

# Chronic debilitating fatigue in Irish general practice: a survey of general practitioners' experience

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## SUMMARY

**Background.** Doctors are called upon to treat chronic debilitating fatigue without the help of a protocol of care.

**Aims.** To estimate the incidence of chronic debilitating fatigue in Irish general practice, to obtain information on management strategy and outcome, to explore the attitudes of practitioners (GPs) towards the concept of a chronic fatigue syndrome (CFS), and to recruit practitioners to a prospective study of chronic fatigue in primary care.

**Method.** A total of 200 names were selected from the database of the Irish College of General Practitioners (ICGP); 164 of these were eligible for the study.

**Results.** Altogether, 118 questionnaires were returned (72%). Ninety-two (78%) responders identified cases of chronic fatigue, giving an estimated 2.1 cases per practice and an incidence of 1 per 1000 population. All social classes were represented, with a male to female ratio of 1:2. Eleven disparate approaches to treatment were advocated. Many (38%) were dissatisfied with the quality of care delivered, and 45% seldom or hardly ever referred cases for specialist opinion. The majority (58%) accepted CFS as a distinct entity, 34% were undecided, and 8% rejected it. Forty-two (35%) GPs volunteered for a prospective study.

**Conclusion.** Chronic fatigue is found in Irish general practice among patients of both sexes and all social classes. Doctors differ considerably in their management of patients and are dissatisfied with the quality of care they deliver. Many cases are not referred for specialist opinion. A prospective database is required to accurately assess the scale of this public health problem and to develop a protocol of care.

**Keywords:** fatigue; protocols; questionnaire survey; quality of health care.

## Introduction

FATIGUE is a widespread finding in population studies.<sup>1-3</sup> It is also one of the most common complaints made by patients to their doctors in both general practice<sup>4-7</sup> and hospital-based medicine.<sup>8</sup> The attending clinician, who must consider a formidable

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range of differential diagnoses in the management of these patients, is presented with a time-consuming and challenging task. In the face of such difficulty, doctors are likely to experience considerable frustration and helplessness.<sup>9</sup>

Fatigue has long been recognized as an intrinsic component of psychiatric symptomatology<sup>10,11</sup> and, at times, the forerunner of overt affective symptoms.<sup>12</sup> It is not surprising then that many studies reveal a high level of psychiatric disorder — and a paucity of organic findings — in patients presenting with a chief complaint of chronic fatigue.<sup>5,7,13,14</sup> However, psychological factors do not account for all cases. This has been confirmed in several studies by the conspicuous and reproducible finding of 'an irreducible minority' who defy both psychiatric and physical explanations of fatigue.<sup>16</sup>

The phenomenon of chronic unexplained fatigue, although not new,<sup>17-20</sup> has given rise in recent years to various descriptions of an officially recognized CFS.<sup>21-25</sup> However, fundamental differences exist between proposed definitions, particularly with regard to the inclusion criteria for confounding premorbid and current psychiatric histories. These differences, together with other operational difficulties, such as the heterogeneity of CFS,<sup>26</sup> have hampered the development of good-quality epidemiological research.<sup>27-30</sup> Consequently, estimates of incidence vary by several orders of magnitude (1–1800 cases per 10 000 population<sup>30</sup>).

Furthermore, and notwithstanding the universal agreement of an overlap between CFS and psychiatric symptomatology,<sup>16,31-34</sup> the medical profession has long since been split on questions of aetiology. Thus, CFS is variously said to represent a psychiatric disorder,<sup>35,36</sup> a sociocultural phenomenon,<sup>37,38</sup> and an organic illness.<sup>39</sup> Proponents of the last hypothesis readily concede that CFS is complicated in a substantial number of cases by *de novo* psychiatric symptoms.<sup>9,13</sup> Nevertheless, this 'fruitless dichotomy'<sup>31</sup> between physical and psychological hypotheses is now so profound that some doctors simply refuse to accept the existence of CFS as a distinct clinical entity.<sup>40-42</sup>

It would appear, then, that the patient presenting with chronic debilitating fatigue of unknown origin does so to a divided profession. It is reasonable to assume that the quality of medical care that these patients receive will depend, at least in part, on the attitudes and beliefs of the individual doctors they happen to consult. This state of affairs is likely to persist in the absence of an evidence-based consensus protocol of care for the clinical management of patients with chronic debilitating fatigue of unknown origin. This study seeks to estimate the incidence of chronic debilitating fatigue of unknown origin in Irish general practice, to obtain information on the management and outcome of affected patients, to explore the attitudes and beliefs of Irish general practitioners (GPs) towards the concept of a distinct chronic fatigue syndrome, and to invite GPs to participate in a prospective study of chronic debilitating fatigue in primary care.

## Method

### Sample frame

General practice in Ireland is a two-tier service, which provides state-funded care to 38% of the population and private care to the

remainder. The former are registered with specific practitioners and are therefore a relatively stable population. The latter move freely between practitioners. Individual practices may thus comprise public patients, private patients, or a combination of both. Furthermore, very large numbers of patients may be assigned to a single doctor, who may employ 'assistant practitioners'. The majority of practising primary care physicians are members of the ICGP.

#### *Recruitment of GPs*

Two hundred doctors were selected at random from the database of the ICGP. The sample population was then compared with the register population to ensure that the sample was representative of Irish general practice.

#### *Questionnaire and definitions*

A purpose-designed questionnaire was tested by pilot study and sent to each selected GP. In a covering letter, chronic debilitating fatigue was defined as a fatigue that had been present for at least six months, that could not be explained by psychiatric or physical means, and that had caused a significant reduction in quality of life. Responders were asked to include patients whose fatigue appeared after an episode of infection, and who complained of fatigue in spite of adequate psychiatric treatment.

Personal data was obtained from each responder concerning practice size, health board area, sex, and age group. This information was compared demographically with the ICGP and health board databases.

The questionnaire comprised a series of open and closed questions. Responders were asked to enumerate current patients with chronic debilitating fatigue of unknown origin within their practice. They were also asked to declare their management and referral strategies and to rate their satisfaction with the quality of care they deliver themselves and receive from their referrals. Responders were then asked whether they accepted the existence of a distinct clinical entity referred to as CFS, whether they considered CFS as a diagnostic possibility in their own fatigued patients, and if they felt confident in making a diagnosis of CFS. Finally, an invitation was given to each responder to participate in a prospective study on chronic debilitating fatigue in primary care. Non-responders were followed up by repeat postal questionnaire and telephone contact.

#### *Data collection analysis*

Data from completed questionnaires were analysed by 'Epi-Info' version 5.00, the statistical package of the Centre for Disease Control, Atlanta, USA. Categorical analysis was performed using the chi square test.

## **Results**

#### *Response rate*

Twelve of the 200 GPs selected were deemed ineligible for the study because they were found to be retired from general practice. A further 24 were deemed ineligible because they could not be contacted by telephone, having not responded by post. The final study sample thus comprised 164 doctors. The response rate among these was 72% (118), of whom 30 were women and 88 were men.

#### *Participant characteristics*

Demographic comparisons revealed that the study sample contained more male doctors under the age of 45 years than the register population (see Table 1). There were no significant differ-

ences between female participants and the register. All health board regions were represented. The average list size in this study was 1960. However, owing to the methodological difficulties mentioned above, some responders declared what in effect is their 'group size' rather than their individual practice load. This will have artificially inflated the list size in this study.

#### *Perceived incidence of chronic debilitating fatigue*

Ninety-two (78%) responders identified current patients with chronic debilitating fatigue in their practices. Of these, 52 gave details of 139 patients, 47 men and 92 women. Forty responders provided no information on numbers of cases. Each of these must have at least one case, giving a lower bound of 1.5 cases per practice. If the 40 practices with an unknown number of cases are assumed to average the same number of cases as those that did provide details, then the estimated incidence would be 2.1 cases per practice and 1 per 1000 population.

#### *Patient demographics*

All social classes were represented among the cases. Although not reaching statistical significance, there were more male than female patients in social class 1 and more female than male patients in social class 4.

Table 2 shows the results of specific questions asked in the questionnaire. Thirty-eight (45%) responders used several disparate terms for medical certification purposes, such as 'back pain', 'anaemia', 'depression', 'neurosis', or 'any other prominent symptom reported by the patient'. Some commented that they were inclined to use labels that they felt would be acceptable to medical referees. Non-drug treatments were preferred by 23 (19%), some of whom specified exercise ( $n = 3$ ), acupuncture ( $n = 2$ ), and psychotherapy ( $n = 3$ ). One responder listed 'hormone replacement therapy' and one advocated 'listening' as a possible treatment. The preferred specialty for referral was general medicine (66% of referrals), with other referrals going to psychiatry (16%) or immunology (8%). There were occasional referrals to neurology, psychology, endocrinology, infectious diseases, and rheumatology. Three (2%) said they would refer to a GP colleague.

Sixty-eight (58%) responders believed that CFS is a distinct clinical entity. However, when asked if they would entertain the diagnosis of CFS in a given patient with chronic debilitating fatigue, 97 (82%) respondents said they would, whereas 21 (18%) said they would not (Table 3).

There was no statistically significant correlation between sex, age, satisfaction, or confidence ratings of responders and any other parameters measured. Forty-two (35%) responders declared an interest in a prospective study of chronic debilitating fatigue in primary care.

**Table 1.** Comparison of sample population with Irish College of General Practitioners' register population for sex and age.

Sex and age	Register population (%)	Sample population (%)
Men < 45 years	572 (39)*	51 (58)
Men > 45 years	878 (61)*	37 (42)
Women < 45 years	393 (66)	22 (73)
Women > 45 years	203 (34)	8 (27)

\* $\chi^2 = 11.79$ ,  $P = 0.0005$ .

**Table 2.** Results of specific questions on the questionnaire.

What diagnosis do you offer on medical certificates?	'Postviral', 'viral', 'ME' <sup>*</sup>	27 (32%)
	Chronic fatigue	20 (23%)
	Other <sup>†</sup>	38 (45%)
What are your treatment preferences?	Antidepressants	88 (75%)
	Vitamins	67 (59%)
	Analgesics	13 (11%)
	Tranquillisers	5 (4%)
	Non-drug treatments <sup>†</sup>	23 (19%)
How often do you refer for a specialist opinion?	Almost always	20 (17%)
	Usually	45 (38%)
	Seldom	37 (31%)
	Never	16 (14%)
How satisfied are you with quality of care you deliver?	Very satisfied	7 (6%)
	Quite satisfied	66 (56%)
	Quite dissatisfied	43 (36%)
	Very dissatisfied	2 (2%)
How satisfied are you with the quality of care received from your referrals?	Very satisfied	8 (7%)
	Quite satisfied	68 (58%)
	Quite dissatisfied	36 (30%)
	Very dissatisfied	6 (5%)
Do you accept CFS as a distinct clinical entity?	Accept	68 (58%)
	Do not accept	10 (8%)
	Undecided	40 (34%)
How confident are you in diagnosing CFS?	Very confident	4 (3%)
	Quite confident	36 (31%)
	Not so confident	52 (44%)
	Not at all confident	26 (22%)

\*Myalgic encephalomyelitis. <sup>†</sup>See text.

**Table 3.** Percentage of GPs who accept CFS as a distinct clinical entity.

	Accepted	Not accepted	Undecided
Among the general population	58	8	34
Among the GP's patients	82	18	

## Discussion

This study clearly demonstrates the occurrence of chronic debilitating fatigue of unknown origin in Irish primary care. The majority of GPs surveyed recognized such patients within their practice. The data, which suggest an average of 2.1 cases per practitioner and an incidence of 1 per 1000 population, is in keeping with previous studies of fatigue in the community.<sup>42,43</sup> It should be noted, however, that our figures are probably diluted by the occasional submission of group rather than individual list size. Cases were identified retrospectively by responder recall, with no attempt made to validate cases or match them with proposed definitions for chronic fatigue syndrome (CFS). Our data refer, therefore, to the perceived incidence of idiopathic chronic fatigue and not to CFS *per se*. By thus avoiding prejudicial diagnostic labels,<sup>17</sup> we have obtained relevant information concerning patients whose quality of life is adversely affected by unexplained fatigue. We have also procured an insight into the difficulties faced by doctors when they are called upon to manage such patients without the help of an evidence-based consensus protocol of care.

The popular belief that chronic fatigue states occur stereotypically among middle-class women is questioned by this study, in

which all social classes are equally represented, with a male to female ratio of 1:2. Notwithstanding the possibility that recall bias favoured the reporting of exceptions to stereotypes, our data show that such cases can and do occur in practice.

The average age of patients (38 years for women and 35 years for men) also suggests that diagnostic criteria for somatization disorder<sup>44</sup> — which requires an age of onset below 30 years — would not be met in this cohort. However, precise and validated information on duration of illness etc., which was not sought in this study, would be necessary to clarify this point. We plan to provide more robust data in a future prospective study.

Chronic fatigue states remain a controversial issue in medicine. Terms such as 'chronic fatigue syndrome' and its synonyms, 'myalgic encephalomyelitis' and 'post-viral fatigue syndrome', are as likely to evoke scepticism as sympathy. This may represent something of a dilemma for GPs when they are asked to certify illness for their fatigued patients. Some GPs commented that they were likely to use terminology that they felt would be acceptable to medical referees. This camouflage phenomenon may represent a fear that patients with chronic fatigue will not obtain adequate socio-economic support if the true nature of their illness is declared.

Antidepressants,<sup>45,46</sup> essential fatty acids,<sup>47</sup> analgesics,<sup>46</sup> cognitive behavioural therapy,<sup>48-50</sup> rest,<sup>51</sup> and graduated exercise programmes<sup>52</sup> are variously said to have a place in the management of chronic fatigue. This therapeutic uncertainty is reflected in the present study, in which respondents listed 11 disparate approaches to treatment. Although not asked to give reasons for their choice of therapy, it is clear that doctors differ considerably in their approach to management. Furthermore, many doctors were dissatisfied with the quality of care they deliver to fatigue patients, and tacitly expressed a desire to improve care by volunteering for a prospective study. Provider satisfaction ratings for medical care in general<sup>53</sup> are much higher than those reported here, suggesting that there is indeed 'no clinical problem more demanding of the art of medicine than the management of lassitude'.<sup>9</sup>

There was no statistical evidence of association between the decision to refer and any other parameter measured. With this in mind, and given the high level of self-dissatisfaction among responders, it is surprising that so many of them seldom or hardly ever refer these patients for a specialist opinion. Although not asked to give a reason for their decision, it is possible that responders fail to refer in the belief that 'nothing can be done' for the fatigued patient.

If this holds true of referral rates for chronic fatigue throughout primary care, it has important implications for research. Our data suggest that specialist clinics are not dealing with the full spectrum of fatigue, and may in fact see little more than half of those affected. Consequently, reports emanating from secondary and tertiary centres of excellence may not be truly representative of the illness. To rectify this, future research must include the significant involvement of primary care physicians.

When they are referred, patients are mostly sent to general physicians or psychiatrists. The preference for internal medicine may be indicative of the doctor's conviction of physical disease, the doctor's need to 'exclude organicity', or the patient's request for full physical assessment. Most responders were satisfied with the quality of care their patients received from referrals, but many were not. However, as mentioned above, this did not appear to affect the decision to refer.

Sixty-eight (58%) GPs expressed an acceptance of CFS as a distinct clinical entity, 40 (34%) were still undecided, and 10 (8%) did not accept it. However, when asked if they would consider a diagnosis of CFS in their own patients with chronic debili-

itating fatigue, 97 (82%) responders said they would, whereas 21 (18%) would not. This suggests that most ( $n = 29$ , 72%) of the 'undecided' group tend more towards acceptance than towards rejection of CFS as a distinct entity. Notwithstanding their willingness to consider CFS in the differential diagnosis of fatigued patients, most participants lacked the confidence to make such a diagnosis.

## Conclusions

This study demonstrates the occurrence of chronic debilitating fatigue among patients of both sexes and all social classes within Irish general practice. It also reveals that the majority of doctors surveyed accept the concept of a distinct CFS. However, it is clear that the management of chronic fatigue is problematic. This is reflected in the disparate approaches to treatment, the camouflage of medical certificates, the lack of confidence in the diagnosis of CFS, and the responders' own dissatisfaction with the quality of care they deliver to the fatigued. Notwithstanding, and for reasons not explored in this study, many doctors choose not to refer fatigued patients for a specialist opinion. Consequently, reports from specialist centres may not be fully representative of the illness.

## Recommendations

A prospective validated database of patients with chronic debilitating fatigue is required. This would allow an accurate assessment of the scale of this public health problem. It would also provide information on long-term outcome and effective management strategies. Only then will an evidence-based consensus protocol of care be established. It is imperative that primary care physicians be involved in any such project.

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