

UCSF

UC San Francisco Electronic Theses and Dissertations

Title

Hormone Therapy Decision Making in Older Women

Permalink

<https://escholarship.org/uc/item/70v4k4b2>

Author

Hunter, Mary M

Publication Date

2018

Peer reviewed|Thesis/dissertation

Hormone Therapy Decision Making in Older Women

by

Mary MacWilliams Hunter

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

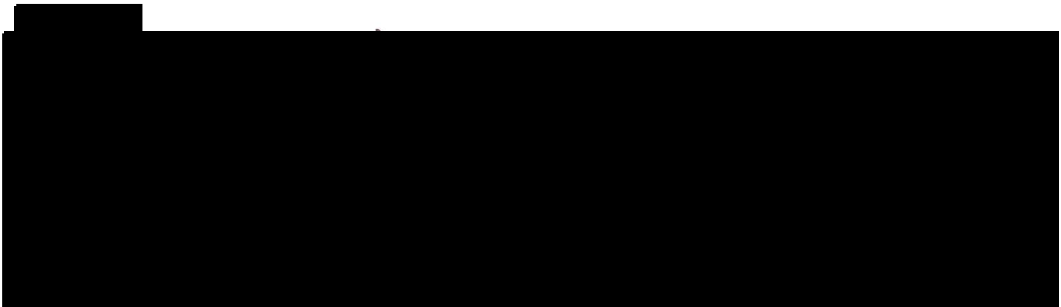
Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO



Committee in Charge

Hormone Therapy Decision Making in Older Women

Copyright 2018

Mary MacWilliams Hunter

Acknowledgements

This dissertation research was supported by the National Institute of Nursing Research (NINR) of the National Institutes of Health under Award Number F31NR015170.

This NINR fellowship enabled me to take full advantage of the research training resources at UCSF. I sincerely appreciate being given this opportunity.

I am tremendously grateful for the support and encouragement of my family, friends, and fellow students. Bob Hunter, PhD, is lovingly appreciated for everything he does to support me.

Sincere thanks go to the following individuals associated with UCSF for their valuable contributions to my education: Janine Cataldo, PhD, Adele Clarke, PhD, Carol Dawson-Rose, PhD, Alison Huang, MD, Jeff Kilmer, Kathy Lee, PhD, Stephen Paul, PhD, Roberta Rehm, PhD, Janet Shim, PhD, Margaret Wallhagen, PhD, and Elizabeth Watkins, PhD. Meg Wallhagen has been a wonderful mentor, and she deserves particular recognition.

Hormone Therapy Decision Making in Older Women

Mary MacWilliams Hunter

Abstract

Using menopausal hormone therapy (HT) for more than five years puts women at increased risk for breast, ovarian, and endometrial cancer, cardiovascular disease (CVD), gallbladder disease, incontinence, and dementia. For this reason, HT is not recommended beyond this therapeutic window, except in rare circumstances. Nevertheless, data on filled prescriptions indicate that over a third of HT prescriptions are written for women over age 60. These alarming facts raised the research questions: "What factors influence older women to use HT beyond the menopause transition?" and "How do older women weigh the risks and benefits of HT?"

Conventional grounded theory methods were used to interview 30 long-term users of systemic HT, code transcripts, and analyze data. Results showed that long-term users perceived that HT gave them control of numerous symptoms they attributed to menopause, enabled them to maintain attributes associated with youth and femininity, and helped them avoid diseases associated with aging, such as dementia and CVD. Risk was rarely mentioned in interviews; it was generally disregarded; and most participants did not know that age and length of HT use increase the risk of breast cancer. Users were observed to be the primary drivers of long-term HT, although gynecology specialty providers played a major role by giving reassurance about risk and continuing to prescribe HT.

Arguing that the science behind the quantification of HT risk is faulty, some hormone manufacturers promote HT for long-term use. This promotion is largely directed at gynecology

specialists through strategies such as ghostwriting, and, as a consequence, many of them remain skeptical of prescribing guidelines that recommend limiting duration of use. Key concepts from the literature on decision making that help explain disregard of risk information were identified.

Study findings are applicable to any clinical encounter that involves weighing benefit and risk. Recommendations to providers: Learn to distinguish science from marketing. Help patients understand that positive feelings about treatment may be based on unrealistic expectations for efficacy and underestimation of risk. Discuss judgment biases and cite base rates when providing risk statistics in clinical encounters. Such interventions could potentially strengthen joint decision making and improve patient outcomes.

Table of Contents

Chapter 1. Introduction	1
Chapter 2. Literature Review	9
Chapter 3. Conceptual and Theoretical Framework	26
Chapter 4. Methodology and Methods	36
Chapter 5. Results	48
Chapter 6. Discussion	64
References	81

List of Tables

Participant Characteristics/	Table 1		48
------------------------------	---------	-------	----

List of Figures

Relational Map of Aging Women’s Health Care Arena/	Figure 1		67
Model of a Two-System Cognitive Process Incorporating the Concept of Temporality/	Figure 2		73

Chapter 1

Introduction

As an introduction to this dissertation, the risks, prescribing guidelines, prescribing patterns, prevalence, promotion, and history of menopausal hormone therapy (HT) are described. The chapter concludes with a statement of the research purpose and the research questions.

Risks of Hormone Therapy

The cumulative lifetime incidence of breast cancer in the US is one in eight women (ACS, 2018; Chen, 2018). Primary risk factors for women who do not carry genes that increase their risk above the average rate are increasing age, timing of initiation of HT, and duration of HT use (V. Beral, Reeves, Bull, Green, & Collaborators, 2011; Chlebowski, Anderson, Aragaki, & Prentice, 2016). Estrogen-receptor-positive breast cancer is most strongly associated with the use of HT (Farhat, Walker, Buist, Onega, & Kerlikowske, 2010; Suhrke, Maehlen, & Zahl, 2012). About 41,000 women in the US will die from breast cancer this year (ACS, 2018), and breast cancer is a major cause of morbidity and mortality among older women. The mean age at diagnosis is 61 years, and approximately 69 percent of breast cancers are diagnosed in women over 55 years of age (NCI, 2018).

There is controversy about the risk of breast cancer from unopposed estrogen. The unopposed estrogen therapy arm of the WHI showed no increased risk (Anderson et al., 2004), while a reanalysis of data from 51 epidemiological studies comprising 52,705 women with and 108,411 women without breast cancer and the Million Women Study (MWS) showed increased risk if therapy was initiated within five years of menopause (V. Beral, Collaborative Group on

Hormonal Factors in Breast Cancer, 1997; V. Beral et al., 2011). In the MWS, a prospective UK study comprising 4.05 million woman-years of follow-up, it was determined that the timing of initiation of HT has an impact on relative risk (RR). In the MWS, the overall RR of developing breast cancer in women currently using HT who started within five years of menopause compared with never users was 1.43 for users of estrogen-only HT and 2.4 for users of estrogen-progestin formulations (V. Beral et al., 2011). The reanalysis of data from 51 epidemiologic studies found that for each year a woman uses HT, the risk of breast cancer increases by approximately 2.3 percent (V. Beral, Collaborative Group on Hormonal Factors in Breast Cancer, 1997). Five years after quitting, the relative risk returns that of a non-user.

Breast cancer is not the only significant health risk associated with HT. The incidence rates of ovarian cancer, coronary heart disease, ischemic stroke, deep vein thromboembolism, dementia, gallbladder disease, pancreatitis, and urinary incontinence are all increased in HT users (Chen, 2018; Collaborative Group on Epidemiological Studies of Ovarian et al., 2015; Manson et al., 2013; Nabel, 2013; Oskarsson, Orsini, Sadr-Azodi, & Wolk, 2014).

Prescribing Guidelines

Most women start using HT to treat bothersome symptoms during the menopause transition. The risk of HT in women under age 60 for less than five years is considered reasonable by expert panels such as editorial boards at UpToDate, Inc. (UpToDate.com, 2018). Because risks for breast cancer and other diseases increase with length of use, UpToDate® prescribing guidelines advise that HT be prescribed at the lowest effective dose for the shortest duration possible, no longer than three to five years (with rare exceptions, such as for osteoporosis that cannot be treated with bisphosphonates). Providing data only on risks and

benefits of HT for a duration of less than five years in women under 60 years of age, the authors emphasize this point (Martin & Barbieri, 2018b). UpToDate® guidelines are used by 90 percent of academic medical centers in the US, including the medical centers of the University of California, testifying to UpToDate.com’s reputation for science-based information.

In contrast, Position Statements and other materials on the North American Menopause Society (NAMS) website are subtly but substantially different from the recommendations of UpToDate.com. For example, UpToDate.com offers no suggestion that the risks of HT beyond five years can be counterbalanced by “quality of life” as is asserted in NAMS publications. The NAMS website hosts a decision tool to help women make decisions about HT use based on the impact of menopausal symptoms on “quality of life” (NAMS, 2018).

A number of individuals on Advisory Panels identified as authors of Hormone Therapy Position Statements of the North American Menopause Society (NAMS) reported relationships with hormone manufacturers (NAMS, 2012, 2017). The NAMS website addresses the needs of patients, clinicians, and corporate sponsors. Unlike NAMS, UpToDate, Inc. accepts no funding from pharmaceutical companies, medical device manufacturers, or any other commercial entity (UpToDate.com, 2017).

Prescribing Patterns and Prevalence Data Reflect HT Marketing to Providers

Estrogen was widely promoted within established medicine for disease prevention until the Heart and Estrogen/Progestin Replacement Study (HERS) and WHI randomized clinical trials determined that it increased the risk of cardiovascular disease and breast cancer (Hulley et al., 2002; Hulley et al., 1998; Rossouw et al., 2002). The prevalence of HT use among women 50-74 years of age in the US before publication of WHI findings was well over 30% based on

insurance claims made for filled prescriptions (Ettinger et al., 2012). Prevalence dropped significantly after publicity surrounding the WHI, as did incidence rates of invasive breast cancer and ductal carcinoma in situ (Farhat et al., 2010). Despite an overall drop in use, HT prescribing among gynecologists increased between 2002 and 2009, while prescribing by internists declined (Brett, 2010; Brett, Carney, & McKeown, 2005; Steinkellner et al., 2012).

The marketing of HT to providers helps explain this discrepancy. HT marketing has long included direct contact by drug representatives, the provision of samples for patients, authoring and sponsoring continuing education (CE) courses, and orchestrating the publication of professional journal articles with a promotional message (Fugh-Berman, 2010). Specifically, manufacturers hire marketing firms to author and sponsor CE courses, write and submit conference abstracts, and compose medical journal articles but then arrange to have physicians assume authorship. This is known as ghostwriting. Much of the literature in gynecology specialty journals such as *Menopause* minimizes the risk of HT, whereas articles in non-specialty medical journals, such as the *Journal of the American Medical Association* and the *New England Journal of Medicine*, do not minimize HT risk (Fugh-Berman, McDonald, Bell, Bethards, & Scialli, 2011; Fugh-Berman & Scialli, 2006).

Fugh-Berman et al. (2011) examined articles that comprised reviews, editorials, comments, or letters on HT prescribing published between 2002 and 2006 (Fugh-Berman et al., 2011). They found that articles with a promotional tone were twice as likely to be authored by physicians with ties to hormone manufacturers than articles written by others. They found five themes in articles written by authors with industry ties: (a) the risks of HT have been exaggerated, (b) randomized clinical trials are not better than observational studies for determining the risks of HT, (c) the study populations used in the WHI were inappropriate for

determining risks, (d) ongoing studies are expected to demonstrate protective effects from HT, and (e) different formulations and doses have different risk/benefit profiles, so prescriptions tailored to an individual woman based on her unique attributes may be beneficial and have minimal risk. Articles by different “thought leaders” with ties to the pharmaceutical industry contained text repeated word-for-word, suggesting ghostwriting

Despite current recommendations to prescribe HT only to women under age 60, more than a third of HT prescriptions in the US in 2015 were written for women over the age of 60 (Weissfeld et al., 2018). In 2015, the prevalence of use of estrogen pills and transdermal patches in the US ranged from 6.76 percent in women between 60-64 years of age to 1.56 percent in women over 74 years of age. These percentages do not include estrogen prescriptions obtained through Medicare, nor do they take into account vaginal estrogen or compounded hormones. According to a 2015 survey conducted by NAMS, the fraction of all women on HT who used hormones from compounding pharmacies was 35 percent (Gass et al., 2015). Compounded hormones, also known as “bioidentical” hormones, are not regulated by the US Food and Drug Administration (FDA) and they are not covered by health insurance. For these reasons, use patterns and health effects are difficult to quantify.

Although a trend toward prescription of lower HT doses has been observed, there is no evidence to support the intuitive hypothesis that lower doses are associated with lower risk for cancer, and only 25 percent of all HT prescriptions were written for low-dose therapy through 2009 (Corbelli & Hess, 2012; Ettinger et al., 2012). Standard or high-dose oral formulations remained the most common regimens observed through 2009, and the average length of use had steadily increased from 2002 to 2009 (Hersh, Stefanick, & Stafford, 2004; Steinkellner et al., 2012). The evidence on prescribing practice and use prevalence suggests that a significant

number of women use FDA-regulated HT, non-FDA-regulated HT, or both types, longer than five years. The evidence also suggests that industry efforts to discredit science showing risk from long-term use have been largely successful.

The History and Promotion of HT—The Medicalization of Menopause

The history of estrogen manufacturing and promotion is instructive for exploring historical and social reasons why women resist quitting HT. Starting in the latter half of the nineteenth century, hormone transplants and injectable or oral hormone preparations were widely believed to be capable of restoring health and prolonging life. Public fascination with hormone treatments such as insulin and thyroid extracts inspired early drug manufacturers in the US and Europe to synthesize sex hormones, and sales of hormone products enabled a number of companies to experience tremendous growth during the 1930s, despite the economic depression that hindered most other types of manufacturing during this era (Watkins, 2007).

In the early period of hormone manufacturing, HT was promoted to physicians for relief of their patients' hot flashes and vaginal dryness, prevention of chronic disease, stabilization of mood, cosmetic benefit, and for extending or restoring youthful vigor. Ayerst, a hormone manufacturer that by the late 1960s spent a million dollars annually on hormone advertising, secretly paid a gynecologist, Robert Wilson, to write *Feminine Forever* (Wilson, 1966). This best-selling book helped cement in the American consciousness a connection between HT and the healthy aging of women (Rothman & Rothman, 2003; Watkins, 2007). According to Dr. Wilson, menopause is an estrogen deficiency degenerative disease that requires treatment of all women who are otherwise "castrates" if not given hormones. He claimed that HT prevented cancer, and he denied evidence that showed estrogen was carcinogenic (Neel, 2002). *Feminine*

Forever helped create a discourse that: (a) sold the concept and the product known as “hormone replacement therapy,” (b) pathologized and medicalized menopause, (c) contributed to a fear of menopause and aging (d), promoted a belief that HT could slow the aging process, and (e) conceptually related serum estrogen levels to the value (and self-esteem) of women (Coney, 1994).

After Wyeth Laboratories, then a division of American Home Products, acquired Ayerst in the late 1980s, Wyeth continued to aggressively market HT. This included overseeing the publication of ghost-written professional journal articles claiming HT could improve facial skin and prevent disease (Fugh-Berman, 2010). In the 1980s through the first half of 2002, print and television advertisements used glamorous celebrities to market Premarin® unopposed estrogen therapy and Prempro® estrogen-progestogen therapy directly to women. By the late 1990s, Premarin® and Prempro® product sales comprised almost 70% of the menopausal HT market in the US, and by 2001, these products generated \$2 billion in sales annually (Petersen, 2002). Wyeth Laboratories was acquired by Pfizer in 2009. In 2018, the valuation of the estrogen-containing HT market in North America alone exceeds 12 billion US dollars (GrandviewResearch, 2018).

Background Summary and Research Questions

Arguing that the science behind risk quantification is faulty, pharmaceutical companies continue to promote HT for long-term use. This promotion, primarily directed at gynecology specialists through strategies such as ghostwriting, encourages providers to ignore prescribing guidelines. This fact, combined with patient demand for HT, results in the prescription of HT long past menopause.

Despite feminist critique and advances in education, health policy, and women's legal rights since *Feminine Forever* was published, it is reasonable to wonder if women who are now over 60 years of age have perceptions of HT that reflect the promotion of HT as anti-aging therapy. Moreover, exposure to ever-increasing options for and uptake of cosmetic procedures and other supposedly anti-aging innovations may contribute to perceptions of HT benefits. The finding that HT is most prevalent among college-educated White women and is low in most other races and socioeconomic groups (Brown et al., 1999; Keating, Cleary, Rossi, Zaslavsky, & Ayanian, 1999; Krishna, 2002; Lock, 1998) may reflect this exposure.

Differential uptake of HT may also reflect differences between social classes, racial and ethnic groups, and geographic regions, particularly in regard to the social desirability of a youthful appearance (Coney, 1994; Gannon, 1999). The idea that women who place a high value on preserving youthfulness, and who believe that HT is effective for accomplishing this, might be willing to overlook health risks was suggested by a review of the literature.

Because the risks of HT are disproportionately concentrated in long-term users, understanding the reasons women continue to use it beyond the menopause transition is important. Research questions addressed in this study are: What factors influence some women to use HT beyond the menopause transition? How do women weigh the risks and benefits of HT? What is the role of providers in long-term HT use? Knowledge resulting from an inductive study exploring these questions can inform strategies to promote improved clinical decision making, and this could result in a reduction in HT use and less HT-associated disease.

Chapter 2

Literature Review

Why do women over age 60 continue to use hormone therapy (HT) despite the risks? What do long-term users of HT perceive to be the benefits? Which risks concern them? How do they weigh perceived benefits and risks in making their decisions? Literature that pertains to these questions includes studies on: (a) women's perceptions of menopause, aging, and HT; (b) women's beliefs about the risks and benefits of HT and the ways they use this information in making HT decisions; and (c) providers' roles in HT decision making.

In this review, I both summarize and critically evaluate relevant literature. A general description of this body of literature is presented first. Then, a critical review focuses on six salient qualitative studies of midlife women. Following the critique is a synthesis of themes relevant to this research that combines results from the six critiqued studies with findings from additional research literature. Questions arising from the literature review conclude the chapter.

General Description of Literature Related to HT Decision Making

Various research approaches, both quantitative and qualitative, have been used to study HT decision making. Data-gathering methods have included surveys and questionnaires, on-line forums, focus groups, and interviews. A systematic review and meta-synthesis of HT knowledge and perception based on issues raised in 11 qualitative studies conducted after 2002, although innovative in design, added little to what had been reported in the literature earlier (Tao, Teng, Shao, Wu, & Mills, 2011). Two key findings of the meta-synthesis were: (a) a large percentage

of women received information on HT from the Internet and popular media, and (b) the women taking part in the reviewed studies evidenced a low level of concern regarding the risks of HT.

The studies evaluated in this review were selected based on their relevance to the research questions. This body of literature happens to be entirely qualitative in methodology and methods, although quantitative methods were used in some studies to produce descriptive statistics or to associate participants' demographic characteristics with particular findings.

The studies addressed women's perceptions of HT benefits and risks. They were typical of either (a) social science or (b) medical practice literature with an emphasis on education and counseling. Articles in the social science literature included qualitative descriptive studies, ethnographies, and grounded theory research. Some articles discussed social theory (such as feminism), nursing theory (e.g., Orem's theory of self-care and Meleis' transitions theory) or introduced new theory (Im & Lipson, 1997; Kolip, Hoeffling-Engels, & Schmacke, 2009; Quinn, 1991; Stephens, Budge, & Carryer, 2002). Other studies adopted an international perspective, included recent immigrants, or were conducted outside the US (Deeks, Zoungas, & Teede, 2008; Erol, 2011; Fauconnier, Ringa, Delanoe, Falissard, & Breart, 2000; Fisher, Sand, Lewis, & Boroditsky, 2000; Hunter & Liao, 1994; Hunter, O'Dea, & Britten, 1997; Im & Lipson, 1997; Krishna, 2002; Lock, 1998; Marmoreo, Brown, Batty, Cummings, & Powell, 1998).

The purpose of many studies published prior to 2002 was to gain information that could improve women's adherence to HT, which the researchers assumed to be safe and effective (Fisher et al., 2000; Krishna, 2002; Limouzin-Lamothe, 1996; Marmoreo et al., 1998; Phelan et al., 2001). Typical of this approach is a study on a decision aid structured to encourage women to use HT for cardiovascular disease and osteoporosis prevention, providing a woman's medical history did not suggest a greater-than-average risk for breast cancer (O'Connor et al., 1998).

A limitation noted by many of the authors is that White and well-educated women comprised the majority of participants. This reflects the fact that some studies selected participants who were HT users or patients in gynecology specialty clinics; however, this does not explain the lack of diversity in other studies dealing with attitudes about menopause. Another limitation is that very few women over age 60 who used HT were included in any of this research, and the few instances in which older women comprised part of a study population, age of participant was not associated with quotes or themes.

Critique of Six Salient Qualitative Studies Related to HT Decision Making

Six qualitative studies that address my research questions are discussed below. Each of them provided valuable insights for data analysis. The articles are alphabetically ordered, and criteria for assessing rigor are those emphasized by Beck, namely: credibility, dependability, confirmability, transferability, and authenticity (Beck, 2009).

Hunter, O'Dea, and Britten, 1997. Hunter, O'Dea, and Britten published a “thematic discourse analysis” describing how women in the UK accounted for their decisions about HT. Forty-five women aged 49-51 (seven using HT), were interviewed in depth by a health psychologist who used a semi-structured format that broadly addressed menopause in terms of health and lifestyle (Hunter et al., 1997). The study sought to describe the extent to which women use medical models in discussions of HT decision making, and the authors concluded that most women in this study did not. Although participants were recruited from gynecology specialty practices and interviews took place in a medical setting, most of these women described menopause as a natural process that did not require therapy unless specific symptoms required treatment, such as severe hot flashes. Some women expected that HT could improve

mood and appearance, while other women were skeptical of such claims. Some women believed that HT was not natural, and they felt that having HT-induced periods was unnatural as well.

Hunter et al. concluded that beliefs about HT are contextual, and enabling women to voice their own opinions and make HT decisions that are consistent with their values is not often recognized as a necessary part of providing HT decision support. A strength of the study report is the insightful discussion section that cites related literature addressing the importance of empowering women. Issues raised included stigma, power and gender relationships, and the need to take into account variation in racial, ethnic, and other social backgrounds. A weakness of the study is its abbreviated data analysis, which consisted of dividing quotes into two sections: (a) perceived advantages and disadvantages of HT, and (b) reasons given for decisions to take or not to take HT. Response examples were reported in a straightforward manner without further thematic analysis, and this represents a missed opportunity for finding additional meaning in interview data. Although the findings of Hunter et al. are intuitively credible and likely to reflect the experiences of participants, there was no mention of peer review, reflexive memo writing, field notes, or validation by participants. Study methods were not fully described, and auditability (confirmability) was not addressed.

Kolip, Hoefling-Engels, and Schmacke, 2009. Kolip, Hoefling-Engels, and Schmacke used a grounded theory approach to describe how postmenopausal women in Germany view HT (Kolip et al., 2009). They interviewed 31 women in 2005, and used grounded theory methods for data collection and analysis. The study included three women over 60 who were current users of HT, however, the authors did not associate specific themes or quotes with individual participants or participant categories (such as age or current or past HT use), and the issue of using HT outside of treatment guidelines was not addressed. The study sought to assess

women's "subjective logic" for using HT, to explore their motives, and to learn how individual women weigh the risks and benefits of HT. Their analysis resulted in five prototype user attitudes: integrity-preserving (preserve self-image, physical well-being); performance-oriented (slow the aging process, function as before); searching (doubt a HT decision); faith in medicine (trust and please one's provider by using HT); and benefit-generalizing (hold anti-aging beliefs, attribute good health and non-menopausal symptom relief to HT). The authors suggested that women's attitudes fall into overlapping patterns that are subject to change over time.

The strengths of this study include its rich descriptions and well-chosen quotes. The authors expressed surprise that menopausal symptoms were seldom mentioned in interview data as motives to use HT, and they observed that some participants attributed positive effects to HT that are not supported by scientific evidence (such as stress relief, fewer wrinkles, and improvement in chronic ailments, such as rheumatism). They acknowledged that interviews did not fully explore "benefit-generalizing," and this approach could comprise a focus for future research. Although they reported that a need for control was a characteristic of the "integrity-preserving user," they did not fully develop this concept in their analysis. It would be useful to explore these concepts among a sample of women who have used HT longer than five years. The study report included comprehensive descriptions of methods used to conduct interviews and analyze transcribed data. Efforts to enhance credibility included use of a reconstructive analytical procedure and peer review.

Marmoreo, Brown, Batty, Cummings, and Powell (1998). Marmoreo, Brown, Batty, Cummings, and Powell addressed the topic of HT decision making using a modified grounded theory approach (Marmoreo et al., 1998). Fifty-six Canadian menopausal or postmenopausal participants responded to a newspaper ad or poster advertising a study on HT decision making.

Participants were purposively selected for assignment to one of eight heterogeneous focus groups. Each group consisted of never users, former or off-and-on users, and current users, with the objective of fostering “open and spontaneous discussion.” The numbers and ages of women in each category were not provided, nor was it stated whether using HT included both systemic and vaginal estrogen. Two of the eight focus groups were excluded because data on use of HT were missing, and 25 percent of participants were continuous HT users, indicating a sample of 10 or 11 HT users. The mean age of participants was 56 with a range of 44-73. Due to the small number of HT users overall, few of the 10 or 11 HT users were likely to be over age 60. Themes developed from analysis of focus group data were not associated with women in a particular use or age category.

Focus groups were facilitated by a family physician and a psychologist, and two broad questions were used to start discussions: “What are your ideas and perceptions about HRT?” and “What has been helpful in terms of your decision to take or not to take HRT?” The study report described the approach to analysis in detail, including efforts to ensure credibility. Analysis resulted in four themes called “spheres of influence.” These themes were referred to as: (a) a woman’s internal influence, or “the interface between her perceptions and feelings,” (b) interpersonal relationships, (c) ongoing external or societal influences, and (d) the consequences resulting from the HT decision. The authors describe a “dynamic interplay” between the spheres of influence, and they hypothesized that an especially positive or negative sphere of influence, termed a “weighted influence,” could alter the decision-making process. Quotes were selected to illustrate weighted influences.

The physician’s role was not explained in terms of its place within the spheres of influence, but one might assume that physicians are part of external influence, and their advice

related to the sphere of consequence. A weakness of the conceptual model is the lack of clarity regarding the physician's role, especially in light of the authors' suggestion that the relationship between a woman and her physician could comprise a "weighted influence." Although the study reflected little of the bias toward use of HT for disease prevention in currency in the 1990s, the authors stated their motivation was to learn how to help women appreciate HT's benefits. The primary practice implication was that physicians should listen to patients to learn how to best address their concerns.

The authors observed that the concept of "control" of "the condition" was addressed by all study participants, however, this concept was not specifically addressed in focus group discussions or developed in analysis. Future studies might explore this concept, as it appears to be a theme in this body of literature. Techniques used to enhance credibility included a thorough description of the sample including composition of focus groups, reflexivity in analysis, and observation of focus groups (with the writing of field notes, one assumes). Additional efforts to ensure auditability were not explicit other than mention of verbatim transcription of focus group recordings.

Stephens, Budge, and Carryer, 2002. In a qualitative study conducted in New Zealand, Stephens, Budge, and Carryer focused on the meaning of HT in relation to various discursive constructions of the meaning of menopause (Stephens et al., 2002). The study sample consisted of 48 women aged 45-60 who were selected randomly from election rolls and sent letters inviting them to participate. Additional women were recruited with newspaper advertisements. Focus groups were purposively formed based on HT use: never, formerly, and current. Nineteen of the 48 women used HT currently. Major "interpretive repertoires" identified were: threatening change, natural, biomedical, and drug. HT was characterized within these interpretive

repertoires as: a beauty product (threatening change); a poison (natural), a medicine (biomedical); and a drug of dependence (drug). The authors suggested that providers become familiar with these discourses in order to improve collaborative HT decision making.

The strengths of this study include its clear description of study methods and well-chosen quotes. A limitation of the design recognized by the researchers was the fact that some women's voices were overwhelmed by more vocal focus group participants. The study's thematic analysis of the discursive construction of menopause represents a Foucauldian post-modern philosophical perspective. Analysis of focus group data, in which quotes were placed within larger conversations, reflected a constructivist view of analysis. Efforts to ensure credibility, integrity, and auditability included complete descriptions of the sample, data collection methods, and analysis. Analysis incorporated a recursive process and peer review, and the final product reflected creativity and an artfulness that did not detract from the credibility of the study.

Theroux (2010). Theroux conducted a qualitative study in the US on HT decision making (Theroux, 2010). Data gathering comprised 21 interviews (face-to-face except for two telephone interviews) of seven women aged 48-58. Initial interviews were followed by additional interviews at six and twelve months, giving this study a unique longitudinal aspect. The author, a women's health nurse practitioner with a PhD, stated her intent to develop a decision support model. As the author stated, she did not move far from the data with analysis when she identified four major themes: experiencing changes, searching for answers, making the decision, and women's needs. Theroux concluded that making a decision about HT is a non-linear process, and that women change their minds. She also concluded that unrealistic fears about HT interfered with decision making, that shared decision making is improved when nurse

practitioners are prepared as coaches, and that the North American Menopause Society is a good resource for gaining this expertise.

Although Theroux did not use a grounded theory methodology, she suggested that future studies would benefit from such an approach. Limitations of the study are its low number of participants, simplistic thematic analysis, and bias toward a pharmaceutical-industry-associated educational resource. Theroux reported using field notes taken from telephone conversations to document the tones of conversations, however, she made no mention of reflexive memo writing. At the conclusion of the study, Theroux conducted additional interviews with six participants who had read a preliminary summary of the findings. In addition to member checking, the author listed prolonged engagement with participants, maintenance of an audit trail, and review of findings with other nurse practitioners and nurse researchers as methods used to ensure trustworthiness.

Walter and Britten, 2002. Walter and Britten conducted a qualitative study using focus groups and interviews to explore patients' understandings of HT risk in the UK (Walter & Britten, 2002). Like the Marmoreo et al. (1998) study, the lead author of this study was a physician. The study was part of a larger body of research to identify effective ways of framing risks in clinical encounters. The sample was comprised of 40 women 50-55 who were never-, ex-, and current-users of HT recruited from two gynecology practices. Major findings were: there is interplay between knowledge and core beliefs; patients prefer to form their own conclusions about risk likelihood; there is a tradeoff between risk likelihood and suffering; and family history influences understanding of risk. The authors suggested that the meanings of particular risks are modified by age, experience, and emotion. Imagery of danger, for example, appeared to modify perception of risk, weighing of risk versus benefit, and subsequent behavior.

The authors hypothesized that there is an emotional (non-cognitive) component to risk perception, and emotions that result from a synthesis of risk knowledge and core beliefs act as a “filter” to prevent contamination of core beliefs by risk information.

Although Walter and Britten did not use the term “grounded theory,” this study is an example of a modified grounded theory approach, and the resulting hypothesis resembles a grounded theory. Their analysis employed the “framework” method, and examples of thematic codes included references to beliefs about womanhood, fatalism, control, and choice. The concept of control was explored in terms of controlling risk, rather than controlling a “condition” as in other studies. In terms of applicability to my inquiry, this study’s limitations are its narrow focus on framing risk information and the fact that the sample consisted of younger women than my population of interest. The study’s primary value from my perspective is the idea that emotion plays a role in decision making. The importance of emotion posited by Walter and Britten calls to mind the role emotion plays in risk assessment suggested by psychologists who study decision making and bias, such as Kahneman, Slovic, and Tversky (Kahneman, Slovic, & Tversky, 1982). The research report included informative details on the background and purpose of the study, sample used, data collection methods, and a brief summary of data analysis using the framework method. The findings are believable, they reflect creativity, and they are likely to be transferrable to other situations involving decision making.

Synthesis of Information on HT Decision Making in the Literature

Dominant themes that surfaced in the literature review are discussed below. These themes were apparent not only in the six qualitative studies selected for critical review, but also in this body of literature as a whole. For perspective regarding the timing of studies relative to

publication of results from the Women's Health Initiative in 2002, keep in mind the length of time it may have taken for a study to be published after data collection and analysis.

Menopause: A salient theme for older women on HT. Menopause is often the first obvious sign of aging, and most women who start HT initiate it close to menopause. In a grounded theory study, Kolip et al. reported that interviews were initiated by asking all participants to provide a narrative recalling the first signs of menopause (Kolip et al., 2009). They found that starting with this narrative helped reveal a woman's motives and internal logic regarding the HT decision.

Menopause and aging are linked conceptually, and both tend to have negative connotations in English-speaking countries and Western Europe (Krishna, 2002; Lock, 1998). For her dissertation, UCSF nursing doctoral student Linda Crocket McKeever conducted an interpretive study of the menopause experience (McKeever, 1988). McKeever wrote that, because the dominant culture in the US fails to formally recognize a positive change in status with menopause, women are motivated to postpone menopause by using HT. Controlling menopause symptoms and slowing the aging process are both powerful motivations for using HT, and some women believe that by doing so they delay or avoid menopause and signs of aging (Fauconnier et al., 2000; Fisher et al., 2000; French, Smith, Holtrop, & Holmes-Rovner, 2006; Hunter, 1993; Hunter & Liao, 1994; Hunter et al., 1997; Kolip et al., 2009; Limouzin-Lamothe, 1996; Stephens et al., 2002).

For some women, menopause presents emotional and physical difficulties related to changes in self-image, and interview data suggested that many women believed that depression, anxiety, and emotional lability are caused by menopause (Bauld & Brown, 2008; French et al., 2006; Kolip et al., 2009). Bauld and Brown (2008) and Krishna (2002) reported that women

who held more negative beliefs about menopause and aging experienced more physical and psychological symptoms with menopause (Bauld & Brown, 2008; Krishna, 2002).

Along with intention to slow the aging process, factors associated with intent to use HT among pre-menopausal women included poor self-esteem and depressed mood (Fauconnier et al., 2000; Fisher et al., 2000; French et al., 2006; Hunter, 1993; Hunter & Liao, 1994; Hunter et al., 1997; Limouzin-Lamothe, 1996; Marmoreo et al., 1998; Rolnick, Kopher, DeFor, & Kelley, 2005; Stephens et al., 2002). Controlling emotional lability was frequently cited as a reason for using HT (Fisher et al., 2000; Kolip et al., 2009; Limouzin-Lamothe, 1996) and some women adjusted dosing based on their emotional states (Kolip et al., 2009).

Perceived benefits of HT. The literature review indicates that one of the primary predictors of HT use is severe hot flashes; the primary perceived benefit of HT is control of hot flashes; and the major predictor for restarting HT after trying to quit is resumption of hot flashes (French et al., 2006; Grady, Ettinger, Tosteson, Pressman, & Macer, 2003; Hunter et al., 1997). Controlling hot flashes was one of the most frequently cited benefits deemed to outweigh HT risks (French et al., 2006; Hunter et al., 1997; Limouzin-Lamothe, 1996; Rolnick et al., 2005).

In contrast to findings suggesting that control of hot flashes was the most important perceived benefit of HT, others noted that many HT users minimized symptoms such as hot flashes and instead expressed appreciation for various other perceived benefits (Kolip et al., 2009). These perceived benefits, mentioned in a number of studies (Deeks et al., 2008; French et al., 2006; Hunter, 1993; Hunter et al., 1997; Kolip et al., 2009; Limouzin-Lamothe, 1996; Marmoreo et al., 1998; Stephens et al., 2002), included improvement in mood, weight control, lessening of fluid retention, stress reduction, and delayed aging, which included better skin texture and tone, increased energy, and greater sex drive. In addition to these perceived benefits,

participants in the Kolip et al. study attributed to HT improvement in chronic ailments, such as rheumatic pain, and they reported adjusting dosages based on the perceived effect (Kolip et al., 2009). Disease prevention as a benefit of HT was a common theme in HT studies conducted before 2002 (Marmoreo et al., 1998; Stephens et al., 2002).

Fear/Risk of not using HT. Women in several studies spoke of the fear or risk of not using HT for prevention of disease, for prevention of menopausal symptoms, for prevention of emotional lability, or for slowing the aging process (Marmoreo et al., 1998; Stephens et al., 2002). The risks of not slowing the aging process, not preventing diminished sex drive, and not preventing emotional lability were sometimes mentioned in the context of a need to avoid endangering one's relationship with an intimate partner (Marmoreo et al., 1998; Stephens et al., 2002). In a multi-ethnic study in the US using an on-line forum, Im & Lipson concluded that the need to control menopause-associated symptoms and the effects of aging is a characteristic of well-educated White women, the primary users of HT (Im & Lipson, 1997).

Osteoporosis prevention was the primary focus of a study in which Turkish women were interviewed about their knowledge of osteoporosis risk and their perceived benefit of prevention from HT (Erol, 2011). The study took place following a media campaign initiated by pharmaceutical interests on osteoporosis prevention using HT. The campaign linked the risk for osteoporosis to the covering of women's bodies (which is mandated by culture, religion, and law) preventing sun exposure. The campaign was seen by the author as appropriation of cultural practices and fears in order to sell HT. The study is unique in that it employed situational analysis theory and methods to explore the cultural meanings of HT as well as contextual aspects of HT decision making.

The authors of several studies suggested that psychological drug dependence, or fear of non-use, may be partly responsible for long-term use (Hunter et al., 1997; Marmoreo et al., 1998; Stephens et al., 2002). An article in *The Lancet* introduced the issue of HT drug dependence by suggesting that both physical and psychological dependence can be caused by estrogen (Bewley & Bewley, 1992). These authors mentioned the possibility of “rebound” symptoms as well as the psychological pain of giving up perceived anti-aging benefits.

Conflict and confusion regarding HT risk and benefit. Most of the studies in this body of literature examined HT risk perception, which was a dominant theme in studies published after 2002. In response to widespread publicity surrounding the WHI finding that HT increased breast cancer risk, many women quit HT entirely, some later restarted it, some lowered or skipped doses, and some changed type of hormone preparation (French et al., 2006; Grady et al., 2003; Rolnick et al., 2005). Concern about breast cancer risk and general uncertainty about health risks associated with HT remained dominant themes for the next decade. Women in many studies expressed confusion about HT risks and benefits, citing conflicting information in the media (French et al., 2006; Hunter et al., 1997; Krishna, 2002; Rolnick et al., 2005; Theroux, 2010).

An example of confusing information is the Kronos Early Estrogen Prevention Study (KEEPS) trial sponsored by the Kronos Longevity Research Institute (KLRI) that was designed to determine whether estrogen, when taken early in menopause, could prevent cardiovascular disease (CVD) and/or cognitive decline (KLRI, 2005). The KEEPS study was largely conducted to test the “timing” hypotheses, which suggested that the WHI report of more CVD and dementia after use of HT were findings associated with starting HT well after menopause, rather than early in menopause, as is normally the case.

At the 2012 annual meeting of The North American Menopause Society (NAMS), the authors of the KEEPS study announced that they had preliminary findings showing that HT was protective against CVD and dementia when started early in menopause. Press releases and related articles appeared widely in the popular media such as USA Today and WebMD, giving the public the impression that there was evidence to support these conclusions. However, the assertions made in 2012 were not supported by study data, and it was not until 2014 that results on CVD outcomes showing no protection were published in a peer-reviewed journal (Harman et al., 2014). Results indicating no improvement in cognition were published in 2015 (Gleason et al., 2015). These negative findings were not widely publicized; however, a claim of no adverse effects of treatment in the KEEPS Study is partly responsible for ongoing misconceptions about HT risk among providers and patients. The short length of the study precludes reassurance about long-term use.

A reassuring provider—the most significant predictor of HT use. McKeever noted that society gives doctors great authority, and this influences many women to accept a medicalized interpretation of menopause and to follow a doctor's advice to use HT (McKeever, 1988). Having a reassuring and informative provider was found to be the most significant predictor of HT use, and decision support was identified as a perceived need in a number of studies (French et al., 2006; Kolip et al., 2009; Marmoreo et al., 1998; Phelan et al., 2001; Sveinsdottir & Olafsson, 2006; Theroux, 2010). Phelan et al. found that a visit with a gynecology specialist within the previous two years was a predictor of a positive attitude toward HT (Phelan et al., 2001). Conversely, they also found that women who indicated that friends were an important source of information were likely to have negative attitudes toward HT.

Kolip et al. reported that some women agreed to use HT primarily to please their doctors, considering it a breach of faith to argue against this advice (Kolip et al., 2009). When they felt comfortable with HT, women expressed appreciation for being relieved of the burden of making the decision. Other women in this study provided narratives about questioning the advice of doctors, and some told of being “threatened” by warnings of mental and physical consequences if they declined prescription of HT. The authors concluded that seeking gynecologic care at menopause almost inevitably resulted in prescription of HT, and that women lacked other sources of information and support for menopause-related concerns.

Questions Arising from the Literature Review

The majority of studies cited in this review of the literature included few women over 60 years of age. A primary reason for the younger research population is that many of the studies focused on the decision to begin HT prior to or during menopause. Much of the existing literature dealt with expectations of HT benefits, and the purpose of many studies was to increase uptake of HT and improve adherence.

Factors influencing HT decisions may be different for older compared to younger women. Older women may perceive the risks and benefits of HT differently due to age- or cohort-specific medical or personal histories, and they may also be weighing alternate priorities or conflicting beliefs about HT.

Positive benefits associated with HT may be somewhat different for older users compared to the expectations of women approaching menopause. A related unexplored question is whether original expectations for HT were met, and whether they evolved into different expectations and

attributions of benefit. For example, do older women, who are more likely to experience chronic conditions, attribute symptom improvement to HT?

Are older women confused about HT risks, or do they actually not care about risk? Are they fatalistic? Are concerned prescribers trying to persuade older patients to stop HT? Has using HT become more of a practice than a decision? Does a need for control play a significant role in long-term use, i.e., control of aging, symptoms, or in terms of disease prevention?

Some women in prior studies expressed anger about being given misinformation (Marmoreo et al., 1998; Stephens et al., 2002). Apparently, few of them suspected corporate deception (French et al., 2006). Information is rarely published about the practice of ghostwriting, about monetary awards made to women who developed breast cancer while taking Prempro® HT, and the related fact that Wyeth knew about breast cancer risk while publicly denying it (Feeley, 2012). Might women who have used HT for a long time respond to such information by becoming angry? Might such knowledge and an emotional response affect perception of benefit vs. risk?

This body of literature has shown that having a prescriber who considers HT safe and effective is a powerful predictor of use among younger menopausal women. Is HT use in older long-term users as strongly associated with prescriber belief and behavior, or are older women the principal drivers of the prescribing process?

Chapter 3

Conceptual and Theoretical Framework and Philosophical Assumptions

Symbolic interactionism and situational analysis theories comprise the conceptual and theoretical framework for this grounded theory research project (Blumer, 1969). While symbolic interactionism theory explains basic social processes in which the individual is the unit of analysis, situational analysis theory provides a broader perspective for exploring social change and impacts on human health and behavior from such forces as historical events, social trends, technology, politics, and policy.

These theories, which are closely related to each other and to grounded theory methodology and methods, shaped study design and strengthened analysis. Descriptions of the two theories with references to this project are presented below. A description of feminist philosophical assumptions guiding this project concludes the chapter.

Symbolic Interactionism Theory

Symbolic interactionism theory, an approach to the study of group life and human conduct, is the foundational theory undergirding the grounded theory research methodology (Strauss & Corbin, 1998). The theory grew out of pragmatist philosophy, which was a reaction by scientific realists against classical rationalism in science (Godfrey-Smith, 2003). Pragmatists, among them George Herbert Mead, were a diverse group of philosophers who shared a belief that humans play an active role in the production of their reality, a reality full of meaning.

This perspective contrasts with the approach of many scientists, who tend to attribute human behavior to stimuli, conscious or unconscious motives, and other psychological inputs.

The pragmatist perspective also differs from that of earlier sociologists, who generally attributed human behavior to social structures, i.e., social position and roles, cultural norms, and social pressure. Herbert Blumer, a student of Mead's, believed that by considering only psychological and socio-structural explanations for human behavior, "the meanings of things . . . are either bypassed or swallowed up in the (psychological and socio-structural) factors used to account for behavior" (Blumer, 1969, p.3).

Meanings derived from social interaction. Blumer wrote that symbolic interactionism rests on three premises: (a) human beings *act* toward *objects* on the basis of the meanings that the things have for them, (b) the meanings of these things are derived from social interaction, and (c) these meanings are handled through an interpretive process (Blumer, 1969).

The process of deriving meaning from social interaction has two steps. In the first step, the actor *indicates* to herself things that have meaning – she is interacting/communicating with herself, and language (which is a type of symbol) is an important element in the process. The second step involves a process of transforming meanings "in light of the situation in which (she) is placed and the direction of (her) action. . . . It is necessary to see that meanings play their part in action through a process of self-interaction" (Blumer, 1969, p.5). In this way, people interpret social situations to derive meanings that affect their behavior.

"The nature of an object . . . consists of the meaning that it has for whom it is an object. . . . The meaning of a thing for a person grows out of the ways in which other persons act toward the person with regard to the thing" (Blumer, 1969, p. 4). This is different from the classical rationalist position that meaning exists in the intrinsic makeup of the object itself or from psychological elements in the person for whom the thing has meaning. "Failure to see their

objects as they see them . . . is the gravest kind of error that the social scientist can commit” (Blumer, 1969, p. 5).

Objects relevant to this research include the concepts menopause, femininity, and aging, as well as the concept (and medical technology) hormone therapy (HT). The meanings of these objects are seen to have “grown out of” various ways individual women have interacted with others in regard to them. “Schemes of interpretation” of the meanings of these objects are maintained or altered through an ongoing process of confirmation or redefinition resulting from social interaction, including interaction with providers. Data analysis in this project largely focused on the meanings of these objects to participants and how these meanings affected the decision to continue HT.

Redefinition of objects and contested meanings. Blumer noted that the redefinition of objects takes place in situations where there is conflict, and contesting the definitions and meanings of objects contributes to social change. An example of this process is the redefinition of menopause that took place in the early 20th century with the development of pharmaceutical estrogen (notably Premarin® HT). Marketers of Premarin® HT asserted that menopause itself, not particular symptoms, was a pathology and that “hormone replacement therapy” was appropriate and safe for all women. The redefinition of menopause that accompanied the development and marketing of Premarin® HT is at the center of an ongoing debate in which a medicalized view of menopause is in conflict with a belief that menopause is a normal developmental stage of life.

In that a central feature of symbolic interactionism is the “inseparability of the individual and the context within which the individual exists,” (Handberg, Thorne, Midtgaard, Nielsen, & Lomborg, 2015, p. 1023) the symbolic interactionism framework recognizes broad societal

influence on meaning making. However, because the unit of analysis is the individual, and the “basic social process” is the focus of analysis, factors impacting meaning making outside of the basic social process paradigm may be overlooked. Examples of factors that might be overlooked in an examination of HT decision making are historical events, health policy, economics, and structural power dynamics. In addition, symbolic interactionism generally does not call attention to influences that are non-human, such as science and technology.

Situational Analysis Theory

Recognizing limitations inherent in the symbolic interactionism theoretical framework, Strauss, Strauss & Corbin, and Clarke worked to expand on it (Clarke, 2005; Strauss, 1987; Strauss & Corbin, 1990). Anselm Strauss first used the geographic, or ecological, imagery of Chicago School sociology to illustrate a “social worlds and arenas” analytic approach, and others, including his student at the University of California San Francisco (UCSF), Adele Clarke, built on this approach.

Social worlds/arenas theory is a conflict theory (i.e., it deals with power inequalities that produce conflict), and as such it is a logical precursor to situational analysis. Conflict theories are useful when situated knowledges with competing discourses are the focus of inquiry. Social worlds/arenas maps aid in conceptualizing conflict (“over differences at least of perspective”) among competing discourses (Clarke, 2005, p. 48). Creating and using these maps in analysis is discussed in Chapter 4, Methodology and Methods.

Action is not enough—consider the situation. In developing situational analysis theory, Clarke’s work built on Strauss’s social worlds/arenas framework and Foucault’s historicized view of social interaction, an approach that emphasizes “the gaze” of power and the

significance of discourse. Clarke noted that other practitioners of grounded theory had come to assume that knowledge is situated and socially constructed, and multiple interpretations were being routinely considered in grounded theory analyses. However, she took this assumption further, and her research demonstrated the advantages of the unique approach she developed. Clarke asserted that situational analysis is a necessary adjunct to symbolic interactionism and grounded theory methodology because, as a theory/methods package, complexity and variation in qualitative analysis are better addressed using a postmodern epistemic perspective.

Clarke wrote that to really see how meaning is produced and redefined, it is necessary to use a wide lens to incorporate everything in the situation. “Here, the situation of inquiry itself broadly conceived is the key unit of analysis” (Clarke, 2005, p. xxxv). She asserted that thinking of the situation as “context” is faulty. “Conditional elements of the situation . . . (are) . . . not merely surrounding it or framing it or contributing to it. They *are* it” (Clarke, 2005, p. 71). This is one of Clarke’s central points, and she acknowledged that Foucault (Foucault, 1975) provided inspiration for this insight.

Non-human actants and boundary objects. Situational analysis theory addresses meaning making among groups of actors. It stresses the importance of non-human actants and the significance of boundary objects (objects that mark sites of controversy). Clarke wrote that humans and non-humans are co-constitutive—they “make each other up” (Clarke, 2005, p. xxxv). Her work, and that of her students, demonstrates the value of the situational analysis conceptual framework and analytic strategy for exploring the meanings of medical technologies.

Non-human actants and medical technologies relevant to my research include HT in its various forms, “anti-aging” cosmetic treatments, hormonal regimens for treatment of gynecologic conditions, and drugs used for disease prevention. Other non-human actants

relevant to this project are pharmaceutical corporate earnings, FDA rulings, HT prescribing guidelines, and discovery documents from law suits against HT manufacturers.

Competing discourses. Clarke credited the writings of Foucault as inspiration for her focus on negotiated discourses and power. In developing the situational analysis perspective, she put emphasis on coexisting and competing situated knowledges and their corresponding discourses, stressing that they must always be included in analysis.

A number of situated knowledges with corresponding discourses compete in the arena of women's health care. The conflict between a *medicalization of menopause* discourse promulgated by the hormone manufacturing industry and a *menopause is a natural phase of human development* discourse represented by the feminist women's health movement is central to my research. Other contested discourses related to this project are: (a) "bioidentical hormone therapy" is safer than pharmaceutical hormone preparations, and (b) individualized prescription of hormone therapy should be based on "quality-of-life" assessment, regardless of prescribing guidelines. These and numerous other discourses characterize a debate about the boundary object HT.

A somewhat resolved debate about the meaning and use of the terms "hormone replacement therapy" and "HRT" illustrates conflict between the discourses mentioned in the previous paragraph. Among HT users, a discourse favoring inclusion of the word "replacement" in the term has prevailed since the 1960s. Publication of the Women's Health Initiative (WHI) results in 2002 changed many users' perceptions of "HRT" and threatened to unseat "HRT" as the preferred term for menopausal and post-menopausal hormone therapy. Feminist activists generated a discourse opposing the medicalization of menopause, and their discourse gained power as women learned of an association between cancer and estrogen, and as women rejected

the idea that replacement of estrogen was even a valid concept. A symbolic outcome of the conflict between the discourses is current use (by most medical professionals) of the term “hormone therapy (HT)” rather than “hormone *replacement* therapy.” This debate demonstrates how important language is as a symbol of meaning and how symbolic language can characterize a discourse.

Philosophical Assumptions

I hold a feminist philosophical perspective. I believe that the medicalization of menopause is a discourse harmful to women, and that this discourse was created by the hormone manufacturing industry. The purpose of this section is to expand on these beliefs.

Feminist epistemological view. Feminism is a philosophical perspective that examines relationships between gender and power in order to realize social justice for women (Rogers, 2005). A principle incorporated in all feminist philosophies is an appreciation of women’s lives, experiences, ideas, and needs (Routledge, 2007). A feminist perspective avoids presenting women as people who have problems that are caused by their sex or gender; instead, it places women’s issues within a social structure that devalues them (MacKinnon, 2009).

There are a number of feminist philosophies. However, within all of them “there is the belief that androcentric bias pervades all existing theories of knowledge rendering them theoretically and methodologically flawed” (Routledge, 2007, p. 284). The aims and products of science reflect androcentrism, and all knowledge produced by science is situated in a given androcentric perspective (Harding, 2006).

Examples of the tendency to exclude the viewpoints of women are numerous within the health care arena. They include: (a) application of medical protocols to both genders when they

have only been examined for safety and efficacy in men, (b) promotion of products such as oral contraceptives and HT without sufficient data to prove their safety and efficacy, (c) historical resistance to train women in research sciences and to fairly reward those who enter the field, and (d) the overall failure of powerful entities within health care and research science to treat women in a moral and ethical manner (Harding, 2006).

The medicalization of menopause and HT promotion—concern among feminists.

Feminine Forever, the book by Robert Wilson that was discussed in Chapter 1, represents an androcentric discourse that has long dominated a debate about the meaning of menopause (Wilson, 1966). Wilson asserted that menopause is a hormone deficiency disease, and that women can stay youthful looking, sexually attractive, and available for sex indefinitely, as long as they remain on “hormone replacement therapy.” In framing menopause as a pathology and describing women who fail to replace hormones as sexless and unattractive, the discourse represented in this best-seller discouraged and disempowered women.

Like Wilson’s book, much of the promotional material for HT from the 1950’s through the 1970’s emphasized HT-related benefits for men, particularly husbands and physicians. These supposed benefits included improved mood, greater physical attractiveness, and a higher libido (Watkins, 2007). As a body of literature, HT promotion clearly demonstrated an androcentric perspective.

As a social justice movement, feminism began, in part, as a reaction to the notion that aging lowers the value of women in society as leaders, as workers, and as sexual partners (MacKinnon, 2009). The feminist movement gained strength in the 1960’s and 1970’s, the same period when *Feminine Forever* was a best seller. A feminist discourse related to women’s health in general and menopause and HT in particular is exemplified by the publication of *Our Bodies*

Ourselves: The Boston Women's Health Guide (Boston Women's Health Book Collective, 1973).

Murtagh and Hepworth suggested that feminist discourses dealing with menopause and HT provoked a reframing of HT decision making by hormone manufacturers and prescribers (Murtagh, 2005). These authors argued that referring to HT as preventive medicine represented an effort to co-opt feminist ideals of empowerment and individual choice. They noted that “as a concept upon which to base decision making, individual choice fails to account for differences of power in society. . . . To be sick of a preventable disease is morally reprehensible, if menopause is a disease and its consequences are preventable” (p. 285). They concluded that understanding power relations is key to addressing the broader issue of choice.

Nelly Oudshoorn, a feminist researcher in science and technology, studied the question of why there is much more attention given to female sex hormones than male sex hormones by the pharmaceutical industry and medicine (Oudshoorn, 2001). She hypothesized that because there was already a network established to provide medical care to women, this network was easily utilized to market hormone products. Oudshoorn wrote that “the gynecological clinic functioned as a powerful institutional context that provided an available and established clientele with a broad range of diseases that could be treated with hormones” (Oudshoorn, 2001, p. 205). Her Foucauldian description of the “institutionalism” of the “hormonally constructed” female body includes a discussion of women as both research subjects and consumers of the products of science.

It is glib, but perhaps true, to say that a male-dominated corporate structure in a male-dominated society influenced a historically male-dominated medical profession to provide misinformation to women who were wondering whether to use HT. Moreover, the enduring

medicalization of menopause discourse that promises users they can control the ravages of age and prevent disease makes the decision to discontinue HT very difficult.

Concluding Thoughts on Theoretical Framework and Philosophical Assumptions

A study design based on the closely-related theories of symbolic interactionism and situational analysis proved useful for conducting this inductive exploration of the phenomenon of HT use outside of prescribing guidelines. Both theories address the creation of meaning through social interaction, and the writings of Blumer and Clarke, in particular, helped guide data analysis (Blumer, 1969; Clarke, 2005).

A situational analysis focus on non-human actants and boundary objects was necessary to fully examine the promotion and use of a medical technology and the conflicting discourses characterizing the phenomenon. Without taking the broader social situation into account, the impact of male-dominated corporate interests might have been left out of analysis. The promotion of HT as safe and effective for preventing disease and delaying aging is not only duplicitous but also misogynistic, as it contributes to excess disease and psychological drug dependence in older women. The phenomenon studied and the results of analysis are directly related to social justice for women.

Chapter 4

Methodology and Methods

This chapter begins with an explanation of why a grounded theory methodology and methods were selected. The remainder of the chapter describes the nature and size of the sample, data collection methods, data analysis, and steps to assure rigor.

Why Use a Grounded Theory Research Design?

Answering the research questions and understanding the meanings of menopause, aging, and hormone therapy (HT) for long-term users were primary objectives of this dissertation research. To accomplish these objectives, an inductive and interpretive research methodology was deemed most appropriate. The project employed a grounded theory methodology and methods partly because the theories undergirding grounded theory, symbolic interactionism and situational analysis, help explain how the meanings of objects are historically, socially, and culturally bound. Symbolic interactionism assumes that the meanings of objects (this term includes concepts such as menopause, aging, and HT) are derived from interactions within and between individuals. Situational analysis assumes that objects or social phenomena (such as the practice of using or prescribing HT beyond a lower-risk period) are also derived from interactions among social groups, objects, and competing discourses. It accommodates a larger variety of actants than does symbolic interactionism.

A grounded theory methodology allows a researcher to inductively discover possible explanations for previously unexplained phenomena by developing substantive theory grounded in data. Strauss and Corbin used the terms “explanatory power” and “predictive ability” to indicate the conditions that engender certain phenomena (Strauss & Corbin, 1998). They wrote

“the real merit of a substantive theory lies in its ability to speak specifically for the populations from which it was derived to apply back to them” (Strauss & Corbin, 1998, p. 267). Additional aspects of Strauss and Corbin’s approach include an emphasis on “trustworthiness” rather than the positivist concept of “truth” for verification. They acknowledged that the voice of the researcher affects the research process, and this acknowledgement suggests movement toward a constructivist epistemology.

The first researcher to call her method constructivist grounded theory was Kathy Charmaz, who was trained in sociology at the University of California San Francisco (UCSF) under Strauss and Corbin. Her writings on conducting interviews emphasize a symbolic interactionism approach in that she focuses on meanings and social interaction. According to Charmaz, interview stories are reconstructions of a prior reality (Charmaz, 2014).

Charmaz emphasized that reflexivity is a key element in conducting grounded theory research. Reflexivity refers to the conscious process in which a researcher examines how her social background and prior assumptions influence the research process and affect the results of analysis. Charmaz encouraged examination of possible power imbalances in relationships between researchers and participants, as these can affect social interaction during an interview and influence the composition and flow of a narrative.

Human Subject Assurance

This research was approved by the UCSF Institutional Review Board (IRB). The IRB study number is 13-11474. Interviews were begun in 2013, and the final interview was conducted in December, 2017.

Nature and Size of Sample

Typically, in a grounded theory study, 20-30 participants are interviewed in an effort to achieve theoretical saturation, i.e., data are collected until no new themes are revealed that aid in answering the research question(s). Although it is usually considered unreasonable to generalize based on theory derived from studies with samples from specific populations having only 20-30 participants, the themes observed and theory developed using grounded theory methods can advance science by providing hypotheses to test or by suggesting new questions to ask. This was an aim of this grounded theory dissertation research.

Inclusion criteria for participation included age 60 or older, born female, English speaking, and currently using oral or transdermal estrogen or estrogen/progestin therapy. There was no upper age limit for inclusion, as women of advanced age are often prescribed HT, and there was no added risk of participating in the study related to advanced age.

Recruitment was conducted primarily in an urban area on the West Coast of the US. Four of the 30 participants were recruited in a small city in the Northern Rocky Mountain region of the US. Volunteers responded to posters and flyers they encountered in public places and to ads in neighborhood newsletters, on Craigslist® classified advertising website, and on NextDoor® private social network. Most participants responded to online ads and contacted me via email to volunteer. Communication regarding scheduling interviews was done via email.

Participants included a practicing internist, a nurse practitioner who specialized in treatment of menopause, two retired nurses, and two other retired medical professionals. Demographic characteristics of the 30 participants are shown in Table 1 in Chapter 5.

Because the coastal region where most of the participants were recruited is racially and ethnically diverse, it was anticipated that the sample would reflect this diversity to the extent HT

is used by diverse racial or ethnic groups. It was apparent early on that the sample lacked racial and ethnic diversity, and extra effort was made to reach out to African American, Latina, and Asian women. This “theoretical sampling” was attempted using personal connections (“snowball sampling”), placing ads in appropriate neighborhoods, and using images of women of diverse races in photos. Despite these efforts, the sample consisted almost entirely of White women.

Data Collection Methods

A structured process of concurrent data collection and analysis was used. Collection of data involved interviews lasting approximately one hour. Interview settings suggested to participants included a private room in a university library, a private office in an academic building, or any private location selected by a participant. About half of the interviews were conducted in my home office, and the remainder took place in participants’ homes or in community meeting rooms they arranged to use. Feedback I received about selecting a location indicated that women who opted to come to my home were avoiding readying their homes for a visitor. “I would have had to vacuum” was a typical comment. The residence was two blocks from a mass transit station, however, most women drove their cars and parked on the street in front of the house.

Before an interview, participants completed a demographic questionnaire and signed a consent form. The questionnaire was designed to allow for description of the sample in manuscripts: year of birth; race/ethnicity; highest level of education; age at last menstrual period; age HT was started; type of HT used presently; and relationship status—partnered/single/widowed/divorced. The consent document also asked them to indicate whether

they would be willing to return for a second interview by checking a box. Three women were interviewed a second time, mainly to learn whether their thoughts about using HT had changed. One of these interviews was conducted on the phone.

The process of exchanging pleasantries, obtaining informed consent, and collecting demographic data took about 10 minutes. Participants were given a \$25 gift card for each interview as a token of appreciation for sharing their time and thoughts.

Interviews were structured to elicit narratives that revealed thoughts, feelings, and knowledge about menopause, aging, HT, the risks and benefits of therapy, and the roles others played in deciding whether to continue HT. Each participant was asked to think aloud about what she may have been feeling or thinking as she approached menopause. I sometimes asked, “What was the experience of menopause like for you?”

This approach usually resulted in a lengthy narrative that addressed the benefits of HT, and I did not need to ask “What benefits have you noticed from taking estrogen?” If a woman did not talk about risk (and most didn’t), I asked whether she had any concerns about risk. Other questions addressed the role a health care provider may have played in the decision-making process, e.g., “Who or what helped shape your views about HT?” Another question designed to elicit information about education sources and social influences was “Where do you go for information about HT?” Prompts and probes (“Can you say more about that?” “What was that like?” “How did that feel?”) were used to encourage a more detailed response or a return to a particular comment or topic. Although an interview guide had been prepared, the questions in the guide were not useful or needed, because the answers arose organically in the context of narratives.

Data Analysis Methods

Interviews were recorded on a smart phone. The first five recordings were transcribed verbatim by me; the remaining recordings were transcribed verbatim by a professional service. These transcripts comprise the data that were analyzed. Methods used for analysis are described below.

Sensitizing concepts. Grounded theory methodology acknowledges the fact that researchers begin an exploration with “sensitizing concepts,” ideas that sensitize a researcher to the kinds of questions that could be used to start an inquiry. “Guiding interests, sensitizing concepts, and disciplinary perspectives often provide us with such points of departure for developing, rather than limiting, our ideas” (Charmaz, 2006, p. 17) Schwartz-Shea & Yanow referred to a researcher’s initial expectations as educated provisional inferences to be explored (rather than hypotheses to be tested) (Schwartz-Shea & Yanow, 2012). An example of a sensitizing concept, a disciplinary perspective that is guiding this project, is the idea that the menopause experience is salient to the hormone therapy decision process.

Memo writing. Memos and field notes were kept throughout data collection and analysis to record observations, make comparisons, see connections, and formulate questions. Writing memos was also a structured way to practice reflexivity. Field notes were useful for helping me recall the atmosphere of an interview as I listened to recordings and read transcripts.

Situational analysis mapping. Strauss had proposed an analytic scheme he termed a “conditional matrix” (Strauss, 1987). Adele Clarke, a UCSF sociologist who was a student of Strauss, later adapted this matrix as a way to account for contextual conditions in grounded theory analyses. While symbolic interactionism theory focuses on interactions within and between individuals to explain action in terms of basic social processes, situational analysis uses

a wider lens to incorporate everything in the situation. “The situation of inquiry itself broadly conceived is the key unit of analysis” (Clarke, 2005, p. xxxv).

Clarke’s writings on situational analysis methods include instructions for mapping procedures that are useful extensions of grounded theory coding and analysis. In situational analysis, maps are used to depict complex interactions and positional relationships that help describe multiple “truths.” Any number of connections, interactions, or negotiations, can be mapped on a relational map. Stimulating thinking is one of the objectives of mapping a situation, and Clarke advised researchers to make maps until there is “saturation”—until no new ideas result from the process (if that is possible).

During this research, the process of making “messy” maps helped as “mind dumps.” In these unstructured exercises, words reflecting difference and conflict related to the medical technology HT provided information about assumptions made early in the project. Relational maps, such as the one included in Chapter 6, illustrate elements of positionality among various “worlds” in the arena of women’s health care.

Comprehensive analyses of social phenomena—such as the practice of continuing or prescribing HT beyond a lower-risk period—must ultimately include every significant feature of the complex world in which a phenomenon is observed. Included among these significant features are the various discourses that serve to define “knowledges” and guide action. Addressing relevant discourses in analysis is necessary for understanding phenomena that are characterized by conflict. The prescription of HT outside of treatment guidelines is an example of social and medical debate characterized by ongoing conflict.

Coding. Interviews were transcribed verbatim and initially coded one line at a time. Line-by-line open initial coding progressed to intermediate, axial, thematic, and theoretical coding. NVivo® coding software was used to organize data for analysis (NVivo, 2018). Themes were developed as interview data were processed, and these themes guided sampling and interview strategies as the study moved forward. A description of coding is presented below.

Initial and intermediate coding and categorization of data. In the writings of Glaser, Strauss, Corbin, Charmaz, and Clarke, the words “concepts,” “codes,” and “categories” have the same or similar meanings. The qualifier “initial” is a term used by Charmaz, while “open” is used in the writings of Glaser, Strauss, and Corbin to refer to the same level of coding. Low level concepts are given initial (or open) codes that act as a form of shorthand to label “conceptual reoccurrences and similarities in the patterns of participants’ experience.” One function of initial coding is the “fracturing” or opening up of data by identifying conceptual possibilities (Glaser & Strauss, 1967).

Groups of initial codes form a category, a higher-level concept. Codes are often written in the form of gerunds, a practice that suggests process or action (Charmaz, 2006). In vivo codes are taken directly from the data, and they may be modified to gerunds as well. “Avoiding hormonal out-of-wackness” is an example of an in vivo code in gerund form used in this project.

In this study, only the first five transcripts were coded line by line. Once a list of initial codes was generated, relevant sections of text (usually several lines) were labeled using these low-level codes. New low-level codes were created when they surfaced in the data.

Intermediate coding refers to the integration of categories and their inherent properties. By grouping codes, categories are formed, and the researcher may start to identify patterns. It is

at this stage that attention is paid to properties of categories in an attempt to explain them in depth. Axial coding is a form of intermediate coding in which connections are made between categories. Relational statements can be made at this level of analysis that can be recorded as hypotheses or propositions (Glaser & Strauss, 1967).

Early in analysis, I tried adding valence, or properties of categories (e.g., positive vs. negative, strong vs. weak), to coding but found it cumbersome. However, this technique did serve to highlight intra-interview inconsistencies. That is, many transcripts contained contradictory statements that were not perceived as such (if true) by the person being interviewed, and they may have reflected a tension between competing thoughts. Inconsistencies may also reflect a dynamic in the interview process in which a participant anticipates a particular reaction on the part of the interviewer during the social interaction. Inconsistencies are apparent in some quotes used to illustrate themes in Chapter 5, Results.

Selecting core categories. Strauss and Corbin defined a core category as “the central phenomenon around which all the other categories are integrated” (Strauss & Corbin, 1990, p. 116). Charmaz and Clarke observed that more recently there is less emphasis in grounded theory on selecting a core category (Charmaz, 2006; Clarke, 2005). They advocated a broader approach that describes how categories and sub-categories can be integrated to form grounded theory. At this stage of analysis, theoretical sampling focuses on collecting data that will theoretically saturate the core category and sub-categories. Core categories in this study were “(using HT for) control” and “fearing quitting.”

Theoretical sampling, theoretical sensitivity, theoretical saturation, and developing theory. As defined by Glaser and Strauss, theoretical sampling is the process of data collection for the purpose of generating theory whereby the researcher decides what data to collect next in

order to develop theory as it “emerges” (Glaser & Strauss, 1967, p. 45). Additionally, it is through “theory-directed” sampling that it is possible to examine concepts from alternate perspectives and to pose questions that come up during constant comparative analysis (Strauss, 1987). Charmaz wrote that theoretical sampling becomes important once categories have been developed, because it allows for confirmation, clarification, and expansion of categories (Charmaz, 2006). An example of theoretical sampling in this project was the purposive selection of women over age 70 in the final stages of recruitment to determine whether having a sample with an older mean age added anything new to analysis. Another example was an attempt to recruit non-White participants for the same reason.

Glaser and Strauss identified theoretical sensitivity as an important attribute of a researcher using grounded theory (Glaser & Strauss, 1967). This refers to having insight into what is meaningful and significant in the data. Glaser and Strauss introduced the term “theoretical saturation” to describe a point in analysis when additional data contribute no new codes pertinent to a category (Glaser & Strauss, 1967). In this project, data contributed no new codes when approximately half of the interviews had been analyzed.

Charmaz wrote that a strength of grounded theory methods is that “budding conceptualizations can lead researchers in the most useful, emergent, and often unanticipated theoretical direction to understand their data” (Charmaz, 2006, p. 201). She was writing about using abductive reasoning when inductive logic fails to account for a surprising finding. The process involves re-examining data through constant comparative analysis, possibly gathering additional data, and considering imaginative hypotheses while maintaining a critical or skeptical point of view. As an example, the finding (surprising to me) that long-term users had little

knowledge or concern about HT risk prompted an investigation into the psychology of decision making and an increased focus on risk perception in subsequent interviews.

As noted earlier in this chapter, Schwartz-Shea and Yanow suggested that theories produced in grounded theory analysis are educated inferences and not hypotheses, partly because they are contextualized historically and culturally, and generalizing findings is not a primary objective (Schwartz-Shea & Yanow, 2012). My perspective is that theories derived from grounded theory research can later be tested as hypotheses, and this hypothesis testing can determine whether the theories are in any way generalizable.

Assuring rigor. The primary aim in qualitative research is to give the voices of participants priority over the preconceived assumptions of researchers, and a study is considered trustworthy if findings reflect their perspectives. A rigorous research process yields trustworthy findings (Sandelowski, 1993). Characteristics that reflect a rigorous research process are transparency and validity (Whittemore, Chase, & Mandle, 2001). Transparency means that the research report provides a thorough description of the research process, an audit trail. A valid, or credible, study is one in which the data are represented accurately. Means for enhancing credibility may include reflexivity, prolonged engagement, and peer review (Cresswell, 2013). Rigor in this project was assured by providing an audit trail, writing memos and field notes, representing data accurately, and having work products reviewed by advisors and peers.

Another way to enhance validity would have been to ask participants to comment on the research report, a practice known as member checking (Whittemore et al., 2001). Sandelowski argued that participants' perceptions are subject to change, making member checking unreliable (Sandelowski, 1993). Birks and Mills agreed, suggesting that "the process of concurrent data generation or collection and analysis subsumes the strategy of member checking in grounded

theory analysis” (Birks, 2011, p. 99). I agree that member checking may be unreliable, and I did not incorporate it in my efforts to ensure rigor. Efforts to ensure rigor are reflected in the next chapter, Results.

Chapter 5

Results

Thirty long-term hormone therapy (HT) users 60 years of age and over were interviewed in this qualitative study using the constructivist grounded theory methodology and methods described in Chapter 4. Analysis was aimed at inductively discovering explanations for the previously insufficiently explored phenomenon of post-menopausal women using HT beyond the recommended menopause transition phase. Demographic characteristics of the participants are summarized in Table 1.

Table 1.
Participant Characteristics

<u>Characteristic</u>	<u>Number</u>
Number of participants	30
Age	
Mean	68
Range	61-80
Education	
Some college, no degree	2
Bachelors	11
Masters	11
PhD/MD/DDS	6
Race	
White, non-Hispanic	29
Asian	1
Relationship status	
Single	2
Partnered	21
Divorced	6
Widowed	1

Preface to Presentation of Results

Two research questions defined the project. The first question was “What factors influence older women to use HT beyond the menopause transition?” This question addresses (a) the role of health care providers, (b) the content and source of information on HT benefits and risks to which women and their providers had been exposed, and (c) other social and psychological factors that may have influenced a woman’s decision to continue HT. The second question was “How do older women weigh the risks and benefits of HT in deciding whether to use it beyond the menopause transition?” This question addresses women’s perceptions of the benefits and risks of HT, perceptions shaped by factors such as those addressed in the first question. The second question also addresses the process of decision making.

The themes and theory that comprise these results are grounded in a collection of narratives produced during research interviews, which are social interactions. These results are an interpretation of the participants’ social worlds as revealed in their narratives. Charmaz wrote that interview stories are reconstructions of a reality (Charmaz, 2006). Even though they were derived from reconstructions of reality, the themes and theory generated during the analysis are presented as valid because I stayed close to these data throughout the analytic process.

The quotes selected to serve as examples of major themes are representative of the sentiments expressed by a number of participants. Participants will be able to identify their own voices. Most of them will recognize, in the voices of others, perspectives similar to their own. In quotations my voice is shown in italics. Because this sample was quite homogenous in regard to both demographics and perspectives, I chose not to provide ages or other personal information about the speakers, with a few exceptions.

In part because I am similar to the participants in age, education, and social class, the emotional tone of interviews was cordial. Many women explained that their positive experiences with HT motivated them to participate. Most spoke readily and fluently and did so with a display of humor. During many interviews, I rarely spoke other than to say “uh huh,” because the research questions were addressed as the participants told their stories. Early on, before I learned to trust the recording app on my phone, I worried considerably about not capturing a participant’s words. The data were rich with relevance, and I imagined I might “shoot myself” if an interview was not recorded.

Quantifying terms such as “some,” “a number,” “many,” and “most” are used throughout this chapter. The dictionary definition of “some” is “being one, a part, or an unspecified number of something (Merriam-Webster, 2018). In this document, “some” or “a number” indicates three or more. The definition of “many” is “consisting of or amounting to a large but indefinite number.” Used here, it indicates 10 participants or a greater number. The definition of “most” is “the majority.” In this document, “most” indicates more than 15, as there were 30 participants.

Perception of Benefit

Women interviewed in this study were primarily focused on the benefits of HT, and most of them used the terms “hormone replacement therapy” and “HRT” rather than the currently-preferred term “hormone therapy.” As discussed earlier in this report, the two different terms for menopausal hormone therapy represent competing discourses. The word “replacement” implies that HT restores missing hormones that are necessary for health and normal physical and cognitive function. Use of this word suggests that postmenopausal women who do not use “HRT” experience more disease and are less feminine because they lack critical hormones. Use

of the terms “hormone replacement therapy” and “HRT” aligns with a medicalized view of menopause. Medicalization of menopause is the discourse repeatedly referenced in these interviews—all of the participants used these terms. The bulk of interview data are stories about perceived benefits, and coding of transcripts reflects this. At the stage of intermediate, or focused, coding, benefits are grouped by category, generally using gerunds.

Controlling symptoms and preventing disease. Codes included in this category included *reducing* the number or severity of hot flashes, *maintaining* a normal weight, athletic ability, or sexual function, and *improving* mood, mental clarity, or sleep. Another group of intermediate codes that referenced perception of benefits included *preventing* diseases such as colon cancer, dementia, heart disease, and osteoporosis. Quotes illustrating these categories of codes appear below in the section on the themes *control* and *fear of quitting*.

Maintaining a youthful appearance. Although some women denied that HT could preserve a youthful appearance, many credited HT for their youthful appearance in regard to skin tone, quantity or color of hair, body shape, weight, or athleticism. On the other hand, some women said they started HT expecting it to help them maintain a youthful appearance, although they now had doubts about whether it had. Some speculated that they might now look older had they not used HT. The woman quoted below and many others mentioned that they looked younger than their peers.

So I guess the reasons, if you ask me the reasons why I want to stay on HRT, I feel like it's continuing a general overall vibrancy, more youthful vibrancy than aging, and skin elasticity is one of those things. I think of myself as having more energy than my friends who are not on HRT, that I have more energy. My skin looks better than theirs.

It was not uncommon for a participant to comment that personal appearance was not a primary reason to use of HT. The woman quoted here considered improved skin a side benefit.

I think it certainly has helped the condition of my skin and therefore my appearance, and that's a nice side benefit. But interestingly, that wasn't really one of the big factors that caused me to decide to do HRT. It's just been sort of a, "Oh wow. That's nice." I mean and since I had my eyes done when I was 50 and had some liposuction under my chin at that age, I can't say why I didn't think more about that, but I didn't.

Feeling happy, healthy, and productive on hormones. Many women said they felt happy and healthy on HT. The woman quoted below said that estrogen made her feel good generally.

I was wondering if you could try to come up with words to describe how estrogen makes you feel good.

I think it gives me a sense that I'm well, that that stuff is inside of me working to ease my joints, working to help my really badly sun-damaged skin. It might be lubricating my eyes. I have a feeling that estrogen is a drug that we were supposed to have if we were a woman and that yanking those parts out did mean something to my health other than periods . . . I feel like when I put it in, I'm not harming myself . . . my general sense is that it's helping me age easier . . . I just have a feeling that it's lubricating me kind of from the inside out, that it kind of does that for me.

Other women spoke about mood regulation, mental clarity, and sleep. For a number of women, concern about work performance motivated them to start HT.

. . . I retired in 2004 . . . I got a wonderful new Ob-Gyn who said that all of the professional women in her practice took on hormone replacement because otherwise their brains wouldn't work. I thought, "I understand, why I took it. Yes." I think there was one time when I stopped taking it, my brain turned to mush. It's just totally fuzzy, and that's not okay for me. Even now that I'm retired, that's not okay for me. I do have some occasional editing, and I don't have confidence I could do it without hormone replacement.

Another participant started HT and quickly felt she was "back" to her premenopausal state. Having a better memory had multiple positive effects.

. . . And it was intense and busy work. And a lot of people relied on me. And I began to realize that I wasn't remembering as well as I had been able to remember. . . So I went to my doctor, my internist, and told her what was going on. She said she was pretty sure that I was in a perimenopause or premenopausal period and that—I can't remember if she tested my blood for my hormone levels at that point, but she said—now I

remember this conversation so clearly, because it was hilarious to me. She said she was going to give me a little pink pill [laughter], and that she was pretty sure that within a couple of days I would no longer have any trouble with my memory. And I thought, "Yeah, right." Okay. But I filled the prescription and began taking it. And within two days my memory was almost photographic. I mean, it was incredible, the dramatic improvement. And I had no further problem. And consequently, my mood improved dramatically . . . I was just back. And it was fabulous. I also, of course, started sleeping really well. Everything got better.

Lack of Concern about Risk

Concerns about risk rarely came up without prompting. Most participants had little knowledge of the risks of long-term HT. The idea that risk increases over time—that long-term users are at greater risk than are women who use HT three to five years—was almost absent from interview data, suggesting that such a distinction was not considered by the majority of participants.

When asked about risk, many participants spoke of a negative (or positive, interestingly) family history of breast cancer. Many credited HT with protection against diseases that are, in fact, more prevalent among long-time HT users. Many stated that a provider had reassured them that their risk from using HT was minimal. Some women reported that their providers had used the phrase "It's a quality of life (decision or issue)," and a specific code was created for this. Others stated that they did not pay attention to risk information because they had heard conflicting information, and a code was created for this. Some spoke of deliberately choosing not to consider risk information in deciding whether to use HT. The focused code that includes this group of codes is "perceiving and disregarding risk."

The following two quotes refer to being reassured about HT risk by a provider. These participants also referenced their family histories as providing reassurance.

. . . my original doctor . . . explained the difference between the study that was done, the big quote "definitive" study, and said, "Hey, this was very different. These people

didn't start taking hormones until 10 years later . . . they were on Provera and Premarin. And you've not been on either of those two, and you're on the lowest dose possible, and you seem to have no ill effects. And you have no family history and blah, blah, blah, blah, blah." So I've not felt any worry about any of that. My older sister also continued to take hormones for many, many, many years. Now she's got dementia, but she's also been diabetic for 30 years, and didn't take care of herself . . . So I never worried about that.

The next women's story touched on several common coding categories: provider reassurance, quality of life, and negative family history of breast cancer. Note that she was 63 at the time of this interview. When she was interviewed again four years later, she was still using HT. The quote demonstrates that while some women may think about risk, they also have a fear of quitting.

I always said I was going to quit them when I was 62. I wasn't going to stay on them very long cause I was following the research, saying well, people who are on it less than 5 years or so I was thinking okay . . . so I was thinking at 62 I'll get off of them. It's really hard to get off of them.

Have you tried?

No.

But you don't feel comfortable doing that?

Well even now, I mean like . . . I . . . we've adjusted the dose, and . . . I trust my doc. She makes me come in every year for a, she will not renew my prescription until I come in, I have to have all my blood work done . . . She always makes me do a breast exam and a pelvic exam before she refills the prescription, and . . . I trust her, you know, counsel. She said it's really up to you . . . she said "it's a question of quality of life . . . you're not having any of the side effects." There's no history of breast cancer in my family . . . So anyway, I keep thinking that I should get off of them.

And what's your thinking? Tell me more about that.

Well, just because the research does say long-term use of hormones . . . I mean the body is designed to naturally . . . The female body was designed for female hormones to decrease as you get older. That's the way nature designed us. I think one of the reasons I stay on it is because I think it does keep you younger, keeps me younger. I really think it gives me more energy, I think I have the effects . . . I believe my body has always had a lot of estrogen. I mean that's just the kind of person I am. And I think that for me not to have that estrogen would be . . . I keep thinking I'm gonna try it . . . But I don't

wanna go through the getting on and off. I just haven't wanted to go on and off. I felt like I was better staying on. And I think I've reduced the dosage down to what . . . point five. Is that a lot? I don't even know if that's a lot.

Another woman spoke about the fact that there are conflicting data on risk. She had made a choice to not “go there”—to not find out whether HT was associated with an increased risk for dementia.

I wanted to ask you if you'd ever heard or read anything about an association between dementia and hormone therapy?

You know I haven't, although I'm sort of vaguely aware that there may be something out there. My mom was diagnosed with Alzheimer's when she was--right when she turned 84, but I'm pretty sure it'd been going on for a couple of years and she knew it. But I haven't . . . you know, over time, like 20, 30 years, there have been many conflicting reports, observations about dementia and all of the things that may be impacting it. I would be surprised if there isn't some relationship. But at this point, maybe I have chosen not to read about that because I don't want to know [laughter]. Having been on hormone replacement for a long time, I prefer to think there's either no impact or only a positive one on delaying dementia. But I could be wrong. As I said, I've chosen not to go there. Denial is an interesting thing, especially for a scientist.

Core Categories and Major Themes

Two closely-related major themes resulted from coding interview data—*control* and *fear of quitting*. These themes are “two sides of the same coin” in that quitting or being forced to quit HT would presumably result in loss of control. A related theme is *managing providers to maintain control*.

Control. *Control* is a core category and the major theme in interview data. The word “control” means both (a) an action taken to avoid potential threats, and (b) the outcome of perceived control that results from taking such action. Perceived control is thought to reduce stress (Wallhagen, 1998).

Controlling the threat of symptoms. When participants spoke of benefits such as reducing hot flashes, improving mood or sleep, or maintaining sexual or cognitive function, they were talking about controlling the threat of symptoms. The action they took to exert control was using HT. Symptom relief, or the perception of symptom reduction, gave them a sense of control.

Preventing disease. Many women expressed the hope that their use of HT would prevent dementia and cardiovascular disease, and most expected it to help them avoid osteoporosis. They used HT as a form of instrumental control to minimize the threat of disease. Those who had not been diagnosed with disease perceived that HT was helping them control their health.

Preventing age-related decline. Preventing declines in stamina, agility, cognition, sexual function, or appearance concerned the majority of participants. For most of them, “estrogen deficiency” represented age-related decline, and HT was perceived to be necessary for avoiding this. Because they used HT, they felt in control. The woman quoted next attributed her walking speed to HT.

When I walk, I feel like I'm a vigorous walker. I have a friend who is younger than I am who had ovarian cancer, so she cannot be on HRT. She and I have travelled together. . . I have to slow myself down for her to keep up with me at a pace.

The next participant asserted, somewhat tongue-in-cheek, that she managed to avoid menopause altogether. Menopause was an ongoing threat, and using HT gave her a sense of perceived control over this threat.

But you know and then there's me, and I like to think I didn't have my menopause. This is how I'm totally in denial about having gone through it because that's what this whole thing does for me. It's crazy.

Although gradual functional changes over time are expected with aging, and many (if not most) older adults manage to stay active and enjoy sex, a number of participants assumed that

being physically active and enjoying sex would cease without HT. Attributing their vitality and sexual enjoyment to HT, these women maintained a sense of control over their sexual lives by staying on HT, and they feared living without it.

Fear of quitting. Another core category and recurring theme in these data is fear of quitting, which denotes fear of loss—loss of any perceived benefit or loss of a sense of control. Although, logically, fearing quitting HT is somewhat a corollary to perceiving that HT affords control, quotes about fearing quitting seemed to warrant their own codes.

Many women worried about the possibility of no longer having symptom control or a way to maintain their current mental or physical state or sexual relationship. They were also concerned about not preventing disease.

Interestingly, when asked what they expected to happen if they were forced to quit HT, some women expressed uncertainty about HT's efficacy. However, no one wished to test that hypothesis by stopping. The woman quoted below expressed doubt about HT's efficacy. Despite her uncertainty, she felt that stopping was risky.

Maybe I'd be exactly the same now if I'd never taken a thing. And that includes vitamins, all the thousands and thousands of dollars I spent on vitamins. And hormones may have been for naught. I mean, if I had not taken anything, I might be exactly the same as I am, but I have no way to know that . . . I look at other women my age. They look older. I don't know. Maybe that has nothing to do with what I take. Maybe it has everything to do. And as I say, I have no way of knowing. I go completely on faith that I seem to be okay now, so why stop anything and risk going backwards? . . . I may not feel anything different, in which case I would say, "Well I guess that was a waste of time and money." But my intuition tells me that it's useful in some way and so I would be upset if I were denied access to those things because I believe strongly enough that they work and if they take them away, I might be proved wrong or I might suddenly deteriorate. I don't know what would happen to me. I'm afraid to stop taking all that stuff at this point.

This quote is from a woman who had thought about quitting for a financial reason.

Well, I have actually, I have to say, been thinking about talking to my doctor about stopping. But that's actually for a financial reason, because my medical insurance has boosted my copay on this—way up. And it's costing me a lot of money. And I'm on a limited income. And I don't know how—there's some apprehension involved in wondering what kinds of symptoms you would revert to. I mean, if I started losing my mind again I think I'd go right back on it.

Some women feared that without HT they would no longer feel or appear youthful or feminine or have a healthy libido. The woman quoted below was fearful that if she stopped HT, she would be unable to enjoy sex due to vaginal dryness and thinning skin. (She remarked later that she and her husband used a lubricant because, even with HT, she felt dry.)

What do you think, other than having hot flashes, it might feel like or be like if you did stop? What would be different?

Well, I think there's vaginal dryness. Which is big. You know, I still have a very nice sex life, and I'm afraid that if I stopped taking them, it would affect that. And I'm not ready to give that up . . . And so, I don't want to give that up . . . I think if I, you know, didn't have a partner that was still sexually active, I would be more willing to give it up.

The next participant also assumed her sexual desire would disappear if she quit estrogen. Like others who associated their sexual health with HT, she assumed that women who did not use HT were probably unable to want sex or to enjoy it.

I've only been married for three and a half years, this time, and sexual desire is a biggie, although I don't know what it would be without it, but I don't want to take a chance because of the stories that friends have told me about "Oh, I went through menopause, and I just never wanted to have sex again" and I'm like "Oh my gosh, that's really not going to work for me."

Other woman feared cognitive changes if they stopped HT. They spoke of being worried that symptoms such as forgetfulness, mental foginess, and irritability would return.

What other things do you think would change?

You mean if I went off of them?

Um hmm.

I don't know. I mean I would be concerned about the mental fogginess because I'm already getting more forgetful. I'm already feeling less clear than I used to. And so, if I were to stop taking those and have that play out as being foggy or whatever, I wouldn't like that either . . . And irritability, mood swings, those kinds of things. Those wouldn't be any fun.

Many women talked about their fear of losing athletic ability or giving up an active lifestyle. The “quality of life” phrase used in this quote was used by many participants.

Well, you're still skiing, you're still hiking, you're still doing (crosstalk)

Yeah. So if hormones are helping me do that, that's the quality of life piece that, you know, the decision for me . . . I don't know, maybe it would still be the same if I went off of them, but I don't know that I'm willing to take that step—unless somebody can give me some research saying “this is bad.”

For all of the “true believers” in HT I spoke with, maintaining a sense of control required ongoing use of HT, and they were afraid to quit. While some women anticipated eventually stopping HT, they chose to continue it in the immediate future. Both thinking about quitting and taking action to quit were put off to some later time. HT had become a long-established habit or practice, and this routine, along with fear of quitting, reinforced use. As one woman said as she walked me to my car after her interview, “It's just been part of my life for so long.”

Managing providers to maintain control. Providers play a major role in the phenomenon of long-term HT, although HT users in this sample of women appear to be the primary drivers. Some women spoke about managing providers to continue taking HT. Managing providers is directly related to control and fear of quitting. Some participants spoke of the threat of losing access to pills or patches because their health insurer had determined that HT

should not be prescribed to women over age 60 or 65, and some suggested that a policy to deny HT based on age is unnecessarily discriminatory.

By arranging to see providers within their insurance networks who were willing to prescribe HT beyond age 60 or 65, most participants had avoided the threat of having to pay out-of-pocket for medical services or prescriptions. Some did pay for HT out-of-pocket, primarily those who used a combination of FDA-approved hormones and compounded hormones. The woman quoted here is someone who used both types of hormones, paying for compounded hormones out-of-pocket. I introduced the idea of being directive with providers. This quote also addresses risk and using HT to prevent disease.

Some people, you might or might not be among them, are very directive with their health care providers. They know what they want to do. And they're more or less going to go to providers that will do exactly what they want.

I wouldn't say that so much. I will do my research and I might have a point of view about it . . . with Dr. (A) I would not propose anything different than what she's doing. She has the knowledge, she does the research, I don't. And I trust her. With Dr.(B), less so. Because I don't know that she would necessarily agree with all the hormones that I take . . . I know she refuses to test me on any of them . . . I mean, I just spent close to \$1,000 to get tests done, and I do every year. And she wouldn't do hardly any of them, so I can't direct her to do it. If I could I would [laughter]. But I don't necessarily have an opinion in advance of what I want to do. I have a need, like when I had low energy and I consulted Dr. (C), but I never presume to tell—I was paying her a lot to tell me. And I don't really need any other doctors to do what I want now . . . or I'll change doctors until I find one that seems to agree with my point of view. But I don't recall ever directing, mainly because with Kaiser I know they're going to go by the book. They are very, as Dr. (B) says, "evidence-based." That sounds like it could be okay except all of the evidence is funded by the drug companies . . . I guess directive isn't a word I would use. I would say I'm more involved and concerned. And I don't automatically take what they say as truth. I'll generally do my own research on it and might consult a different doctor like Dr. (D) and Dr. (E). Probably they don't agree on the need for me to take various things. But at this point at least some research has caught up enough so that Dr. (B) believes that Climera has a—I wish I could remember that word, a way of preventing depression. Or a way of dealing, of preventing, dementia. It's a protective effect against dementia. So both (A) and (B) seem of that opinion, so that's great. But if they weren't, I wouldn't argue with them. I would go to a different doctor. So I guess in that sense, I would be looking for someone that I could direct.

Summary

Reflecting on my preconceptions, writing memos, and repeatedly listening to, reading, and coding transcripts resulted in the conclusion that control is the major theme in these data. Using HT enabled these women to believe they could control symptoms they associated with being post-menopausal. Most of them perceived that HT gave them a way to prevent disease and delay age-related decline. Most feared that if they quit HT, they would suffer losses, such as loss of vitality, strength, libido, and health. All of the participants stories endorsed a medicalized view of menopause.

None of the participants expressed concern about risk, although some acknowledged there may be some risk from using HT. Some who acknowledged risk spoke of disease-prevention benefits they felt counterbalanced other possible risks. Some who acknowledged that HT posed risks spoke of making a conscious choice not to think about it. Many others discounted risk information as inconsistent, unconvincing, or inapplicable to their use of HT. Very few made a distinction between the risk of short- vs. long-term use.

Although providers may not be the primary drivers of HT use in this sample of women, they were a major influence. Providers either gave reassurance about risk, or they discouraged use yet continued to prescribe it. Reassuring statements of providers that were referenced by participants reflected messaging similar to that seen in publications of The North American Menopause Society (NAMS) and in ghost-written medical journal articles. These statements included reference to better “quality of life” on HT and to the inapplicability of data derived from studies testing HT formulations that differed from the type or dose of HT they had prescribed. Many women believed that HT could prevent cardiovascular disease, dementia,

incontinence, and other diseases that are actually positively associated with HT use, and some said this information came from providers.

Theory Grounded in the Data

The woman quoted below had experienced two mastectomies and a cholecystectomy. She had persisted in finding a provider who was willing to prescribe HT despite her medical history.

So it always seemed to me that estrogen was a natural substance that your body produced, and when you're young and you're healthy you feel well. When you go through menopause and you stop producing estrogen, you don't feel as good, so to replace it seemed like a natural thing to me. It didn't seem foreign or harmful, because it was just giving back to you what you had before. So I've always embraced the idea of estrogen because it seemed like a natural part of your make up to begin with.

This quote was recorded at the end of an interview. After I switched of the recorder, she added that she would not feel feminine if she did not take estrogen.

Many participants' narratives suggested that estrogen "replacement" enabled them to retain feminine identities despite potential threats. Potential threats included age-related physical changes these women associated with estrogen "deficiency" as well as a perceived lowering of their social standing because of these physical changes. The theory that resulted from analysis is this: *Some women who choose to continue HT beyond the menopause transition do so in order to maintain a valued sense of self and a feminine identity.*

The theory resulted, in part, from abductive reasoning. The work of Kathy Charmaz, who studied people struggling to adjust to life with acquired disabilities, provided insight into the motivation of some long-term users of HT (Charmaz, 1983). Charmaz theorized that an individual dealing with losses caused by a disability strives to maintain a valued sense of self. A woman threatened by menopause and aging may use HT for the same reason.

This theory is a reasonable extension of the main theme resulting from coding, that use of HT gives users the perception of control. Because estrogen is linked to being female, and levels of endogenous estrogen drop with menopause, it is not surprising that some women believe it is necessary to take estrogen after menopause to remain feminine.

Chapter 6

Discussion

The primary objective of this research was to answer this question: “What factors influence older women to use HT beyond the menopause transition?” The question addresses historical, social, and psychological factors that may have impacted a woman’s decision to continue HT. Key findings are summarized below.

Control, the Medicalization of Menopause, and Retaining a Feminine Identity

One’s perceived effectiveness in dealing with the environment is culturally bound, and perception of control derives from interactions between individuals and their environments that have “historical as well as present meanings” (Wallhagen, 1998, p. 121). A hallmark of American culture is the belief that people are in control of their well-being, and this includes being able to slow age-related processes (Lachman, 2006).

Study findings reflect a dominant discourse in the arena of women’s health care, the medicalization of menopause, and nearly all participants believed they were receiving benefits beyond menopause symptom management and prevention of osteoporosis. Most participants believed using HT prevents disease and slows the aging process. Faced with threats to their physical, cognitive, and emotional wellbeing related to aging and the stigma of aging, continuing to use HT gave participants the perception of control. It also gave them a way to maintain a valued self-image in which femininity and youthfulness were linked to estrogen “replacement.” The perception that estrogen preserves femininity and delays aging relates directly to the theory

that emerged from analysis: *Some women who choose to continue HT beyond the menopause transition do so in order to maintain a valued sense of self and a feminine identity.*

As noted in Chapter 4, Schwartz-Shea and Yanow wrote that theories produced during grounded theory analysis are educated inferences that are contextualized historically and culturally, and generalizing findings is not a primary goal (Schwartz-Shea & Yanow, 2012). Also, noted earlier, my perspective is that theories derived from grounded theory research can be tested as hypotheses, and hypothesis testing can ultimately determine whether the theories are generalizable and useful. One might argue that the theory presented here has already been tested in that it has been a central premise in the marketing of HT, at least since *Feminine Forever* was published in 1966.

Weighing Risks and Benefits

Another objective of the research was to answer this question: “How do older women weigh the risks and benefits of HT in deciding whether to use it beyond the menopause transition?” The question was devised to address the process of decision making.

When the project began, I thought that a woman using HT made a conscious decision to continue each time she took a pill or applied a patch. I now believe that long-term users have become habituated to HT, and as they reflect on and appreciate qualities within themselves they attribute to estrogen, the HT habit is reinforced. All of the women in this study sample had made a decision to use HT long ago, using it had become an established practice, and nearly all of them intended to continue indefinitely.

These true believers did not worry about risk. The study sample, comprised entirely of long-term HT users, were “true believers” who perceived a cornucopia of benefits. They did

not talk about weighing the benefits of HT against its risks. Risk was mentioned only when participants were directly questioned, and, as a group, they demonstrated scant knowledge of risk and showed little appreciation or appetite for information about it.

Making a distinction between short- vs. long-term HT risk—ghostwriting and risk perception. Most participants made no distinction between the risks of short- vs. long-term use of HT. The absence of this conceptual distinction in the data is informative, because duration of HT use directly affects level of risk (Martin & Barbieri, 2018a).

The fact that risk is directly related to age and duration of use, and that long-term users may fail to appreciate this, is relevant to joint decision making about HT in a clinical setting. Prescribing guidelines caution that HT entails more risk than benefit when used by women who are long past the menopause transition. Scientists, researchers, hormone marketers, providers, and health policy makers who are engaged in a debate about prescription of HT after age 60 represent opposing discourses addressing length of use and HT risk.

Adele Clarke wrote that it is important to examine sites of conflict, instances in which opposing discourses meet resistance (Clarke, 2005). To explain long-term use of HT, it is helpful to examine the social, psychological, historical, and scientific origins of the opposing discourses. Figure 1 is a relational map of the arena of women's health care and an illustration of key social worlds and discourses impacting HT decision making. The value of Clarke's emphasis on using situational maps to help locate hidden or underappreciated elements in a social situation is illustrated in this map. The hidden "worlds" of ghostwriting and women diagnosed with breast cancer are highlighted with shading on the relational map. These worlds were hidden to long-term HT users in this study.

Ghostwriting is a seriously underappreciated element in the health care arena. In 2010, Senator Charles Grassley chaired a committee that produced a report titled “Ghostwriting in Medical Literature” (Grassley, 2010). In testimony to this committee, the editor of a peer reviewed specialty medical journal informed committee staff that at least a third of the papers submitted to that journal were written by science writers hired by a marketing agency under contract to a pharmaceutical company. This editor stated he was concerned that medical literature “has become inundated with repetitive promotional articles.” The report cites Wyeth’s use of the firm DesignWrite, LLC, to promote HT as an example of this phenomenon.

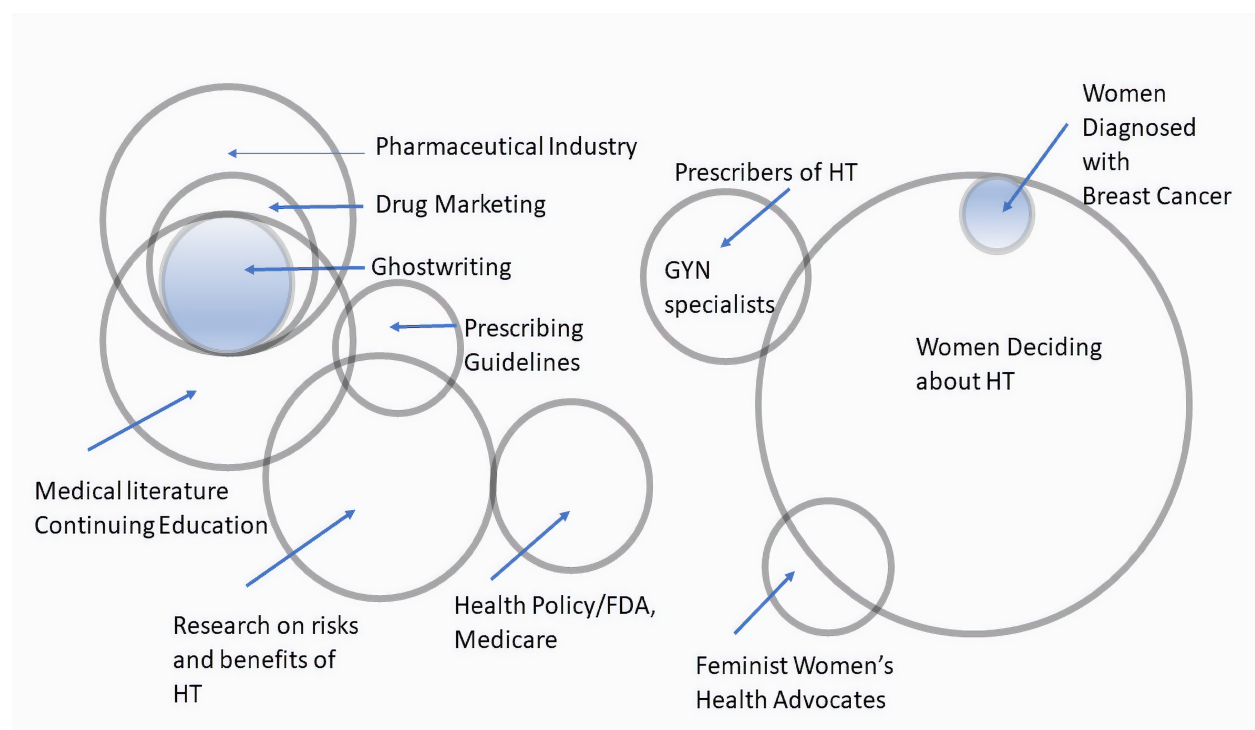


Figure 1. Relational Map of Aging Women's Healthcare Arena
Each circle represents a “world” within this arena.

Comparing/Contrasting Findings from Previous Research

Findings from this study were compared with findings from the six salient studies critiqued in Chapter 2. This study sample was relatively homogenous, and data analysis showed little variation in perception of HT benefit or risk. All of the long-term users in this study vigorously defended their decisions to start HT and to continue using it.

Risk perception. Although risk perception was a prominent topic in earlier studies, concern about risk was almost absent in these data. There are several possible explanations for a focus on risk in earlier studies. Some of them included both users and non-users, and data from mixed focus group encounters were used for analyses. Additionally, some studies focused specifically on risk perception with the acknowledged purpose of finding reassuring ways to present risk information and improve adherence to HT.

Medicalized view of menopause. HT users in earlier studies endorsed a medicalized view of menopause, and this view was also held by the long-term users in this study. Non-users in earlier studies were observed to doubt HT efficacy for disease prevention and for resisting signs of aging (Hunter et al., 1997). While there is no evidence to suggest that the views of non-users would be different now, our sample of long-term users rarely expressed doubt about the efficacy of HT.

As seen in earlier studies, nearly all participants in this sample referred to HT as “HRT,” suggesting that the term “replacement” was meaningful to them. Additionally, this term was used by the authors of most earlier reports. “HRT” came into common use due to widespread estrogen promotion in the latter part of the 20th century. This promotion involved enlistment of the medical profession (particularly gynecology specialists), who were encouraged to build

larger and more profitable practices by offering “HRT.” Among participants in this study, use of the word “replacement” may reflect their older ages and long exposure to the original terminology. It also suggests agreement with the medicalization of menopause discourse.

Control. “Control” had been recognized as a major theme in several of the reviewed studies, and the concept emerged as a dominant theme in the interviews of all 30 women in this research project. Marmoreo et al. observed that “control of the condition,” was mentioned in focus groups (Marmoreo et al., 1998). Although these authors did not specify exactly what “the condition” referred to (menopause? hot flashes? old age?), they considered the concept of control significant in their data, and they suggested it should be examined in future studies.

By calling out “performance-oriented,” “integrity-preserving,” and benefit-generalizing” (overlapping) prototypical user attitudes, the authors of a German study lent support to the idea that an aim of using HT is to exert control (Kolip et al., 2009). These researchers highlighted the concept of control in regard to the “integrity-preserving” user. Their report indicated that control was in play when HT was used to control symptoms, slow the aging process, and preserve one’s self-image. Participants in the present study were similarly convinced that HT gave them control of symptoms and of some aspects of the aging process.

Walter and Britten (2002) wrote that control was a major thematic code in their data; however, they explored control in terms of controlling risk rather than controlling a condition (Walter & Britten, 2002). Because the UK study’s focus was entirely on HT risk perception, this is not surprising. They concluded that risk knowledge and core beliefs are synthesized, and emotions that result from this synthesis act as a “filter” to prevent contamination of core beliefs by risk information. Later in this chapter, the idea that risk information may be filtered out through a process involving emotion is revisited.

Role of prescribers. Kolip et al. (2009) addressed provider influence, noting that some women appreciate having a provider make decisions for them while reassuring them about risk (Kolip et al., 2009). Marmoreo et al. wrote about provider influence in regard to it being a “sphere of influence” when making a decision to use HT (Marmoreo et al., 1998). They acknowledged that they were motivated to learn more effective ways to help women appreciate the benefits of HT.

Women in the present study spoke of appreciating reassurance from providers; however, they did not want their providers to decide when they should stop. Many spoke of the need to find and retain supportive providers who would continue to provide prescriptions for HT.

A women’s health nurse practitioner stated that her 2010 study was designed to help women decide to start HT (Theroux, 2010). She was concerned that women had unrealistic fears about HT that interfered with decision making, and she wanted to provide reassurance. In contrast, the present study explored perception of HT risk with the ultimate goal of gaining knowledge useful for discouraging long-term use that is inconsistent with prescribing guidelines.

Searching. A category of user recognized by Kolip et al. was “searching” (searching for answers, doubting a decision) (Kolip et al., 2009), whereas none of the women in the present study appeared to fit that category. Although some participants said that they might consider discontinuing HT at some point in the future, none doubted the decision to continue in the immediate future.

Ignoring Risk—Perspectives of Psychologists

I expected to find that women weighed HT risks against benefits in a systematic and cautious process. Research participants in this study were highly educated, a number with

careers in science, and learning that they disregarded risk information was very surprising. I turned to literature on health-related decision making to help me understand how risk information might be ignored. Judgment of risk from the perspective of psychologists was deemed to be the most promising approach to explaining this finding.

Two-system model of mental operations. The writings of Daniel Kahneman, Paul Slovic, and Amos Tversky, among others, on a two-system model of mental operations and on judgment bias help explain study findings (Kahneman, 2011; Kahneman et al., 1982). This theoretical model of cognitive function illustrates how judgment biases arise, and how they affect decision making. Their two-system model of mental operations is summarized below. Following this discussion, an adaptation of the original model is presented with an explanation of added features that are useful in explaining study results.

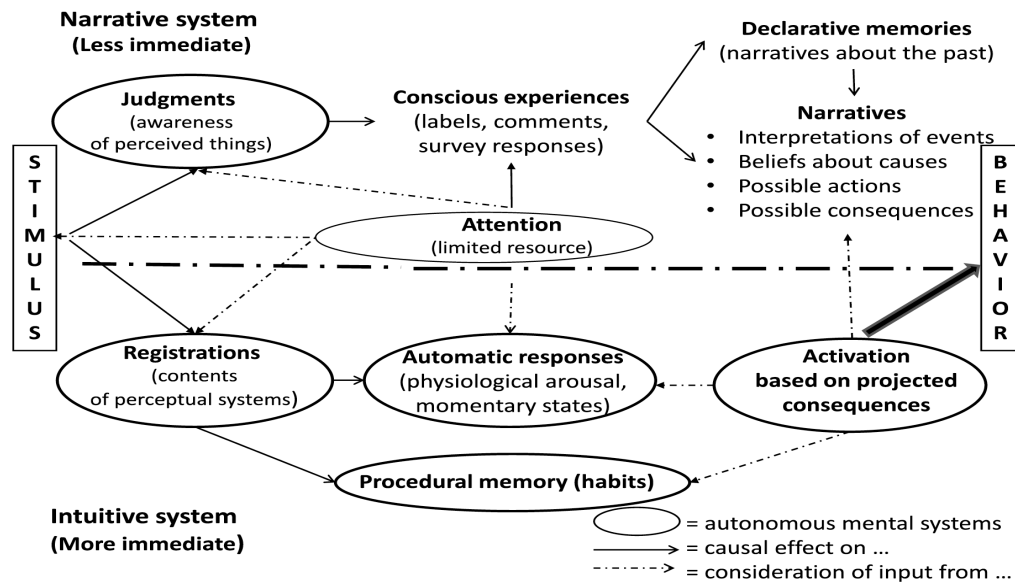
Systems 1 and 2 are “agents” within the mind that represent (a) automatic and (b) effortful systems of thinking. The automatic system starts making a decision by determining intuitively whether or not to believe a statement is true. Because system 1 does not deal effectively with logic or statistics, detailed information is underutilized or ignored, and system 1 may suggest an incorrect/untrue intuition. Unless a statement is immediately rejected, system 1 will automatically process the information as if it were true. Initial “hunches” about a topic tend to persist.

System 2 is subsequently mobilized to increase cognitive effort to confirm or deny an intuition suggested by system 1. System 2 may endorse an incorrect intuition and express it as a judgment without critical examination. System 2 avoids unnecessary cognitive effort, and it generally works on data retrieved from memory. Put another way, after system 1 generates a suggestion in the form of an impression, intuition, intention, or feeling (emotion), system 2 is

more likely to accept the information as true than to reject it as false. If a suggested intuition is particularly desirable (e.g., HT helps skin remain elastic, HT prevents dementia), it is easily believed. Likewise, if the suggested intuition produces a positive emotion, this enhances its credibility. Consequently, initial stances on issues are usually retained.

Two-system model adaptation. Figure 2 is a model of a two-system cognitive process integrating the concept of temporality with the original two-system model of Kahneman et al. (Cook et al., 2018). The nursing theorists who developed this adaptation of the model renamed system 1 the “intuitive” system and system 2 the “narrative” system. They developed the model to describe and test inconsistencies between “good intentions” and actual health behaviors. The model puts an emphasis on time, i.e., whether a decision or behavior is linked to the immediate present or a possible future. The horizontal line across the center signifies “temporal immediacy,” the authors’ term for the role of time in the cognitive process resulting in a judgment.

Finding that *control* was a key motivation for using HT, examining a model that puts an emphasis on temporality was helpful. Applying the perspective of one psychologist, using HT as a form of instrumental control allowed the women I interviewed to believe that they were *minimizing maximum future adverse events* (Miller, 1979). Another way of saying this is: Using HT gave participants the perception that they were reducing the likelihood they would experience negative consequences related to being post-menopausal in the future. These future adverse events, or negative consequences, included age-related disease and various forms of age-related decline. Promoting healthy behaviors to improve future health, a focus of Cook et al., is somewhat analogous to promoting HT to improve future health.



Cook, P.; Schmiede, S.; Reeder, B.; Horton-Deutsch, S.; Lowe, N.; Meek, P. (2018). [Temporal Immediacy: A Two-System Theory of Mind for Understanding and Changing Health Behaviors](#). *Nursing Research*, 67(2):108-121. DOI: 00006199-201803000-00008.

Figure 2. Model of a Two-System Cognitive Process Incorporating the Concept of Temporality

By including narratives and labels in the model, the authors highlighted the importance of language and social process in decision making (Cook et al., 2018). Symbols and language, (which can be symbolic) are reshaped in social interactions. The model illustrates how this input is accessed in a fluid manner, thereby playing a role in both phases of the decision-making process.

According to symbolic interactionism theory, social process involves interaction with oneself and anticipation of future social interactions (Blumer, 1969). This process of meaning making, which takes place over time, involves both language and symbols. Language patterns and discourses evolve through social interaction, and they ultimately reflect the realities of the cultures in which they develop. In this way, language and symbols affect meaning making and decision making.

Examples of language and symbols that were examined in this project are “HRT” and “replacement.” Nearly every mention of HT in interview data was either the term “HRT” or “hormone replacement therapy.” Clearly, “replacement” (of estrogen) holds particularly powerful meaning for long-term users—it is part of their cultural script. Symbolic meanings for “hormones,” “estrogen,” “menopause,” and “femininity” have become part of a language and discourse consciously created by estrogen marketers (Watkins, 2007). A phrase that has been added to this list in recent years is “quality of life.” The phrase is symbolic and activating. It suggests that using HT enhances one’s quality of life, whether or not it relieves bothersome symptoms.

Cognitive biases. Both the original and the “temporal immediacy” (Cook et al., 2018) versions of the two-system model help explain cognitive biases, which are systematic errors in judgment that occur in certain circumstances. Cognitive biases result from interaction between the two systems. Because we are all susceptible to judgment biases, they are routinely exploited in marketing. Cognitive biases that help explain findings from this study are anchoring bias and confirmation bias.

Anchoring bias. “Anchoring” on a belief solidifies a position or point of view, it reinforces a decision, and it can interfere with critical examination (or re-examination), as described earlier. Study data suggest that numerous perceived benefits serve as anchors for decisions to continue using HT. An anchoring bias for some women was estrogen’s efficacy in preventing hot flashes. Although a number of participants experienced hot flashes while using HT, they assumed their hot flashes would be more frequent or severe without it. Other participants anchored their decisions to continue HT on perceived cognitive effects. These included preventing mood swings and depression and clearing “foggy” thinking. Many women

in the study credited estrogen with anti-aging properties, and although some of them rejected the idea that HT had helped keep them young in appearance, a belief in anti-aging efficacy (e.g., keeping them energetic, strong, or agile) served as an anchor. Believing that HT improved “quality of life” was another anchor.

Confirmation bias. Once a judgment is made, information that confirms its validity is sought, allowing firmly-held beliefs to stand despite conflicting evidence. Because risk information is often presented in the form of statistics, and statistics are not easily retained in memory, risk information is easy to ignore. On the other hand, general reassurance that HT risk is “low” or that minimal risk is counterbalanced by disease prevention is information that can easily be remembered, as shown in these data. Provider reassurance that HT is beneficial and safe had helped many participants confirm their decisions to continue it indefinitely.

The following example illustrates both anchoring bias and confirmation bias. A participant with a science PhD had read that the incidence of colorectal cancer was lower with the use of HT, and she anchored her decision to use it largely on that piece of information. She did not know (because she didn’t check?) or recall (because risk information is detailed and statistics are difficult to remember?) that among HT users, cancer diagnoses are made at later stages, and death rates from colon cancer are higher (Simon et al., 2012). [Menopausal hormone therapy is not recommended for prevention of colon cancer (Simon et al., 2012).] Evidence that contradicted the anchoring belief had been filtered out, and the decision to use HT remained firm.

Emotion affects risk assessment—the affect heuristic. As mentioned earlier in this chapter and in Chapter 2, Walter and Britten conducted a qualitative study in the UK using focus groups and interviews of 40 women aged 50-55 to explore their understandings of HT risk

(Walter & Britten, 2002). They reported that the meanings of particular risks are modified by age, experience, and emotion. They hypothesized that there is an emotional component to risk perception, and emotions that result from a synthesis of risk knowledge and core beliefs act as a “filter” to prevent contamination of core beliefs by risk information.

Their hypothesis may help explain the lack of concern about risk observed in this study. Older HT users had negligible concern about risk, in part, because of long exposure to promotional messaging emphasizing benefits. An emotional affinity for HT based on perceived benefit engendered by promotional messaging may have anchored their original decisions to use HT. Women in this study appeared to be receptive only to reassurance about risk, information that confirmed their decisions to continue. They had filtered out risk concerns.

The affect heuristic, first described by the psychologist Paul Slovic, is more or less an umbrella judgment bias, and it helps explain absence of concern about risk in a similar manner (Slovic, Peters, Finucane, & Macgregor, 2005). Science has demonstrated that when people see great benefit in something, they tend to underappreciate associated risk— an inverse relationship exists between perception of benefit and perception of risk. Tests of this phenomenon have included the use of questionnaires to gauge an individual’s perception of benefit vs. risk in regard to a technology, e.g., nuclear power or self-driving cars. Data from the present study confirm that women who believe HT is marvelous tend to think it is safe. The corollary of this observation has been demonstrated in studies that included non-users. Women who eschew HT tend to not appreciate purported benefits and to emphasize associated risk.

Base rate neglect. An additional judgment bias that comes into play in these data is base rate neglect. Study findings support the observation that risk data are misperceived partly as a result of a tendency to ignore base rates. One in eight women in the US are diagnosed with

breast cancer during her lifetime, and the two most important risk factors among women who do not carry genes that magnify risk are age and use of HT ("Cancer Stat Facts: Female Breast Cancer," 2017). This base rate came as a surprise to 28 of 30 participants in this study.

Limitations

A number of factors influenced the research process and may have impacted results. Several of these factors are discussed below.

Author's biased perspective. I am biased toward following consensus health guidelines such as UpToDate® HT prescribing guidelines (Martin & Barbieri, 2018b). Earlier in this dissertation, I acknowledged having a feminist philosophical perspective. I stated that feminism is a social justice movement that began, in part, as a reaction to the notion that aging lowers the value of women in society. I have long observed that some women are willing to risk their health by using HT in hopes of maintaining youthful qualities. Numerous friends and acquaintances have been diagnosed with breast cancer while on HT, and this, too, created bias. It has also been very motivating. The primary reasons for my undertaking this study were (a) concern for the health of women and (b) a sense of the injustice of misleading HT marketing, particularly materials that play on gender and aging stereotypes.

My biased perspective on the hormone manufacturing industry made me particularly sensitive to narratives that seemed to echo marketing messages. As a women's health nurse practitioner, I have been the recipient of unmeasurable amounts of HT promotional material and I regularly read gynecology specialty journals, so I recognize common themes. I have studied hormone industry marketing practices for over three decades, and I have my own collection of classic ghost-written articles and lawsuit discovery documents. The results of this thoroughly-

described grounded theory undertaking, incorporating a systematic analysis of the narratives of 30 long-term users, illustrate how effective HT marketing really is.

I have done my best to practice reflexivity during the research process. I kept field notes and memos that detailed observations, examined assumptions, and posed questions I hoped to answer. Discussions with advisors and colleagues were part of a conscious process of examining how my background and prior assumptions influenced the research process.

Study population lacked diversity. The study population consisted entirely of HT “true believers,” and all except one of the 30 participants were White, well-educated, and well-insured. I enrolled all eligible women who responded to ads placed in communities with women of diverse races and ethnicities. I made extra efforts through friends to recruit African American women to no avail. I like to think that non-White women are less vulnerable to HT marketing efforts rather than less able to access HT, but I do not really know if that is true.

Coding done by author. After the first five interviews, most coding was done by me alone, although coding of a number of transcripts was reviewed by my primary advisor, Dr. Meg Wallhagen. Dr. Wallhagen shared her ideas about themes found in the data, and she provided feedback on ways in which the data were considered under themes. I attempted to find another student who would work with me on coding our respective interview data, but these efforts were unsuccessful. It is unclear whether more collaborative coding would have altered analysis, and I welcome collaboration in future efforts to analyze these data.

Concluding Thoughts and Broader Implications

Long-term users in this study believed that they had benefited greatly from HT in ways that were difficult to verify and often too good to be true. Having been exposed for decades to

widespread HT promotion in popular media (e.g., Oprah Winfrey and her orbit, Suzanne Somers, Jane Fonda), they may associate estrogen with glamour, celebrity, and prolonged youthfulness. Perceiving enhanced vitality, thinking clearly, looking attractive, and feeling rather well, they gave credit to HT rather than to factors they embodied, such as good genes, healthy behaviors, strength of character, or joy of life. Perception of risk was not a significant factor in deciding to continue HT, and most did not know that long-term use entails greater risk than use for less than three to five years. For all 30 participants, using HT had become a routine that gave them a sense of control they were afraid to give up, and the practice of using “hormone replacement therapy” had been reinforced by habit.

A proportion of women who start HT around the time of menopause will not want to quit after the three- to five-year limit on use that is recommended. At last count, over a third of US women prescribed systemic estrogen were older than age 60, and the average duration of use had lengthened each year (Steinkellner et al., 2012; Weissfeld et al., 2018). It appears likely that the hormone industry is relying on this trend to continue. As providers, it is our responsibility to inform long-term users of HT’s limited benefit and not-so-limited risk. Continued prescription of HT is too often an act of surrender to a patient who is psychologically dependent on a drug that benefits her little and may cause great harm.

Study findings are applicable to any clinical encounter that involves jointly weighing benefit and risk. It is important to discuss judgment biases, cite base rates when providing risk statistics, and help patients understand that positive feelings about treatment may be based on unrealistic expectations and underestimation of risk. This research suggests that these interventions could potentially strengthen joint decision-making and improve patient outcomes.

Lastly, unless providers learn to distinguish science from marketing, misinformation about risks and benefits will continue to influence drug prescription. At the conclusion of many interviews, I asked participants if they knew anything about the practice of ghostwriting. With one exception, they were unaware that some medical journals publish articles falsely attributed to physician “authors” that are actually written by marketing companies under contract to drug manufacturers. The fact that marketing messages may masquerade as science is underappreciated by members of the medical and nursing professions, and it is not surprising that few patients have this information. My research focus moving forward is on exposing ghostwriting and developing tools to help providers distinguish science from drug marketing.

References

ACS, A. C. S. (2018). Retrieved from

<https://www.cancer.org/content/dam/CRC/PDF/Public/8577.00.pdf>

Anderson, G. L., Limacher, M., Assaf, A. R., Bassford, T., Beresford, S. A., Black, H., . . .

Women's Health Initiative Steering C. (2004). Effects of conjugated equine estrogen in postmenopausal women with hysterectomy: the Women's Health Initiative randomized controlled trial. *JAMA*, 291(14), 1701-1712.

doi:10.1001/jama.291.14.1701

Bauld, R., & Brown, R. (2008). Stress, psychological distress, psychological factors, menopause symptoms, and physical health in women. *Maturitas*, 62, 160-165.

Beck, C. T. (2009). Critiquing qualitative research. *AORN J*, 90(4), 543-554.

doi:10.1016/j.aorn.2008.12.023

Beral, V., Collaborative Group on Hormonal Factors in Breast Cancer. (1997). Breast cancer and hormone replacement therapy: collaborative reanalysis of data from 51 epidemiological studies of 52 705 women with breast cancer and 108 411 women without breast cancer. *The Lancet*, 350(9084), 1047-1059.

doi:[https://doi.org/10.1016/S0140-6736\(97\)08233-0](https://doi.org/10.1016/S0140-6736(97)08233-0)

Beral, V., Reeves, G., Bull, D., Green, J., & Collaborators, M. W. S. (2011). Breast cancer risk in relation to the interval between menopause and starting hormone therapy. *J Natl Cancer Inst*, 103(4), 296-305. doi:10.1093/jnci/djq527

Bewley, S., & Bewley, T. (1992). Dependence and oestrogen replacement. *Lancet*, 339(8796), 814-815.

- Birks, M. M., J. (2011). *Grounded theory: A practical guide*. London: Sage.
- Blumer, H. (1969). *Symbolic interactionism; perspective and method*. Englewood Cliffs, N.J.,: Prentice-Hall.
- Boston Women's Health Book Collective. (1973). *Our bodies, ourselves/ a book by and for women*. New York: Simon & Schuster.
- Brett, A. S. (2010). Differences between gynecologists and primary care physicians in hormone therapy prescribing: why they matter. *J Womens Health (Larchmt)*, 19(12), 2153-2156. doi:10.1089/jwh.2010.2411
- Brett, A. S., Carney, P. I., & McKeown, R. E. (2005). Brief report: attitudes toward hormone therapy after the Women's Health Initiative: a comparison of internists and gynecologists. *J Gen Intern Med*, 20(5), 416-418. doi:10.1111/j.1525-1497.2005.0089.x
- Brown, A. F., Perez-Stable, E. J., Whitaker, E. E., Posner, S. F., Alexander, M., Gathe, J., & Washington, A. E. (1999). Ethnic differences in hormone replacement prescribing patterns. *J Gen Intern Med*, 14(11), 663-669.
- Cancer Stat Facts: Female Breast Cancer. (2017). Retrieved from <https://seer.cancer.gov/statfacts/html/breast.html>
- Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociol Health Illn*, 5(2), 168-195.
- Charmaz, K. (2006). *Constructing grounded theory*. Thousand Oaks, Calif.: Sage Publications.
- Charmaz, K. (2014). *Constructing grounded theory* (2nd edition ed.). Thousand Oaks, Calif.: Sage.

- Chen, W. (2018). Menopausal hormone therapy and the risk of breast cancer. Retrieved from UpToDate.com
- Chlebowski, R. T., Anderson, G. L., Aragaki, A. K., & Prentice, R. (2016). Breast cancer and menopausal hormone therapy by race/ethnicity and body mass index. *J Natl Cancer Inst, 108*(2). doi:10.1093/jnci/djv327
- Clarke, A. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Thousand Oaks, CA: Sage.
- Collaborative Group on Epidemiological Studies of Ovarian, C., Beral, V., Gaitskell, K., Hermon, C., Moser, K., Reeves, G., & Peto, R. (2015). Menopausal hormone use and ovarian cancer risk: individual participant meta-analysis of 52 epidemiological studies. *Lancet, 385*(9980), 1835-1842. doi:10.1016/S0140-6736(14)61687-1
- Coney, S. (1994). *The menopause industry: How the medical establishment exploits women*. Alameda, CA: Hunter House.
- Cook, P. F., Schmiede, S. J., Reeder, B., Horton-Deutsch, S., Lowe, N. K., & Meek, P. (2018). Temporal immediacy: A two-system theory of mind for understanding and changing health behaviors. *Nurs Res, 67*(2), 108-121. doi:10.1097/NNR.0000000000000265
- Corbelli, J. A., & Hess, R. (2012). Hormone therapy prescribing trends in the decade after the Women's Health Initiative: how patients and providers have found a way to sleep better at night. *Menopause, 19*(6), 600-601. doi:10.1097/gme.0b013e318255b441
- Cresswell, J. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.

- Deeks, A., Zoungas, S., & Teede, H. (2008). Risk perception in women: a focus on menopause. *Menopause*, 15(2), 304-309. doi:10.1097/gme.0b013e31812f7b65
- Erol, M. (2011). Melting bones: The social construction of postmenopausal osteoporosis in Turkey. *Soc Sci Med*, 73(10), 1490-1497. doi:10.1016/j.socscimed.2011.08.033
- Ettinger, B., Wang, S. M., Leslie, R. S., Patel, B. V., Boultware, M. J., Mann, M. E., & McBride, M. (2012). Evolution of postmenopausal hormone therapy between 2002 and 2009. *Menopause*, 19(6), 610-615. doi:10.1097/gme.0b013e31823a3e5d
- Farhat, G. N., Walker, R., Buist, D. S., Onega, T., & Kerlikowske, K. (2010). Changes in invasive breast cancer and ductal carcinoma in situ rates in relation to the decline in hormone therapy use. *J Clin Oncol*, 28(35), 5140-5146. doi:10.1200/JCO.2010.29.5121
- Fauconnier, A., Ringa, V., Delanoe, D., Falissard, B., & Breart, G. (2000). Use of hormone replacement therapy: Women's representations of menopause and beauty care practices. *Maturitas*, 35(3), 215-228.
- Feeley, J. (2012). Pfizer paid \$896 million in Prempro settlements. Retrieved from <https://www.bloomberg.com/news/articles/2012-06-19/pfizer-paid-896-million-in-prempro-accords-filing-shows-1->
- Fisher, W. A., Sand, M., Lewis, W., & Boroditsky, R. (2000). Canadian menopause study-I: Understanding women's intentions to utilise hormone replacement therapy. *Maturitas*, 37(1), 1-14.
- Foucault, M. (1975). *The birth of the clinic; an archaeology of medical perception*. New York,: Vintage Books.

- French, L. M., Smith, M. A., Holtrop, J. S., & Holmes-Rovner, M. (2006). Hormone therapy after the Women's Health Initiative: a qualitative study. *BMC Fam Pract*, 7, 61. doi:10.1186/1471-2296-7-61
- Fugh-Berman, A. (2010). The haunting of medical journals: how ghostwriting sold "HRT". *PLoS Med*, 7(9), e1000335. doi:10.1371/journal.pmed.1000335
- Fugh-Berman, A., McDonald, C., Bell, A., Bethards, E., & Scialli, A. (2011). Promotional tone in reviews of menopausal hormone therapy after the Women's Health Initiative: an analysis of published articles. *PLoS Med*, 8(3), e1000425. doi:10.1371/journal.pmed.1000425
- Fugh-Berman, A., & Scialli, A. (2006). Gynecologists and estrogen: an affair of the heart. *Perspect Biol Med*, 49(1), 115-130. doi:10.1353/pbm.2006.0006
- Gannon, L. (1999). *Women and aging: Transcending the myths*. New York: Routledge.
- Gass, M. L., Stuenkel, C. A., Utian, W. H., LaCroix, A., Liu, J. H., Shifren, J. L., . . . other experts in women's h. (2015). Use of compounded hormone therapy in the United States: report of The North American Menopause Society Survey. *Menopause*, 22(12), 1276-1284. doi:10.1097/GME.0000000000000553
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory; strategies for qualitative research*. Chicago,: Aldine Pub. Co.
- Gleason, C. E., Dowling, N. M., Wharton, W., Manson, J. E., Miller, V. M., Atwood, C. S., . . . Asthana, S. (2015). Effects of hormone therapy on cognition and mood in recently postmenopausal women: Findings from the randomized, controlled KEEPS-Cognitive and Affective Study. *PLoS Med*, 12(6), e1001833; discussion e1001833. doi:10.1371/journal.pmed.1001833

Godfrey-Smith, P. (2003). *Theory and reality : an introduction to the philosophy of science*.

Chicago: University of Chicago Press.

Grady, D., Ettinger, B., Tosteson, A. N., Pressman, A., & Macer, J. L. (2003). Predictors of difficulty when discontinuing postmenopausal hormone therapy. *Obstet Gynecol*, 102(6), 1233-1239.

GrandviewResearch. (2018). North American hormone replacement therapy market share, by product. Retrieved from www.grandviewresearch.com/industry-analysis/hormone-replacement-therapy-market

Grassley, C. (2010). *Ghostwriting in Medical Literature*. Retrieved from <https://www.grassley.senate.gov/news/news-releases/grassley-releases-medical-ghostwriting-report-recommends-nih-promote-transparency>

Handberg, C., Thorne, S., Midtgaard, J., Nielsen, C. V., & Lomborg, K. (2015). Revisiting symbolic interactionism as a theoretical framework beyond the grounded theory tradition. *Qual Health Res*, 25(8), 1023-1032. doi:10.1177/1049732314554231

Harding, S. (2006). *Science and social inequality: Feminist and postcolonial issues*. Urbana, IL: University of Illinois.

Harman, S. M., Black, D. M., Naftolin, F., Brinton, E. A., Budoff, M. J., Cedars, M. I., . . . Hodis, H. N. (2014). Arterial imaging outcomes and cardiovascular risk factors in recently menopausal women: a randomized trial. *Ann Intern Med*, 161(4), 249-260. doi:10.7326/m14-0353

Hersh, A. L., Stefanick, M. L., & Stafford, R. S. (2004). National use of postmenopausal hormone therapy: Annual trends and response to recent evidence. *JAMA*, 291(1), 47-53. doi:10.1001/jama.291.1.47

- Hulley, S., Furberg, C., Barrett-Connor, E., Cauley, J., Grady, D., Haskell, W., . . . Group, H. R. (2002). Noncardiovascular disease outcomes during 6.8 years of hormone therapy: Heart and Estrogen/progestin Replacement Study follow-up (HERS II). *JAMA*, 288(1), 58-66.
- Hulley, S., Grady, D., Bush, T., Furberg, C., Herrington, D., Riggs, B., & Vittinghoff, E. (1998). Randomized trial of estrogen plus progestin for secondary prevention of coronary heart disease in postmenopausal women. Heart and Estrogen/progestin Replacement Study (HERS) Research Group. *JAMA*, 280(7), 605-613.
- Hunter, M. S. (1993). Predictors of menopausal symptoms: Psychosocial aspects. *Baillieres Clin Endocrinol Metab*, 7(1), 33-45.
- Hunter, M. S., & Liao, K. L. (1994). Intentions to use hormone replacement therapy in a community sample of 45-year-old women. *Maturitas*, 20(1), 13-23.
- Hunter, M. S., O'Dea, I., & Britten, N. (1997). Decision-making and hormone replacement therapy: a qualitative analysis. *Soc Sci Med*, 45(10), 1541-1548.
- Im, E., & Lipson, J. (1997). Menopausal transition of Korean immigrant women: a literature review. *Health Care for Women International*, 18, 507-520.
- Kahneman, D. (2011). *Thinking, fast and slow*. New York, NY: Farrar, Straus and Giroux.
- Kahneman, D., Slovic, P., & Tversky, A. (1982). *Judgment under uncertainty: Heuristics and biases*. New York, NY: Cambridge University Press.
- Keating, N. L., Cleary, P. D., Rossi, A. S., Zaslavsky, A. M., & Ayanian, J. Z. (1999). Use of hormone replacement therapy by postmenopausal women in the United States. *Ann Intern Med*, 130(7), 545-553.

KLRI. (2005). KEEPS Study. Retrieved from

<https://clinicaltrials.gov/ct2/show/NCT00154180>

Kolip, P., Hoefling-Engels, N., & Schmacke, N. (2009). Attitudes toward postmenopausal long-term hormone therapy. *Qual Health Res*, 19(2), 207-215.

doi:10.1177/1049732308328053

Krishna, S. (2002). Attitudes towards menopause and hormone replacement therapy in different cultures. *Internation Congress Series*, 1229, 207-214.

Lachman, M. E. (2006). Perceived control over aging-related declines: Adaptive beliefs and behaviors. *Current Directions in Psychological Science*, 15(6), 282-286.

Limouzin-Lamothe, M. A. (1996). What women want from hormone replacement therapy: results of an international survey. *Eur J Obstet Gynecol Reprod Biol*, 64 Suppl, S21-24.

Lock, M. (1998). Menopause: Lessons from anthropology. *Psychosomatic Medicine*, 60, 410-419.

MacKinnon, C. (2009). Applying feminist, multicultural, and social justice theory to diverse women who function as caregivers in end-of-life and palliative home care. *Palliative and Supportive Care*, 7, 501-512.

Manson, J. E., Chlebowski, R. T., Stefanick, M. L., Aragaki, A. K., Rossouw, J. E., Prentice, R. L., . . . Wallace, R. B. (2013). Menopausal hormone therapy and health outcomes during the intervention and extended poststopping phases of the Women's Health Initiative randomized trials. *JAMA*, 310(13), 1353-1368. doi:10.1001/jama.2013.278040

Marmoreo, J., Brown, J. B., Batty, H. R., Cummings, S., & Powell, M. (1998). Hormone replacement therapy: determinants of women's decisions. *Patient Educ Couns*, 33(3), 289-298.

- Martin, K., & Barbieri, R. (2018a, Last update August 2018; Last literature review October, 2018). Menopausal hormone therapy benefits and risks. *Menopausal Hormone Therapy Benefits and Risks*. Retrieved from https://www-uptodate-com.ucsf.idm.oclc.org/contents/menopausal-hormone-therapy-benefits-and-risks?source=see_link
- Martin, K., & Barbieri, R. (2018b). Treatment of menopausal symptoms with hormone therapy. UpToDate Retrieved 01/26/2018, from UpToDate.com <https://www-uptodate-com.ucsf.idm.oclc.org/contents/treatment-of-menopausal-symptoms-with-hormone-therapy>
- McKeever, L. (1988). *Menopause an uncertain passage, an interpretive study*. (doctoral), University of California, San Francisco,
- Merriam-Webster. (2018). Retrieved from Merriam-Webster.com/dictionary
- Miller, S. M. (1979). Controllability and human stress: Method, evidence and theory. *Behaviour Research and Therapy*, 17(4), 287-304.
doi:[https://doi.org/10.1016/0005-7967\(79\)90001-9](https://doi.org/10.1016/0005-7967(79)90001-9)
- Mutagh, M. H., J. (2005). Narrative review of changing medical & feminist perspectives on menopause: from femininity and aging to risk and choice. *Psychology, Health & Medicine*, 10(3), 276-290. doi:10.1080/13548500500093225
- Nabel, E. G. (2013). The Women's Health Initiative--a victory for women and their health. *JAMA*, 310(13), 1349-1350. doi:10.1001/jama.2013.278042
- NAMS. (2012). The 2012 hormone therapy position statement of: The North American Menopause Society *Menopause*, 19(3), 257-271.
doi:10.1097/gme.0b013e31824b970a

- NAMS. (2017). The 2017 hormone therapy position statement of The North American Menopause Society. *Menopause*, 24(7), 728-753.
doi:10.1097/GME.0000000000000921
- NAMS. (2018). Utian Quality of Life Scale. Retrieved from
[https://www.menopause.org/publications/clinical-practice-materials/menopause-qol-instrument-\(uqol\)](https://www.menopause.org/publications/clinical-practice-materials/menopause-qol-instrument-(uqol))
- NCI, N. C. I. (2018). Retrieved from <https://seer.cancer.gov/statfacts/html/breast.html>
- Neel, J. (Producer). (2002, 01/18/2018). The marketing of menopause: Historically, hormone therapy heavy on promotion, light on science. [Radio broadcast and web page.] Retrieved from <https://www.npr.org/news/specials/hrt/index.html>
- NVivo. (2018). QSR International Pty Ltd.; NVivo qualitative data analysis Software, Version 12.
- O'Connor, A. M., Tugwell, P., Wells, G. A., Elmslie, T., Jolly, E., Hollingworth, G., . . . Drake, E. (1998). A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Educ Couns*, 33(3), 267-279.
- Oskarsson, V., Orsini, N., Sadr-Azodi, O., & Wolk, A. (2014). Postmenopausal hormone replacement therapy and risk of acute pancreatitis: a prospective cohort study. *CMAJ*, 186(5), 338-344. doi:10.1503/cmaj.131064
- Oudshoorn, N. (2001). *On bodies, technologies, and feminisms*. Chicago: University of Chicago Press.
- Petersen, M. (2002). <http://www.nytimes.com/2002/07/10/us/wyeth-stock-falls-24-after-report.html>. *NY Times*. Retrieved from
<http://www.nytimes.com/2002/07/10/us/wyeth-stock-falls-24-after-report.html>

- Phelan, E. A., Buist, D. S., Anderson, L. A., Newton, K. M., Delaney, K. M., & LaCroix, A. Z. (2001). Understanding attitudes of older women toward hormone replacement therapy. *Prev Med*, 32(1), 49-56. doi:10.1006/pmed.2000.0768
- Quinn, A. A. (1991). A theoretical model of the perimenopausal process. *J Nurse Midwifery*, 36(1), 25-29.
- Rogers, B. (2005). *Developing nursing knowledge: Philosophical traditions and influences*. New York: Lippincott Williams & Wilkins.
- Rolnick, S. J., Kopher, R. A., DeFor, T. A., & Kelley, M. E. (2005). Hormone use and patient concerns after the findings of the Women's Health Initiative. *Menopause*, 12(4), 399-404. doi:10.1097/01.gme.0000148644.55486.36
- Rossouw, J. E., Anderson, G. L., Prentice, R. L., LaCroix, A. Z., Kooperberg, C., Stefanick, M. L., . . . Writing Group for the Women's Health Initiative, I. (2002). Risks and benefits of estrogen plus progestin in healthy postmenopausal women: principal results From the Women's Health Initiative randomized controlled trial. *JAMA*, 288(3), 321-333.
- Rothman, S., & Rothman, D. (2003). *The pursuit of perfection: The promise and perils of medical enhancement*. New York: Random House.
- Routledge, F. (2007). Exploring the use of feminist philosophy within nursing research to enhance post-positivist methodologies in the study of cardiovascular health. *Nursing Philosophy*, 8, 278-290.
- Sandelowski, M. (1993). Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *ANS Adv Nurs Sci*, 16(2), 1-8.
- Schwartz-Shea, P., & Yanow, D. (2012). *Interpretive research design : Concepts and processes*. New York, NY: Routledge.

- Simon, M. S., Chlebowski, R. T., Wactawski-Wende, J., Johnson, K. C., Muskovitz, A., Kato, I., . . . Prentice, R. L. (2012). Estrogen plus progestin and colorectal cancer incidence and mortality. *J Clin Oncol*, 30(32), 3983-3990. doi:10.1200/jco.2012.42.7732
- Slovic, P., Peters, E., Finucane, M. L., & Macgregor, D. G. (2005). Affect, risk, and decision making. *Health Psychol*, 24(4s), S35-40. doi:10.1037/0278-6133.24.4.s35
- Steinkellner, A. R., Denison, S. E., Eldridge, S. L., Lenzi, L. L., Chen, W., & Bowlin, S. J. (2012). A decade of postmenopausal hormone therapy prescribing in the United States: Long-term effects of the Women's Health Initiative. *Menopause*, 19(6), 616-621. doi:10.1097/gme.0b013e31824bb039
- Stephens, C., Budge, R. C., & Carryer, J. (2002). What is this thing called hormone replacement therapy? Discursive construction of medication in situated practice. *Qual Health Res*, 12(3), 347-359. doi:10.1177/104973202129119937
- Strauss, A. (1987). *Qualitative analysis for social scientists*. Cambridge Cambridgeshire; New York: Cambridge University Press.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research : grounded theory procedures and techniques*. Newbury Park, Calif.: Sage Publications.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques, 2nd ed.* Thousand Oaks, CA: Sage.
- Suhrke, P., Maehlen, J., & Zahl, P. H. (2012). Hormone therapy use and breast cancer incidence by histological subtypes in Sweden and Norway. *Breast J*, 18(6), 549-556. doi:10.1111/tbj.12001

- Sveinsdottir, H., & Olafsson, R. F. (2006). Women's attitudes to hormone replacement therapy in the aftermath of the Women's Health Initiative study. *J Adv Nurs*, 54(5), 572-584. doi:10.1111/j.1365-2648.2006.03862.x
- Tao, M., Teng, Y., Shao, H., Wu, P., & Mills, E. J. (2011). Knowledge, perceptions and information about hormone therapy (HT) among menopausal women: a systematic review and meta-synthesis. *PLoS One*, 6(9), e24661. doi:10.1371/journal.pone.0024661
- Theroux, R. (2010). Women's decision making during the menopausal transition. *Journal of the American Academy of Nurse Practitioners*, 22, 612-621.
- UpToDate.com. (2017). Conflict of Interest Policy. Retrieved from <https://www.uptodate.com/home/conflict-interest-policy>
- UpToDate.com. (2018). Retrieved from <https://www.uptodate.com/home/about-us>
- Wallhagen, M. (1998). Perceived control theory: a recontextualized perspective. *Journal of Clinical Geropsychology*, 4(2), 119-140.
- Walter, F., & Britten, N. (2002). Patients' understanding of risk: a qualitative study of decision-making about the menopause, and hormone replacement therapy in general practice. *Family Practice*, 19, 579-586.
- Watkins, E. S. (2007). *The estrogen elixir : a history of hormone replacement therapy in America*. Baltimore: Johns Hopkins University Press.
- Weissfeld, J. L., Liu, W., Woods, C., Zhang, R., Li, J., van der Vlugt, T. H., & Slaughter, S. R. (2018). Trends in oral and vaginally administered estrogen use among US women 50 years of age or older with commercial health insurance. *Menopause*, 25(6), 611-614. doi:10.1097/GME.0000000000001054

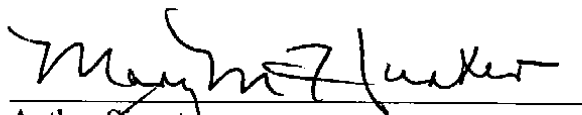
- Whittemore, R., Chase, S. K., & Mandle, C. L. (2001). Validity in qualitative research. *Qual Health Res*, 11(4), 522-537. doi:10.1177/104973201129119299
- Wilson, R. (1966). *Feminine forever*. New York: M. Evans and Company.

Publishing Agreement

It is the policy of the University to encourage the distribution of all theses, dissertations, and manuscripts. Copies of all UCSF theses, dissertations, and manuscripts will be routed to the library via the Graduate Division. The library will make all theses, dissertations, and manuscripts accessible to the public and will preserve these to the best of their abilities, in perpetuity.

Please sign the following statement:

I hereby grant permission to the Graduate Division of the University of California, San Francisco to release copies of my thesis, dissertation, or manuscript to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.



Author Signature

10/12/2018

Date