

Studies and surveys implicate potential iatrogenic harm of cognitive behavioral therapy and graded exercise therapy for myalgic encephalomyelitis and chronic fatigue syndrome patients.



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Cognitive behavioral therapy (CBT) and graded exercise therapy (GET) are declared to be effective and safe therapies for Myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS). Medical policies in various countries, e.g. the UK and the Netherlands, recommend CBT and GET as evidence-based treatments. But studies and patient surveys in several countries indicate that CBT often has no effect at all and that CBT and GET has detrimental effects in a large subgroup of patients.

Editorial

ME is a disease characterized by distinctive muscular symptoms, including muscle weakness and myalgia after minor exertion lasting for days, neurological symptoms implicating cerebral dysfunction, symptoms indicating circulatory impairment and other symptoms [1,2]. CFS is primarily defined by (unexplained) chronic fatigue, which must be accompanied by at least four out of eight ‘additional’ symptoms [3]. ME and CFS are incorrectly conceived as ‘similar disorders’ [4]. But the case criteria define three patient groups: ME and/or CFS patients [5], labeled as ME/CFS patients within this context.

Cognitive behavioral therapy (CBT) and graded exercise therapy (GET) are declared to be effective [6,7] and safe [7,8] therapies for Myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS). Medical policies in various countries, e.g. the UK [9] and the Netherlands [10], recommend CBT and GET as evidence-based treatments.

However various studies implicate that CBT, GET and other behavioral interventions, including graded activity, have negative effects on (subgroups of) ME/CFS patients.

Núñez and co-workers [11] observed that adding CBT and GET to pharmacological treatment had a negative effect on SF-36 physical functioning and pain scores. Jason and others [12,13] found that ‘non-pharmacologic therapies’ had a negative effect on the mean SF-36 physical functioning score (changes from 5 to -35) of a large subgroup of CFS patients, with lymphocyte subsets data suggesting an elevated humoral immune response (Th2/B Cell). Although ‘Guided graded Exercise Self-help’ (GET) was qualified as “a moderately effective and safe intervention” [14], the investigators acknowledged that a patient subgroup had deteriorated after the GET trial, possibly due to “a worse exacerbation of symptoms in response to GET” [15].

In various surveys [16-18] most ME/CFS patients experienced no improvement after CBT and more than half of the patients reported GET made them worse. A detailed analysis [18] of a large-scale patient survey in the UK [19] shows that, when combinations of therapies are excluded, 73% of the patients they stayed the same after CBT, while 8% of the patients improved and 18% got worse. No less than 74% of the patients reported worsening of

their symptoms after GET, 14% of the patients experienced no change and only 12% reported improvement after GET. In a recent patient survey in the Netherlands [20] 11% reported CBT had improved their health situation, 36% experienced no change, and 53% reported CBT had worsened their condition. 63% reported GET had made their symptoms (much) worse and 34% reported no change. Only 3% of the patients experienced improvement after GET. One could argue that patient surveys (through the internet) are potentially prone to many biases, but a study [21] found that 'unsolicited' web-based patient ratings of care correlate well with conventional research findings, i.e. formal measurements.

As affirmed by the medical authorities in the US recently, "ME/CFS is a serious, chronic, complex, multisystem disease" [4] with "strong evidence" indicating that "immunologic and inflammatory pathologic conditions, neurotransmitter signaling disruption, microbiome perturbation, and metabolic or mitochondrial abnormalities are potentially important for the definition and treatment of ME/CFS [22]. Exertion has (prolonged) negative effects in ME/CFS [4]. For that reason studies and surveys indicating potential harm of CBT and GET in large subgroups of ME/CFS patients should be taken seriously. The 'safety claim' is at odds with several observations.

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