



Alternative diagnoses to chronic fatigue syndrome in referrals to a specialist service: service evaluation survey

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DECLARATIONS

Competing interests

PDW has done consultancy for the Department for Work and Pensions and a re-insurance company

Funding

AD and TL were supported by the East London Foundation Trust

Ethical approval

Not applicable

Guarantor

PDW

Contributorship

PDW and MM conceived the idea; AD and TL collected the data; AD, TL and PDW analysed the data; all authors wrote and approved the final version

Summary

Objective To assess the accuracy of diagnoses made by referrers to a chronic fatigue syndrome (CFS) service.

Design Retrospective service evaluation surveys of both rejected referral letters and medical case-notes after full clinical assessment.

Setting A specialist CFS clinic in London, UK.

Participants In the first survey, we assessed rejected referral letters between March 2007 and September 2008. In the second survey, we ascertained the primary diagnosis made in case-notes of 250 consecutive new patients assessed between April 2007 and November 2008.

Main outcome measures Reasons for rejection of referrals and primary diagnosis in those assessed.

Results In the first survey, 154 out of 418 referrals (37%) were rejected. Of these, 77 out of the available 127 referrals (61%) had a likely alternative diagnosis. In the second survey of clinically assessed patients, 107 (43%) had alternative medical/psychiatric diagnoses, while 137 out of 250 (54%) patients received a diagnosis of CFS. The commonest alternative medical diagnoses of those assessed were sleep disorders and the commonest alternative psychiatric diagnosis was depressive illness. Altogether 184 of 377 (49%) patients had alternative diagnoses to CFS.

Conclusions Half of all the referred patients to a specialist CFS clinic had alternative medical and psychiatric diagnoses. Specialist medical assessment for patients with unexplained, disabling, chronic fatigue needs to incorporate both medical and psychiatric assessments.

Acknowledgements

None

Reviewer

Hugh Rickards

Introduction

Chronic fatigue syndrome (CFS) occurs in 0.4–2.5% of the population, depending on how it is defined.¹ CFS is characterized by post-exertional fatigue not relieved by rest, lasting more than six months' duration. The symptoms are not due to any alternative medical or psychiatric disorder, and can be accompanied by impairment of short-term memory and concentration, headache, tender lymph nodes, sore throat, post-exertional malaise lasting more than 24 hours, muscle pain, multi-joint pain, and unrefreshing sleep.² CFS causes a significant functional impairment. It is a clinical diagnosis made after excluding any explanatory medical or psychiatric disorder. There are no laboratory investigations to confirm the diagnosis of chronic fatigue syndrome.³

The NICE guideline for the assessment and management of CFS recommends that a diagnosis of CFS in adults should be made in primary care.⁴ Patients are then referred, if their illness is long-lasting or complex, to specialist CFS clinics for confirmation of the diagnosis and management of their illness. However, general practitioners (GPs) do not feel confident in making the diagnosis.⁵ To compound this, some specialist CFS clinics do not employ doctors, and rely on an accurate diagnosis being made in primary care.

Newton and colleagues have recently shown that misdiagnosis is common in patients seen in a specialist service.⁶ They found that 40% of referrals to a specialist CFS service had an alternative diagnosis, most commonly primary sleep disorders (including obstructive sleep apnoea) and psychiatric disorders (including depression, anxiety and post-traumatic stress disorder). This study aimed to explore the prevalence of alternative diagnoses in patients referred with a definite or provisional diagnosis of CFS.

Methods

These service evaluation surveys were conducted at the specialist CFS clinic at St Bartholomew's Hospital, London. This service accepts referrals from primary care for assessment and management of patients with CFS. All the referrals were routinely screened by both a consultant liaison psychiatrist and a consultant physician in

infectious diseases. Once the referral had been accepted, the patient was offered an assessment that included a detailed history, physical and mental state examination and laboratory investigations. Management plans depended on the diagnosis following the assessment.

The first survey examined all the referrals which were rejected between March 2007 and September 2008. The survey was based on analyses of the letters to the referrer in all the cases not accepted. The second survey studied 250 consecutive new patients assessed in the same clinic, between April 2007 and November 2008, for the primary diagnosis following clinical assessment. This survey examined the case-notes for outcomes of assessments. In both surveys, the most recent case-notes and letters were examined in cases where the outcomes were not clear.

Results**Rejected referrals**

A total of 418 referrals were received during this period, out of which 154 (37%) were rejected. One hundred and twenty-seven (82%) rejection letters were analysed for reasons for rejection. No information was available for the remaining 27 referrals, which were most likely sent back to the referrer for further action. Ninety-six (76%) of the 127 rejected referrals had been received from GPs, with the remaining referrals received from other medical specialties including endocrinology, psychiatry, neurology and paediatrics. Although the majority of letters written back to the referrer, explaining why a referral had been declined, gave only one reason, a significant proportion cited two or three reasons (one case even having five reasons), and the overall number of reasons being 197 in the 127 referral letters. In all, 77 out of 127 rejected referrals (61%) were thought likely to have alternative medical and/or psychiatric diagnoses; in total 119 likely alternative diagnoses.

Fifty-two (26%) reasons for rejection were on the grounds of a likely alternative psychiatric diagnosis, of which 24 (12%) were due to depressive disorder, 16 (8%) were due to an anxiety disorder, and the remaining were due to other psychiatric conditions (Table 1). There were 67 (35%) reasons in referrals that were declined due to likely alternative medical diagnoses. The majority

of these were due to chronic pain being the primary problem (32, 16%). A further eight (4%) had sleep disorders. Other common diagnoses are shown in Table 1. Forty-nine (25%) reasons in referrals that were rejected were due to alternative CFS services being closer to where the patients lived.

Alternative diagnoses in patients assessed

The second survey examined primary diagnoses made in the 250 patients following clinical assessment; 137 (54%) patients were diagnosed with CFS. 53 (21%) of patients received an alternative medical diagnosis, the commonest of which were

Table 1
Reasons for rejected referrals and diagnoses after assessment

	<i>Declined referrals, n = 197 (n = number of reasons)</i>	<i>Patients assessed, n = 250 (n = number of patients)</i>
Chronic fatigue syndrome	–	n = 137 (54%)
Psychiatric diagnoses	n = 52 (26%) Depression = 24, 12% Anxiety disorders = 16, 8% Somatoform disorders = 3, 2% Dissociative disorders = 2, 1% Others = 7, 4% (eating disorders = 2, substance misuse = 2)	n = 54 (22%) Depression = 27, 11% Anxiety = 14, 7% (GAD = 10) Stress-related disorders = 6, 2% (PTSD = 4) Somatoform disorders = 3, 1% Others = 4, 1.6% (eating disorders, bipolar disorder and OCD)
Medical diagnoses	n = 67 (35%) Sleep disorders = 8, 4% Pain disorders = 32, 16% (fibromyalgia = 9) Endocrine disorders = 6, 3% (diabetes mellitus = 2) Nutritional disorders = 5, 3% (iron deficiency = 2, pathological obesity = 2) Musculo-skeletal disorders = 3, 2% Gastro-intestinal disorders = 7, 4% (Coeliac disease = 2, Crohn's disease = 3) Infections = 4, 2% Others = 2, 1% (abnormal blood tests)	n = 53 (21%) Sleep disorders = 15, 6% (sleep apnoea = 9) Pain disorders = 6, 2% Endocrine disorders = 7, 3% Nutritional disorders = 7, 3% (Vit D deficiency = 4, pathological obesity = 3) Musculo-skeletal disorders = 3, 1% Gastro-intestinal disorders = 5, 2% (Coeliac disease = 3) Neurological disorders = 3, 1% Others = 6, 2% (cardiac disorders and infections)
CFS services nearer to patients	n = 49 (25%)	–
Miscellaneous reasons	n = 29 (14%) Fatigue not meeting criteria for CFS = 4, 2% Need more information = 4, 2% Need GP referral = 6, 3% Need PCT funding = 4, 2% Wants antiviral treatment = 2, 1% Wants private treatment = 2, 1% Housebound = 2, 1% Second opinion = 2, 1% Others = 3, 1.5% (underage, confidentiality, previously declined CBT/GET)	n = 6 (2.4%) Fatigue not meeting criteria for CFS = 3, 1% Recovered from CFS = 2, 1% No conclusive diagnosis = 1, 0.4%
N.B. Referrals were sometimes rejected for more than one reason		

primary sleep disorders, endocrine disorders, nutritional disorders, and pain disorders (Table 1). Fifty-four (22%) patients received an alternative psychiatric diagnosis; most commonly a depressive illness, then an anxiety disorder (Table 1).

Discussion

Almost half (49%) of all patients referred to a specialist CFS service did not have a diagnosis of CFS. Thirty-seven percent of referrals, screened by both a psychiatrist and a physician, were declined at the point of referral, sometimes for more than one reason, of which 61% were for likely alternative medical and psychiatric diagnoses. A further 46% of patients assessed did not receive a diagnosis of CFS. We expected a significant minority of referrals not to have a diagnosis of CFS, but did not expect that so many of the assessed patients would not have a diagnosis of CFS.

The strengths of this paper are that the two surveys studied referrals and assessments over the same 18 months period with a large number of cases. Both the surveys were carried out at similar times and the results are complementary. The limitations of this paper are that it is based on two surveys of only one service; we cannot be sure that the rejected referrals did not have a diagnosis of CFS; and the information from this cannot answer the primary question on effective identification and management of CFS in primary care.

These figures are reflected in a study by Euba and colleagues, which showed that 44% of patients referred to specialist clinic did not receive a diagnosis of CFS.⁷ A more recent study found that 40% of patients diagnosed with CFS in a specialist centre did not have CFS.⁶ Added to our findings, this would suggest that between 40–50% of patients referred to specialist services do not have a diagnosis of CFS.

Patients with chronic fatigue in general have strong diagnostic associations with both psychiatric and medical conditions.^{8,9} Teasing these out to accurately identify patients with CFS, especially in the absence of confirmatory laboratory investigations, can be difficult. Harvey and Wessely suggest that looking for common medical and psychiatric illnesses in patients with chronic fatigue

will improve their rate of detection.³ They add that a basic mental state examination is the most productive tool, as depression is the most common exclusionary and co-morbid condition with CFS. The most commonly applied research diagnostic criteria for CFS stresses the importance of a mental state examination.¹⁰ Even specialist doctors trained in CFS can make errors of psychiatric diagnoses, with non-psychiatrists missing psychiatric diagnoses more than psychiatrists.¹¹ A diagnosis of depressive illness is more likely than CFS when fatigue is relieved rather than exacerbated by exertion, when fatigue is not the primary symptom, and when low mood dominates the clinical picture.

Bowen and colleagues found that 48% of GPs were not confident of making a diagnosis of CFS, and 41% were not confident enough to provide treatment.⁵ Despite guidance now being available,⁴ a qualitative study suggested that GPs were not confident in making a diagnosis of CFS, with concerns that such a label might be harmful to the patient.¹² The current evidence suggests that a diagnosis of CFS probably is helpful and enabling, so long as it leads to a constructive treatment plan.¹³

The NICE guideline states that primary care doctors should diagnose patients with CFS and identify patients for referral onto specialist CFS services.⁴ Accurate diagnosis of the primary condition and identification of co-morbid illnesses will help in better management of the illness and improve quality of life. However, diagnosing CFS can be complicated, as described above, and specialist CFS services are well placed to provide such a service, especially if they have a mix of specialist clinicians who can accurately identify CFS and exclusionary medical and psychiatric illnesses. We argue that the NICE guideline's advice to diagnose within primary care may not be the best guidance, and more specialist CFS services (with a mix of specialist doctors) are needed to provide a diagnostic service that meets the requirements of patients. However, this has to be balanced against resources available, and commissioners of services will have to consider how best to provide a clinically effective service to patients while being cost-effective at the same time.

In conclusion, this paper replicates two previous studies finding high rates of misdiagnosis in patients accepted and assessed in a secondary

care CFS service. The NICE guideline suggests that patients with CFS should be diagnosed and managed in primary care, and specialist CFS services used for patients with severe and disabling symptoms. Our results suggest that this may not be the best guidance. These results have implications for training, care pathways and service design, particularly in primary care and those specialist services without a doctor. Specialist services need doctors who are equally confident in making both medical and psychiatric diagnoses.

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