

Ruffled feathers?

Margaret Williams 18th November 2012

For someone who insists that he has moved away from the world of ME/CFS research, Simon Wessely shows remarkably ruffled feathers in his latest rant about the troubled terrain of ME/CFS.

Wessely's attack on the Scottish Public Health Network's Health Care Needs Assessment for people living with ME/CFS (Charlotte Smith, Simon Wessely: JNNP: 17th November 2012:10.1136/jnnp-2012-303208) is a very suave piece of writing but does not stand up to scrutiny.

Wessely seems patently on the defensive: could this be because both the FINE and PACE Trials failed to produce any evidence of recovery using the interventions on which Wessely has staked his professional career?

His praise of the PACE Trial (with which he was involved as Director of the Clinical Trial Unit) is evidentially insupportable: participants who had the same scores on entry and on completion were judged to be "within the normal range"; it had no control group, was unblinded, and committed the cardinal sin of trial design by altering the outcome measures so as to give the impression that an unsuccessful intervention favoured by the investigators was a success when in fact the results were so bad that 21 months later, no recovery rates have been (nor, it is understood, are they to be) published.

Furthermore, considering the lack of detail provided by the PACE Trial Investigators, it seems that CBT and GET did not result in any significant improvement in employment hours or welfare benefit claims (which included income-related and disability benefit claims as well as private pension and income protection claims); indeed, CBT and GET seem to have resulted in worse outcomes for private payment claims

(<http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0040808>).

For a start, which patients is Wessely talking about when he states his only-too-obvious satisfaction that neurological signs are not recognised as part of CFS or ME?

Despite his best efforts to overturn the WHO classification, ME/CFS remains a classified neurological disorder (WHO ICD-10 G93.3) and anyone who bothers to look can find abundant evidence of neurological signs, for example, going back as far as Dr Ramsay (Myalgic Encephalomyelitis and Postviral Fatigue States: The Saga of Royal Free Disease. A Melvin Ramsay. Gower Medical Publishing, 1988) right up to the most recent Consensus Primer for Medical Practitioners, which clearly shows it to be a neurological disease (Myalgic Encephalomyelitis -- Adult and Paediatric International Consensus Primer for Medical Practitioners, Bruce M Carruthers et al. 2012).

It is curious how Wessely seems so keen to dismiss the evidence of neurological signs and symptoms, when his own work favours the Oxford criteria which specifically exclude those with neurological disease. How “scientific” is this? His reference to the refusal of UK neurologists to accept ME as a neurological disorder is based on the psychiatrists’ own initiative in conducting a survey of a limited number of neurologists.

To dismiss patients’ experiences because they have not been subjected to rigorous clinical trial standards is to dismiss the reality of their suffering: the job of a doctor used to be to diagnose accurately and then to support and help patients, not to diminish even further the residual quality of their life by rejecting the evidence of their profound suffering by minimising the degree of that suffering.

Wessely says *“There is no particular reason why graded exercise carried out under appropriate professional supervision should be harmful”*, but objective and reproducible evidence has demonstrated that ME *“is characterised by an inability to produce sufficient energy on demand”* (Myalgic Encephalomyelitis -- Adult and Paediatric International Consensus Primer for Medical Practitioners, Bruce M Carruthers et al. 2012).

Wessely refers, somehow jubilantly, to the failure of the 2009 Judicial Review of the NICE Guideline (CG53) which recommends CBT and GET; what he does not mention is the fact that NICE threatened the Claimants’ lawyers with massive punitive damages if they did not withdraw their evidence, so the lawyers caved in to NICE’s threats with the result that about 60% of the evidence was never heard by the Court.

The Scottish Public Health Network is to be commended for listening to world class clinicians and scientists rather than to psychiatrists with vested financial interests in maintaining ME/CFS as a psychosomatic disorder who compile and promote guidelines that ignore the biomedical evidence-base.

In his latest article, Wessely purports to be concerned that the media, health service planners and patients themselves are being denied accurate information about the “*evidence-base*” on the effectiveness of CBT and GET but concludes that once this evidence is made available, patients with ME/CFS “*can make up their own minds*”.

Patients with ME have made up their own minds and have made an informed choice: if Wessely’s interventions worked, they would be queuing up in droves, but this is not so.

Leading clinicians and scientists in the field have already discovered that his interventions do not work: “*The premise that cognitive therapy (eg. changing ‘illness beliefs’) and graded activity can ‘reverse’ or cure this illness is not supported by post-intervention outcome data. In routine medical practice, CBT has not yielded clinically significant outcomes for patients with ME/CFS*”(Chronic Fatigue Syndrome Myalgic Encephalomyelitis – A Primer for Clinical Practitioners. International Association for CFS/ME, 2012 edition).

For the record, there is an error in the enumeration of the references in Wessely’s article.