Graded Exercise Therapy (GET)/Cognitive Behavioural Therapy (CBT) is often counterproductive in Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS)

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Dear Editor,

We would like to comment on Van Cauwenbergh et al. [1] in which the authors outline guidelines for graded exercise therapy (GET) and cognitive behavioural therapy (CBT) for ME/CFS.

In this context, it is essential to make a distinction between ME [2], CFS and chronic fatigue (CF). While postexertional malaise, a long-lasting increase in symptoms, like pain and cognitive impairment, after a minor exertion is mandatory for ME, it is not obligatory for the diagnosis of CFS.

Van Cauwenbergh et al. [1] stipulate that the rationale for CBT and GET is kinesiophobia, resulting into the avoidance of behaviour and deconditioning. However, there is no correlation between kinesiophobia and exercise capacity, activity limitations, or participation restrictions in CFS patients with widespread muscle or joint pain [3]. Deconditioning and psychological variables also do not account for the symptoms [3].

The authors [1] claim that CBT/GET is an evidence-based effective therapy for CFS. However, most of the studies reviewed in [1] are studies on the effectiveness of CBT/GET in chronic fatigue (CF), not in CFS, let alone ME [2]. A recent large-scale trial in the UK showed that the effectiveness of CBT and GET in CF [1] in terms of ‘fatigue’ is 30% and 28%, respectively, while fatigue decreases in 15% of the cases by standard medical care. While CBT/GET results into a decrease in fatigue in some CF patients [3], there is no substantial clinical improvement in objective measures, for example activity levels, exercise capacity/oxygen uptake or distance walked in 6 minutes [1,3].

Even more, CBT/GET is often counterproductive. A long-lasting negative impact of exertion on in ME/CFS has been observed repetitively [3]. Data of Nijs et al. [4], for example, show that an one-off walking exercise with intensity and duration limits results in an increase in pain lasting more than 24 h. Research [3] has demonstrated that exercise has a (strong) negative effect on the physiological exercise capacity 24 h later and that CFS patients are unable to sustain low target activity levels, indicated by reduced total activity after 4–10 days. A randomized controlled trial [5] observed that pain had increased and physical function had declined 12 months after CBT/GET.

A distinction between ME, CFS and CF is essential. CBT/GET is not an evidence-based effective approach and often has a negative effect in ME/CFS [3]. Future studies should explore the biological abnormalities in ME and CFS in more detail and the effect of exertion in well-defined subgroups to avoid iatrogenic harm.

Conflicts of interest
The authors would like to declare that they have no conflicting interests.

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