

## Evidence Review C - Barriers and facilitators to accessing health and social care services

### Review Question 1 - What are the barriers and facilitators to the diagnosis of ME/CFS?

#### Summary of the qualitative evidence Table 3 (pages 16-18)

**There is again a thrust towards specialist services as a solution, in contrast to the content of the papers cited in the Summary of the qualitative evidence:**

For example, paper 36, which is cited in support of 'Referral to specialist services' as a facilitator focuses on GP views. One GP commented:

*"Well, I don't think there is anyone to refer to. The specialist clinic is a waste of time; they just hold their hands up, "what can we do? Why, what are they sending this to us for?"*

Main findings include:

*"the value of referral to secondary care was disputed, either in enabling a diagnosis to be made or offering support to the GP in supporting and managing the patient."*

The researchers conclude:

*"The provision of services to support GPs develop confidence to make the diagnosis of CFS/ME and manage and support patients with this complex debilitating condition is necessary."*

The same themes are echoed in Table (page 25) summarising barriers and facilitators to diagnosis in children and young people: these we have not reviewed at all.

### Review Question 2 - What are the barriers and facilitators to the care of people with ME/CFS?

#### Summary of the qualitative evidence Table 5 (pages 41-42)

**The issue regarding advocacy of specialist services not being borne out by the cited evidence arises here also.**

For example, Study 36 is cited in support. See cited extracts above regarding the content of the paper.

**Reviewing the main findings emerging from the research studies reviewed on barriers and facilitators to care indicates that not all of these were focussed on 'ME/CFS' as defined in the draft guideline.** If lack of 'PEM' as an essential recruitment criterion in cause to downgrade research on interventions, should not this also have a bearing on the relevance or otherwise on studies concerning barriers and facilitators to accessing health and social care?

**There are also a number of findings which speak to the study author's perceptions of 'ME/CFS'**

For example:

*"Patients may experience difficulty implementing certain treatment models into their life."*  
(This linked to - and only to - a publication on the failed FINE trial)

*"Patients' beliefs and attitudes towards ME/CFS and treatment"*

*"Personal attributes and motivation"*

These reported findings (if indeed they were reported, we have not reviewed all papers) are presented without reflection or comment.

With regard to this review question we have looked at the counterpart Table concerning children and young people (Table 6, page 52-53) and find indications of similar issues

### **Study excluded 'due to saturation being reached'**

Among the 17 studies excluded from consideration in respect of this Review Question, on the ground that 'saturation' had been reached *i.e.* no new information was emerging for this specific theme is this:

(59) Gerghy K, Hann M, Kurtev S Geraghty K, Hann M, Kurtev S. *Myalgic encephalomyelitis/chronic fatigue syndrome patients' reports of symptom changes following cognitive behavioural therapy, graded exercise therapy and pacing treatments: Analysis of a primary survey compared with secondary surveys.* Journal of Health Psychology. 2019; 24(10):1318-1333 <https://journals.sagepub.com/doi/full/10.1177/1359105317726152>

**Abstract:** *Cognitive behavioural therapy and graded exercise therapy are promoted as evidence-based treatments for myalgic encephalomyelitis/chronic fatigue syndrome. This article explores patients' symptom responses following these treatments versus pacing therapy, an approach favoured by many sufferers. We analyse data from a large cross-sectional patient survey (n = 1428) and compare our findings with those from comparable patient surveys (n = 16,665), using a mix of descriptive statistics and regression analysis modelling. Findings from analysis of primary and secondary surveys suggest that cognitive behavioural therapy is of benefit to a small percentage of patients (8%–35%), graded exercise therapy brings about large negative responses in patients (54%–74%), while pacing is the most favoured treatment with the lowest negative response rate and the highest reported benefit (44%–82%).*

It is clear that the findings emerging from this study are not reflected in the list of findings in respect of this review question. Therefore, if considered pertinent to this review question, the findings of this study should have been included.

NB: This study was among the 13 papers identified by NICE as pertinent to requirement to undertake this guideline development exercise when reaching decision on this in September 2017 (the study having just been published on line at this time). See:

<https://www.nice.org.uk/guidance/cg53/evidence/appendix-b-summary-of-evidence-highlighted-to-nice-during-consultation-pdf-4602203535>

The 25% ME Group  
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