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Women at mid-life: symptoms, attitudes, and choices, an internet based survey

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Abstract

Objectives: This Internet-based survey questioned middle-aged women (age 35-69) regarding their current attitudes, beliefs, symptoms, and treatment choices surrounding the climacteric. *Methods:* 448 respondents completed the 189 item, WEB-based survey that included measures of quality of life, lifestyle habits, anxiety symptoms, and questions regarding attitude toward and sources of information about *menopause*. *Results:* Three relationships were hypothesized and supported: frequency of self-reported *menopause* symptoms would be: (1) negatively associated with healthy behaviors; (2) positively associated with anxiety; (3) positively associated with stress. All measures were self-report. Fatigue, muscle and joint aches, and impatience were the most commonly reported symptoms. No particular symptom was strongly correlated (r > 0.4) to lifestyle behaviors. Questions regarding information exchange reveal that many women are not consulting with their healthcare providers about HRT or frequently discussing alternatives. Many receive health information from lay sources. *Conclusions:* There is a need for improved information exchange on this subject. Our results are similar to those found using large randomized telephone survey methods, which supports the use of the Internet as a reliable and convenient venue for gathering data regarding health issues. It is important to consider healthy lifestyle behaviors toward the regulation of the climacteric syndrome. © 2001 Elsevier Science Ireland Ltd. All rights reserved.

Keywords: Menopause; Climacteric syndrome; Internet; Attitudes; Information; Hormone replacement therapy

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¹ Since this study was done, the International Menopause Society, working with its international policy group, the Council of Affiliated Menopause Societies (CAMS) has developed standard definitions to be used in the field of menopause research. *Menopause*, or *natural menopause*, refers to the biological event of the cessation of menstruation for a year due to loss of ovarian follicular activity. *Climacteric* refers to the phase of life in which a woman moves from a reproductive to a non-reproductive state. This phase is more individually variable, extending before the perimenopause, through perimenopause, menopause, and past postmenopause. *Climacteric syndrome* refers to the symptoms that sometimes occur with the climacteric. [15]. In the present paper, we are looking at self-reported experience and symptoms that subjects attribute to menopause. The most appropriate term for a focus on this time of life and symptoms, and the one used in this paper, is *climacteric syndrome*. Yet *menopause* was used in our interactions with subjects, as it is the recognized term often used by the public to refer to this time of life. To accurately report our measures and results, and allow for comparisons to other work, in this paper we will remain true to the language that our subjects saw. Thus, this paper will use the terms *menopause* and *perimenopause*, presented in italics: (1) if these are the words that our subjects saw and interacted with; and (2) in reference to wording in measures that use these terms. Additionally, the terms will appear in plain text if used per the International Menopause Society definition.

1. Objectives

Today, most women will live well past the menopause¹. The treatment most often offered by medical practitioners for reduced follicular activity is hormone replacement therapy (HRT). Yet use of this therapy remains controversial. Further, while there is much research on HRT, little is known about the correlates of climacteric experience and possible non-hormonal leverage points for treatment [1].

Current standards of medical practice posit the use of HRT as appropriate for most women, not just for those who experience symptoms [2]. Yet, HRT has a very low compliance rate in the United States; estimates vary by study design and population from only about 15 [3] to 54% [4]. Hypothesized causes of non-compliance include unpleasant side effects [3], and a lack of physician education [5]. Low prevalence of acute physical symptoms may also be a factor. Twenty years ago only 4–20% of women reported serious symptoms [6], and more recent reports show the same [3].

Much menopause research focuses on patient compliance with HRT regimens and HRT's ability to decrease vasomotor symptoms. But there is debate over the use of HRT to treat decreased estrogen production [7]; for example some focus on the long-term benefits of HRT while others see universal hormone use as overmedicating. Still. less is known about where women get their information about menopause and HRT, and what symptoms might be experienced beyond the vasomotor. Further, the low compliance rate of HRT suggests that other points of intervention deserve scrutiny as adjuncts or alternatives to HRT regimens. In the present study we look at the association between climacteric experience: and (1) certain lifestyle behaviors; (2) the psychological state of anxiety; (3) the contextual influence of stress.

The connections between anxiety and climacteric syndrome [8] and life stress and climacteric syndrome [9,10] are well substantiated. This present study explores the relationship between both stress and anxiety, and climacteric syndrome. We see both stress and anxiety as potentially influential. We also examine the links

between symptoms and healthy lifestyle behaviors such as diet and exercise, as these have been essentially ignored in the popular media [11].

This study was designed to: gather information regarding types and severity of physical/emotional disturbances experienced by women at mid-life, record the most utilized sources of health and *menopause* information, explore associations between climacteric syndrome and lifestyle behaviors, stress, and anxiety. Specifically, three relationships were hypothesized: the frequency of reported climacteric symptoms will be: (1) negatively associated with healthy behaviors; (2) positively associated with stress.

The Internet was used to solicit subjects and collect survey responses. The Internet is developing as a resource for data collection as it becomes accessible to a broader range of people. The greater availability of Web television and phones incorporating e-mail are two examples of modes of expansion [12]. In 1994 about 4 million people linked to online services. These numbers have been growing in America, as have their European and Canadian counterparts [13]. It is true that households whose primary supporter is affluent, well-educated, White or Asian are more likely to possess a personal computer. Still, all recorded demographic groups increased ownership between 1990 and 1997 according to the U.S. Department of Labor [14]. As accessibility becomes less of an issue, the use of the Internet for research purposes will become more popular. The Internet is potentially one of the most economical forms of data collection. It offers a level of anonymity that is especially helpful when collecting information on sensitive issues [12]. Researchers can also compare results found using the Internet to those found using more traditional methods to validate the Internet as a measuring instrument.

2. Methods

2.1. Sample

The sample self-selected from visitors to the Women's Health Interactive Web site. This site

Table 1 Sample characteristics

Place of residence	U.S. (91%)
Place of birth	U.S. (82%)
Type of care	
Western doctor	90%
	(N = 383)
Complimentary	5%
	(N = 21)
Use HRT currently	31%
	(N = 130)
Ever use HRT	$19\% \ (N = 57)$

Table 2
Menopause symptoms reported in last month^a

Symptom	N (% reporting)
Feeling tired or worn out	380 (89%)
Feeling a lack of energy	355 (83%)
Being impatient with other people	336 (80%)
Aches in back or neck or head	336 (80%)
Feeling depressed, down or blue	323 (76%)
Aching in muscles and joints	329 (76%)
Decrease in stamina	325 (76%)
Feeling anxious or nervous	305 (76%)
Feeling bloated	317 (73%)
Experiencing poor memory	315 (73%)
Flatulence (wind) or gas pains	316 (73%)
Accomplishing less than use to	305 (71%)
Feelings of wanting to be alone	297 (70%)
Weight gain	293 (69%)
Being dissatisfied with personal Life	274 (68%)
Difficulty sleeping	274 (65%)
Hot flushes or flashes	272 (63%)
Decrease in physical strength	274 (63%)
Changes in appearance in texture or tone of skin	269 (63%)
Change in sexual desire	267 (62%)
Low back pain	269 (62%)
Dry, itching skin	263 (61%)
Frequent urination	247 (57%)
Avoiding intimacy	235 (55%)
Sweating	221 (54%)
Night Sweats	227 (54%)
Involuntary urination when laughing or coughing	229 (53%)
Vaginal dryness during intercourse	190 (45%)
Increased facial hair	175 (40%)

^a Menopause symptom reporting Table 2 displays the number and percent of subjects reporting various symptoms associated with menopause.

uses an interactive environment to provide information, advice, services, and a forum for learning about women's health issues. The creators of Women's Health Interactive offered the authors the opportunity to place measures on their site for the purposes of data collection.

Women who self-defined as experiencing the symptoms of *menopause/perimenopause* were invited to participate in a research study about *menopause*. After reading a statement of consent and confidentiality, potential subjects who agreed to offer research consent could move on to answer the three-page questionnaire. Subjects answered the questions on the WEB page and information was electronically passed to the database at *Women's Health Interactive*. Subjects could decide not to participate at any point before submission of the completed questionnaire page. Sets of data collections were sent to the researchers every 2 months.

The climacteric status of our sample was supported in three ways. First, all subjects self-defined as experiencing *perimenopause* or *menopause* symptoms. Second, subjects ranged in age from 35 to 69 years of age with a mean age of 47 and a standard deviation of 5.6. McKinlay, Brambilla and Posner [16] purport 47 as the average menopausal transition time, a time when vasomotor symptoms peak. Third, all subjects answered yes to at least seven items of the 29-item checklist of symptoms associated with *menopause*.

About 10% of those that viewed the questionnaire finished the survey. Most (91%) live in, and 82% were born in, the United States. Eighty-two percent have received gynecological care in the last year. Most subjects visit a Western Doctor for their care (90%). There were only 30 distinct accounts of the use of Herbalists, Chinese Doctors, Ayurvedic Doctors, Naturopaths, or Holistic Doctors. Only 31% (n = 130) were currently using HRT and 19% of those that reported not using HRT had used it at sometime in the past (see Table 1).

Frequencies of self-reported *menopause* symptoms can be found in Table 2. Feeling tired and lacking energy were the most frequently reported symptoms. All symptom categories were reported by at least 40% of the respondents.

2.2. Description of measures

The Health-Promoting Lifestyle Profile II is a 52-item behavior rating scale. It uses a four-point response format to record the frequency of self-reported health-promoting behaviors. It taps into the domains of health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management. Questions are asked as frequencies (Never, Sometimes, Often, Routinely) of behaviors. For example questions include 'Take some time for relaxation each day' and 'Eat 2–4 servings of fruit each day'. It has been used frequently in published work and has good reliability and validity [17].

The General Symptom Stress Measure was developed to measure perceived stress in the general population. It was developed by researchers at The Division of Behavioral Medicine at Beth Israel Deaconess Hospital in Boston and has been used clinically for 12 years. It is a 10-item measure which records perceived degree of stress in areas of life such as work, family, finances, neighborhood, and health. Respondents are asked to check the number corresponding to the degree of stress felt in each area (1 being no stress and 10 being the worst stress possible). It achieved good internal consistency (Cronbach's alpha of 0.7) using the present sample and its years of clinical use speak to its solid face validity.

The Spielberger State-Trait Anxiety Inventory, state portion of the short form, was used. This state anxiety measure is 10 items and utilizes a four-point response format. Respondents are asked to check the number corresponding to how they generally feel (1 being "very much' to 4 being "not at all'). Items include "I feel calm", "I am tense", and "I am relaxed". Reverse coded items were properly adjusted for analysis. This measure is stable and comparable to the well-used 40-item State-Trait Anxiety Inventory [18]. It achieved a Cronbach's alpha of 0.9 in this sample.

The Menopause Quality of Life Questionnaire, developed by John Hilditch and Jaqueline Lewis in 1992, was the outcome measure used. It is a 29-item checklist and scale of degree of discomfort (1 being bothered only a little and 6 being bothered a lot) associated with reported experi-

ence of *menopause*. Specific questions are listed in Table 2. We collected data on both symptom experience and degree. This analysis used the outcome of symptom experience, not degree of experience. It is a very comprehensive measure with solid psychometric properties [19].

2.3. Analysis plan

Expected standards of confidentiality were followed. Submissions were protected once received and only the authors had contact with the data. E-mail addresses and names were only used for the data cleaning process and were not associated with any other part of the analysis.

We performed extensive data cleaning with particular attention paid toward duplicate entries. We were sensitive to the anonymity that data collection using the Internet offers. Although we have no reason to believe that subjects would falsify their identity to submit more than one questionnaire, duplicates were labeled as such if both the name and e-mail address of a subject were identical in more than one case. This happened in a few cases in which subjects apparently submitted the entry without double checking their e-mail address: the mistake was obvious for in all cases the first in a pair of duplicate entries had an invalid e-mail address. For example subjects submitted top level domains such as 'cmo' instead of 'com'. Uncontroversial duplicates, in which the only differences were obvious e-mail mistakes, were removed. This was the only consistent data cleaning problem. More generally, although individuals could offer duplicate submissions, we do not believe this occurred any more frequently than might happen with the more popular forms of data collection, such as mail and telephone surveys.

We then conducted the descriptive analysis and linear regression modeling using the STATA statistical analysis package. Exploratory data analysis was performed using tabulations, and variable plots. No outliers were found. Linearity was assessed and supported using residual plots. The three linear models described here use straight sum scores of the variable indicated; that is scores for each measure are simple totals. These

Table 3 Information exchange

	% (of N)
Where women receive information about 1	HRT
Magazines and books	70% (426)
other women	50% (426)
Internet	40% (426)
TV and radio	23% (426)
Seminars	12% (426)
Where women receive health information	
Magazines and books	80% (425)
Other women	60% (425)
Internet	60% (425)
TV and radio	41% (425)
Seminars	21% (425)
Discussions of HRT with Health Care Practitioners (HCP)	
Had discussed HRT with (HCP)	66% (412)
HCP start discussion	51% (283)
Subject start discussion	49% (283)
Discussion of HRT with HCP included	
Benefits of HRT	54% (426)
Risks of HRT	44% (426)
Alternatives to HRT	17% (426)
Costs of HRT	5% (426)

sums were used as final scores. All outcome coefficients were significant to P < 0.001. Regression coefficients and confidence intervals are shown in Table 4.

3. Results

3.1. Healthcare provider information sources

Discussions with Healthcare Practitioners about HRT were reported by 66% of women. In 49% of the cases reporting the subject started the discussion about HRT; the remaining cases re-

Table 4 Menopause symptoms and stress, anxiety, and health behaviors

Model	Regression coefficient	Wald test P	95% CI
Health behaviors on reported menopause symptoms	-1.51	P<0.001	(-1.98, -1.02)
Anxiety on reported menopause symptoms	0.45	P < 0.001	(0.33, 0.56)
Stress on reported menopause symptoms	0.79	P < 0.001	(0.61, 0.96)

ported that the Healthcare Practitioner started the conversation. Most distressing is the unbalanced nature of these recalled discussions. About half of the women remember the benefits of HRT being discussed (54%), but only 44% remember discussion of the risks of this medication. Only 5% of the conversations reportedly included mention of the costs of HRT, and 17% reported that their discussion included information about alternatives to HRT.

3.2. Non-provider information sources

Table 3 displays where women reported getting their health information and specifically their information about HRT. Magazines and books were popular sources of information. That many women use the Internet as a source of information is not surprising given our sampling technique. Still, even without considering the Internet a major source of information, the proportion of women that receive health information from nonmedical sources is very high. Most women (70%) are receiving HRT information from magazines and books, and 50% receive information from other women. Almost a quarter sited the television and radio as sources. Few (only 12%) cited seminars as a source of information. The same pattern of use was described for information about health more generally.

3.3. Lifestyle behaviors and climacteric syndrome

All of the linear regression models used to test our hypotheses can be found in Table 4. A negative relationship was estimated between lifestyle behaviors and total number of reported menopause symptoms. Specifically, scores on the Lifestyle Profile measure can be expected to de-

crease 1.51 points for every one-unit increase in the *Menopause Quality of Life Measure*.

3.4. Anxiety and climacteric syndrome

A positive relationship between total scores on the *Menopause Quality of Life Measure* and the *Spielberger Anxiety Measure* was estimated. More reported symptoms are associated with greater anxiety.

3.5. Stress and climacteric syndrome

A positive relationship was found between total number of reported *menopause* symptoms and stress; more symptoms are associated with higher stress scores. Specifically scores on the *General Symptom Stress Measure* increased 0.79 for every one-unit increase in the *Menopause Quality of Life Measure*.

3.6. Assertive health consumers

Over half (66%) of the respondents had discussed HRT with a healthcare practitioner. Women who had discussed HRT were more likely to report positive health behaviors (coefficient = $7.951821\ P < 0.005.\ 95\%CI\ 2.483587\ 13.42006$). Although this difference is statistically significant it is less than one standard deviation of the health behaviors scale. Half of this 66% had initiated this discussion with their provider; but patient initiation of the HRT discussion was not significantly related to increases in healthy behaviors. Thus it appears that there *is not* a group of women in our sample which is particularly more assertive about health issues than the rest of the sample.

3.7. HRT, symptoms, and behaviors

We looked at the relationships between ever using HRT and currently using HRT with scores on the *Lifestyle Behaviors* measure and the *Menopause Quality of Life Measure*. None of these relationships were even marginally significant. Thus in this sample, HRT use status was not significantly related to healthy lifestyle behaviors, or to current severity of *menopause* symptoms.

4. Conclusion

This Internet-based survey sought the current attitudes, beliefs, symptoms, and treatment choices surrounding menopause from a group of middle-aged women (age 35-69) who self-defined as experiencing menopause or perimenopause symptoms. Results suggest that some professional sources of health information are deficient. Interactions were inconsistent across the population, in occurrence and initiator. These interactions often neither included information such as the risks of HRT, nor addressed areas of interest to many women such as information about health habit behaviors and alternatives to HRT. Only 66% of respondents had discussed HRT with their healthcare provider and only 17% of respondents reported that they had talked with their healthcare provider about alternatives to HRT. Given the recent increase in attention to alternatives [21] this percentage is low.

Decisions made regarding exercise, nutrition, and hormone replacement therapy are likely to have a major impact on long-term health. For example, women who are overweight need information regarding cardiac risk; women who are thin or underweight need information regarding osteoporosis. Risk reduction and health promotion efforts are likely to have a powerful impact on the incidence of these disease states now, and as the mid-life cohort ages.

Overall, women are utilizing many sources of information on general health and HRT. Most use some informal source of information, such as the Internet, magazines, and books. Similar percentages for magazines and books have been reported elsewhere by Kaufert et al. [20]. Yet, the Kaufert et al. study found lower percentages for TV and radio as well as for informal contacts. Informal contacts in the Kaufert et al. study were 'family and friends', and this category gathered only 15% of total respondents. The present study used a different categorization, 'other women', and this category was checked as a source of information for 50% of respondents. This is an interesting difference, and may point to a difference in style of information exchange between women that use the Internet, and those that do

not. This difference may also be due to the study populations used. Kaufert et al. [20] used a random sample of women 45–60, whereas our sample self-selected as symptomatic and thus may more closely resemble a clinical sample. In addition, our subjects may be more active information consumers as they initiated participation in our study. Regardless, that we found women utilizing many lay sources of information, such as other women and magazines and books, with great frequency, points to the need for accurate lay health information.

In considering professional sources of information, we found that healthcare providers may be focusing on the benefits of HRT while offering less information concerning risks, costs, and alternatives. This is significant for a few reasons. First, most women do not choose HRT, and for these women, information regarding alternatives, such as exercise and nutritional change, are essential. Second, as positive lifestyle behaviors are associated with fewer symptoms, all women might benefit from lifestyle changes regardless of their HRT decision.

The amount of potential benefit for only a small amount of behavior change may be very large. Each point on the *Health-Promoting Lifestyle Profile* scale represents movement in only one category, from one measure of frequency to another (for example, from 'Never' to 'Sometimes'). Thus a small behavior change might show a great amount of change in symptom experience. A different study design is needed to test this hypothesis.

The negative relationship between lifestyle behaviors and symptoms is promising. Still, due to our study design we are not able to determine if engaging in more healthy behaviors decreases the frequency of some *menopause* symptoms. Alternatively, those women with more symptoms may have less ability to perform healthy behaviors, or the result could be caused by other unidentified factors. However, there is much published support for an association between lifestyle behavior and *menopause* symptoms, specifically that an increase in healthy behaviors should help overall health, and relieve *menopause* symptoms or their perceived severity [22].

We share the excitement of other researchers that the Internet will continue to be a viable source of health promotion and data collection [12,13]. This

venue offers the anonymity that is required to get accurate data surrounding sensitive issues such as menopause. However, use of the Internet for research presents specific challenges. Most generally, gaining representative samples can be difficult because Internet use is not yet equally or randomly observed in the United States. Most users are male (66%), have an average household income of \$69000 [12], and are between 45 and 54 years old [14]. Still, computers and linkages are becoming increasingly common. Four million home computers were linked in 1994; this figure is not taking into account the computers available in the workplace. The use of the Internet via home computers, Web television, and phones incorporating e-mail, has been growing rapidly [12,13]. The age group with the largest increase in ownership is 55-64 year olds [14]. As accessibility becomes less of an issue, representative samples will be easier to obtain, and the use of the Internet for research purposes will become even more popular.

The Internet is potentially one of the more economical forms of data collection. The information gathered can also be of good quality, but it is up to the researcher to offer evidence of data quality. In the present study, we did not collect socioeconomic information, but we do know that for the time the survey was presented to the public, 76% of those that registered with the WEB site were consumers: 24% were health professionals. We also found sample proportions of reported information sources that replicate those found by large-scale surveys [20]. Thus while, we may know less about our sample gathered with anonymity on the Internet, we have confidence that our sample acts in a similar way to samples we do know much about. Still, the impact of our results would be strengthened if we knew more about the population.

In this same vein of generalizability, our sample consists of women who self-selected as experiencing *menopause* or *perimenopause* symptoms. The relationships that we found, while significant in our sample, may not hold true in the general population. An interesting next step for this project, would be to repeat sampling using multiple diverse populations, such as multiple WEB sites, some which are not menopause related, and targeting adult symptomatic and asymptomatic women.

The highly significant positive associations between both: (1) increased anxiety; and (2) increased stress scores, with increasing self-reported menopause symptoms demand further study. The direction of effect can not be assessed in this cross-sectional design but some models suggest that felt anxiety may lead to symptom expression [8]. As there is evidence that it is possible to decrease the anxiety surrounding menopause treatment merely by providing patient education [23], it follows that better information might lead to reduced symptom experience. This is an interesting question for a different study design. Further, the relationship between stress and symptoms adds to the decades of work linking women's stress and the experience of menopause [9,10], and supports the use of programs to reduce stress at this time of life.

These results highlight the value of stress management and anxiety regulation as modifiable factors that may help relieve climacteric syndrome. This is not a call for a return of the definition of menopause as psychopathology, but rather an acknowledgement that physical and psychological variables interact to create the level of distress experienced during the climacteric. We need increased attention to the: (1) connections between climacteric syndrome and healthy lifestyle behaviors; (2) practices that buffer stress and reduce anxiety; (3) treatment options that do not carry the risks or worry of HRT. Such interventions may be more accepted by women who are not willing to use HRT.

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