

ADDENDUM to Some Concerns about the NICE Draft Guideline on “CFS/ME”

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The NICE Draft Guideline gives cognitive behavioural therapy (CBT) and graded exercise therapy (GET) a ringing endorsement and recommends CBT/GET for all adults and children with “CFS/ME” who wish to get better.

Apart from advising that symptoms should be managed “conventionally, as per usual clinical practice”, no other intervention is recommended.

The NICE Draft Guideline relies upon the updated Systematic Review carried out by the York Centre for Reviews and Dissemination that is published in the Journal of the Royal Society of Medicine (Interventions for the treatment of patients with chronic fatigue syndrome/myalgic encephalomyelitis: an updated systematic review. Duncan Chambers, Anne-Marie Bagnall, Susanne Hempel, Carol Forbes. JRSM 2006;99:506-520).

The systematic review team stated that only randomised or controlled clinical trials were eligible for inclusion in their review, which resulted in 8 trials meeting the inclusion criteria for assessment of CBT (or modified CBT) and 5 trials for assessment of GET. Given that only 5 of the CBT trials score 10 or above out of a possible 20 on the Review team’s own “validity scale” – and that one of these is non-significant -- this is a very small “evidence-base” indeed upon which to make such resounding recommendations for what is effectively a wall-to-wall management regime.

The small sizes of the patient groups in the CBT trials alone (less than 50 participants in the CBT arm in all but one trial) means that no reliable conclusions can be drawn from them, yet the impression is conveyed that what is recommended are well-researched, effective treatments.

The most worrying thing is that reliance only on clinical trial “evidence” means that the York Review team has virtually confined itself to research generated by a handful of UK psychiatrists and their continental adherents.

As Dr Neil Abbot of ME Research UK says in the latest issue of the Warwickshire Network for ME e-magazine:

“RCTs (random controlled trials) are the best evidence of efficacy, all things being equal. But in ME/CFS the majority of RCTs are biopsychosocial trials of non-specific management strategies (ie. CBT/GET). Such trials are expensive to conduct, and it is the biopsychosocial experts who have been able to access the funding to conduct them. This means that any time a ‘review’ of the literature is done, the dominant ‘therapies’ are psychosocial ones. The fact that these trials of CBT and GET have had relatively unspectacular results is less important to reviewers than that fact they are ‘positive’. This is very nice indeed for the psychosocial professionals, but a disaster for the large number of patients with signs and symptoms of a biomedical illness who need detailed clinical assessment and biomedical investigation instead of strategies to manage their ‘illness beliefs’. In short, the accepted strategy of looking at formal ‘evidence’ is flawed in the case of ME/CFS because the evidence-base is skewed”.

In other words, review conclusions are based on NUMBER and QUALITY of positive and / or negative trials, and since the psychiatric lobby wins hands down on a purely NUMERICAL count of published studies (because no comparable funding has been made available for biomedical studies), the outcome can safely be predicted, as indeed has happened.

If ever there was a “vicious circle” in ME/CFS, far from it being due to patients’ fear of activity leading to deconditioning leading in turn to on-going fatigue, as Wessely School psychiatrists relentlessly assert, it is the vicious circle that has been created by the psychiatric lobby itself to ensure that only its own views prevail.

Further, in the text of the JRSM article the York Review team only mentioned the immunological or pharmaceutical interventions that had negative side-effects, yet one (included) study which treated hormone and nutritional deficiencies was ranked 19 but was not even mentioned in the text (none of the CBT studies scored as high as 19).

For the Review team to fail to discuss studies of interventions other than CBT/GET that by their own measures scored better than the average for CBT (which was 9.5) is surely remarkable, and raises the issues as to how recommendations for CBT/GET can be made on such a defective body of evidence, and at whose insistence.