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Journal

Journal of Women's Health, 6(4)

ISSN

1540-9996

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Publication Date

1997-08-01

DOI

10.1089/jwh.1997.6.459

Peer reviewed

Women's Beliefs and Decisions About Hormone Replacement Therapy

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ABSTRACT

To examine preventive health practices in older women, we conducted computer-assisted telephone interviews with 1082 women aged 50–80 who were enrollees of Group Health Cooperative of Puget Sound (June–November 1995; 80.3% response rate). We sought to describe the women's reasons for initiating, discontinuing, or not initiating hormone replacement therapy (HRT). HRT use was categorized as current (42.5%), past (20.9%), or never (36.6%) based on the interviews. The reasons most frequently cited by current users for initiating HRT were menopausal symptoms (47.3%), osteoporosis prevention (32.4%), and physician advice (30.3%). The most frequently cited reasons for quitting HRT were side effects (26.6%), physician's advice (22.9%), fear of cancer (15.4%), and not wanting menstrual periods or bleeding (15.2%). Of past users, 53.8% reported stopping HRT on their own, and 46.2% did so at their physician's advice. The reasons most commonly cited by never users for not initiating HRT were that hormones were not needed (49.9%) and that menopause is a natural event (17.9%). Among never users, 33.1% reported considering HRT, only 46.6% discussing it with their provider, and 5.0% being given an HRT prescription they did not fill. Many women made decisions about HRT independent of interactions with health care providers. Better understanding of the beliefs and decisions that influence women's choice to use or not use HRT is needed to develop more effective counseling strategies.

MUCH REMAINS TO BE LEARNED about the prevailing reasons women in the United States initiate, maintain, or stop hormone replacement therapy (HRT, here used to mean postmenopausal estrogen replacement with or without progestins).¹ Few population-based studies have examined how women make decisions about HRT,^{1–4} and none of these studies included women beyond the age of 65.

Many currently published studies are from European populations,^{5–12} specially selected study populations,¹³ or convenience samples.^{1,14–17} Furthermore, the risk/benefit picture has changed dramatically over the last 30 years and continues to change rapidly as our understanding of the influences of HRT on various aspects of women's health increases.

The U.S. Preventive Services Task Force rec-

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This work was supported by grant U48/CCU009654-04 from the Centers for Disease Control and Prevention, and by the Office of Women's Health, Centers for Disease Control and Prevention, Atlanta, Georgia.

[Editor's note: See also Bastian et al. (p. 467) and WebWatch (p. 481) in this issue.]

ommends that all perimenopausal and postmenopausal women be counseled about the potential benefits and risks of hormone prophylaxis.¹⁸ Therefore, to find out more about HRT as part of a study on preventive health practices in older women, we explored decision making about this therapy among female members of a large health maintenance organization in Washington state. We sought to describe women's reasons for initiating, discontinuing, or not initiating HRT.

SUBJECTS AND METHODS

The study was conducted at Group Health Cooperative of Puget Sound (GHC), a staff-model HMO that provides medical care to more than 370,000 people in western Washington, including about 43,000 women aged 50–80. Methods for recruitment, informed consent, and the survey were approved by human subjects review committees at GHC, the University of Washington, and the Centers for Disease Control and Prevention (CDC). Our survey recruitment target was 1000 perimenopausal and postmenopausal women. We randomly selected 1520 women who met our eligibility criteria: aged 50–80 years, enrollment at GHC for at least 2 years before January 1, 1995, and having an identified primary care physician. To increase participation of minority women, we oversampled women in the three GHC clinics with the highest minority representation by a 3:1 ratio. Women who completed the survey received a \$10 check for their participation. As many as 26 attempts were made to reach the sampled women (mean = 3.86). After letters of invitation were mailed to all the selected women, 125 women were found to be ineligible: 11 were deceased, 27 were too ill, 2 were out of town during the survey period, 39 had severe language or hearing problems, 24 had disenrolled from GHC, 19 had no identifiable telephone number, and 3 had no telephone. Of the 1395 remaining women, 1120 (80.3% response rate) agreed to participate and completed the telephone interview. One completed interview was lost because of a software problem, 1 woman who completed an interview was found to be ineligible, and 36 inter-

viewed women were deleted from this analysis because they were premenopausal (still menstruating regularly and not using HRT). Thus, our final survey sample for this analysis included 1082 women.

The average interview completion time was 29 min (range 14–103 min). Survey items examined for the present study included demographic information, menopausal status, HRT practices, and reasons for initiating or not initiating HRT, changing the way HRT was taken, or stopping HRT. Questions about the reasons for HRT practices were open ended, and unlimited responses were permitted. Women whose periods had become infrequent or very irregular were classified as perimenopausal ($n = 50$). Women who were still having periods and taking hormone pills ($n = 35$) and women whose periods had stopped completely for at least 12 months ($n = 997$) were classified as menopausal/postmenopausal. Given the small number of perimenopausal women and women taking HRT who were still having periods, we chose to pool their responses with those of other menopausal/postmenopausal women. Response categories were created a priori to make coding easier for the interviewer. Responses not fitting predetermined categories were coded as "other" and recorded verbatim. We used self-reported HRT because survey questions about HRT decisions were based on answers to questions about HRT use. Women who reported they were currently using HRT were classified as current HRT users, women who reported not currently using HRT but using it in the past for at least 3 months were classified as past users, and those who reported never using HRT or having used it for less than 3 months were classified as never users. We classified 396 women as never users, of whom 66 reported having used HRT but not for 3 months at a time. Because of the survey design, these 66 women skipped some of the questions asked of other never users, and thus for some questions the number of never users with responses is 330 rather than 396.

Statistical methods

Differences in demographic characteristics by HRT use were compared using Chi square

statistics. Differences in the reasons for initiating or not initiating HRT or changing or stopping HRT were compared using age-adjusted proportions (direct adjustment to the age distribution of the entire sample). Logistic regression was used to compare, given a woman's response to these questions, the likelihood of being a current or past HRT user vs. never using HRT. Because we sought to better understand the reasons behind the decisions women made about HRT, we adjusted associations only for age and hysterectomy, the two factors we found to be most strongly associated with HRT status. Other variables examined but not controlled included race, education, marital status, smoking history, Quetelet index, and history of a first-degree relative with breast cancer.

RESULTS

We classified 460 women (42.5%) as current users, 226 women (20.9%) as past users, and 396 women (36.6%) as never users of HRT. Among

past users, the time since last use of HRT ranged from 3 months to 41.5 years, with a mean time since past use of 14.5 years. Current HRT users were younger, more likely to be either married or living as part of an unmarried couple, more likely to have had a hysterectomy, and less likely to have smoked than were never users (Table 1). There were no differences in Quetelet index or history of a first-degree relative with breast cancer by HRT status.

The reasons most frequently cited by current and past users combined for using HRT were menopause-related symptoms (48.7%), osteoporosis prevention (32.6%), and physician advice (29.6%). A larger proportion of current than past users said that osteoporosis prevention, cardiovascular disease prevention, and physician advice were reasons for HRT initiation (Table 2). All the reasons for HRT use listed in Table 2 except emotional distress were statistically associated with being a current user vs. a past user. Women who said they were taking HRT for osteoporosis prevention were almost five times as likely to be a current rather

TABLE 1. SUBJECT CHARACTERISTICS BY SELF-REPORTED USE OF POSTMENOPAUSAL HRT: GROUP HEALTH COOPERATIVE OF PUGET SOUND, ENPOWER STUDY, 1995

Characteristic ^a	HRT use status		
	Current n = 460 (42.5%)	Past n = 226 (20.9%)	Never n = 396 (36.6%)
Age (years) (%)**			
50-59	51.1	25.7	29.8
60-69	31.7	23.0	30.6
70-80	17.2	51.3	39.7
White race (%)	89.6	88.1	86.1
Education (%)*			
Less than high school	6.8	11.5	10.9
High school graduate	27.0	29.2	27.9
Some college	31.4	33.6	30.1
College graduate	34.9	25.7	31.1
Married/living as married**	68.9	57.5	56.8
Hysterectomy (%)**	49.6	37.2	24.2
Smoking status*			
Current	10.0	12.8	12.2
Past	43.9	37.6	31.65
Never	46.1	49.6	56.2
Quetelet index (kg/m ³) tertiles			
<24	31.7	34.7	34.1
25-28	34.4	31.6	32.8
≥29	33.9	33.8	33.1
At least one 1st-degree relative with breast cancer	15.0	17.3	12.4

^aCategorical variables were tested using Chi square test for heterogeneity.

* $p < 0.01$.

** $p < 0.001$.

TABLE 2. AGE-ADJUSTED PROPORTIONS FOR RESPONSES ABOUT REASONS FOR ESTROGEN USE AMONG CURRENT AND PAST USERS OF POSTMENOPAUSAL HRT AND OR AND 95% CI FOR CURRENT USE VS. PAST USE BY REASONS FOR HRT USE: GROUP HEALTH COOPERATIVE OF PUGET SOUND, ENPOWER STUDY, 1995

Responses to question, "What are/were the reasons that you take/took this pill?"	HRT use status		OR (95% CI) for current vs. past HRT use ^a
	Current n = 460	Past n = 226	
Menopause-related symptoms	47.3	50.2	1.70 (1.12, 2.59)
Osteoporosis, bone loss, fracture prevention	32.4	12.5	4.68 (2.70, 8.11)
Doctor prescribed it, told me to take it	30.3	17.5	3.48 (2.11, 5.75)
Cardiovascular disease prevention	15.6	5.3	2.49 (1.13, 5.53)
Other	13.5	10.8	2.21 (1.18, 4.13)
Depression, anxiety, emotional distress	8.4	9.1	1.00 (0.53, 1.88)
After hysterectomy or oophorectomy ^b	35.1	40.3	2.79 (1.18, 6.60)

^aAdjusted for age (continuous), hysterectomy (yes/no), and all other reasons listed.

^bAmong women with a surgical menopause.

than a past HRT user (odds ratio 4.68, 95% confidence interval 2.70–8.11), and those who said they were taking HRT because their doctor prescribed it or told them to take it were over three times as likely to be a current rather than a past HRT user (odds ratio 3.48, 95% confidence interval 2.11–5.75). Among women with a surgically induced menopause, 35.1% of current users and 40.3% of past users said that hysterectomy was a reason for HRT initiation.

There were 145 (31.5%) current HRT users who reported having to change the way they took their HRT pills or to switch to different pills. The most common reasons cited for making changes in HRT regimens were that menopausal symptoms had not improved (29.0%), physician advice (13.1%), and bothersome side effects (26.9%), including headaches (4.1%), breast pain (6.9%), and emotional distress (6.2%). Among the 88 current users who changed the way they took HRT and who had an intact uterus, 38.6% reported doing so to control bleeding or because they did not want to be bothered by menstrual periods.

Of past HRT users, 53.8% reported stopping HRT on their own; the remaining 46.2% stopped because of their physician's advice. These responses were age related in that younger women were more likely to stop on their own. The age-specific proportions of past users who stopped HRT on their own were 70.2% (age 50–59), 67.3% (age 60–69), and 40.5% (age 70–80).

Among the women who had never used

HRT, 33.1% reported they had considered using it, 46.6% that they had discussed it with their provider, and 5.0% that they had been given an HRT prescription that they did not fill. Among the never users, a higher proportion (49.5%) of those aged 50–59 had considered taking HRT than women aged 60–69 (34.7%) or those aged 70–80 (21.2%). Similarly, a greater proportion of the women aged 50–59 (57.7%) had discussed with their provider taking HRT than had those aged 60–69 (52.6%) or 70–80 (34.3%). Never users aged 50–59 were more likely to believe that they would consider taking HRT in the future (36.2%) than were those aged 60–69 (6.3%) or those aged 70–80 (9.1%).

The most frequently cited reasons for never using HRT were that hormones were not needed (49.9%) and that menopause was viewed as a natural event for which medications were unnecessary (17.9%) (Table 3). Fear of cancer (12.9%), fear of other side effects (12.9%), and doctor advice (13.3%) were the other most commonly cited reasons for not initiating HRT. Among past users, 39% quit because they feared or had experienced side effects, and 15.2% did not want to have periods. Doctor's advice (22.9%) and fear of cancer (15.4%) were the other most frequently cited reasons for stopping HRT. Three of these reasons distinguished never users from past HRT users. Women who reported "not wanting periods" were seven times more likely to be a past user than a never user. Conversely, the belief that menopause is a natural event and that

TABLE 3. AGE-ADJUSTED PROPORTIONS FOR RESPONSES ABOUT REASONS FOR NEVER INITIATING OR STOPPING HRT AND OR AND 95% CI FOR PAST USE VS. NEVER USE BY REASONS FOR NEVER INITIATING OR STOPPING HRT, GROUP HEALTH COOPERATIVE OF PUGET SOUND, ENPOWER STUDY, 1995

Responses to question, "What are the reasons you quit/decided not to take this pill?"	HRT use status		Odds ratio (95% CI) for past vs. never use ^a
	Past n = 226	Never n = 330	
Doctor advised against it	22.9	13.3	1.12 (0.66, 1.88)
Did not want periods/bleeding ^b	15.2	1.6	7.02 (1.90, 26.00)
Did not think I needed them/no need, symptoms were gone, therapy was done	13.8	49.9	0.16 (0.10, 0.25)
Menopause is natural, medication is not needed	2.8	17.9	0.17 (0.07, 0.42)
Feared side effects	7.0	12.9	0.62 (0.61, 1.23)
Fear of cancer	15.4	15.3	0.68 (0.39, 1.16)
Do not like taking pills	6.7	7.8	0.85 (0.39, 1.82)
Other	20.8	16.5	1.17 (0.68, 2.02)
Friends advised against it	1.2	0.7	
Media advised against it	1.2	1.2	
Had side effects	26.6	NA	
Doctor did not mention it	NA	9.7	
Never heard about i	NA	1.2	
Symptoms did not improve	7.9	NA	
Breast pain	2.5	NA	

^aAdjusted for age (continuous), hysterectomy (yes/no), and all other reasons listed.

^bBased on women with a natural menopause.

medications are not needed was strongly associated with being a never user.

Among never users, there was little difference according to age group in reasons for not initiating HRT (data not shown). However, among past users, several differences between age groups in reasons for quitting HRT were noted. Women aged 50–59 more frequently cited lack of symptom improvement (12.7%) and the occurrence of side effects (41.8%) as reasons for stopping HRT than did women aged 60–69 (4.2% symptoms, 15.0% side effects) or women aged 70–80 (5.6% symptoms, 18.8% side effects). The proportions of women aged 70–80 citing physician advice (36.5%) and the belief that they did not need HRT (17.5%) were higher than the comparable proportions for women aged 50–59 (12.7% physician advice, 7.3% did not need HRT) or women aged 60–69 (20.8% physician advice, 8.2% did not need HRT).

DISCUSSION

We employed a cross-sectional population-based survey of perimenopausal and postmenopausal women aged 50–80 to elicit char-

acteristics associated with and reasons for HRT decisions. We found, as have others,^{2–6,20} that current users of HRT were younger, better educated, and more likely to be married than women who had never used HRT. When women were asked their reasons for taking HRT, menopausal symptoms, osteoporosis prevention, cardiovascular disease prevention, hysterectomy, and physician advice were strongly associated with being a current vs. a past user of HRT. These results are consistent with those of others.^{2,5,7,10,11–14,15–17} Nevertheless, many women appear to be either misinformed about the role of HRT in osteoporosis prevention or do not view HRT as personally relevant in fracture prevention. The findings of other investigators suggest that ignorance of HRT's ability to prevent bone loss is very common. For example, Koster⁷ found that only 18% of current HRT users cited osteoporosis as a reasons for HRT use. In a British study, Roberts¹¹ found that only 7% of current users reported using HRT as prophylaxis against osteoporosis. The proportion of current HRT users who cited cardiovascular disease prevention as a reason for HRT use was small. Many women appear unaware or unconvinced of the potential role of HRT in cardiovascular

disease prevention. Cardiovascular disease has rarely been mentioned in other studies as a reason for taking HRT. In a survey in England, only 6.6% of women were aware of the role of HRT in preventing cardiovascular disease.²¹

Not wanting periods was the factor most strongly associated with stopping HRT (past use), whereas the beliefs that HRT was not needed and that menopause is a natural event were most strongly associated with never initiating HRT. The majority of past HRT users stopped HRT on their own, rather than at their physician's advice, although cessation was more common among younger women than women aged 70 and older. Reasons for quitting or not initiating HRT documented in other survey research include the beliefs that HRT is unnecessary and that menopause is a natural event,^{4,6,17} fears about cancer risks,^{10,22-23} the presence or fear of side effects,^{7,10,12,23} physician advice,⁶ the controversial nature of HRT,²³ and that the therapy was meant to be short term.⁶ Concerns about bleeding appear to be a particularly strong deterrent to HRT.^{7,16,19,22,23} For example, Hahn et al.²⁴ found that 89% of women with a uterus who were taking combined therapy quit within 18 months because of withdrawal bleeding, whereas all women with a hysterectomy continued therapy. Similarly, in a randomized trial of continuous combined therapy vs. sequential HRT, breakthrough bleeding was a major cause of changing or discontinuing sequential HRT, whereas women on continuous combined therapy were much more likely to continue HRT.¹⁹ Clearly, the development of HRT treatment regimens that eliminate bleeding is essential to making HRT acceptable for many women.

The strengths of this study include its population-based sample from a large staff-model health maintenance organization, the broad age range of the participants, and the study's ability to elicit information about women's reasons for their HRT decisions. HRT use is quite high in our population compared with those of many other published reports of HRT use in women in the United States.^{1-3,13,17,19} The reasons underlying the relatively high use in our population are unclear. However, HRT use is higher in the West than in other regions of the United States.²⁵ Prevalence of HRT use is increasing throughout the United States,²⁵ and our survey

is more current than those of many other published reports, which may also partially account for our finding a high prevalence of HRT use. Finally, it is possible that the strong commitment to prevention and population-based care at Group Health Cooperative plays a role.

The cross-sectional nature of the data did not allow us to draw conclusions about which factors actually predict HRT initiation, maintenance, or discontinuation. Furthermore, because of the ages of the women interviewed, many were responding to events that occurred decades before the interview, and this could account for some of the differences observed between past and current HRT users. There have been rapid changes in attitudes about the use of HRT over the last 20 years, particularly its use for prevention of osteoporosis and cardiovascular disease. Finally, generalizability of our results is limited to similar, largely working-class and middle-class, well-educated, white populations.

Our findings have several practical implications for developing interventions to promote informed decision making about HRT. Given the central role of health care providers in women's decisions related to HRT, programs should encompass multiple sources of information. For example, in addition to provider counseling, workbooks with tailored feedback about HRT can assist in empowering women with information. Based on the findings of this study, information should include the use of HRT for relief of menopausal symptoms and prevention purposes, the risks and benefits of HRT, and alternative approaches to HRT for prevention of osteoporosis and cardiovascular disease. Nevertheless, many women make decisions about HRT without consulting their health care provider. Women could benefit from a workbook describing strategies to promote effective communication with their health care provider. In particular, strategies should be targeted at assisting women in having a meaningful discussion with their health care provider about HRT. Providers who will be involved in counseling women about HRT might profit by assessing women's perceptions about and experiences with HRT before having a discussion. Finally, counseling interventions need to go beyond a single discussion to help women reassess their earlier decision not to use HRT or to address barriers women confront as they undergo treat-

ment. Bleeding secondary to HRT is a major issue for women, one that if unresolved will lead many HRT users to abandon this beneficial therapy. In summary, better understanding of the beliefs underlying women's decisions about HRT can assist in developing more effective strategies to ensure that women make informed decisions about HRT initiation and maintenance.

ACKNOWLEDGMENTS

The authors acknowledge the contributions of Adele Franks, M.D., and Suzanne Smith, M.D., in the development of this study and the efforts of Ben Givens for his assistance in data preparation and Darlene White for assistance in data collection and study management.

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