Perceived value of treatment among a group of long-term users of hormone replacement therapy

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SUMMARY. There have been many epidemiological studies on the effects of long-term use of hormone replacement therapy, but women's own views of this type of treatment have rarely been investigated. This paper presents data on experiences and perceptions of hormone replacement therapy from 3117 British women receiving the therapy who were attending a specialist menopause clinic, and in whom mortality and cancer incidence were being monitored. Almost 90% of the women claimed to have found the therapy helpful overall, although ascribed benefits for specific 'menopausal' symptoms were often much more equivocal. Data are also presented on women's sources of information about treatment options. More women identified the mass media or a personal contact (48%) than a health professional (41%) as their first source of information, and over 20% indicated that they had exerted pressure on their general practitioner to obtain the therapy. These data point to the key role that general practitioners can play in managing 'menopausal' symptoms once a woman has made the decision to consult.

Introduction

OVER the 30 years or so since the use of oestrogenic substances in the treatment of the menopause first gained some medical credence, the use of exogenous hormones as replacement therapy in the perimenopausal and postmenopausal period has continued to excite controversy. In the last 15 years levels of prescribing have fluctuated dramatically in North America and in the UK.[1] During this period, many epidemiological studies have endeavoured to assess the balance of benefits and risks of long-term use of hormone replacement therapy. Most of this work has concentrated on the effect of long-term use on osteoporosis, on endometrial and breast cancer, and on cardiovascular disease.[1]

The definition of the 'menopausal syndrome' is notoriously problematic. While dramatic changes in hormone levels at the menopause have been demonstrated in clinical populations (decreased oestrogen and sharply increased follicle stimulating hormone and luteinizing hormone levels), there is no evidence that absolute levels correlate with symptoms. Several studies of the 'menopausal syndrome' have been conducted in the developed world and these suggest that only the vasomotor symptoms (that is, hot flushes and night sweats) are clearly associated with the menopause.[2-4]

It is often assumed that there is an association between psychiatric morbidity and the menopause, but there is no clear research evidence for this.[5] Several studies have reported an increased prevalence of 'psychological' symptoms in premenopausal women,[4,6] but studies in normal (that is, non-clinical) populations have strongly suggested that social circumstances (including life events and worry about family and friends[7]) have a significantly more powerful effect than the menopause *per se*.[8]

Cross-cultural work has raised some doubts about the association between even vasomotor symptoms and the menopause. The reporting of vasomotor symptoms, for example, is very low in Japan[9] and absent among rural Mayan women in Yucatan, Mexico;[10] indeed there is no word in either of these cultures for 'hot flush'. Such studies suggest that much of women's experience of the menopause is culturally moulded, and raise questions about the interplay of biological and psychosocial factors as underlying causes of 'menopausal' symptoms. They constitute major evidence against the model of the menopause as an 'oestrogen deficiency disease'.

Studies which aim to assess the effectiveness of hormone replacement therapy in alleviating 'menopausal' symptoms have been conducted.[11-15] Several demonstrate the short-term effectiveness of oestrogens in alleviating vasomotor symptoms, although all have shown a powerful placebo response for many menopausal symptoms including hot flushes. Other symptoms studied (such as well-being or depression) have rarely shown a differential response to active treatment or placebo.

The results reported here are part of a larger epidemiological survey of the effects of long-term use of hormone replacement therapy on mortality and cancer incidence.[16] In a questionnaire sent to the study cohort during the follow-up period, the opportunity was taken to explore the broader social context of hormone replacement therapy use by asking about the women's own perceptions and experience of the therapy.

Method

The 4544 women in the study cohort were recruited from 21 menopause clinics around the UK. Eligible women were current users of hormone replacement therapy who had had at least one year's continuous treatment. During the follow-up period a postal questionnaire was sent in 1983 to 4387 of the women. This achieved a response rate of 79.9% after 484 women known not to have received the questionnaire were excluded.

Two types of questions yielded information on women's experience of the therapy. First, respondents answered a series of open-ended questions to elicit the benefits which they felt they had gained from hormone replacement therapy, the reasons they gave for having been prescribed the therapy, and the reasons why some had discontinued it. These open-ended questions were coded (by the author) by a type of content analysis in which each response was coded into up to three components. For each of the questions about 40 categories of response were identified (on the basis of a detailed examination of a random sample of 100 questionnaires, following the initial checking through of all the completed questionnaires); these categories included both the most numerous and the less common responses of interest. Respondents were then given a checklist of 25 symptoms which have been said to be associated with the menopause and were asked to indicate whether they had been troubled by each of these and, if so, to say whether they felt that hormone replacement therapy had helped, worsened, or made no difference to the symptom. The data were analysed using the Statistical Package for the Social Sciences.[17]

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Subjects

Most of the 4544 women were aged 45–54 years at recruitment (60%) and at first use of hormone replacement therapy (63%). About 6% had never been married and nearly 20% were nulliparous. Distributions by parity, age at first birth, and smoking patterns were broadly similar to those in the population at large.

However, the women in the cohort were atypical of the general population in two respects. First, almost 36% had already undergone hysterectomy at the time of their first use of therapy, some 2–2.5 times the proportion in the British population;[18] this observation is not surprising since hysterectomy (particularly when combined with bilateral oophorectomy) is known to increase the likelihood of receiving hormone replacement therapy.[19-21] Secondly the women in the cohort tended to be of higher social class (based on the occupation of the spouse for currently married women to enable comparisons with census figures) than women in general. Thus twice as many were classified as social class 1 or 2 (46% compared with 23% in the 1971 census). Further details about the characteristics of the women are given elsewhere.[16,19]

Results

Experience of hormone replacement therapy

In general, the 3117 respondents were very enthusiastic about hormone replacement therapy. In response to the open-ended question about perceived benefits, 89.3% of women claimed that the therapy had helped; many remarked that it enabled them to live a 'normal' life again. For example, one woman said that it had:

> 'Restored my sadly diminished self-confidence, enabling me to live a normal active life instead of feeling a decrepit, aching, miserable apology for a human being.'

Among the 2784 women who claimed to have benefited from hormone replacement therapy, the most commonly mentioned benefits were for vasomotor symptoms (41.3%) and general well-being (27.6%). A smaller percentage mentioned beneficial effects for depression, anxiety and tension (15.6%), sexual and vaginal factors (12.8%) and ability to cope (12.0%). All other ascribed benefits were mentioned by less than 10% of these women.

Responses to the checklist of 25 symptoms are shown diagramatically in Figure 1. Despite the fact that this cohort of women are likely to have had more problems with the menopause than an unselected group of peri- and postmenopausal women and would be expected to ascribe a wider range of symptoms to the menopause, many of the symptoms which have been included in the 'menopausal syndrome' had been experienced by only a minority of respondents. Thus, for all but six of the 25 symptoms (hot flushes, night sweats, irritability, depression, tiredness and nervous tension) at least 25% indicated that they had either not experienced a symptom or did not deem that symptom to be relevant to the menopause. Further, a relatively high percentage gave no response for many of the symptoms; this only fell below 10% for hot flushes (Figure 1).

When considering only those who said that they had experienced each symptom, the percentage indicating that hormone replacement therapy had helped exceeded 75% for just seven symptoms (hot flushes, night sweats, cold sweats, irritability, crying spells, depression, and ability to cope), and the therapy was perceived as having an unambiguously beneficial effect only for hot flushes. For all symptoms other than hot flushes, at least 5% and up to 50% of the women who claimed to have experienced a symptom said that hormone replacement therapy had made

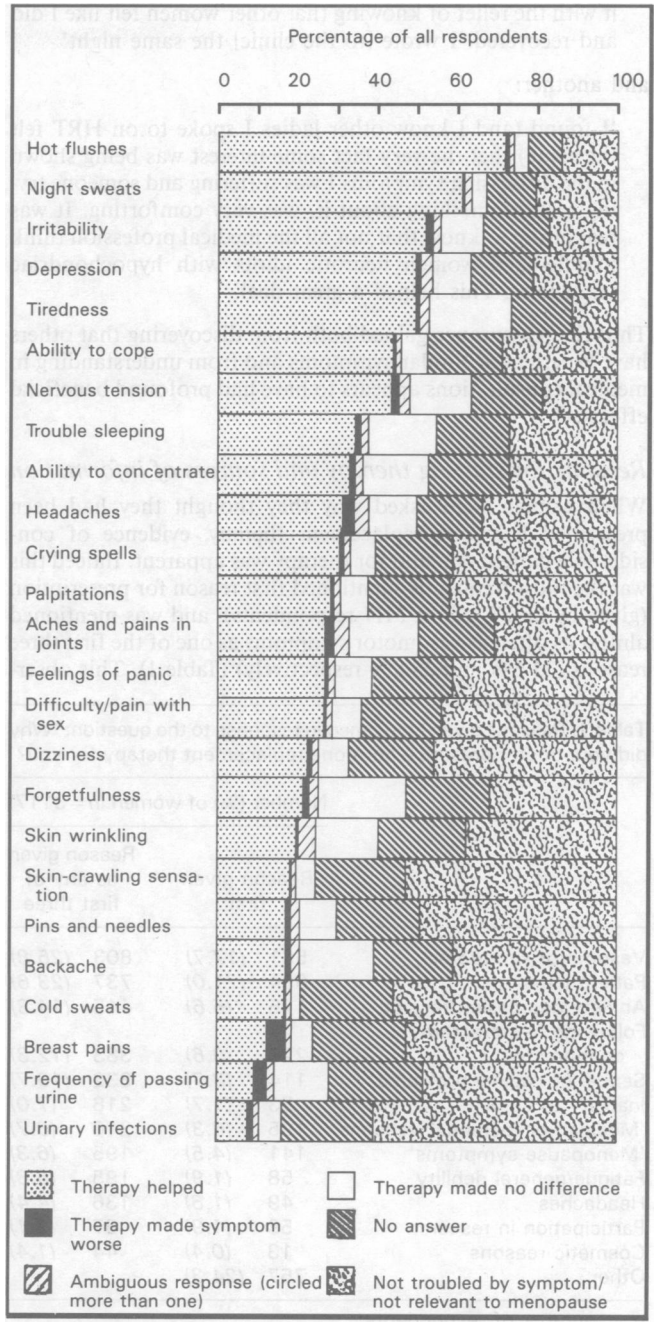

Figure 1. *Women's perceptions of relevance and helpfulness of hormone replacement therapy for specific 'symptoms' (n = 3117).*

no difference, and a very small percentage indicated that it had worsened symptoms. Thus, although almost 90% of respondents said that hormone therapy had helped, perceived benefits for specific symptoms were much lower.

An observation of interest to general practitioners is that many women felt they had benefited greatly by having their problems treated seriously and sympathetically. For example, one woman said:

> 'Of the greatest benefit to me was the chance to talk to an understanding doctor about the symptoms which were physically and mentally draining, but didn't seem important enough to take to an ordinary doctor. My [own] doctor ... gave me the impression that I had to live with it. When I saw a TV programme about HRT I wept all the way through

it with the relief of knowing that other women felt like I did and recovered. I wrote [to the clinic] the same night.'

and another:

'I found (and I know other ladies I spoke to on HRT felt the same) that the very fact some interest was being shown in the distressing symptoms I was suffering and someone trying to do something about it, was very comforting. It was reassuring to know that not all the medical profession think middle-aged women neurotic idiots with hypochondriac tendencies. This helped a great deal.'

Thus the reassurance gained both from discovering that others have experienced similar symptoms and from understanding in medical consultations appears to have had profound beneficial effects.

Reasons for starting therapy and sources of information

When women were asked why they thought they had been prescribed hormone replacement therapy, evidence of considerable patient demand for therapy was apparent. Indeed this was the most frequently mentioned first reason for prescription (given by 21.0% of the 3117 respondents), and was mentioned almost as often as vasomotor symptoms as one of the first three reasons (23.6% and 25.8% respectively) (Table 1). This observation was striking both in terms of the frequency and vehemence of these women's responses (often referring to material in the mass media), and is typified by these examples:

Table 1. Reasons given by women in response to the question: 'Why did your doctor prescribe hormone replacement therapy for you?'

	Number (%) of women ($n = 3117$)			
	Reason given first		Reason given as any of first three	
Vasomotor symptoms	551	*(17.7)*	803	*(25.8)*
Patient initiated	654	*(21.0)*	737	*(23.6)*
Anxiety/depression/tension	175	*(5.6)*	445	*(14.3)*
Following hysterectomy ± oophorectomy	229	*(9.6)*	383	*(12.3)*
Sexual or vaginal problems	114	*(3.7)*	332	*(10.7)*
Inability to cope	53	*(1.7)*	218	*(7.0)*
'Medical' or 'personal' reasons	195	*(6.3)*	210	*(6.7)*
'Menopause symptoms'	141	*(4.5)*	195	*(6.3)*
Fatigue/general debility	58	*(1.9)*	195	*(6.3)*
Headaches	49	*(1.6)*	136	*(4.4)*
Participation in research	58	*(1.9)*	67	*(2.1)*
Cosmetic reasons	13	*(0.4)*	44	*(1.4)*
Other	757	*(24.3)*		

n = number of respondents.

'My GP did not recommend HRT. I had read and heard about it from various sources, mostly from the journalist Wendy Cooper, ... I have recommended HRT to a great many women because of my own experience.'

'The doctor opposed the suggestion totally and I went through the magazine ... to the clinic.'

Indeed, fewer than a quarter of respondents claimed that they had never read or heard anything about hormone replacement therapy and the menopause in the mass media, and a quarter of the women specifically said that they had read *No change* by the journalist Wendy Cooper,[22] an advocate of hormone replacement therapy. It seems that for many women such articles were their first source of information about the therapy. Thus, while 41% of all the women stated that they had first heard about hormone replacement therapy from a health professional, 48% identified the mass media or a personal contact (relative, friend or colleague) as being their first source. The first source of information varied by social class; women who were classified within social classes 1 and 2 most frequently mentioned the mass media as their first source of information while health professionals were cited most often by women in other social classes. Source of information was also associated with the benefits which were ascribed to the therapy. Thus, information in the mass media not only appeared to influence (and perhaps even generate) demand for therapy, but also affected a woman's expectations and perceptions of the treatment (Hunt K, manuscript in preparation).

Discussion

The women in this study necessarily constitute a highly-selected group who, in the context of low levels of use of hormone replacement therapy in this country (and particularly long-term use), have gained access to specialist menopause clinics (themselves a scarce resource) and long-term therapy. Their views, therefore, are unlikely to be representative of a wider group of women. These data, however, are not intended to provide an indication of the scientific value of the therapy, but to explore the subjective experience of a highly-motivated group of users and ex-users of hormone replacement therapy to demonstrate the importance of including such factors in the overall worth of the therapy, and in understanding the motivation to commence, or continue with, therapy.

These women clearly felt that they had benefited from hormone replacement therapy and the data on perceived benefits suggest that the majority of women do find the therapy helpful for vasomotor symptoms. However, responses for many other symptoms yielded more ambiguous results and perceived benefits for specific symptoms were much lower than for overall benefits. Other studies have shown that generalized questions about levels of satisfaction with a treatment or procedure yield much higher positive responses than levels of satisfaction about specific aspects of care.[23] The results presented here are consistent with the randomized controlled trials on the effectiveness of hormone replacement therapy which suggest that the therapy is only directly beneficial for vasomotor symptoms.[14]

However, it is not possible to separate out the positive effects which a referral to a menopause clinic, sympathetic treatment and a prescription for hormone replacement may have had apart from any pharmacological effect. This should not be dismissed as further evidence of the triviality of menopausal symptoms; work in other areas suggests that careful explanation of the consequences of a medical procedure or condition can have marked effects on the patient's experience.[24] It may be, therefore, that some women, having gained reassurance that the symptoms which they are experiencing are not 'abnormal', may choose to manage their symptoms without hormonal therapy.

There are other considerations which should be borne in mind when interpreting responses to the checklist: a substantial number of women either provided no answer or an ambiguous response to some symptoms; the use of a checklist leads to problems of suggestibility; the symptoms on the list may be interpreted differently by different subjects and the threshold at which sensations are subjectively labelled as 'symptoms' may be variable; perceptions of benefit are likely to be influenced by the disruptiveness of any given symptom and women's expectations of the efficacy of treatment.

It seems that material in the mass media has had some effect

both on levels of demand for hormone replacement therapy and on expectations of therapy. As the mass media is an important source of information for many women, there should be concern that material presented therein is well-informed and balanced. Those who prescribe the therapy or who provide other services for menopausal women should be aware of the material in the mass media so that any inaccuracies can be redressed.

The process of decision-making both about whether to start therapy initially and for how long to continue is obviously complex both for the woman and her doctor. The factors influencing this decision depend too on whether therapy is to be long- or short-term, and is seen to be primarily palliative or preventive. The balance of perceived benefits and risks may change with increasing duration of therapy.

General practitioners have a key role in the management of women who have chosen to consult for 'menopausal' problems. As the probable first medical contact, general practitioners have an opportunity to redress any inaccurate or over-enthusiastic expectations of hormone replacement therapy, and to provide any necessary reassurance about symptoms or information about treatment options. Whichever course a woman and her doctor choose to take, a sympathetic attitude to the woman's experience is especially important.

References

1. Hunt K, Vessey M. Long term effects of postmenopausal hormone therapy. *Br J Hosp Med* 1987; **38:** 450-460.
2. McKinlay S, Jefferys M. The menopausal syndrome. *Br J Prev Soc Med* 1974; **28:** 108-115.
3. Thompson B, Hart SA, Durno D. Menopausal age and symtomatology in a general practice. *J Biosoc Sci* 1973; **5:** 71-82.
4. Bungay GT, Vessey MP, McPherson CK. Study of symptoms in middle life with special reference to the menopause. *Br Med J* 1980; **281:** 181-183.
5. Osborn M. Depression at the menopause. *Br J Hosp Med* 1984; **35:** 126-129.
6. Ballinger CB. Psychiatric morbidity and the menopause; screening of general population sample. *Br Med J* 1975; **3:** 344-346.
7. McKinlay JB, McKinlay SM, Brambilla D. The relative contributions of endocrine changes and social circumstances to depression in mid-aged women. *J Health Soc Behav* 1987; **28:** 345-363.
8. Greene JG, Cooke DJ. Life stress and symptoms at the climacterium. *Br J Psychiatry* 1980; **136:** 486-491.
9. Lock M. Ambiguities of aging: Japanese experience and perceptions of menopause. *Cult Med Psychiatry* 1986; **10:** 23-46.
10. Beyene Y. Cultural significance of physiological manifestations of the menopause. A biocultural analysis. *Cult Med Psychiatry* 1986; **10:** 47-71.
11. Coope J, Thomson JM, Poller L. Effects of 'natural oestrogen' replacement therapy on menopausal symptoms and blood clotting. *Br Med J* 1975; **4:** 139-143.
12. Campbell S, Whitehead M. Oestrogen therapy and the menopausal syndrome. *Clin Obstet Gynaecol* 1977; **4:** 31-47.
13. Dennerstein L, Burrows GD, Hyman G, Wood C. Menopausal hot flushes: a double-blind comparison of placebo, ethinyl-oestradiol and norgestrel. *Br J Obstet Gynecol* 1978; **85:** 852-856.
14. Coope J. Is oestrogen therapy effective in the treatment of menopausal depression? *J R Coll Gen Pract* 1981; **31:** 134-140.
15. Sherwin BB, Gelfand MM. Differential symptom response to parenteral estrogen and/or androgen administration in the surgical menopause. *Am J Obstet Gynecol* 1985; **151:** 153-160.
16. Hunt K, Vessey M, McPherson K, Coleman M. Long-term surveillance of mortality and cancer incidence in women receiving hormone replacement therapy. *Br J Obstet Gynaecol* 1987; **94:** 620-635.
17. Nie NH, Hull CH. *Statistical package for the social sciences.* New York: McGraw-Hill, 1975.
18. Alderson M, Donnan S. Hysterectomy rates and their influence upon mortality from cancer of the cervix. *J Epidemiol Community Health* 1978; **32:** 175-177.
19. Hunt K. Use and effects of hormone replacement therapy in contemporary Britain. MSc thesis, Faculty of Clinical Medicine, University of Oxford, 1985.
20. Stadel BV, Weiss N. Characteristics of menopausal women: a survey of King and Pierce Counties in Washington, 1973–1974. *Am J Epidemiol* 1975; **102:** 209-218.
21. Kaufert P. The menopausal transition; the use of estrogen. *Can J Public Health* 1986; **77** (supplement 1): 86-91.
22. Cooper W. *No change. A biological revolution for women (2nd edn).* London: Arrow, 1983.
23. Hall M, Macintyre S, Porter M. *Antenatal care assessed.* Aberdeen: University Press, 1985.
24. Price L. Art, science, faith and medicine: the implications of the placebo effect. *Sociology of Health and Illness* 1984; **6:** 61-73.

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