

Use of formal and informal care among people with prolonged fatigue: a review of the literature

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SUMMARY

Prolonged fatigue is a common symptom in the community and a common complaint in GPs' surgeries. The current consensus is that prolonged fatigue is most appropriately managed within primary care but that quality of care is patchy. Diagnosis is difficult and there is no conclusive evidence about effective treatment. This can lead to confusion and controversy among lay people and health professionals alike. Although the value of a positive doctor-patient relationship is emphasized, general practice consultations are frequently experienced as difficult by both parties. Moreover, little is known about how people access other sources of care and information about prolonged fatigue, such as alternative medicine, self-help groups, lay others, and self care, in conjunction with or as an alternative to care from health professionals. This paper reviews the literature on the nature and extent of the problem prolonged fatigue represents for primary care, and on the use of formal and informal care for prolonged fatigue.

Keywords: prolonged fatigue; management.

Introduction

'PROLONGED fatigue' — that is, severe, medically unexplained, disabling fatigue of longer than one month's duration¹ — is a common symptom in the community and a common complaint in GPs' surgeries. Additionally, prolonged fatigue and chronic fatigue syndrome (CFS) are sources of public concern^{2,3} as well as the focus of enduring, and often scathing, media interest. Controversy and confusion surround the diagnosis and management of prolonged fatigue and CFS. Therefore, fatigue represents a 'problem' for general practice beyond the scale of demand. A significant minority of doctors do not accept the existence of CFS^{4,5} or myalgic encephalomyelitis (ME).⁶ Moreover, rates of diagnosis vary a great deal^{4,7} and there is some concern among GPs about how the diagnosis will be received by others.⁴

This paper reviews the literature on how prolonged fatigue is managed within primary care and outside formal health care services. The multiple ways in which medically unexplained fatigue has been defined are described, and clarification is offered on the distinction between CFS and prolonged fatigue. The prevalence and social distribution are then outlined. Factors shaping the use of GP services for primary care and the management of prolonged fatigue within primary care are then reviewed. The paper concludes with a discussion of other sources of care and information available to people with prolonged fatigue.

Method

The wide-ranging literature reviewed for this paper was accessed by searching the BIDS (Bath Information and Data Services) and

MEDLINE databases for English language studies. References quoted in recent literature were searched manually. References were also identified through general practice specialists with an interest in prolonged fatigue. The recent far-reaching report on CFS by the Joint Working Groups of the Royal Colleges of Physicians, Psychiatrists and General Practitioners (JWG)² contained a substantial literature review, and care was taken to complement rather than replicate this work.

Primary care and community-based studies were selected that related to factors shaping the use of formal and informal care, relationships between health professionals and people consulting with prolonged fatigue, and prevalence and social distribution of prolonged fatigue. Particular emphasis was given to studies that considered lay experience of prolonged fatigue and also health professionals' experience of managing fatigue. This led to the inclusion of much qualitative research — given its standing in many fields as a methodology that has the capacity to elucidate contextual features of events and processes.^{8,9} This review was not systematic in the sense now used within the context of the evidence-based healthcare movement. In 'systematic' reviews, papers are selected for inclusion according to a methodological hierarchy that prioritizes randomized control trials.¹⁰ Since this paper included qualitative and quantitative methods as well as review articles, it was not possible to develop a common hierarchy. The initial selection of papers has been made on substantive grounds and an assessment of methodological merit was made thereafter.

Defining prolonged fatigue

The experience of ongoing, severe, medically unexplained tiredness has been variously described as chronic fatigue syndrome, chronic fatigue, ME, neurasthenia, 'yuppie 'flu', and 'tired all the time'. The variety of labels hint at the conflict surrounding the area, and indeed perpetuate certain misleading myths about the condition.³ Therefore, it is worth spending some time unravelling some of the terms used in this field.

The current clinical and research consensus is that the term 'chronic fatigue syndrome' is a more appropriate clinical definition than 'myalgic encephalomyelitis' or 'ME', which was adopted during the 1980s, since encephalomyelitis is a specific pathological process and there is no evidence that this process is found in patients with prolonged fatigue. However, the term 'ME' continues to be popular among lay people and preferred by self-help groups.^{2,11} Within the UK welfare system, eligibility for benefits is dependent on a diagnosis of 'ME'.^{7,2}

Early criteria for CFS led to the erroneous impression that CFS was a psychiatric illness.³ This was owing to the requirement of a high number of minor symptoms to be found in conjunction with severe fatigue, which resulted in the inclusion of people with high levels of psychiatric co-morbidity.^{3,12} This impression has endured among some health professionals as well as some sections of the media¹³ and the general public,³ despite the modification of the original CFS criteria and research that has highlighted important differences between CFS and psychiatric disorders.^{3,14}

The most widely accepted criteria for identifying CFS syndrome are those developed by the Centre for Disease Control (CDC),¹ and the less stringent 'Oxford' criteria produced at a

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consensus conference.¹⁵ Both specify that tiredness must be severe, have lasted at least six months, and involve substantial or disabling impairment. The CDC criteria also require four associated minor symptoms, and both sets of criteria exclude severe psychiatric disorders such as severe depression and substance abuse. There are some concerns about these psychiatric exclusions,¹ in particular, and about the exclusion of people with psychiatric morbidity from fatigue research more generally.^{2,16} It is often both impractical to try to isolate tiredness from other health problems and premature, in light of limited knowledge about the aetiology of tiredness and of many psychiatric disorders.¹⁶

Since prolonged fatigue represents the greater burden of demand for primary care than CFS, it is the main focus of this paper. This focus encompasses CFS and throughout this review it is indicated whether studies were undertaken only with people with CFS or with broader groups.

Population prevalence and social patterning of fatigue

Estimates of prevalence of CFS and prolonged fatigue depend on the inclusiveness of the definitions used and the research setting.^{3,17} Only a small proportion of the cases of prolonged fatigue reported in the community or seen by health professionals meet the criteria for CFS. Population prevalence rates of CFS are estimated at between 1% and 2%, falling to around 0.5% when recognizable psychiatric disorders are excluded. In contrast, community surveys report population prevalence rates of prolonged fatigue at between 9% and 30%.^{2,7}

Despite being characterized in the popular press as 'yuppie flu', there is no clear-cut population-based evidence linking to suggest that prolonged fatigue or CFS is more common among the middle classes.^{2,7,18} Early studies that found an upper-class bias were misleading because they were based on samples drawn from secondary care, rather than population-based samples.^{3,19-21} and people from high socio-economic groups are more likely to be referred for specialist treatment for tiredness.²⁰

Women are more likely to report experiencing prolonged fatigue than men,^{2,19,20,22-24} especially if they have children aged under six years.²² However, a recent study found that the sex difference is modest once psychological morbidity has been excluded.⁷ Women are also more likely to attribute their fatigue to family responsibilities.²⁵

Demand for care

The role of lay decision-making in understanding demand for care

Little is known about when people feel it is appropriate to consult health professionals and when it is not.²⁶ Rather than being shaped by severity of symptoms alone, lay decision-making about the management of ill-health is the result of interaction between a range of factors including sociocultural background, past medical experiences, the availability or otherwise of advice and support of lay others, and the accessibility of formal health care.²⁷⁻²⁸ In the case of prolonged fatigue, decisions about whether and when to access care may be complicated by concerns about the legitimacy of 'claims' on care. There are two ways in which legitimacy of claims to be ill is undermined.²⁹ Prolonged fatigue can be construed as simply being part of everyday life and, therefore, trivial. Additionally, in the absence of any objectively identifiable physical condition, the problem may be diagnosed as psychosomatic.²⁹ Such diagnoses can be experienced as undermining, because of the social stigma associated with mental distress²⁹ and because of the attendant implications that symptoms might be 'all in the mind'.²⁹⁻³⁰ However, this tendency can be oversimplified. A hos-

pital-based study found that, although generally resistant to psychological diagnoses, people with prolonged fatigue did acknowledge, and indeed volunteer, the role of 'stress' in the onset and perpetuation of tiredness.³⁰

Demand for GP services

Rates of GP consultation for prolonged fatigue as a primary symptom are high. Although precise figures are open to dispute because of different ways of classifying tiredness, between 10% and 20% of GP attenders report prolonged fatigue, and for between 5% and 10% it is the main reason for consultation.² Within primary care, consultations for prolonged fatigue are associated with psychiatric morbidity,³¹ higher levels of fatigue than in the general population,³¹ and being female.^{5,23,31} Individual consultations for fatigue can also be experienced as time-consuming by GPs. One study found that GPs judged that nearly half of all patients (men and women) consulting with prolonged fatigue took up 'excessive' amounts or much of their time.⁵ Additionally, fatigue is associated with frequent use of primary care services for all reasons.^{23,32}

Management of prolonged fatigue within general practice

The poor prognosis associated with specialist treatment for prolonged fatigue has led to the recommendation that prolonged fatigue is best treated within the primary care sector.² However, there is a great deal of variety in how prolonged fatigue is managed,^{2,4,19} and there is no conclusive evidence about effective treatment.^{2,4} A randomized controlled trial has shown that graded exercise is a useful management strategy,³³ but the value of rest and exercise in CFS is contested.³⁴ There has also been promising research on the use of self-help information in conjunction with advice from a research nurse.³⁵ Two recent randomized control trials have also indicated that cognitive behavioural therapy can be beneficial.³⁶⁻³⁷

Diagnosis of CFS also poses dilemmas. On one hand a diagnosis offers a structure for people to understand their condition,^{2,38} and an explanation for family, friends, and employers.^{39,40} However, the majority of GPs in a recent qualitative study had practical and ethical concerns about offering a diagnosis of a condition for which they felt they could not offer effective treatment, and that might become a negative self-fulfilling prophecy.⁴¹ These concerns are echoed elsewhere.^{2,42} In the same study, the majority of patients identified diagnosis as the single most helpful occurrence since they had become ill. Contrary to GPs' expectations, diagnosis was associated with a moderation in health problems.⁴¹

Recent clinical consensus advocates the adoption of a 'biopsychosocial approach' to prolonged fatigue, recognizing that physical and psychological symptoms cannot be considered in isolation from each other, nor can the experience of prolonged fatigue be divorced from its social context.^{2,38,43} Specifically, this involves working towards the establishment of a positive therapeutic relationship over multiple consultations, judicious use of laboratory tests, and encouragement of the gradual resumption of normal activity.^{2,44} Several problems have been noted with this approach. Patients may be resistant to psychosocial assessment and GPs may not be trained to undertake it.⁴⁴ Untrained or inexperienced attempts to adopt a patient-centred, collaborative approach may well be counter-productive.⁴⁵ Moreover, the organization of primary care services may not be conducive to multidisciplinary collaborative approaches while financial considerations may mitigate against labour intensive interventions.^{44,46}

Doctor–patient relationships: the potential for therapeutic alliances

A second key recommendation of the JWG is that prolonged fatigue should be managed through a ‘therapeutic alliance’ between doctor and patient. However, the ambiguity surrounding prolonged fatigue introduces potential for friction into the doctor–patient relationship, and consultations for fatigue can be experienced as difficult by both parties.^{11,39,47} Non-UK studies suggest that patients with prolonged fatigue are more litigious⁴⁸ than a general medical population and more pro-active in changing GPs.⁴⁹ Tensions can arise from GPs and patients holding different views of the aetiology of fatigue⁴¹ and when patients attribute more significance to fatigue than their GPs.¹⁶ People with prolonged fatigue report extreme distress at not being believed by their GPs^{49,50} as well as dissatisfaction with the treatment, emotional support, and information support that GPs offer.⁴⁷ GPs have also been reported to express some dissatisfaction about the quality of care they can provide.^{4,39} In the context of research such as this, it is perhaps not surprising then that prolonged fatigue has been described as a ‘heartsink’⁵¹ condition among GPs.²³ Some groups of patients are more likely to have unsatisfactory consultations than others. For example, a recent qualitative study of consultations for prolonged fatigue found that women were disproportionately likely to have their consultation handled in ways that the researchers defined as ‘paternalistic, derisive, and dismissive’,³⁹ and to be given a psychosomatic diagnosis^{11,39} or a diagnosis of depression.⁵² These findings resonate with a classic study of doctor–patient interactions, which found that female patients were twice as likely to have their ideas evaded during consultations than men.⁵³

Management of fatigue outside GP services

It is difficult to assess the levels of prolonged fatigue that do not come to the attention of the professional services, but the implications from some recent research suggests that this could be substantial. This does not necessarily represent unmet need for medical care, since individuals may not consider their fatigue as a ‘health’ problem,²² or they may be satisfied with their strategies for managing fatigue outside the formal health services. This issue is difficult to judge as there is only a limited amount of research on how people with prolonged fatigue use alternative sources of care, and how informal and professional services interact.

Accessing care from lay others

Several studies report that the experience of not having their condition taken seriously by family and friends is common among people with prolonged fatigue.^{29,54–55} This can be distressing and can make accessing practical and emotional care through social networks problematic. Furthermore, people with CFS report increasing isolation and loss of social roles⁵⁶ as social networks become impaired because they lack the stamina to maintain existing social relationships or to seek out new ones.^{29,54,56} This in turn reduces potential sources of support. Research with people with CFS found that, after a period of initial non-acceptance, family relationships are more likely to survive than friendships^{54,56} and were occasionally strengthened.⁵⁶

Accessing care from alternative medicine

There are no UK studies on the use of alternative therapies for prolonged fatigue, but a Dutch survey found that fatigue is a very common presenting symptom to alternative therapists, and a substantial majority of patients reported that treatment had improved

their symptoms.⁵⁷ Qualitative studies conducted in the US and Australia suggest that people with prolonged fatigue turned to alternative therapy or developed self-management strategies after unsatisfactory medical consultations.^{3,9,29,39,47,58}

Self-help groups and prolonged fatigue

A thriving self-help movement has grown up for people with ME, partially in response to what was perceived to be inadequate and unsympathetic medical services.² However, participation in self-help groups has been associated with worse outcomes for prolonged fatigue, and there have been calls for further research on the role of self-help organizations.⁵⁹

Representations of prolonged fatigue in the media

The role of newspapers and magazines in raising public awareness of prolonged fatigue and in promoting self-diagnosis has been highlighted.¹¹ Indeed, a hospital-based study found that people with prolonged fatigue were more likely to get their information about fatigue from the media and self-help groups than from health professionals.³⁰ Representations of prolonged fatigue in the media often contradict evidence from clinical research.⁶⁰ Interestingly, in light of the sex patterns in consultation for prolonged fatigue, this is particularly apparent in women’s magazines. Negative representations of medical care in the press and self-help literature may fuel the conflict reported between doctors and patients.^{59,60}

Conclusion

Recent policy initiatives emphasize the pro-active role of health care users in working alongside health professionals and the government to improve health.^{61,62} To succeed, such initiatives need to be based on an understanding of people’s strategies in relation to their experience of symptoms and factors that shape the dynamic relationships between health professionals and patients. This review has identified some gaps in the literature on how different sources of professional and non-professional care for prolonged fatigue are accessed, and how these sources interact with one another. Greater understanding of these issues may illuminate the patient’s side of the doctor–patient partnership, and lead to improved prospects for therapeutic alliances.

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