Diagnosis


Diagnosis and management of chronic fatigue syndrome/myalgic encephalitis in black and minority ethnic people: a qualitative study.

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Abstract

Aim This study aims to explore the possible reasons for the lower levels of diagnosis of chronic fatigue syndrome/myalgic encephalitis (CFS/ME) in the black and minority ethnic (BME) population, and the implications for management.

BACKGROUND: Population studies suggest CFS/ME is more common in people from BME communities compared with the White British population. However, the diagnosis is made less frequently in BME groups.

METHODS: Semi-structured qualitative interviews were conducted with 35 key stakeholders in NW England. Interviews were analysed using open explorative thematic coding. Findings There are barriers at every stage to the diagnosis and management of CFS/ME in people from BME groups. This begins with a lack of awareness of CFS/ME among BME respondents. Religious beliefs and the expectation of roles in the family and community mean that some people in BME groups may choose to manage their symptoms outside primary care using alternative therapies, prayer or spiritual healing. When accessing primary care, all participants recognised the possible influence of language barriers in reducing the likelihood of a diagnosis of CFS/ME. Stereotypical beliefs, including labels such as 'lazy' or 'work shy' were also believed to act as a barrier to diagnosis. Patients highlighted the importance of an on-going relationship with the general practitioner (GP), but perceived a high turnover of GPs in inner city practices, which undermined the holistic approach necessary to achieve a diagnosis.
CONCLUSION: Training is required for health professionals to challenge inaccurate assumptions about CFS/ME in BME groups. The focus on the individual in UK primary care may not be appropriate for this group due to the role played by the family and community in how symptoms can be presented and managed. Culturally sensitive, educational resources for patients are also needed to explain symptoms and legitimise consultation.

PMID: 23702254 [PubMed - as supplied by publisher]

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Abstract
PURPOSE: To experimentally assess visual attention difficulties commonly reported by those with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).
METHODS: Twenty-nine ME/CFS patients and 29 controls took part in the study. Performance was assessed using the Useful Field of View (UFOV), a spatial cueing task and visual search.
RESULTS: Patients and controls performed similarly on the processing speed subtest of the UFOV. However, patients exhibited marginally worse performance compared with controls on the divided attention subtest and significantly worse performance on the selective attention subtest. In the spatial cueing task, they were slower than controls to respond to the presence of the target, particularly when cues were invalid. They were also impaired, relative to controls, on visual search tasks.
CONCLUSIONS: We have provided experimental evidence for ME/CFS-related difficulties in directing visual attention. These findings support the subjective reports of those with ME/CFS and could represent a potential means to improve diagnosis.
PMID: 23689679 [PubMed - in process]

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Abstract
The symptom spectrum of Myalgic Encephalomyelitis (ME) was first detailed in 1959 and later operationalised into a diagnostic protocol (Melvin Ramsey). In 1988 the Holmes case definition coined the term chronic fatigue syndrome (CFS). Fukuda's Centers for Disease Control and Prevention criteria are very heterogeneous and comprise patients with milder symptoms than the Holmes case definition. The CDC Empirical Criteria for CFS lack sensitivity and/or specificity. Other CFS definitions, e.g. the Oxford criteria, delineate people with idiopathic fatigue. Some authors make the clinical CFS diagnosis when slightly increased self-rated fatigue scores are present. In 2011, Carruthers' International Consensus Criteria attempted to restore the focus on selecting people who suffer from ME. Cognitive bias in criteria construction, patient selection, data collection and interpretation has led to the current state of epistemological chaos with ME, CFS, CFS/ME and ME/CFS, and CF being used interchangeably. Moreover, none of the above mentioned classifications meet statistically based criteria for validation. Diagnostic criteria should be based on statistical methods rather than consensus declarations. Ongoing discussions about which case definition to employ miss the point that the criteria did not pass appropriate external validation. In 2012, Maes et al. performed pattern recognition methods and concluded that CFS patients (according to Fukuda's criteria) should be divided into those with CFS or ME, on the basis that people with ME display a worsening of their illness following increases in physical or cognitive activity. Both ME and CFS are complex disorders that share neuro-immune disturbances, which are more severe in ME than in CFS. This paper expands on that strategy and details a range of objective tests, which confirm that a person with ME or CFS has a neuro-immune disease. By means of pattern recognition methods future research should refine the Maes' case definitions for ME and CFS by including well-scaled symptoms, staging characteristics and neuro-immune biomarkers, including immune-inflammatory assays, bioenergetic markers and brain imaging.
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**Behaviour Therapy**


**Internet-Based Therapy for Adolescents With Chronic Fatigue Syndrome: Long-term Follow-up.**

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Abstract

OBJECTIVE: Cognitive behavioral therapy (CBT) is known to be an effective treatment of adolescents with chronic fatigue syndrome (CFS), but its availability is limited. Fatigue in Teenagers on the Internet (FITNET), an Internet-based CBT program for adolescents with CFS, has been developed as an alternative to face-to-face CBT. Recently, its short-term effectiveness has been proven in a randomized clinical trial. Here we aimed to assess the long-term outcome of CFS in adolescents after FITNET treatment and after usual care. In addition, factors related to recovery at long-term follow-up (LTFU) for adolescents treated with the FITNET program were investigated.

METHODS: The study was an LTFU of participants of the FITNET trial. Data were completed for 112 (88.2%) of 127 approached FITNET study participants. Primary outcomes were severity (Checklist Individual Strength-20), physical functioning (87-item Child Health Questionnaire), and school/work attendance.

RESULTS: After a mean follow-up of 2.7 years, 66 (58.9%) adolescents had recovered from CFS. Most adolescents who recovered directly after treatment with FITNET were still recovered at LTFU. At LTFU there was no difference between the recovery rates for the different treatment strategies (original randomization: FITNET [64%) versus any form of usual care [52.8%]). Per additional month of "pretreatment disease duration," the odds for recovery were 4% lower (odds ratio: 0.96; 95% confidence interval: 0.93-0.99; P = .016), and per added point on "focus on bodily symptoms" (Body Consciousness Scale) of the mother (0-20 points) the odds for recovery were 11% lower (odds ratio: 0.89; 95% confidence interval: 0.80-0.99; P = .029).

CONCLUSIONS: The short-term effectiveness of Internet-based CBT on adolescent CFS is maintained at LTFU. At LTFU, usual care led to similar recovery rates, although these rates were achieved at a slower pace.

KEYWORDS: FITNET, Fatigue in Teenagers on the Internet, Internet, adolescents, chronic fatigue, cognitive behavioral therapy, follow-up, functioning, recovery

PMID: 23669515 [PubMed - in process]

**Drug Treatments**

- Title: Use of lisdexamfetamine dimesylate in treatment of executive functioning deficits and chronic fatigue syndrome: A double blind, placebo-controlled study

Citation: Psychiatry Research, May 2013, vol./is. 207/1-2(127-133), 0165-1781;1872-7123 (15 May 2013)

Author(s): Young J.L.

Language: English

Abstract: The purpose of this study was to assess the efficacy of lisdexamfetamine dimesylate (LDX) for the treatment of executive functioning deficits in adults (ages 18-60) with chronic fatigue syndrome (CFS). The study’s primary outcome measure was the Behavior Rating Inventory of Executive Function-Adult (BRIEF-A). Secondary outcome measures were standardized assessments of fatigue, pain and global functioning. Twenty-six adults who met criteria for CFS and had clinically significant executive functioning deficits were randomly assigned to a flexible morning dose (30, 50, 70mg/day) of either placebo or LDX for a 6-week trial. The data were analyzed with standard analysis of variance (ANOVA) procedures. Participants in the LDX group showed significantly more positive change in BRIEF-A scores (M<sub>change</sub>=21.38, SD=15.85) than those in the placebo group (M<sub>change</sub>=3.36, SD=7.26). Participants in the active group also reported significantly less fatigue and generalized pain relative to the placebo group.
Although future studies with LDX should examine whether these benefits generalize to larger, more diverse samples of patients, these results suggest that LDX could be a safe and efficacious treatment for the executive functioning deficits often associated with CFS. The possibility that dopaminergic medications could play an important role addressing the symptoms of CFS is also discussed.

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**Effectiveness of Treatments**

  
  **Treatment outcome in adults with chronic fatigue syndrome: a prospective study in England based on the CFS/ME National Outcomes Database.**
  
  Crawley E, Collin SM, White PD, Rimes K, Sterne JA, May MT; CFS/ME National Outcomes Database.
  
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  **Abstract**
  
  Background: Chronic fatigue syndrome (CFS) is relatively common and disabling. Over 8000 patients attend adult services each year, yet little is known about the outcome of patients attending NHS services.
  
  AIM: Investigate the outcome of patients with CFS and what factors predict outcome.
  
  DESIGN: Longitudinal patient cohort.
  
  METHODS: We used data from six CFS/ME (myalgic encephalomyelitis) specialist services to measure changes in fatigue (Chalder Fatigue Scale), physical function (SF-36), anxiety and depression (Hospital Anxiety and Depression Scale) and pain (visual analogue pain rating scale) between clinical assessment and 8-20 months of follow-up. We used multivariable linear regression to investigate baseline factors associated with outcomes at follow-up. Results: Baseline data obtained at clinical assessment were available for 1643 patients, of whom 834 (51%) had complete follow-up data. There were improvements in fatigue [mean difference from assessment to outcome: -6.8; 95% confidence interval (CI) -7.4 to -6.2; P < 0.001]; physical function (4.4; 95% CI 3.0-5.8; P < 0.001), anxiety (-0.6; 95% CI -0.9 to -0.3; P < 0.001), depression (-1.6; 95% CI -1.9 to -1.4; P < 0.001) and pain (-5.3; 95% CI -7.0 to -3.6; P < 0.001). Worse fatigue, physical function and pain at clinical assessment predicted a worse outcome for fatigue at follow-up. Older age, increased pain and physical function at assessment were associated with poorer physical function at follow-up.
  
  CONCLUSION: Patients who attend NHS specialist CFS/ME services can expect similar improvements in fatigue, anxiety and depression to participants receiving cognitive behavioural therapy and graded exercise therapy in a recent trial, but are likely to experience less improvement in physical function. Outcomes were predicted by fatigue, disability and pain at assessment.
  
  PMID: 23538643 [PubMed - in process] PMCID: PMC3665909
  
  http://www.ncbi.nlm.nih.gov/pmc/articles/pmid/23538643/

**Exercise Therapy**

  
  **Chronic fatigue syndrome.**
  
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  **Abstract**
  
  Chronic fatigue syndrome (CFS) is an illness characterized by disabling fatigue of at least 6 months. The aetiology of the condition has been hotly debated. In this chapter the evidence for CFS as a post viral condition and/or a neurological condition is reviewed. Although there is evidence that CFS is triggered by certain viruses in some patients and that neurobiological changes such as hypocortisolism are associated with the syndrome, neither mechanism is sufficient to explain the extent of the symptoms or disability experienced by patients. It is unlikely that CFS can be understood through one aetiological mechanisms. Rather it is a complex illness which is best explained in terms of a multifactorial cognitive behavioural model. This model proposes that CFS is
precipitated by life events and/or viral illness in vulnerable individuals, such as those who are genetically predisposed, prone to distress, high achievement, and over or under activity. A self perpetuating cycle where physiological changes, illness beliefs, reduced and inconsistent activity, sleep disturbance, medical uncertainty and lack of guidance interact to maintain symptoms. Treatments based on this model including cognitive behaviour therapy and graded exercise therapy are effective at significantly reducing fatigue and disability in CFS. This chapter provides a description of these approaches and details of the trials conducted in the area.

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- Disabil Rehabil. 2013 Jun 4. [Epub ahead of print]

**Use of an online survey to explore positive and negative outcomes of rehabilitation for people with CFS/ME.**

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Abstract

Purpose: First, to explore the experiences of people with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) of rehabilitation therapies so as to build an understanding of reasons for the discrepancy between the notably mixed experiences regarding effectiveness reported in patient surveys and the RCT evidence about the efficacy of Graded Exercise Therapy (GET). GET is a form of structured and supervised activity management that aims for gradual but progressive increases in physical activity. Second, to review patient experiences of two related rehabilitation approaches, Exercise on Prescription (EoP) and Graded Activity Therapy (GAT)

Method: An online survey conducted by the charity Action for ME generated qualitative data about 76 patient experiences of rehabilitation undertaken during or after 2008, examined using thematic analysis.

Results: Both positive and negative experiences of rehabilitation were reported. Positive themes included supportive communication, the benefits of a routine linked with baseline setting and pacing, the value of goal setting, and increasing confidence associated with exercise. Negative themes included poor communication, feeling pushed to exercise beyond a sustainable level, having no setback plan, and patients feeling blamed for rehabilitation not working.

Conclusions: The negative themes may help explain the negative outcomes from rehabilitation reported by previous patient surveys. The negative themes indicate rehabilitation processes which contradict the NICE (National Institute for Health and Clinical Excellence) Guideline advice regarding GET, indicating that some clinical encounters were not implementing these. These findings suggest areas for improving therapist training, and for developing quality criteria for rehabilitation in CFS/ME.

Implications for Rehabilitation

The insensitive delivery of rehabilitation support for people with CFS/ME can explain negative outcomes reported in patient surveys. Therapist-patient collaboration, establishing a sustainable baseline and agreeing a setback plan are all examples of higher quality rehabilitation indicated by this research. Greater awareness of the positive and negative experiences of rehabilitation therapies should enable avoidance of the potential pitfalls identified in this research. Positive experiences of rehabilitation therapies include supportive communication with a therapist, treatment which included routines and goals, and value attached to baselines and controlled pacing. By contrast, factors leading to negative experiences include poor communication and support, conflict in beliefs about CFS/ME and rehabilitation, pressure to comply with treatment, worsening of symptoms, baselines experienced as unsustainable, and feeling blamed for rehabilitation not working.

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**Young People**


**Clinical Practice: Chronic fatigue syndrome.**

Werker CL, Nijhof SL, van de Putte EM.

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Abstract

The diagnosis chronic fatigue syndrome (CFS) was conceptualized in the mid-1980s. It is a clinically defined condition characterized by severe and disabling new onset fatigue with at least four additional symptoms: impaired memory or concentration, sore throat, tender cervical or axillary lymph nodes, muscle pain, multi-joint pain, new headaches, unrefreshing sleep or post-exertion
malaise. Chronic fatigue syndrome in adolescents is a rare condition compared to symptomatic fatigue. The estimated prevalence of adolescent CFS ranges between 0.11 and 1.29% in Dutch, British, and US populations. Diagnosis of the chronic fatigue syndrome is established through exclusion of other medical and psychiatric causes of chronic fatiguing illness. Taking a full clinical history and a full physical examination are therefore vital. In adolescence, CFS is associated with considerable school absence with long-term detrimental effects on academic and social development. One of the most successful potential treatments for adolescents with CFS is cognitive behavioural therapy, which has been shown to be effective after 6 months in two thirds of the adolescents with CFS. This treatment effect sustains at 2-3-year follow-up. In conclusion, the diagnosis CFS should be considered in any adolescent patient with severe disabling long-lasting fatigue. Cognitive behavioural therapy is effective in 60-70% of the patients. Prompt diagnosis favours the prognosis.

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Adolescents and mothers value referral to a specialist service for chronic fatigue syndrome or myalgic encephalopathy (CFS/ME).
Beasant L, Mills N, Crawley E.
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Abstract
BACKGROUND: Paediatric chronic fatigue syndrome or myalgic encephalopathy (CFS/ME) is relatively common and disabling. Current guidance recommends referral to specialist services, although some general practitioners believe the label of CFS/ME is harmful and many are not confident about diagnosing CFS/ME. Aim Explore whether or not adolescents and their mothers value referral to a specialist service for young people with CFS/ME.
METHODS: A qualitative study nested within a feasibility study of interventions for CFS/ME [Specialist Medical Intervention and Lightning Evaluation (SMILE)]. In-depth interviews were undertaken with 13 mothers and 12 adolescents participating in the SMILE study. Transcripts were systematically assigned codes using the qualitative data organisation package NVivo and analysed thematically using techniques of constant comparison.
RESULTS: Gaining access to the specialist service was difficult and took a long time. Mothers felt that they needed to be proactive and persistent, partly because of a lack of knowledge in primary and secondary care. Having gained access, mothers felt the CFS/ME service was useful because it recognised and acknowledged their child's condition and opened channels of dialogue between health-care professionals and education providers. Adolescents reported that specialist medical care resulted in better symptom management, although some adolescents did not like the fact that the treatment approach limited activity.
CONCLUSIONS: Adolescents and their mothers value receiving a diagnosis from a specialist service and making progress in managing CFS/ME. General practitioners should support adolescents with CFS/ME in accessing CFS/ME specialist services, consistent with current guidance.
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Quality of Life

'The letting go, the building up, [and] the gradual process of rebuilding': identity change and post-traumatic growth in myalgic encephalomyelitis/chronic fatigue syndrome.
Arroll MA, Howard A.
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Abstract
The aim of this study was to explore the phenomenon of identity change and subsequent post-traumatic growth (PTG) in individuals with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Ten participants (average illness duration 7.4 years) were interviewed (average length,
79 minutes) via a semi-structured interview schedule and verbatim transcriptions were analysed with interpretative phenomenological analysis. The four superordinate themes revealed were 'comparisons of past to present self: "you have to be someone else, and you have to live with that"', 'the effect of social isolation on identity and subsequent insights into others' behaviours', 'contemplation of future and identity: "where do I go from here?'", and 'PTG: "the letting go, the building up, [and] the gradual process of rebuilding"'. These themes outlined the experiences of those with ME/CFS as they underwent changes in identity due to the limitations the condition imposed on activities and roles, understanding others' behaviours after a period of isolation, the comparison of the past self with the present self and finally, the positive growth that was noted by two of the interviewees with regards to a new 'true' self. Despite the distressing and unpredictable nature of ME/CFS, it appears that individuals with this disorder can experience personal growth.

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Databases Searched: MEDLINE, AMED, CINAHL, EMBASE, PSYCINFO, PUBMED, THE COCHRANE LIBRARY

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Date: 22/08/2013

Current awareness services: have your say
The Library and Knowledge Service are currently reviewing current awareness services in order to ensure they best meet the needs of Trust staff. The future of the bulletins will be influenced by the responses we receive to this short survey. We would be grateful if you could participate, and are interested in your views even if you do not read the bulletins you receive. The questions should take no more than five minutes to complete, please follow the link below.
http://www.smart-survey.co.uk/v.asp?i=16900nlxmj