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## The Effects of Hormone Therapy Decision Support for Women with Mobility Impairments

Heather Becker, Ph.D. [Research Scientist], Alexa K. Stuifbergen, Ph.D., R.N., F.A.A.N. [Professor and Associate Dean for Research], and Sharon L. Dormire, Ph.D., R.N. [Assistant Professor]

The University of Texas at Austin, School of Nursing, 1700 Red River, Austin, Texas 78701, Phone: 512-471-9097, Fax: 512-475-8755

Heather Becker: heatherbecker@mail.utexas.edu; Alexa K. Stuifbergen: astuifbergen@mail.nur.utexas.edu; Sharon L. Dormire: sdormire@mail.nur.utexas.edu

### Abstract

Deciding about hormone therapy (HT) use is particularly complex for women with mobility impairments. While HT controls menopausal symptoms, the potential increased risk of blood clots resulting from physical inactivity can contraindicate HT use. These women, therefore, may benefit from interventions to help them tailor standard information about HT. We randomly assigned women to receive either a tailored decision support intervention or standard menopausal information. Both groups (n=176) significantly decreased their decisional conflict and uncertainty, and increased knowledge after receiving the treatment materials. We interpret the findings in the context of limited medical information about HT for women with disabilities.

### Keywords

Women with disabilities; menopause; decision-support

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Recent medical findings have made decision-making about taking hormone therapy (HT) more difficult for mid-life women world-wide. Professional standards now recommend that this decision should be individualized for each woman (The American College of Obstetricians and Gynecologists, 2003 August). In this study, we tested an intervention designed to help women with mobility impairments tailor standard information about HT to their specific risks/benefits.

For women with mobility impairments, the risk/benefit analysis necessary for individual decisions about HT can be complex. These women may enter menopause with decreased weight bearing and aerobic activity, which puts them at greater risk for osteoporosis and cardiovascular problems (Smeltzer, Zimmerman, Capriotti, & Fernandez, 2002; Turk, Scandale, Rosenbaum, & Weber, 2001; Vandenakker & Glass, 2001). Women with cerebral palsy, spinal cord injury, or spinal bifida may face increased risk for thrombosis (i.e., blood clots) due to hypercoagulation states associated with immobility (Vandenakker & Glass, 2001). Women who experience temperature fluctuations as part of their disability may find hot flashes during menopause particularly troublesome. Among people with spinal cord injury, the incidence of skin breakdown and urinary tract infections increases with age and may increase when estrogen levels decrease (Nosek, 2000; Vandenakker & Glass, 2001).

While HT controls menopausal symptoms, the potential for increased risk of thrombosis, as well as potential interactions with other medications (e.g., steroids) can be a contraindication for HT (Welner, Simon, & Welner, 2002). Few studies have looked specifically at HT use among women with disabilities, and most were conducted prior to the discontinuation of the Women's Health Initiative (Becker, Stuijbergen, & Gordon, 2002; Jackson and Wadley, 1999; Kalpakjian, Riley, Quint, and Tate, 2004).

### **Decision Support Interventions**

Health care decisions must often be made in an environment where risks and benefits are associated with all options, leading individuals to experience decisional conflict. To help people make health care decisions, O'Connor and her colleagues developed the Ottawa Decision Support Framework, based upon decisional conflict, social support, and expectancy value theories. This approach has been used internationally to develop support interventions for health care decisions, including HT. These decision aids help patients understand the probable risks and benefits associated with various options, identify their values in regard to these risks and benefits, reduce decisional conflict, and build self-efficacy for active participation with their provider in making the decision (O'Connor et al., 1998a; O'Connor & Jacobsen, 2001).

Following exposure to a decision aid, 94 post-menopausal women significantly improved their knowledge, values congruence, decreased decisional conflict, and had more realistic expectations about HT risks and benefits (O'Connor et al., 1998a). Approximately half the women who had been uncertain at baseline became more certain about their decision after exposure to the aid. In a subsequent study, women receiving the aid had significantly more realistic expectations of benefits and risks and significantly lower Decisional Conflict scores than did women receiving a general educational pamphlet, although their knowledge scores did not differ (O'Connor, et al., 1998b). Other researchers also found that decision support interventions increase knowledge, satisfaction with health providers, self-efficacy and adherence, as well as decreasing decisional conflict among mid-life women (Rothert, et al., 1997; Woods, et al., 2002).

Our purpose in this randomized clinical trial was to test a decision-support intervention, adapted from O'Connor's work, that teaches women with mobility impairments how to tailor information to their specific risk/benefit profile. We hypothesized that women with mobility impairments who received a tailored decision support intervention would report significantly greater satisfaction with their decision, increased HT knowledge, and decreased decisional conflict and uncertainty, compared with women who received a standard educational booklet.

## **Methods**

### **Recruitment**

Following Institutional Review Board approval, project information was sent to disability programs and disability researchers throughout the U.S., including at least one independent living center in each state, and posted on websites for people with disabilities.

Unlike some health care choices, the decision to use HT is not an irreversible decision. Women and their providers alter this decision in response to the changing state of the science on hormone therapy and alternative symptom treatments (Willett, et al., 2000). Because HT decision-making can be so changeable, women were not required to indicate they were presently making an HT decision to participate in this study. Women did have to be between the ages of 40-65 and have at least 2 of 4 mobility limitations identified in the National Health Interview Survey or indicate that they used adaptive equipment because of

mobility limitations. While not all of these women were menopausal (defined as the cessation of menses for at least 6 months), all were in the age range to consider the decision to use HT when they became menopausal.

## Procedure

A questionnaire packet mailed to eligible women included a consent form, questions about health history and demographics, the Decision Conflict Scale, the knowledge test, and a question about the likelihood of taking HT. When baseline questionnaires were returned, women were randomly assigned to either the tailored decision support condition or the NAMS *Menopause Guidebook* condition. They were then mailed the materials for their group and a questionnaire packet that included the Decision Conflict Scale, the knowledge test, the Satisfaction with Preparation for Decision Making Scale, an evaluation of the materials, and an item assessing likelihood of HT use. Women were instructed to complete the questionnaires after reviewing the treatment materials. Follow-up phone calls were made to encourage return of completed questionnaires from those who did not return them within a few weeks.

Six months after participants indicated they had completed their second questionnaire packet, the last questionnaire packet was mailed to them. It included the Decisional Conflict Scale, the knowledge test, a shortened health history form, the Satisfaction with Preparation for Decision Making Scale, and the item about likelihood of taking HT. Women were sent money orders and a summary of the results in appreciation for their participation.

## Instruments

O'Connor's 16-item Decisional Conflict Scale assesses uncertainty about the choice to use HT, values clarity, and perceived support, information and decision making effectiveness (O'Connor et al., 1998a). Higher scores reflect greater decisional conflict. A Coefficient Alpha of .95 was observed in a previous study of women with physical impairments (Becker, et al., 2002).

A 20-item knowledge scale adapted from O'Connor and her colleagues' scale assessed respondents' recognition of the major benefits, risks, and side effects associated with HT use. The scale was modified to be consistent with the most recent scientific evidence about HT and was reviewed by expert consultants. O'Connor et al. (1998a) found that test scores for their original HT knowledge scale improved significantly for women exposed to an HT decision support aid. The internal consistency reliability coefficient for the scale was .86 in a previous study with women with physical impairments (Becker, et al., 2002).

The 11-item Satisfaction with Preparation for Shared Decision Making assessed respondents' perception of their preparation to make an informed decision with a provider. In an on-going study of the decision to take HT, O'Connor (personal communication) reported a Cronbach Alpha coefficient of .90 and a significant difference in scores ( $p < .001$ ) between those who used the decision intervention and those who used a standard educational pamphlet.

Decision to Take HT was assessed by an item asking women to rate how likely they were to think about taking HT. The 11-point scale ranged from zero, anchored "No hormones," to 5, anchored as "Unsure," to 10 anchored as "Yes, hormones." O'Connor et al. (1998b) reported a test – retest correlation coefficient of .91 for this scale. A dichotomous variable was created to represent uncertainty about the decision with ratings of 4-6 considered uncertain and ratings of 0-3 and 7-10 considered certain about HT use.

## Treatment Condition Materials

The women randomly assigned to the experimental condition (i.e., the tailored decision support intervention) received a booklet we developed that outlined risk factors associated with heart disease, osteoporosis, and cancer prevention and early detection strategies. The booklet includes current guidelines from the American College of Obstetricians and Gynecologists, the U.S. Federal Drug Administration, and the North American Menopause Society, as well as available specialized information for this population. For example, the increased risk of thrombosis for those with mobility impairments is explained, as is a coagulation profile. We provide information about the National Center on Physical Activity and Disability to help women with disabilities become more physically active. Women are instructed how to review their current health practices, delineate health questions, clarify their values, identify their preference for participation in decision-making with their providers, and indicate their preference for HT in an accompanying worksheet. Case studies describing women with physical impairments are provided to role model the decision-making process, and women are encouraged to use the results in follow-up visits to health practitioners. The booklet can be viewed at <http://www.utexas.edu/nursing/chpr/docs/community/Becker.pdf>.

We adapted our tailored booklet from the HT decision support materials developed by the Ottawa Decision Support Team (O'Connor, Tugewell, Elmslie, & Jolly, 1996). Our booklet was reviewed by O'Connor and a panel of women's health practitioners and researchers (one of whom is a woman with severe mobility impairments), and a mid-life woman with multiple sclerosis.

Women randomly assigned to the attention comparison condition received the NAMS Menopause Guidebook (2003), which contains a general explanation of menopause, latest clinical guidelines for menopausal treatment, and strategies for achieving optimal long-term health. While the general information about HT risks and benefits is similar in both booklets, the *Guidebook* does not provide information specific to women with mobility impairments.

## Results

Analyses were performed using SPSS. A random sample of questionnaires was rechecked to verify the data entry accuracy. If a scale still had missing data for less than 15% of the items, the mean score for the individual on the scale was imputed; otherwise the entire scale was treated as missing for the individual. Descriptive statistics were computed to profile the sample and to determine the distributions of responses on all study measures. All internal consistency reliability coefficients (Cronbach Alphas) were above .70.

As expected with random assignment to groups, there were no statistically significant differences in baseline outcome measures between the tailored decision support condition and the NAMS *Guidebook* comparison condition (see Table 1). They also did not differ significantly in demographic characteristics, diagnoses, functional limitations, HT use, or age at menopause.

## Sample Description

The 176 individuals who completed Time 3 data collection represented 77% of those who expressed interest and were eligible to participate in the study. Respondents came from 38 states. Six percent were African American, 87% were White, with the remainder other (or multiple) racial groups. Four percent were Hispanic. The average age was 53 years, and 58% had at least a college degree. One third of the sample worked part or full time, but 41% were unemployed due to disability. Thirty-seven percent were post polio; other diagnoses include

spinal cord injury, multiple sclerosis, other neuromuscular or joint/connective tissue disorders, or other chronic health conditions. Fifty-six percent had a bone density test; of these 25% had osteoporosis and 34% had osteopenia. Fifty-nine percent needed some mechanical ambulation assistance most or all of the time, while only 15% needed personal assistance that often.

### Menopausal History

Two-thirds of the sample was menopausal. The average age of natural menopause was 49 years. At Time 1, 23% of the women were current HT users; 30% were past users; and 47% never used HT. Women reported using HT for 9 years on average. Fifteen percent reported contraindications to HT use. Only seven individuals (6 in the decision support intervention group) stopped using HT and 6 (2 in the decision support intervention group) began using HT during the study.

### Evaluation of the Intervention

Most women in both groups rated the materials they received as easy to understand, balanced, and the right length. Approximately 80% of women in both groups offered positive comments about the booklet they received. They most frequently mentioned that the booklets provided useful knowledge and clarified issues. However, 72% of women in the tailored intervention group rated the materials they received relevant to the concerns of women with physical impairments, compared with 59% in the comparison group ( $t=1.87$ ,  $p<.05$ , 1-tailed).

### Hypothesis Testing

Separate  $2 \times 3$  multivariate analyses of variance were used to test for differences between groups across time in knowledge, Decisional Conflict scores, and uncertainty about HT use. As shown in Table 1, both groups significantly decreased their Decisional Conflict scores across time (Wilks Lambda = 51.90,  $df=2/169$ ,  $p<.001$ , partial eta sq.=.38) and their uncertainty (Wilks Lambda=9.61,  $df=2/168$ ,  $p<.001$ , partial eta sq.=.10). Knowledge scores also increased significantly across time for both groups (Wilks Lambda=106.44,  $df=2/172$ ,  $p<.001$ , partial eta sq.=.55). There was no significant time by group interaction on any outcome measure. The largest changes occurred between Time 1 (prior to receiving materials) and Time 2 (immediately after receiving the materials); however neither the intervention or comparison group returned to pre-intervention levels on any of these outcome measures. Women who were menopausal, and those who entered the study trying to make a decision, had the same pattern of results

Satisfaction with Preparation for Decision Making Scores significantly decreased from immediately following the intervention to six months later (Wilks Lambda = 15.94,  $df=1/165$ ,  $p<.001$ , partial eta sq.=.09). There was no interaction between group and time (see Table 1). Those who reported actually seeing their provider during the study had significantly higher scores at the third data collection ( $t=3.25$ ,  $df=1/169$ ,  $p<.001$ ).

### Discussion

Women who were exposed to either the tailored decision support booklet or the standard NAMS *Menopause Guidebook* significantly increased their knowledge and decreased their decisional conflict and uncertainty about HT use. The average change observed in both groups of women has clinical significance; O'Connor (1995) has reported that those with Decisional Conflict Scores greater than 2.5 tend to delay decisions while those with scores less than 2.0 tend to make choices. Improvements in Decisional Conflict scores and certainty about the likelihood of taking HT persisted across the 6-month follow-up period. While

knowledge scores decreased somewhat between the second and third data collection, they were still higher than they had been prior to the intervention. Satisfaction with Preparation for Decision-Making unexpectedly decreased significantly during the 6-month follow-up period. Perhaps by the 6-month time period, women became more aware of the complexity of making this decision, or simply the “halo” effect that typically immediately follows interventions had dissipated. Women who reported actually seeing their provider did have higher scores than did those who had not seen their provider during the study, suggesting the materials may have been most helpful to those for whom preparing for a visit with their provider was most salient.

Both groups significantly improved their knowledge and decreased their decisional conflict and uncertainty about HT use, so our hypothesis was not supported. Both booklets contained similar information, so the increase in knowledge scores is consistent with O'Connor's findings (1998b). The 60-page NAMS *Guidebook* is a well-written, thorough resource; if we had compared our decision support intervention to the small pamphlet many women receive from their providers, we might have seen more differences between the two groups. Not surprisingly, this highly educated group may be skilled at adapting general health information to their needs, thereby benefiting from either booklet.

Both booklets were well received. Women in both groups were most likely to indicate that the booklets helped clarify issues around HT use, even though many would have liked more information tailored to their special needs. Unfortunately, we lack a great deal of definitive information about the effects of HT use for women with mobility impairments because they have generally not been included in medical research on HT. Hopefully, future research will provide improved clinical knowledge, so that more effective tailored interventions can be developed.

Women in this sample were 49 years old on average when they experienced natural menopause (not through hysterectomy). Since the average age of menopause is 51 yr., this finding is consistent with other researchers who reported women with disabilities tend to experience menopause at a younger age than do other women (Jackson and Wadley, 1999; Kalpakjian, Riley, Quint, & Tate, 2004). A recent report from the World Health Organization also documented a younger age of menopause for women with other disabling conditions (Walsh, Heller, Schupf, and van Schroyen Lantman-de Valk, 2000). These women may be losing the protection provided by estrogen at a younger age than women in general. Given the increased risk many women with mobility impairments may face for osteoporosis and thrombosis, the low rates of screening for either of these conditions in this sample is somewhat concerning. Health care providers need to initiate a dialogue about screenings and other preventive measures for these women at a younger age, and this dialogue should consider broadly how menopausal changes affect the lives of women with disabling conditions.

Findings from this study add to our knowledge about menopausal health for women with disabilities. While women throughout the United States participated, the results should be interpreted with caution because this was a self-selected convenience sample living in one country. The group as a whole was highly educated. Future researchers investigating decision support interventions should attempt to recruit more diverse samples, particularly in terms of educational and ethnic group membership, types of disabilities, as well as individuals from other countries besides the United States.

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Comparisons of Outcome Means and Standard Deviations for Tailored Decision Support Intervention and NAMS *Guidebook* Condition Across Time

**Table 1**

Outcome Measures	Tailored Decision Support (n=86)			NAMS Booklet (n=90)		
	Time 1	Time 2	Time 3	Time 1	Time 2	Time 3
Decisional Conflict	2.68	2.14	2.13	2.49	1.99	1.94
S.D.	.78	.65	.70	.83	.58	.73
Knowledge Score	9.44	14.77	12.42	10.17	15.03	13.28
S.D.	4.62	3.62	4.13	3.98	3.20	3.47
Percent Uncertain	40	24	20	31	15	18
S.D.	49	43	40	47	36	39
Satisfaction with Preparation for Decision-Making	2.6	2.6	2.3	2.8	2.8	2.6
S.D.	.92	.92	.97	.77	.77	.96

All changes across time statistically significant at  $p < .001$ .