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General practitioners' attitudes to patients with a self diagnosis of myalgic encephalomyelitis

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Interest in the symptom of tiredness has increased with the suggestion of a syndrome of prolonged fatigue caused by infection. The syndrome is referred to as myalgic encephalomyelitis, even though no evidence exists that sufferers have encephalitis or myelitis. Active support organisations encourage self diagnosis¹ and advise how to approach a general practitioner who "doesn't believe in ME." Problems in doctor-patient relationships may be a factor in persistent disability in fatigue states.3 We therefore used a case vignette method to examine how self diagnosis of myalgic encephalomyelitis could influence general practitioners.4

Subjects, methods, and results

We randomly selected 200 general practitioners from the Scottish Office register and allocated them to be sent one of four case descriptions (see below). Information was deliberately kept sparse to force respondents to call on general attitudes.

Case 1—Mrs M is a 28 year old personnel officer for a computer firm who has previously been in good health. She attended the surgery complaining of general malaise which had lasted for six months. The malaise had increased in severity and by the time she had presented it was accompanied by intermittent abdominal pains, severe tiredness, insomnia, and crying easily for no good reason. She denied any serious financial, social, or marital stressors. She had read newspaper articles about chronic fatigue syndrome/myalgic encephalomyelitis and believed that this was her problem. Physical examination, full blood count, urea and electrolytes, liver function tests, and thyroid function tests showed no abnormalities.

Case 2—This was the same as case 1 except chronic fatigue syndrome myalgic encephalomyelitis was not mentioned.

Case 3—This was identical to case 1 except that the patient was an office cleaner.

Case 4—The patient was an office cleaner but the self diagnosis was not mentioned.

The questionnaire contained nine items examining management issues and attitudes to the patient (table).

Mean scores (95% confidence intervals) on questionnaires for case histories mentioning and not mentioning mvalgic encephalomvelitis

	Myalgic encephalomyelitis mentioned (n=66)	Myalgic encephalomyelitis not mentioned	P value (n=66)
This patient is likely to comply with treatment	3·9 (3·6 to 4·2)	4·3 (4·1 to 4·6)	0.017
I would not want to have this patient on my practice list	2·1 (1·8 to 2·5)	1.5 (1.3 to 1.8)	0.014
This patient poses difficult management problems	4.5 (4.2 to 4.9)	3·7 (3·3 to 4·1)	0.001
This patient is likely to take up a lot of one's time	5·0 (4·8 to 5·2)	4.6 (4.4 to 4.9)	0.023
I would refer this patient to hospital for a second opinion	3·0 (2·6 to 3·4)	2·5 (2·2 to 2·8)	0.049
I would prescribe antidepressants for this patient	4·1 (3·8 to 4·5)	4·2 (3·9 to 4·5)	0.99
This is likely to be caused by psychological factors	4·4 (4·1 to 4·7)	4·7 (4·5 to 4·9)	0.33
This is likely to be caused by physical factors	2·7 (2·4 to 3·0)	2·5 (2·3 to 2·8)	0.49
I would refer this patient for counselling	3·4 (3·0 to 3·7)	2.9 (2.6 to 3.3)	0.07

Level of agreement was indicated on a six point scale and responses to the cases were compared by the Mann-Whitney U test.

We received 132 (66%) usable replies: 37 (74%) for case 1, 35 (70%) for case 2, 29 (58%) for case 3, 31 (62%) for case 4 ($\chi^2 = 3.6$, df=3; P=0.31). Respondents were more likely to refer the personnel officer than the office cleaner for counselling (mean score 3.4 v 4.2; P=0.011); this was the only significant effect of occupation. The table shows the influences of self diagnosis on the mean scores.

Comment

Doctors were more likely to refer the personnel officer than the office cleaner for counselling. This supports previous findings on the social class of people receiving psychological treatment.5

The decision to use antidepressants for someone with abdominal pains, fatigue, and weepiness was unaffected by mention of myalgic encephalomyelitis. Opinions on aetiology were also not significantly influenced. However, self diagnosis led general practitioners to consider the patient less likely to comply with treatment, more likely to pose difficult management problems, and more likely to take up a lot of time. Perhaps as a consequence, the doctors would rather not have such patients on their lists and are more likely to refer for a second opinion. These factors could be partly responsible for patients' numerous accounts of dismissive encounters with general practitioners and hospital doctors.12

The differential diagnosis of myalgic encephalomyelitis mainly consists of conditions defined by symptom patterns—for example, irritable bowel syndrome, fibromyalgia, atypical chest pain syndrome, and affective disorders. Self diagnosis adds to difficulties in communicating the nature and management of these poorly understood illnesses.

Our results suggest that it is not in patients' interests to suggest to doctors that they may have myalgic encephalomyelitis. Because of media interest self diagnosis of myalgic encephalomyelitis will continue, and doctors should remind themselves that resulting attitudes could lead to unsatisfactory consultations, resentment, and perhaps even unnecessarily prolonged disability.

We thank the general practitioners who took time to complete and return the questionnaires.

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