A study of the referral patterns and therapeutic experiences of 100 women attending a specialist premenstrual syndrome clinic

A T Leather MBBS **E F N Holland** MRCOG **G D Andrews** RGN **J W W Studd** MD FRCOG
The Premenstrual Syndrome Clinic, Dulwich Hospital, London SE22 8PT

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Introduction

Premenstrual syndrome (PMS) continues to be a poorly understood and badly treated condition. The current view is that the only effective pharmacological treatments of severe PMS achieve their result by suppressing ovulation and the cyclical ovarian activity that leads to the cyclical symptoms. This therapeutic result can be achieved using GnRH analogues[1], anovulatory doses of oestradiol patches[2] or implants[3], danazol[4] and possibly the combined oral contraceptive pill[5]. It is, however, still commonplace for a whole variety of non-medical and medical treatments to be used to treat this condition. That patients respond to some of these, albeit for short periods of time, demonstrates the great placebo response which has been reported to as high as 95%[3].

At this PMS clinic an average of 10 new and 20 follow-up patients are seen each week. Although the clinic is based in a NHS hospital all the medical staff who run the clinic are financed through research grants. Many of the patients are self-referred and further problems of access to appropriate treatment may arise when the hospital becomes a self-governing trust.

It has previously been reported[6] that menopausal women experience great difficulties in obtaining treatment from their own doctor and are often prepared to travel large distances to attend a specialist clinic, even though the effective treatment for the menopause is comparatively straightforward. These women had often suffered with their menopause for many years and because of the lack of patient information leaflets available have gained most of their knowledge into the condition from media coverage. In order to find out more about the women who are seen in our PMS clinic, we conducted a survey on 100 consecutive new patients. We were particularly interested to discover how PMS affected their lives, how they came to be referred to our clinic and previous treatments used to treat their PMS.

Patients and methods

All new questions attending our PMS clinic were sent a questionnaire 10 days before their appointment which they were asked to fill in by themselves prior to the visit. This was collected by the doctor seeing them in the clinic before the start of the consultation and was briefly consulted to ensure all questions had been answered. When 100 completed questionnaires had been collected the study was stopped.

Correspondence to: Mr J W W Studd, The Premenstrual Syndrome Clinic, Dulwich Hospital, East Dulwich Grove, London SE22 8PT

Table 1. Affect of PMS on lifestyle in 100 PMS women

	Not applicable	Number affected	Severely affected (%)
Work performance	14	80	27.5
Work relationships	23	70	22.1
Household chores	1	97	45.5
Relationship with partner	6	93	82.8
Relationship with children	22	77	61.0
Social relationships	2	94	41.5

Results

The median age of the 100 women referred to the PMS clinic was 35 (range 18-45). They had been suffering with their PMS for a median of 7.5 years (range 2-25). Their PMS occurred for a median of 14 days per month (range 4-18), and when asked how many 'good' days they had per month taking into account any menstrual symptoms, they reported a median of 12 (range 5-20).

The affect of PMS on lifestyle is shown in Table 1. Although most everyday activities are impaired, it is the women's home life and in particular her relationships with her husband (82.8%) and children (61%) that are severely affected compared to her work (27.5%) or social activities (41.5%).

The different treatments and their efficacy are shown in Table 2. These are grouped into the self-help remedies such as stress avoidance, exercise, altered diet, vitamin B6, evening primrose oil, royal jelly, zinc and magnesium and into the prescribed medications such as danazol, oestrogens, combined oral contraceptive, diuretics, tranquillizers, anti-depressants, cyclogest and progestogens.

All the women attending our clinic had tried at least one of the treatments from each group and in many cases they had tried most of them. The median number of self-help remedies tried was four and for prescribed drugs tried was three. The results show that although none of the treatments tried were perceived as very successful many patients had some response to them particularly the self-help remedies. The prescribed drugs such as danazol (60%), anti-depressant (43.3%), combined oral contraceptive (32%), progestogens (26.5%) and tranquillizers (25%) often made the women feel worse whereas the self-help remedies did not.

Table 3 shows the questions asked in the questionnaire and the response rate to each given answer. Although many women had to wait up to 6 months for an appointment to attend the PMS clinic, the

Table 2. Previous treatments tried in 100 women with PMS and how effective they thought they were (expressed as a percentage of those who had ever used them)

	Ever used	Worse (%)	No different (%)	Better (%)
Self-help remedies				
Stress avoidance	31	0	45.2	54.8
Exercise	49	0	52.9	43.1
Altered diet	62	4.8	58.1	37.1
Vitamin B6	92	6.5	69.6	37.1
Evening primrose	74	2.7	60.8	36.5
Royal jelly	26	7.7	69.2	23.1
Zinc	25	0	88.0	12.0
Magnesium	26	0	61.5	38.5
Medical treatments				
Danazol	10	60.0	20.0	20.0
Oestrogens	11	9.1	63.6	27.2
Combined OC Pill	50	32.0	36.0	32.0
Diuretics	41	12.2	41.5	46.3
Tranquillizers	24	25.0	20.8	54.2
Anti-depressants	37	43.3	27.0	29.7
Cyclogest	26	19.2	73.1	7.7
Progestogens	34	26.5	50.0	23.5

Table 3. Questionnaire and response rate to answers

(1) How long have you waited for your appointment?	
0-2 months	31%
2-4 months	49%
4-6 months	20%
>6 months	0%
(2) How far have you travelled to attend this clinic?	
<5 miles	34%
5-20 miles	35%
20-100 miles	28%
>100 miles	2%
(3) How easy is it to find information about PMS?	
Easily	26%
Difficult	64%
Impossible	10%
(4) Where did you find information about PMS?	
Magazines	57%
GPs or family planning	32%
Friends	11%
(5) Who referred you to the clinic?	
GP	60%
Self-referral	26%
Other doctors	14%
(6) If your GP referred you what was his/her attitude?	
Helpful/Understanding	35.0%
Fairly supportive	36.6%
Not interested	13.3%
Totally unhelpful	15.0%
(7) If you referred yourself what was your GP's attitude?	
Helpful/Understanding	19.2%
Fairly supportive	26.9%
Not interested	30.8%
Totally unhelpful	23.1%
(8) How did you find information about our clinic if you referred yourself?	
Magazine	57.7%
Friends	19.2%
Family planning	15.4%
GP	7.7%

median wait was 12 weeks. Only a third of the women attending lived within the boundaries of our catchment area (less than 5 miles from Dulwich Hospital) and many were prepared to travel considerable distances.

Table 4. The acceptability of total abdominal hysterectomy and bilateral oophorectomy followed by oestrogen replacement in women who have completed their families

How many children	Family complete	Would accept TAH/BSO	Not sure but likely
0	7	4	2
1	17	4	6
2	27	8	1
3	16	8	2
4+	5	3	0
Total	72	27	11

Many PMS sufferers found it difficult to obtain information about their condition. Less than a third had found this task easy. The most likely place to find relevant information was not at the general practitioners or family planning clinics but through women's magazines and newspapers.

Even with this severe PMS only 60% of patients were referred by their general practitioner. The rest were self referred (26%) or referred by other doctors (14%). Four women were referred by psychiatrists, the others from either family planning clinics (4) or gynaecologists (6). All the GPs who initiated the patient referral were thought to be sympathetic and understanding by the women. This was not the case when the woman had referred herself or the patient had initiated her referral from the GP.

Finally, we asked those whose families were complete if they would be prepared to have, if offered, a total abdominal hysterectomy with bilateral oophorectomy in order to rid themselves of their PMS and period problems. This question was asked before they attended the clinic and the women were therefore not counselled in any way except that they would receive oestrogen replacement afterwards. The results are in Table 4. Of 72 women (37.5%) whose families were completed 27 said that they would undergo this major operation in order to be relieved of the cyclical symptoms. A further 11 (15.3%) were unsure but thought it probable after further discussion. Thus, 38 (53.8%) women of the 72 with completed families were prepared to have surgical treatment. This included some with no children and several women in their early twenties.

Discussion

Our questionnaire highlights not only the difficulties that women with PMS have in finding information and an effective treatment for their condition but it also reveals that self-help therapies are perceived to be more effective than prescribed treatments. Although there is no apparent scientific basis for the use of non-prescription drugs, there is certainly no harm in the PMS sufferer trying these self-help remedies before consulting her doctor because many, up to 40%, have an apparent improvement in symptoms. Once consulted, however, the doctor should use medical treatments that have been proven to be better than placebo rather than relying on psychoactive drugs and other fashionable but unproven treatment methods such as diuretics, progesterone and progestogens[7].

That so many women still resort to self-referral is disappointing. A better understanding of PMS is needed but, in addition, more information needs to

be made available for women in doctor's surgeries, well women and family planning clinics, rather than relying on media coverage. With the advent of self-governing hospital trusts patients will no longer be able to self refer to hospital clinics and efforts must be made to incorporate such clinics into well women or family planning clinics.

The treatment of women with PMS is often very demanding and many doctors find it particularly difficult as many of the treatments seem to be ineffective. It needs a sympathetic and understanding approach and a knowledge that although the exact aetiology of the condition may be unknown, the biochemical sequelae of ovulation would appear to be a principle factor in the causation of this problem[8]. Apart from the advantage of a large placebo response in the treatment of PMS the therapies which suppress ovulation are the most successful in treating the condition.

The only treatments that have been shown conclusively to be superior than placebo are percutaneous oestradiol either by implants[3] or patches[2], danazol[4] and GnRH analogues[1]. Although these treatments are effective they have side effects. Oestradiol implants used long term may produce myometrial hyperplasia and heavier withdrawal bleeds which may require treatment by hysterectomy[9]. Oestradiol patches may cause skin irritation with discoloration[2], danazol may produce greasy skin, acne and mild hirsutism[10] and GnRH analogues lead to bone demineralization and vasomotor symptoms[11]. These side effects usually limit their long term use for the treatment of PMS. That so many women are prepared to undergo a major operation in the form of a total abdominal hysterectomy with bilateral oophorectomy in an attempt to be free of this disorder confirms the inadequacies of current treatment options and the extent to which severe PMS can destroy women's professional and domestic lives.

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