



Myalgic encephalomyelitis and Chronic Fatigue Syndrome (ME/CFS)

A systematic review

SBU POLICY SUPPORT

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Summary

Aim

The aim of this report was to investigate the available body of evidence for the treatment and prognosis of ME/CFS as well as a review of the health care experiences of patients.

Background

Myalgic encephalomyelitis, also called Chronic Fatigue syndrome (ME/CFS), was first described 70 years ago. The disorder often is preceded by an infection but the pathology and mechanisms behind ME/CFS are still unknown. People with ME/CFS can suffer from a broad spectrum of symptoms, e.g. prolonged fatigue, pain and post-exertional malaise (PEM). Individuals with ME/CFS have decreased activity levels and can have difficulty handling their everyday day duties, work, or studies and maintaining social relationships. For some, the symptoms can be so severe that they are home- or bedbound.

There are no bio markers for ME/CFS that can be used for diagnosis. The criteria for diagnosis have therefore developed over the years and are consensus-based sets of core symptoms. All the criteria include newly-onset severe and persistent fatigue and stipulate that core symptoms must have persisted for at least 6 months. The newer Canadian Consensus Criteria differs from previous criteria in that PEM lasting at least 24 hours after physical or mental exertion is required for a diagnosis. By applying the Canadian Consensus Criteria, the prevalence of ME/CFS is estimated to be about 0,1% of the population.

Differentiating between ME/CFS and other diseases with long lasting fatigue, e.g. stress related exhaustion disorder, can be difficult. Studies show that half of patients referred to specialist clinics for suspicion of ME/CFS were shown to have other diseases after closer examination, mostly sleep or psychiatric disorders.

There is no curative treatment for ME/CFS. Health care therefore aims at relieving symptoms and supporting the patients in the management of their everyday lives.

Content of the report

This report is made up of four systematic reviews, conducted according to international guidelines. The first systematic review focuses on treatments and their effects on fatigue and PEM for persons with ME/CFS diagnosed with the Canadian Consensus Criteria. Treatments that aimed at relieving other symptoms, e.g. sleep problems or pain, or psychological therapies aimed at helping patients manage their disease were not included. Included studies were controlled clinical trials, with or without randomisation.

The second systematic review assesses prognosis for recovery and return to work, while the third investigates whether there are any prognostic factors for improvement and return to work. In the fourth systematic review, we explore how patients experience their health care by reviewing studies that used qualitative methods, such as interviews, to address this question.

The report only includes studies on adults.

Main results

A major finding was that the effects of treatments for patients diagnosed with the Canadian Consensus Criteria on fatigue or PEM cannot be estimated. Most studies used older criteria, mainly the Fukuda criteria, meaning there is a risk that the participants in the studies had other conditions, such as stress related exhaustion disorder or depression. Whether these results are valid for persons diagnosed according to the Canadian Consensus Criteria is therefore unclear.

A small number of studies, most investigating pharmaceutical treatments, used the Canadian Consensus Criteria. None of these studies reported that the drug reduced fatigue.

The prognostic studies identified applied older criteria. Two studies conducted in Scandinavian countries reported that a substantial proportion of the participants had not recovered at follow-up, around 10 years after symptom onset. One English and one Norwegian study found that many patients who had been diag-

nosed in specialist clinics after several years of disease and unemployment, had not yet returned to work or study at follow-ups conducted many years later. Prognostic factors for recovery or return to work could not be evaluated as there were few studies, which were small and had substantial methodological limitations.

The qualitative studies mostly described patient experiences in primary care. Many perceived that getting a diagnosis was a milestone and that individually tailored support was crucial for them to move on with their lives. They experienced the process of obtaining a diagnosis as burdensome and frustrating and felt that they were met with ignorance and lack of understanding.

Discussion

This report shows that there are many scientific evidence gaps regarding ME/CFS. Many gaps, such as methods for diagnosis and efficacy of curative or disease modifying treatments, are related to the lack of understanding of the aetiology behind ME/CFS.

This report also indicates that a thorough diagnostic work-up is crucial. Multidisciplinary specialist competences are necessary to reliably exclude other disorders.

Finally, the absence of evidence for effect of ME/CFS treatments does not mean that the treatments lack effect, but rather indicates that research is needed to clarify the effects of current treatments for people diagnosed with ME/CFS according to the Canadian Consensus Criteria. Meanwhile, it is important to support people with ME/CFS so they can attain the best quality of life, levels of function and participation in society as is possible. Since ME/CFS is relatively uncommon compared to other similar disorders, e.g. stress related exhaustion disorder or chronic pain, specialist clinics for ME/CFS would probably be advantageous, as they would be most likely to be able to closely follow the research and quickly implement new developments into clinical practice.

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