General practitioners' experience of the chronic fatigue syndrome

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SUMMARY. In order to examine the prevalence of patients with symptoms fulfilling the criteria for the chronic fatigue syndrome an extensive survey was carried out of general practitioners on 10 local government lists in two health boards (91% response rate). At the same time practitioners' attitudes to the syndrome and their experience in terms of workload and the characteristics of patients affected were documented. The majority of general practitioners (71%) accepted the existence of chronic fatigue syndrome, but 22% were undecided. The doctors reported a prevalence among their patients of 1.3 per 1000 patients (range 0.3–2.7 for the 10 areas) with a peak in the 30–44 years age group. Female patients were more commonly affected than males (sex ratio 1.8:1.0), but the severity of illness and the use of general practitioner's time was the same among male and female patients. Patients in occupations where they were exposed to infection were affected (teachers and students, 22% of sample; hospital workers, 7%), but many patients were unskilled (8%) and skilled workers (9%). Patients suffering from the chronic fatigue syndrome appear to be a real and distinct group for general practitioners and may represent a substantial part of the workload of doctors in particular areas.

Introduction

AN article on the chronic fatigue syndrome (also known as myalgic encephalomyelitis, Royal Free disease and post-viral fatigue syndrome) in this *Journal*,[1] produced much correspondence. Even though the chronic fatigue syndrome has been described as one of the *causes célèbres* of the 1980s, it is a real concern to the public.[2] As primary care physicians, general practitioners have to deal with most of the public's anxieties about this illness, yet, few large studies of the condition have been carried out in general practice.

As important as the patients' expectations are the attitudes of general practitioners. A decade ago, most doctors did not accept the existence of the chronic fatigue syndrome,[3] but there is little information on doctors' attitudes now. Changes of attitudes are not only dependent on new published data, but also on the practitioner's personal experience. Thus, practitioners may be more influenced by their patients' complaints than topical articles about a hypothetical problem.

One difficulty is that there is no generally acceptable case definition for the chronic fatigue syndrome and case definitions used in other countries may not be applicable to the UK.[4] However, a case definition has been proposed for the UK.[4] This study was designed to examine the prevalence of patients fulfilling such strict criteria in a large area made up of two health boards. At the same time, practitioners' attitudes to the chronic fatigue syndrome were assessed, and their experiences documented in terms of workload and the characteristics of patients affected by the syndrome.

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Method

A postal questionnaire was sent to all 195 general practitioners on the 10 local government lists of the Highland health board and Western Isles health board. Information was requested on the size of each doctor's practice and whether the doctor was single handed or worked in a group practice.

The practitioners were asked if they accepted the existence of the chronic fatigue syndrome with possible answers of yes, no or undecided. In addition, the practitioners provided the following information for all their patients fulfilling the strict diagnostic criteria:[4] age; sex; occupation; length of illness; the practitioner's perception of the patient's severity of illness (mild, moderate or severe); work or school (full time, part time, none); and the practitioner's perception of the time spent with the patient (little, average, a lot or excessive).

Results from the 10 local government lists for each answer in the questionnaire were compared by analysis of variance, chi square analysis and student's *t*-test. Results for male and female patients were compared using chi square analysis and student's *t*-test.

Results

A total of 178 replies were received (91%). The total list size of the respondents represented 92% of all the patients in the two health boards (218 993/238 409). The response rate in the 10 local government areas ranged from 76% to 100%, with four areas achieving a 100% response. Among the respondents, 39 (22%) were in single-handed practice, with the remaining 139 in group practice.

Overall, 126 general practitioners (71%) accepted the existence of the chronic fatigue syndrome, but 12 (7%) did not and 40 (22%) were undecided. A total of 293 patients fulfilled the diagnostic criteria for the chronic fatigue syndrome and this represented a prevalence of 1.3 per 1000 patients. However, among the 10 areas the prevalence ranged from 0.3 per 1000 patients, to 2.7 per 1000 patients. In the area of the largest prevalence 37 patients were from one group practice in which there had been an outbreak of Bornholm's disease in the previous five years. The diagnosis in these patients was made clinically. This was the only practice to report a recent epidemic of a viral infection. Even if the data from this practice were ignored, the incidence for the area would be 1.7 per 1000 patients — similar to the overall figure.

Comparing the three areas with the lowest preval-ence rates with the three areas with the highest prevalence, showed that there were significantly more single-handed practices in the lowest prevalence group (16/38, 42%) than in the group with the highest prevalence (7/46, 15%) (chi square test, $P<0.01$).

Detailed patient information was available for 289 patients (187 women and 102 men; sex ratio 1.8:1.0). Two practitioners felt unable to provide information on four patients. Information on occupation was available for only 275 patients: 61 patients (22%) were teachers or students; 43 (16%) were retired; 36 (13%) were housewives; 31 (11%) worked in service industries (shops, hotels, banks); 24 (9%) were secretarial or clerical staff;

24 (9%) were skilled workers (painters, joiners, fitters, electricians, and so on); 23 (8%) unskilled workers; 19 (7%) hospital workers; and 14 (5%) professional workers (lawyers, ministers, civil servants, and so on).

The age distribution of the 289 patients is shown in Figure 1. There is a peak prevalence in the range 30–44 years. However, if the length of illness is subtracted from the age to give the age at onset, a different pattern is obtained with a peak for male patients at 35–39 years, but a double peak for female patients at 25–29 years and 40–44 years (Figure 2). The mean ages of the patients are shown in Table 1. There were no significant differences in the mean ages of the patients in any of the areas or between female and male patients in these areas.

The severity of the illness was not significantly different for female and male patients (Table 1). Nevertheless, more male patients were in full-time work or attending school full time than females (Table 1, $P<0.001$), and more female than male patients were at home ($P<0.01$). The amount of time the general practitioners spent with the patients was similar for female and male patients (Table 1).

Discussion

The validity of the results of a postal questionnaire depends on the response rate achieved.[5] In this study excellent cooperation was received from local general practitioners and 100% response rates were achieved in four of the 10 areas. The overall response rate of 91% is greatly in excess of the 75% required, for unbiased and representative results.[5] Although many doctors do not accept the existence of the chronic fatigue syndrome,[4,6] the vast majority (71%) of the sample in this study did. Nevertheless, 22% of the sample were undecided.

There is little information on the epidemiology of the chronic fatigue syndrome.[7] This study has shown that the prevalence in

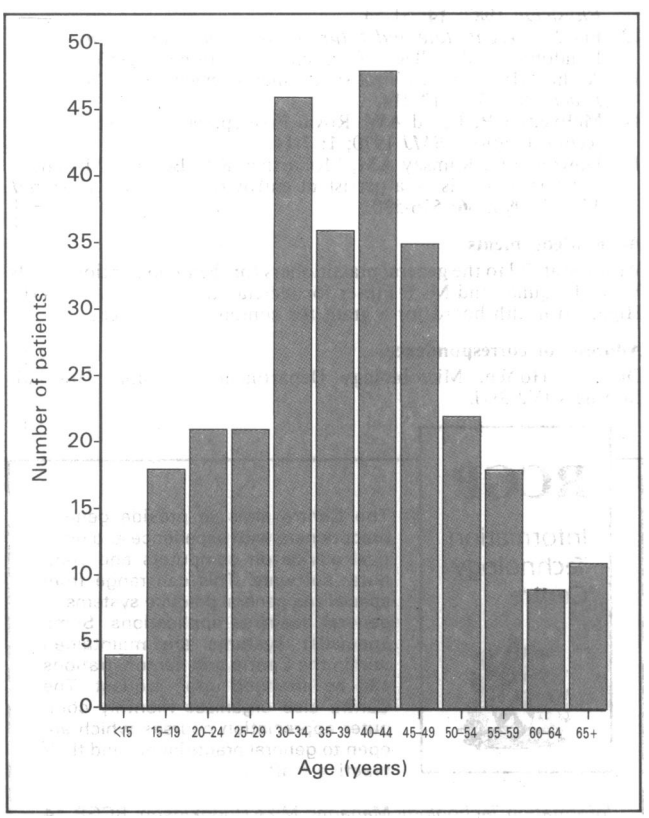

Figure 1. *Age distribution of the 289 patients suffering from the chronic fatigue syndrome.*

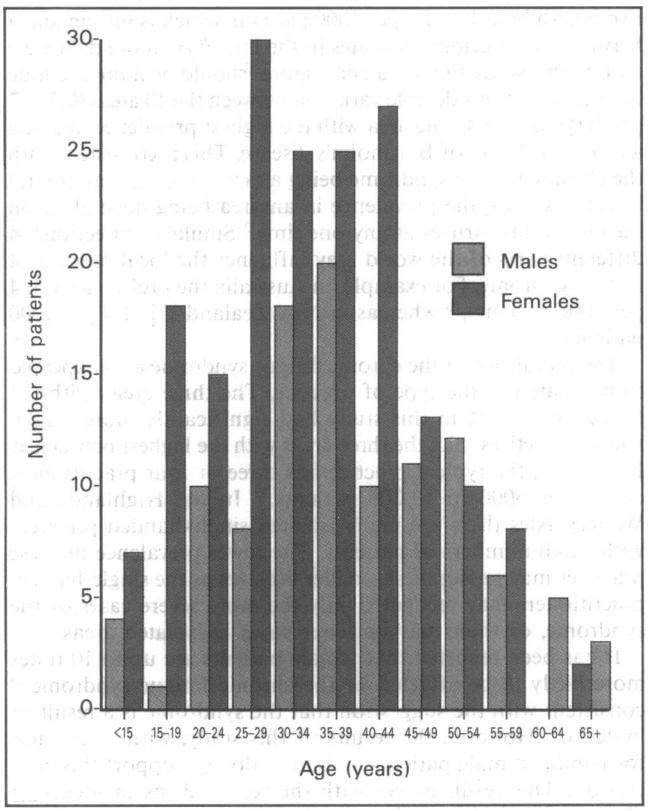

Figure 2. *Age at onset of the chronic fatigue syndrome shown separately for males (n = 102) and females (n = 187).*

Table 1. Characteristics of male and female patients suffering from the chronic fatigue syndrome.

	Female patients ($n = 187$)	Male patients ($n = 102$)
Age (years)		
Overall mean (SD) for 10 areas	38.2 (13.4)	40.8 (12.5)
Range (SD) in means for 10 areas	33.3 (17.9)–46.3 (16.1)	32.0[a]–49.0 (12.5)
Length of illness (months)		
Overall mean (SD) for 10 areas	33.2 (35.2)	30.1 (38.8)
Range (SD) in means for 10 areas	14.1 (14.5)–72.6 (83.0)	7.0 (4.4)–56.2 (103.1)
Severity of illness (% of patients)		
Mild	*16*	*24*
Moderate	*55*	*49*
Severe	*30*	*27*
Attendance at work/school (% of patients)		
Full time	*22*	*48*
Part time	*19*	*12*
None	*59*	*40*
Time spent by GP (% of patients)		
Little	*12*	*13*
Average	*41*	*46*
A lot	*38*	*33*
Excessive	*9*	*8*

SD = standard deviation. *n* = total number of patients. [a] This is age of one patient.

two health boards is 1.3 per 1000 patients which is intermediate between two previous estimates in the UK.[8,9] As more data were used in this study the prevalence figures should be more accurate but there was considerable variation between the 10 areas (0.3–2.7 per 1000 patients). The area with the highest prevalence had had a recent outbreak of Bornholm's disease. This is consistent with the chronic fatigue syndrome being a rare complication of viral infections, with the prevalence in an area being dependent on the circulating viruses at any one time.[3] Similarly, infections in different parts of the world may influence the local prevalence of the syndrome. For example, in Australia the prevalence is 0.4 per 1000 patients,[10] whereas in New Zealand it is 1.3 per 1000 patients.[11]

The prevalence of the chronic fatigue syndrome also appeared to be related to the type of practice. The three areas with the lowest prevalence in this study had significantly more single-handed practices than the three areas with the highest prevalence. In the UK, the typical practice has three or four practitioners caring for 6000 to 10 000 patients.[12] In the Highlands and Western Isles there are many isolated single-handed practices with small numbers of patients. The lower prevalence in these practices may reflect these smaller list sizes as the single-handed practitioners may recognize only the more severe cases of the syndrome, or there may be fewer cases in isolated areas.

It has been reported that female patients are up to 10 times more likely to be affected by the chronic fatigue syndrome,[13] consistent with the suggestion that the syndrome is a result of hysteria.[14] However, the results of this study, with a sex ratio for female to male patients of 1.8:1.0, do not support this conclusion. This result agrees with the reported sex incidence at diagnosis[7] and with the fact that female patients are more likely to suffer from chronic illness.[4] Our figures represent the prevalence in general practice and are different from the 3.0:1.0 ratio found in hospital specialist referrals.[15]

The results of this study show that all age groups are affected by the syndrome with a peak in the 30–44 years age group. This is similar to the results found for hospital referrals.[15] However, for the age of onset there is a peak at 35–39 years for male patients and a double peak at 25–29 years and 40–44 years for female patients. This double peak was previously reported for patients in Scotland at diagnosis of the chronic fatigue syndrome.[7]

One recent study found that 41% of patients with the chronic fatigue syndrome were employed in health care or teaching.[15] In this study the largest group were teachers or students (22%), followed by retired people (16%), housewives (13%) and those working in the service industry (11%). There were fewer hospital workers (7%) than found in other studies.[15] These findings appear to be consistent with greatest prevalence in those who are most exposed to infection. Several respondents, who were undecided about the existence of the chronic fatigue syndrome, felt that they may be persuaded if the illness were found in non-professionals. In this study 9% of patients were skilled workers and a further 8% were unskilled workers.

Although female patients may be more likely to suffer from chronic illness,[4] it was noticeable that our results show a similar distribution of severity of illness in male and female patients. The finding that significantly more male patients were in full-time employment may reflect the pressure on men to continue to earn money, or their lack of opportunity for part-time work. It was reassuring that the results did not show significant differences between male and female patients in the use of general practitioners' time. Although the majority of patients took little or average amounts of time, 47% of female patients and 41% males took a lot or excessive amounts of time. As female patients tend to consult practitioners more than males,[12] the finding that more female than male patients took a lot or excessive amounts of their doctor's time may reflect such sex differences rather then the illness.

The cooperation of the general practitioners in this study has produced the largest and most relevant study of its kind in the UK. The results clearly show variations between geographical areas with an overall prevalence of 1.3 per 1000 patients. This represents a significant number of patients and almost half the patients require a lot or excessive amounts of time from their general practitioner. We believe that patients suffering from the chronic fatigue syndrome are a real and distinct group for general practitioners and that they may represent a substantial part of the workload of doctors in particular areas.

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