health issue. If a woman's health education is to include menopause as the natural event that it is, then it is reasonable to reduce reliance on the medical community as the sole source of that information. As English (2012) stated, utilizing a community-based, health promotion approach takes the idea of health education away from providing literature when an individual is sick, to health promoting activities within an individual's community, such as in community kitchens or programs created by faith-based organizations.

In this case, menopause may not be taught in soup kitchens, but the pre-menopause course discussed earlier, offered by the Couple-to-Couple League, was founded by two lay Catholics as part of a natural family planning series. This course demonstrates that there are ways to incorporate community-based menopause education into educational initiatives with larger overall goals.

## Recommendations for Further Research

As an exploratory study, this research demonstrated that there is a need to further understand how women inform themselves about the menopause transition, what may help them in that investigation—and what may stand in their way.

Although there were a sufficient number of respondents for this study, expanding the study to include a larger number of participants would allow the analyses to make more definitive statements.

Including a question on the instrument asking where women learned about the study would allow the researcher to understand where recruiting has been successful.

Hispanic women, in general, did not investigate menopause, indicating it is just *cambio de vida*, an inevitable change of life. It may be worthwhile to explore if there are health disadvantages for Hispanic women who choose not to inform themselves, and therefore, may not recognize or acknowledge when a menopause experience is other than normal.

Participants became fatigued at the repetitive nature of the questions. Conducting face-to-face interviews could likely reduce that fatigue, with the research seen as more of a conversation than a task. Additionally, a focus group study would allow participants to build on each others' experiences as they share their own stories.

Women in this study indicated that their husbands, “just didn’t get it.” More research is needed regarding the attitudes of men toward a woman’s menopause transition, and what they may see as their role in the process.

This study focused on women living in the United States, from primarily a Western cultural worldview. Additional studies regarding women from other countries, as well as women from other-than-Western cultures, are needed.

In addition to studying women from other countries and cultures, more research is needed regarding the attitudes of men from other countries, as well as from other-than-Western cultures, toward a woman's menopause transition, and what they may see as their role in the process.

More research is needed to understand how much of the memory loss experienced beginning at the time of the perimenopause transition is actually due to the perimenopause transition, and how much is natural aging.

In this study, only women with graduate or professional degrees used the word *loss* to describe the symptom information they sought, specifically loss of libido, memory loss, weight loss, etc. Research to understand whether women's perception of loss is due to their own experience or whether loss is a learned concept could be informative.

Although this research examined the motivations of women who had researched menopause, it did not ask women who had not researched menopause if they had experienced symptoms. Therefore, this research did not clearly determine whether there is a relationship between having symptoms and seeking information about menopause. Additionally, the extent of foreknowledge women not researching menopause possessed was not fully explored. Research seeking to understand how influential being symptomatic, as well as a woman's understanding of her aging process, impact her information seeking might be beneficial.

Women were concerned about the safety of HRT, and many sought information regarding alternative therapies. Research investigating why women choose the treatment option they do, as well as the degree to which they are satisfied with their choices, could be investigated .

One of the inclusion criteria for participants in this study was they had not had menopause induced. Therefore, the women in this study were free to anticipate and fret, remain uninformed of, or continue to ignore, the process as they advanced toward natural menopause. However, research investigating the way in which women who learn they are suddenly to begin menopause through surgery, chemotherapy or other artificial measure, inform themselves about menopause is worthy of investigation.



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## Appendices

## Appendix A Study Participation Invitation—Flyer



Hello.

Women's Health at Mid-life  
A doctoral study

An online survey for  
women, age 35-55

All information is anonymous and confidential. No  
personal information will be collected.

Your participation is voluntary and uncompensated.

visit:

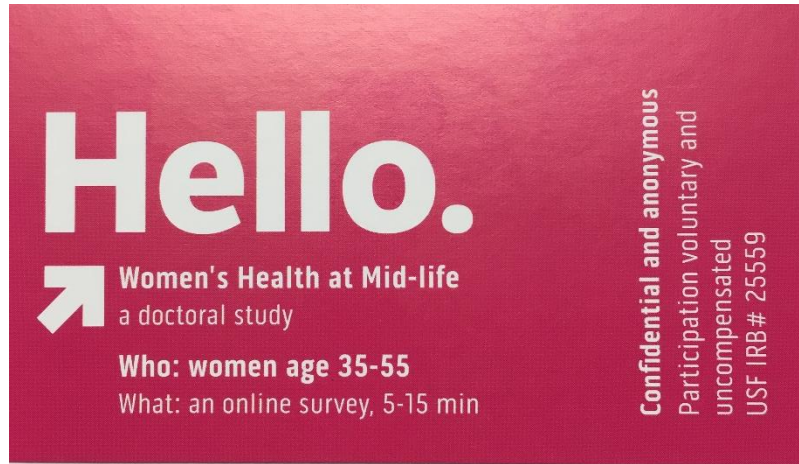
<http://tinyurl.com/lsItHot>

or scan here

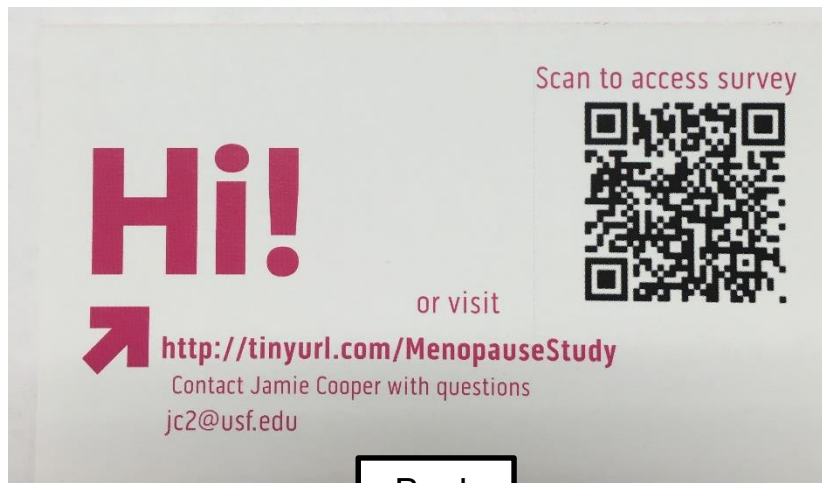


 eIRB: # 25559

Appendix B Study Participation Invitation—Business Card



Front




Back



## Appendix C—A Copy of the Survey Instrument

Following is a copy created from screen shots of the online survey instrument.

This questionnaire is complex in that it is branched and utilizes skip logic. Each potential variation is shown utilizing arrows  to indicate a point where a choice can be made, and then displays where the questionnaire leads from that choice.



## Appendix C, continued

The purpose of this *anonymous* survey is to learn what steps, if any, women living in the United States, who have not had surgical menopause, took when seeking information about menopause. The survey is in two parts: First a few demographic questions so we can learn a little about you, and then second, a few questions about how/if you sought to learn about menopause on your own.

Completion of this survey can take between 5-30 minutes. Participation is completely voluntary; you will not be compensated for your time.

Continuing with the survey will indicate your consent. Thanks in advance for your time!

eIRB#25559

**\*\*Although it may seem intuitive, please read each set of instructions carefully \*\***

Survey Powered By Qualtrics

>>

## Appendix C, continued

**ABOUT YOU:** The following questions will give us a little background information to allow us to place your answers in context.

**Please indicate your age.**

- Under 35
- 35-39
- 40-44
- 45-49
- 50-55
- Over 55

**Please indicate your marital status.**

- Single
- Married
- Divorced
- Widowed
- Other

**Please indicate your highest level of education.**

- |               |   |
|---------------|---|
| High school   | Graduate degree                         |
| Some college  | Professional degree (PhD, JD, MD, etc.) |
| 2-year degree | Other <input type="text"/>              |
| 4-year Degree |   |

**Please indicate the race/ethnicity with which you identify.**

- |                  |                            |
|------------------|----------------------------|
| Black            | Native American            |
| Hispanic         | White                      |
| Asian            | Other <input type="text"/> |
| Pacific Islander |                            |

## Appendix C, continued

Have you ever sought information about any health condition?

Yes

No

No

Next Page

Answering **Yes** here takes the respondent to the next question researching health conditions.

Yes

What health condition(s) have you sought information about?

Survey Powered By [Qualtrics](#)

>>

## Appendix C, continued

The following questions will help us understand when/if you **FIRST** sought information about menopause. When answering, please refer only to your *initial* actions, and **NOT** steps you have taken since that time.

Have you sought information about menopause?

Yes  
 No

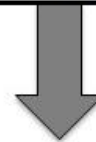
A **Yes** answer to this question directs the respondent to p. 155

Survey Powered By [Qualtrics](#)

>>

Answering **No** here takes the respondent to the next set of questions asking about why she may not have done any investigation.

Next page



## Appendix C, continued

No

Have you not sought information about menopause because you're too young?

Yes

No

Have you not sought information about menopause because you're not interested?

Yes

No

Have you not sought information about menopause because you hadn't really thought about it?

Yes

No

Have you not sought information about menopause because you're afraid of what you'll find out?

Yes

No

Have you not sought information about menopause because you're embarrassed?

Yes

No

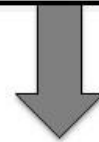
Is there another reason you haven't sought information about menopause?

Have you sought information about a health condition?

Yes

No

Next page



Appendix C, continued

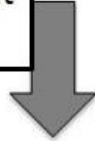
Yes

If a respondent indicates she has researched health condition(s)

What health condition(s) have you sought information about?

Survey Powered By Qualtrics

After answering this question, the respondent will be taken to the end.



If a respondent indicates she has not researched health condition(s) she will be directed right to the end of the questionnaire.

No

Thank you so much for taking the time to participate in this study.

Please pass the survey link along to your friends and family who are eligible to participate (women 35-55)!!

<http://tinyurl.com/MenopauseStudy>

## Appendix C, continued

The following questions will help us understand when/if you **FIRST** sought information about menopause. When answering, please refer only to your *initial* actions, and **NOT** steps you have taken since that time.

Have you sought information about menopause?

Yes  
 No

Survey Powered By Qualtrics

>>

Answering **Yes** here takes the respondent to the next question asking what types of symptoms.

At what age did you **FIRST** seek information about menopause?

<input type="checkbox"/> Younger than 20	<input type="checkbox"/> 35-39
<input type="checkbox"/> 20-24	<input type="checkbox"/> 40-44
<input type="checkbox"/> 25-29	<input type="checkbox"/> 45-49
<input type="checkbox"/> 30-34	<input type="checkbox"/> 50-55

What prompted you to begin looking for information about menopause?

Did you experience any menopause symptoms **PRIOR** to your search?

Yes  
 No

No  
Continue to p.159

## Appendix C, continued

What kinds of symptoms?

Yes

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>>



## Appendix C, continued

The next questions ask about places you might have gone to find information, why you sought information from that place (or why you didn't), and what kind of information you sought.

We recognize that you may have sought different kinds of information from different sources, so though it may seem repetitive, please answer each question.

Did you receive information from your health care provider?

Yes  
 No

Answering **Yes** here takes the respondent to the next questions asking about her HCP.

Survey Powered By Qualtrics

Yes

Who initiated the discussion, you or your health care provider?

I asked questions first.  
 My health care provider brought it up.  
 I'm not sure.

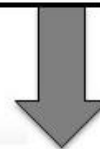
Did your health care provider recommend you research menopause on your own?

Yes  
 No

Were you encouraged to research menopause from someone other than a health care provider PRIOR to you searching for information on your own?

Yes  
 No

Next Page



## Appendix C, continued

Did you receive information from your health care provider?

Yes

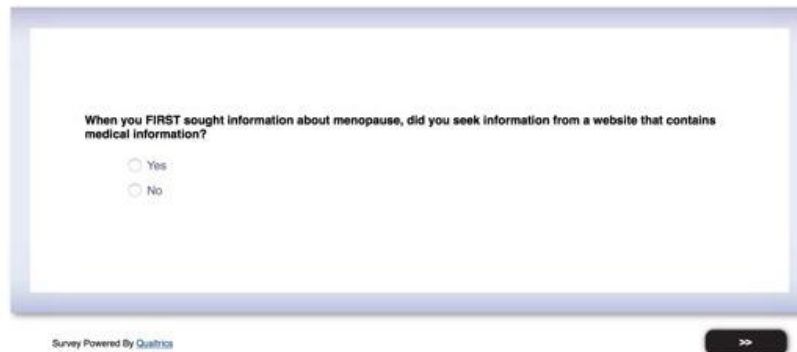
No

Answering **No** here, the respondent will be directed to the next set of questions asking about her search.

Survey Powered By [Qualtrics](#)

>>

## Appendix C, continued



When you **FIRST** sought information about menopause, did you seek information from a website that contains medical information?

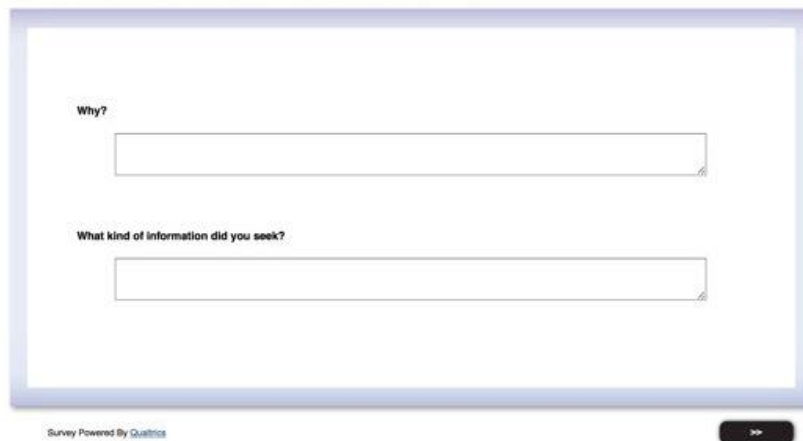
Yes

No

Survey Powered By Qualtrics

>>

Each of the following questions asking about where a woman searched will branch to one of two follow-on questions asking either why, or why not. These answer choices will be shown only once here for brevity.



Why?

What kind of information did you seek?

Survey Powered By Qualtrics

>>



Why not?

Survey Powered By Qualtrics

>>

## Appendix C, continued

When you **FIRST** sought information about menopause, did you seek information from a non-medical website?

Yes  
 No

Survey Powered By [Qualtrics](#)

>>

When you **FIRST** sought information about menopause, did you seek information from a book?

Yes  
 No

Survey Powered By [Qualtrics](#)

>>

When you **FIRST** sought information about menopause, did you seek information from a magazine?

Yes  
 No

Survey Powered By [Qualtrics](#)

>>

## Appendix C, continued

When you FIRST sought information about menopause, did you seek information from your friends?

Yes

No

Survey Powered By [Qualtrics](#)

>>

When you FIRST sought information about menopause, did you seek information from your mother?

Yes

No

Survey Powered By [Qualtrics](#)

>>

When you FIRST sought information about menopause, did you seek information from a family member (not your mother)?

Yes

No

Survey Powered By [Qualtrics](#)

>>

## Appendix C, continued

When you FIRST sought information about menopause, did you seek information from a talk show host or other media personality?

Yes

No

Survey Powered By [Qualtrics](#)



When you FIRST sought information about menopause, did you seek information from TV, film, or other media?

Yes

No

Survey Powered By [Qualtrics](#)



When you FIRST sought information about menopause, did you seek information from a women's health center?

Yes

No

Survey Powered By [Qualtrics](#)



## Appendix C, continued

When you **FIRST** sought information about menopause, did you seek information from a class?

Yes  
 No

Survey Powered By [Qualtrics](#)

>>

No

Next Page

↓

Is there somewhere else you went for information not included above?

Yes  
 No

Answering **Yes** here takes the respondent to the next question asking where else she sought information.

Survey Powered By [Qualtrics](#)

>>

Yes

Please indicate where, and what type of information you sought.

Survey Powered By [Qualtrics](#)

>>

## Appendix C, continued

**No** **Next Page**

Did you have any concerns about the accuracy of the information you found?

Yes  
 No

Answering **Yes** here takes the respondent to the next questions asking about her search for the accuracy of her information.

Survey Powered By Qualtrics

**Yes**

**No** **Next Page**

Did you try to verify information you were unsure about?

Yes  
 No

Answering **Yes** here takes the respondent to the next questions asking about her search for the accuracy of her information.

Survey Powered By Qualtrics

**Yes**

How did you verify the accuracy of the information you found?

Survey Powered By Qualtrics



## Appendix C, continued

The following questions ask about experience(s) you may have had in learning about menopause **AFTER** your initial experience.

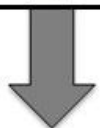
Did you continue to search for information after your first experience finding information?

Yes  
 No

Survey Powered By Qualtrics

No

Next Page



Answering **Yes** here takes the respondent to the next questions asking about the continuation of her search.

Yes

Please indicate where, and what type of information you sought.

Survey Powered By Qualtrics

## Appendix C, continued

Is there information you were/are looking for that you haven't been able to find?

Yes  
 No

Survey Powered By [Qualtrics](#)

No

Next Page

>>

A screenshot of a survey question. The question is "Is there information you were/are looking for that you haven't been able to find?". There are two radio button options: "Yes" and "No". The "No" option is selected. A callout box with a black border contains the text "No" and "Next Page" with a downward-pointing arrow. The survey is powered by Qualtrics, and there is a "Next" button (represented by two right-pointing arrows) at the bottom right.

Answering **Yes** here takes the respondent to the next question asking about information she couldn't find.

What kind(s) of information were you unable to find?

Survey Powered By [Qualtrics](#)

>>

A screenshot of a survey question. The question is "What kind(s) of information were you unable to find?". Below the question is a large, empty text input field. The survey is powered by Qualtrics, and there is a "Next" button (represented by two right-pointing arrows) at the bottom right.

## Appendix C, continued

Was there/has there been another person assisting or guiding your search?

Yes

No

No

Next Page

Survey Powered By Qualtrics

>>

Answering **Yes** here takes the respondent to the next questions asking about assistance during her search.

Yes

Who assisted/guided your search? (Relationship only, i.e. physician, friend, etc.)

Survey Powered By Qualtrics

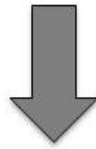
>>

## Appendix C, continued

Is there anything else about your search for information about menopause that you would like to share? Anything you think was intriguing, or frustrating, or helpful, or just might be of interest to the researchers or other women?

Survey Powered By [Qualtrics](#)

>>



**End**

Thank you so much for taking the time to participate in this study.

Please pass the survey link along to your friends and family who are eligible to participate (women 35-55)!!

**<http://tinyurl.com/MenopauseStudy>**

## Appendix D

### Correlation of Research and Survey Questions

Table D1

Table Correlating Research Questions and Survey Questions

Research Question	Survey Question
<b>RQ#1.</b> To what extent are women between the ages of 35-55 engaging in self-directed learning about menopause?	Have you sought information about menopause? At what age did you first seek information about menopause?
<b>RQ#2.</b> What motivates women to seek information about menopause?	Did you receive information about menopause from your health care provider? Who initiated the discussion, your or your health care provider? Did your physician recommend you research menopause on your own? Were you encouraged to research information on menopause by someone other than a HCP prior to you searching for information about menopause? Who suggested you research menopause?

Appendix D Cont.

	Research Question	Survey Question
<b>RQ#2 Cont.</b>	What motivates women to seek information about menopause?	What prompted you to begin looking for information about menopause?  Did you experience any menopause symptoms prior to your search?  What kinds of symptoms?
<b>RQ#3.</b>	To what extent are there differences in identified resources and topics based on age, marital status, level of education, and race/ethnicity?	Please indicate your age. Please indicate your marital status. Please indicate your highest level of education. Please indicate the race/ethnicity with which you identify.
<b>RQ#3. and RQ#4.</b>	To what extent are there differences in identified resources and topics based on age, marital status, level of education, and  What are the socio-ecological factors that most influence women's self-directed learning actions in their search for information about menopause?	When you first sought information about menopause, did you seek information from:  a website that contains medical information?  a non-medical website?  a book?  a magazine?

Appendix D Cont.

Research Question	Survey Question
<b>RQ#3 and RQ#4 Cont.</b> To what extent are there differences in identified resources and topics based on age, marital status, level of education, and What are the socio-ecological factors that most influence women's self-directed learning actions in their search for information about menopause?	your friends? your mother? a family member (not your mother)? A talk show host or similar media personality? TV, film, or other media? a women's health center? a class? Is there somewhere else you went for information not included above? Please indicate where and what type of information you sought? Is there another person assisting or guiding your search? Who is assisting/guiding your search? (Relationship only, i.e. physician, friend, etc.)

Appendix D Cont.

Research Question	Survey Question
<b>RQ#4.</b> What are the socio-ecological factors that most influence women's self-directed learning actions in their search for information about menopause?	<p>What prompted you to begin looking for information about menopause?</p> <p>Did you experience any menopause symptoms PRIOR to your search?</p> <p>Did you receive information from your HCP?</p> <p>Did your HCP recommend you research menopause on your own?</p> <p>Were you encouraged to research menopause from someone other than a health care provider PRIOR to you searching for information on your own? Who suggested you research menopause?</p> <p>Have you not sought information about menopause because you're too young?</p> <p>Have you not sought information about menopause because you hadn't really thought about it?</p> <p>Have you not sought information about menopause because you're afraid of what you'll find out?</p>



Appendix D Cont.

Research Question	Survey Question
<b>RQ#4 Cont.</b> most influence women's self-directed learning actions in their search for information about menopause?	Have you not sought information about menopause because you're embarrassed?  Is there another reason you haven't sought information about menopause?  Is there information you were/are looking for that you haven't been able to find? What kind of information?  Did you continue to search for information after your first experience finding information?  Did you decide not to continue your search because all of your questions were answered?  Did you decide not to continue your search because you lost interest?  Did you decide not to continue your search because it was just too scary?  Did you decide not to continue your search because it was too hard to find information?  Did you decide not to continue your search because you didn't have time?  Is there another reason you chose not to continue your search?

## Appendix E—Participant Informed Consent and IRB Approval Letter



### **Informed Consent to Participate in Research**

Information to Consider Before Taking Part in this Research Study

**Pro # 25559**

Researchers at the University of South Florida (USF) study many topics. To do this, we need the help of people who agree to take part in a research study. This form tells you about this research study. We are asking you to take part in a research study that is called: The Self-Directed Learning Actions of Women Regarding the Menopause Transition

The person who is in charge of this research study is Jamie Cooper. This person is called the Principal Investigator.

#### **Purpose of the Study**

The purpose of this study is to learn if women between the ages of 35-55 choose to learn about menopause, and if they do, when and how.

#### **Why are you being asked to take part?**

We are asking you to take part in this research study because you are a woman in that age range and we are interested in your experiences.

#### **Study Procedures**

If you take part in this study, you will be asked to complete an online survey which can take between 10 – 30 minutes, depending on your answers.

#### **Alternatives / Voluntary Participation / Withdrawal**

You have the alternative to choose not to participate in this research study

You should only take part in this study if you want to volunteer; you are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study

## **Appendix E, continued**

### **Benefits and Risk**

We are unsure if you will receive any benefits by taking part in this research study.

This research is considered to be minimal risk.

### **Compensation**

We will not pay you for the time you volunteer while participating in this study.

### **Privacy and Confidentiality**

We must keep your study records as confidential as possible. It is possible, although unlikely, that unauthorized individuals could gain access to your responses because you are responding online.

Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are: the Principal Investigator, the advising professor, and the University of South Florida Institutional Review Board (IRB).

- It is possible, although unlikely, that unauthorized individuals could gain access to your responses. Confidentiality will be maintained to the degree permitted by the technology used. No guarantees can be made regarding the interception of data sent via the Internet. However, your participation in this online survey involves risks similar to a person's everyday use of the Internet. If you complete and submit an anonymous survey and later request your data be withdrawn, this may or may not be possible as the researcher may be unable to extract anonymous data from the database.

### **Contact Information**

If you have any questions about your rights as a research participant, please contact the USF IRB at 974-5638. If you have questions regarding the research, please contact the Principal Investigator at [jc2@usf.edu](mailto:jc2@usf.edu).

We may publish what we learn from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are. You can print a copy of this consent form for your records

I freely give my consent to take part in this study. I understand that by proceeding with this survey that I am agreeing to take part in research and I am 18 years of age or older.

## Appendix E, continued



### IRB Study Processing Completed

To: Jamie Cooper  
RE: SDL and Menopause  
PI: [Jamie Cooper](#)  
Link: [Pro00025559](#)

You are receiving this notification because processing has been completed on the above-listed study. For more information, please navigate to the project workspace by clicking the Link above.

Please note, as per USF IRB Policy 303, "Once the Exempt determination is made, the application is closed in eIRB. Any proposed or anticipated changes to the study design that was previously declared exempt from IRB review must be submitted to the IRB as a new study prior to initiation of the change."

If alterations are made to the study design that change the review category from Exempt (i.e., adding a focus group, access to identifying information, adding a vulnerable population, or an intervention), these changes require a new application. However, administrative changes, including changes in research personnel, do not warrant an amendment or new application.

Given the determination of exemption, this application is being closed in ARC. This does not limit your ability to conduct your research project. Again, your research may continue as planned; only a change in the study design that would affect the exempt determination requires a new submission to the IRB.

**DO NOT REPLY:** To ensure a timely response, please direct correspondence to **Research Integrity & Compliance** either through your project's workspace or the contact information below.

#### **Research Integrity & Compliance**

University of South Florida - Research and Innovation

ARC Help Desk (eIRB, eIACUC, eCOI): (813) 974-2880

Email: [rsch-arc@usf.edu](mailto:rsch-arc@usf.edu)

Mail: [12901 Bruce B. Downs Blvd, MDC 35, Tampa, FL 33612-4799](#)

Template: 000 - IRB Study: Certified Exempt

## Appendix F—Additional Respondent Comments

**Q - Is there anything else about your search for information about menopause that you would like to share? Anything you think was intriguing, or frustrating, or helpful, or just might be of interest to the researchers or other women?**

---

It is a very personal and unique experience. Your experience will not necessarily be like another woman's, even close family members.

---

how little medical research has been done on menopause, how you can avoid the whole menopause experience safely but not many talk about it which I learned from my primary care physician

---

There should be much more discussion about the memory loss and cognitive impairment. For about 5 years my cognitive capacity was drastically affected and once I got through menopause I have felt back to normal mentally/intellectually

---

I find it interesting that some people use vitamins to lessen the hot flash/night sweats. Not sure if this really works and I have a hard time swallowing a lot of vitamins.

---

I wonder if there is a book that has chapters about women from different cultures going through menopause. It would be interesting to see what their expectations, reactions and feelings are.

---

I am probably not a good person to ask since my level of curiosity on this topic is minimal.

---

maybe a talking guide that I could use when speaking to my physicians? questions I could/should be asking? could well care visits cover every 6 months so I have an opportunity to talk one to one to my doctor rather than waiting until I have a problem; might actually save money since I might not stay on medications as long or switch to an alternative sooner

---

I have been shocked at how people have attributed my symptoms to some kind of personal malfeasance. There is advice to eat well, exercise, manage stress, get good rest, but NOTHING on how to engage in productive conversations with colleagues about the changes and how to keep communication open to avoid misunderstanding. Every time I have attempted to have these conversations, I have been met with what feels like skepticism. I even had a number of issues come up in my performance

## Appendix F, continued

appraisal that were directly related to times when I attempted to keep track of information in a new way to assist with memory changes (labeled as "micro-management"), forgetting names (actually labeled as "racial insensitivity"), failing to complete a task that I agreed to perform and completely forgot about (labeled as "making excuses" and "lying"). I am both frustrated and curious how colleagues can attribute such negative motivations to such simple occurrences. I really am struggling with this and think it would be an extraordinary topic for research.

---

It is frustrating that estrogen tabs for vaginal dryness are so expensive (\$500 for 3-month supply). Without them, sexual intercourse would be prohibitively painful for me.

---

I did learn that even buying a hormone cream from a health food store to alleviate the symptoms from hot flashes do contain hormones that can cause a higher risk of breast cancer. Due to the high amount of cancer in my family, I will endure the symptoms without the hormones.

---

Don't assume the only thing women are interested in are the feelings and doubts and fears, some of us actually want some science and ways to assist your body yourself, aside from the general checklist of exercise more, seek support from friends, ask your doctor, all suggestions that are just safe and vague and harmless enough to not get the writer sued or fined. Information on genetic components would be interesting.

---

The process that I have gone through has been a long one full of many tests and lots of waiting. After 3 months, I am still waiting to find out if I have gone into early menopause and what my medical options will be. My regular primary care physician has been wonderful but her expertise has been lacking in this area causing me to seek advice from a specialist. It has been at a very high cost to me financially and all just to get answers and hopefully be able to alleviate my symptoms.

---

I felt like I was starting menopause early and my dr just blatantly said that I wasn't experiencing menopause. Didn't even consider it. I felt she should have listened more and explored that option.

---

The gyn/ob was the least helpful person I spoke to and much less helpful than friends and web sources

---

Symptoms can start much earlier than people want to accept.

---

I seem to notice more of a general attitude of acceptance, normalcy surrounding

## Appendix F, continued

menopause, where my mother and her generation acted like it was the most horrible thing ever. So far, at 50+, it's been no big deal for me. The women I know didn't have any real problems either. I love not having a period every month. If having a period is considered a "curse", then yes we ought to be celebrating our freedom from this monthly disruption in our lives.

---

That everyone is different. I have been having night sweats/hot flashes for 7+ years. And as I read more, I find that if they sustain for more than 5 years it is possible that they may continue for 10years. The severity is reduced, but still present.

---

All doctors need to be educated in all hormones and how they affect one another. One hormone problem does not affect all. Look to research in the 80s and 70s before pharmaceutical companies started getting involved in research studies.

---

Not really. In some ways I feel like I'm too young to be concerned. It's just not a salient worry at this stage in my life. Maybe it should be.

---

a combination of Ayurvedic herbs, Chinese herbs, meditation, yoga, pranayama have made my transition seamless!

---

I often comment to girlfriends how much harder past generations must have had going through menopause. I Googled new symptoms as they arose, thereby avoiding the surprise/fear/shame of not knowing why they were happening, and being able to see what was due to menopause, and realize I wasn't going crazy. The biggest one for me was sound sensitivity. I couldn't tolerate background noise, or sounds that never bothered me before. Thought I was going nuts, then googled it, found it could be due to menopause. That helped tremendously! To know there was a legitimate cause, and I wasn't crazy. I think of past generations who were hindered by lack of access to information, and also the stigma of talking about personal things like menopause symptoms... I am so grateful to have the internet to help me find out what is happening to my body.

---

I find it intriguing and frustrating that it still isn't clear if HRT is safe or not. It depends on who or what you read.

---

that food can make a big difference in our overhaul it can make a difference in symptom management

---

## Appendix F, continued

Well there is a lot of information, studies and experiences out there, you just have to find the one that best fits YOU.

---

What is frustrating is there doesn't seem to be any one thing that consistently helps. I have done hours and hours of acupuncture and herbs, valerian, ginseng, ginkgo. I don't like conventional medicine.

---

I find it dispiriting that my opinion of menopause was that it was pathological.

---

The most important piece that is missing is education during childhood and teen years. We learned a lot about puberty and menses and birth control, but menopause and especially "perimenopause" is not talked about at all. That has been the most shocking thing to me. This is a real thing and no one ever said anything about it when I was growing up. It seems ridiculous that it was left out of all reproductive education. The only thing we ever learned was that eventually, sometime when you are older you will stop having your period.

---

Just info I have already shared. Information is not as readily available as one might believe. Or if it is, it seems to be common thought.

---

To hear positive stories, experiences and to hear/read less scary stories.

---

It would be great if there was one opinion? But there are too many variables and health concerns for individuals

---

everyone knows about hot flashes, but no one talks about so many of the other symptoms such as depression, anxiety, sleep....when you are in the thick of it prior to that last period I really thought i was going nuts. it was only after that last period did alot of the symptoms and issues i was having make sense. the medical profession seemed to treat the symptoms separately not putting together the fact that it was hormone fluctuations of lack of certain hormones triggering things. most of what i figured out i figured out on my own. because i was 48 when i had my last period i was often told i was too young for the symptoms when in fact I had been experiencing symptoms of peri menopause since at least age 40. now that i am 50 and almost 3 years into menopause the extreme symptoms have slowly subsided but i am still getting hot flashes....no one seems to know how long that will last.

---

Sometimes too much information is overwhelming and it is a double edge sword - info sometimes feeds the stress, anxiety and paranoia BUT the alternative which is NO information would be very stressful



## Appendix F, continued

It's a very personal journey that you just experience in your own way. I don't have hot flashes but that is the first thing people think when I ask them about menopause. The raging anger is the worst for me and it is hard to know when it will come until my cycle starts then I understand. I haven't had success in tracking my cycle because it is irregularly irregular. Frustrating!

---

My husband has not been particularly helpful, not because he doesn't care about me, but he totally doesn't 'get' it and I can't share just how uncomfortable I'm feeling (gassy, bloated, old....) with him because besides how self-defeating that is, what's he going to do. I hate how isolated I feel. If I had more girlfriends around it would help. I guess, having an online community is the closest you can get to that.

---

Online information is helpful and allows for privacy and anonymity, but some sites link to other sites that are not as reliable or are just looking for a place to market or sell a product. The intimacy of friendship and womanhood is difficult to communicate online. Books are great resources (I'm a reader at heart.), but the personal touch is missing. Women friends are to be treasured. Menopause seemed like something that I was going to look forward to ~ Yay! No more periods! However it seems now that there are trade-offs that present different challenges.

---

I hate that they tell me my sex drive is all in my mind. It isn't in my mind. I have tried everything for these hot flashes and while some antidepressants work for about a year, they seem to wear off and the hot flashes keep coming. I am not comfortable doing hormonal treatment, so I guess I just suffer and try to make myself have sex at least once a week.

---

My husband, friends, and family are the only reasons I did not go insane

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Each woman is different and I wanted to hear all of the stories.

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Sorry, I have up the search years ago. I hope your research leads to access to better information.

---

The mood swings are few, but hot flashes are often and I thought they were a phase that would end. I understand they may occur for years to come, and so WHY didn't anyone TELL ME BEFORE?? I want to tell every young woman what she is in for, I have many women in my life and No One Told Me until I got old enough to start this????

---

## Appendix F, continued

I think that the doctors office (and/or gyno) should give out information automatically. Or at least mention it specifically and ask if you have questions... I don't think most people or at least I didn't bring it up to the Dr, besides saying I had terrible dryness... she prescribed vagifem, but I wasn't sure if the dryness was due to Menopause or what??

---

There are not enough meaningful studies\Your doctor may not be up on best advice for your particular situation due to lack of studies and lack of your genetic info.

---

My only advice would be to use the internet for general information only and do not try to self-diagnose. Always consult with your primary care physician.

---

It would have been nice to be able to learn what the aggregate experiences were for lots of women.

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Beware of the greedy doctors! I was told multiple times (once by my Dr's receptionist) that I should just go ahead and have a hysterectomy- no medical reason, just that it would bring a quick end to symptoms- crazy!

---

I wish more info was available about natural hormone replacement

---

No. I would only recommend talking to your GYN and looking on the internet.

---

I think the hardest part is the lack of sleep and subsequent brain fog make it hard to process information of any kind, including something to solve the problem. You start out frustrated and irritable.

---

I read enough to realize that it is different for every woman, and until I begin the transition, it's hard to know what specific concerns I will have.

---

I birthed 7 children, the last at the age of 40. I still haven't had a hysterectomy as my previous gynecologist had suggested (almost insisted) and I still haven't used pharmacological drugs to alleviate symptoms. Sex is still fine and I'm still having hot flashes, for at least the past 10 years. I've heard some women have them until the end. I haven't used herbs but a few times to alleviate the symptoms. I rarely have pap smears.

---

The attitude I'm finding is that menopause is normal and nothing to be concerned about. I fear this is the attitude my doctor will have should I encounter problems during menopause.

## Appendix F, continued

Severe sleep disturbance. I take valerian root and melatonin to sleep

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In doing a little Internet research and talking with friends and family, it seems the experience varied from woman to woman.

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Friends can offer advice about what to watch out for in the future. Though my questions were not about vaginal dryness (didn't know it was a symptom), a friend offered the suggestion that if it happened in the future to try progesterone cream. Heads up info is always useful.

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The frustrating thing is there is no single way it happens. Therefore, one can know a ton of info, but still not know what it will be like for themselves or what is best for each individual to do.

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I would be interested in seeing statistics on how many women suffer various symptoms, particularly how many women have a relatively symptom-free menopause like myself.

---

I do know that many women my age had mothers who had hysterectomies. They mentioned their own mother was not a resource due to this reason.

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## Appendix G, continued



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**Title:** Development of the PRO-SDLS: A Measure of Self-Direction in Learning Based on the Personal Responsibility Orientation Model:

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### **About the Author**

Jamie Cooper has been passionately involved with both education and women's issues for many years. This research has afforded her the opportunity to work on both together. She has earned Master's degrees in Secondary Education and English: Written Communication, and has taught at all educational levels, from Montessori pre-school through higher education. Through her training, raising a family, and her own life experiences, she has come to have an acute interest in topics involving women's health in general, as well as women's healthy aging. She looks forward to continuing her research in these fields.