Original Research Paper

Decision making New Zealand women speak about doctors and HRT

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KEY POINTS

- Women find the decision about using HRT difficult and need clear, comprehensive information about advantages and disadvantages for them personally
- The same consultation style will not suit all women. Different women have different learning styles and needs
- Doctors need to talk with women about their preferred level of involvement in decision making about HRT
- Women's experiences, understandings and attitudes need to be included in the decision-making process about HRT
- There is a real need for women to be listened to and supported by their doctors, both in starting and ceasing the use of HRT

ABSTRACT

Aim: To describe peri-menopausal women's experiences with their GP or gynaecologist in relation to their decision making about hormone replacement therapy (HRT).

Method: Eighty women participated in private interviews or focus group sessions to discuss menopause and their attitudes to the use of HRT. All data were fully transcribed and subjected to thematic analysis.

Results: The women's interaction with their doctor was a predominant feature of their accounts. The characteristics of patient/doctor consultation that were identified as significant include: provision of information, consultation style, and women's expectations of doctors.

Conclusion: We found that women are seeking improved information about the management of menopause. Contact with a doctor is often sought for reassurance and information and is not necessarily a request for treatment. Women described consultations as characterised by either paternalism or partnership and expressed some dissatisfaction with both.

INTRODUCTION

The population of peri-menopausal and menopausal women is steadily increasing[1] and there is growing public awareness of the existence of hormone replacement therapy (HRT). This is now marketed directly to women, as well as to medical practitioners, as a means of alleviating menopausal symptoms and preventing osteoporosis and coronary heart disease. This brings the management of symptoms and the possibility of prophylaxis together within one regimen, thus complicating the decision-making process. In addition, there is prevailing public mythology that taking HRT may prolong youthfulness.[2] Thus even women who see menopause as a natural process or who are symptom-free are confronted with the possibility of HRT to maintain health and wellbeing.

The decision to use HRT is complex and often difficult, particularly in the face of continuing scientific uncertainty.[3,4] Recent studies have identified important factors which influence women's decision making. These include the experience of immediate menopausal symptoms, perceived negative side effects of HRT, fear of future illness, and the positive and negative experiences of peers. Equally important influences are resistance to the use of any medication, and reluctance to interfere with a natural process.[5-9] Doctors have also been found to be an important influence on decisions, whether for or against the use of HRT.[7,10]

Three generally accepted medical approaches to decision making; "paternalistic", "shared" or "informed", have been identified.[11] The paternalistic model is traditional but recently, in line with the trend towards patients as informed consumers, a shared decision-making approach has been favoured. It is not always easy for mid-life women, who are accustomed to the paternalistic model of medical care, to play an active role in medical decision making and many have been described as "reluctant collaborators".[12] Charles and colleagues have suggested that the medical practitioner must be aware of different approaches to decision making so that individual patient preferences can be respected.[11]

In order for people to be able to participate in decisions about their own health they need to have sufficient knowledge and understanding to be able to make informed choices. The first recommendation of the Core Services Report, in regard to HRT,[13] is that:

All women and relevant health-care providers should have access to unbiased, accurate information about menopause and climacteric symptoms, about the effects of HRT on these symptoms, and about the acute side effects of HRT.

One problem, however, is the non-availability or relative inaccessibility of such information. A number of international studies have reported that women receive information about HRT primarily from media, friends and relatives,[14-16] and a recent New Zealand survey has supported this finding for women who have never used HRT.[17] The same study showed that doctors are an important source of information for those who use or have used HRT. However, from the physicians' perspective,

studies in Europe and the US have shown that practitioners may underestimate their patients' need for information.[18,19]

HRT is a medication available only on prescription in New Zealand, and the prescribing physician has a very important role to play in assisting women with their personal choice. There has been very little research on HRT decision making in New Zealand, despite a recent survey of 496 mid-life women demonstrating that 25 per cent of women were currently using, and 14 per cent had previously used, HRT.[20] This is greater than any previous estimates of use rates in this country.[13,21]

The aim of the present study was to investigate women's decisions about HRT use, and a recurrent theme was the role of the doctor in the decision-making process. This paper presents a summary of women's experiences and expectations of consultations with their doctors in relation to menopause and HRT. Throughout the paper the term HRT refers to hormone replacement therapy in the form of prescribed tablets and patches.

METHOD

One hundred and forty women from the Manawatu electoral roll were sent information and letters requesting their participation; 32 responded. Advertisements in English and Maori in local newspapers and distributed to social groups resulted in a further 48 participants. The total sample of 80 women, aged 42-60, comprised 27 (34 per cent) HRT users, nine (11 per cent) former users and 44 (55 per cent) non-users. Forty eight women chose to participate in focus group sessions and 32 in private interviews, which were held at a time and place to suit the participants. Prior to the interviews each participant read the information sheet again, asked any questions which arose from it, and signed a consent form to tape-record the interviews – which lasted from 20 minutes to two hours. The private interviews were semi-structured: the interviewer covered a set of questions, but focused on those areas that interested the participant. The focus groups were assembled according to HRT use: three groups were HRT users, two were non-users and two mixed. A moderator used two or three key questions to initiate discussion, with occasional probes to refocus. At the conclusion of each focus group the tape-recorder was turned off and women were given the opportunity to ask questions of the registered nurse present. All interviews were transcribed and then analysed separately by all three authors to identify the main themes. An inductive approach was adopted and analysis followed Burnard's[22] approach to analysing interview transcripts, the aim of which is to systematically identify and record the themes and issues addressed in the interviews and to link the themes and interviews together.

RESULTS

A number of themes emerged with respect to medical consultations about menopause: (a) information, its availability and content; (b) consultation style; and (c) women's perceptions of doctors in the context of menopause.

Information

One theme which emerged related to the difficulty that women had experienced in accessing adequate information about menopause and HRT. Women had also expressed difficulty with knowing what constitutes "normal", in terms of peri-menopausal and menopausal experience. Variations in menstrual patterns caused particular concern and were the reason for many women visiting their doctors, looking for advice and reassurance. As one woman said: "People don't talk a lot, they keep it hidden away, and doctors don't know much or don't seem to want to know."

Much of the written and audiovisual information supplied through doctors' surgeries is supplied by pharmaceutical companies such as Wyeth Ayerst, Pharmacia & Upjohn, and Ciba-Geigy, and this was viewed as propaganda at worst and biased at best.

Fears were verbalised about the possibility of hearing only the good side of HRT because doctors and pharmaceutical companies were perceived as affiliated. It was observed that pamphlets are superficial whereas more extensive literature is not always accessible or balanced.

Women want to have clear, well-written, unbiased information about HRT that they can take home and consider carefully, before making a decision about initiating use.

There was an expectation that doctors would know enough about both menopause and HRT to be able to support a woman in her decision making, and that they would provide ongoing support and information (ie, new findings on HRT) once the decision has been implemented.

There was a feeling that doctors were not always forthcoming with information, and women did not always know what to ask. As one woman said, "You've got to rely on more than just gossip in women's magazines, and I think you have got to know enough so you can ask your doctor the right questions too."

Concern was also expressed about the level of explanation provided about results of examinations and blood tests.

A number of doctors had reportedly suggested that their patients should be using HRT but could not satisfactorily explain why. For instance: "He said, 'Oh you're nearly 60, you'd better go onto HRT' and I said to him 'What for?' and he said 'Oh it just might make your older life more comfortable'."

Another theme was women's expressed surprise that their GP did not seem to be any better informed than they themselves were about menopause and HRT; some commented that they felt their own searching had elicited more information than the GP appeared to have.

Women did accept this responsibility, by saying, eg: "Ultimately it is your decision but in conjunction with the advice you seek from the GP alone, or specialist and peers." Women were concerned to find information independently and to avoid taking the easier option of handing over responsibility to their doctor and becoming a passive recipient of the decision made. The researchers noted that each focus group was characterised by women sharing their hunger for information and their enthusiasm for contributing to other women's knowledge.

Prior to participating in the research, participants had frequently been quite industrious in searching for information but had not found what they needed. A clear theme which emerged from the data helped to explain their lack of satisfaction. This theme related to women's difficulty in interpreting risk/benefit

ratios in a way that had personal relevance. As one woman said, "I had a lot of sort of individual issues that I thought weren't discussed. I don't think that treatment was ever discussed in relation to me as an individual, it was more generic information."

Concern was expressed that both GPs and pharmaceutical companies are keen for women to use HRT so that both will profit, through women's attendance at regular medical consultations and through purchase of the drug itself. HRT was also viewed by some participants as another example of medical control of women's bodies during what is essentially a normal transition process.

Consultation style

Two main styles of medical consultation were identified. These were labelled "paternalistic" or "partnership", and neither was entirely satisfactory for women in the context of menopause. This seemed to be confounded by uncertainty about the accuracy of attributing certain experiences to menopause and the issue of treatment versus prophylaxis.

A paternalistic consultation was characterised by the doctor taking responsibility for decision making, and caused women to feel that they had been "rail-roaded" into a decision that was not necessarily a good one.

Alternatively, when doctors worked hard to be consultative, to share information and respect the woman's own wisdom, this too created vulnerability and uncertainty. To a large extent the uncertainty was exacerbated by a sense that available information, as previously discussed, was biased by pharmaceutical company preparation or was insufficiently comprehensive. There was evidence of different views among women of this age group. Some clearly felt that an authoritative decision was appropriate whereas others described their need for a more consultative relationship.

When women expressed satisfaction with their medical care, certain features characterised the doctor/patient relationship. Openness towards alternatives, and provision of support were seen as positive attributes possessed by some practitioners.

As one woman explained: "He's interested, does a lot of reading himself, and explains what is going on." Other women believed that they sensed a lack of interest in either menopause as a life stage, or themselves as patients. Doctors were frequently described as "not interested", "unhelpful" and "not wanting to listen". Some women felt that they were being treated like hypochondriacs because they were presenting with a series of vague complaints that were difficult to quantify.

In addition, many of the symptoms which troubled women were highly personal, intimate and potentially embarrassing. Participants expressed the need for a high level of comfort and assured interest and concern before they felt able to confide in their doctors. One woman described this discomfort in her comment: "He's not a doctor that you could talk to about things like that ... Doctors are very conservative with those sort of things." In contrast, we were surprised by the high level of intimacy and personal detail present during the interviews and focus groups.

Women were quick to sense when a doctor believed that HRT was a desirable option and noted that some doctors were particularly persuasive in their method of presenting information or advice about HRT. One woman reported: "He said, you know, his wife when she gets to menopause she will definitely be put on it... and I

said to him 'How long will I have to take them?' and he said 'As long as I think you need them', so I don't know how long that will be." Another woman noted: "I went to the doctor and said to him that I felt I may be going through menopause and his reaction was 'Well we'll just put you on HRT', like it was a magical wonder-drug that was going to make me instantly better." This woman was concerned that her doctor didn't ask her for details of her experience and did not explore options for management. She has not returned for a further consultation. Conversely, women who wanted to try HRT sometimes did not feel supported in their decision. One woman indicated that her doctor made it very clear that he did not want her to be using HRT, even though she found it very helpful, and constantly told her that she should cease using it but without providing a reason for this advice.

A further finding in the context of the consultation process was related to the monitoring of women who were using HRT. A wide range of experiences was reported, with some women being given repeat prescriptions in the absence of any physical examination or real discussion, and others receiving regular cervical smears, mammograms, blood tests, blood pressure and cardiovascular checks. There was a lack of consensus among women about what was appropriate and what they could expect from their GPs. Some women commented that the process of finding an appropriate HRT regimen seemed somewhat random and induced a sense of being a guinea-pig.

Women's perceptions of physicians

Women are aware of the recent change in physician/patient relationships. They were brought up to have "the utmost faith" in their doctor, but the situation has changed and comments like the following reflect the change: "Doctors in those days were, God and you didn't question their knowledge at all, whereas now I would ask every question available and I wouldn't care how much time I took up." It was suggested that: "the new-generation doctors are playing a massive part in this because they are more approachable, you can talk to them about those sorts of things and they will actually understand"; a stance that is much appreciated. One woman, who felt powerless in her younger days, had adjusted her outlook and described doctors as being there to work for women: "on the payroll like a lawyer or an accountant."

A minor theme was a lack of trust in doctors' opinions. An example of this arose when there was contradiction between the women's experience of symptoms and the evidence provided by laboratory analysis: "GPs seem to have this idea that once your FSH level was above this certain number then it is definite that you are premenopausal, so (you) kind of feel like a fraud if your number isn't big enough." Medical uncertainty about the length of time women should use HRT and how to cease use was also a common theme in the discussions. One woman wanted to know how long she could safely continue to use it but said she hadn't talked to her GP about this issue: "I know if I go to my doctor now I don't even know if she knows, what she'll tell me or what she'll advise me … um … and I won't particularly trust what she says, you know what I mean?"

As a result of these issues, some women accept but do not fill their prescriptions and don't necessarily inform the doctor. Other women stop taking HRT without consulting their GP and just don't return. Others are caught between dissatisfaction with their medical care and the custom of loyalty to one practitioner.

DISCUSSION

In making sense of the findings of this study it is important to remember that

volunteers may be expected to have different views to those of participants who have been randomly selected. Therefore, whereas the themes arising from the analysis represent the views of the women involved in the study, they can not be interpreted as representing the views of all mid-life women in New Zealand.

A major concern for mid-life women as expressed in this study is the lack of unbiased literature to facilitate informed decision making about HRT. As in previous studies,14-16 women reported getting most information from friends and the media but expressed their dissatisfaction with this source. They generally saw the general practice environment as the appropriate source for information and discussion. In addition to insufficient information about reasons for taking HRT, a major concern was expressed about the lack of advice women receive about how and when to cease treatment. Interestingly, many women avoided discussing this issue with their GPs, and many had not informed their doctor of their decision but simply stopped, abruptly and possibly inappropriately.

The most important finding about consultations is that, regardless of consultation style, women need to feel listened to and many do not currently have that experience. The majority of women discussed their need to be acknowledged as individuals with different attitudes and problems. They also described the desire to be given opportunities to talk about physical and psychological health issues. With respect to consultation procedures, most women viewed the monitoring of blood pressure, hormone levels and mammograms as an integral part of care.

The HRT decision was identified as extremely difficult for most women. There is no simple answer as to who should make the decision, but women's needs should be paramount. It was evident that some women would like the decision to be made for them and want more guidance than they are receiving. Others, however, are concerned that it is the doctor who is making the decision and feel that the power has been taken away from them. Most women want to be well informed and to make their own decision, while being supported by their doctor. Consequently, doctors should be aware that employing the same decision-making style for all women is not appropriate and a patient-centred approach23 should be employed. The way in which a decision is arrived at should be openly discussed, and women should be able to choose the level of involvement with which they feel most comfortable.

The results of this study suggest that, although some women are satisfied with their health care, there is dissatisfaction and confusion among mid-life women. The study suggests several key points which could facilitate constructive encounters between women and their physicians. These are:

- the choice of an appropriate consultation and decision-making style, based on discussion with the woman herself
- the need to elicit information from women regarding their personal needs, circumstances and attitudes as well as their medical histories
- clear explanations of any prescription, procedures or tests and reasons for their use
- the provision of current information about HRT, duration of safe use and means of terminating treatment, based on national guidelines.

The study findings suggest these measures will provide women with increased comfort and certainty. Women made it clear that trust in the prescribing physician's knowledge, integrity and professionalism will be improved if these issues are taken into account. All health professionals concerned with this aspect of health care will

need to take responsibility for the provision of improved information in a variety of forms tempered to the learning styles and needs of different women.

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