

Science versus Psychiatry – again

Malcolm Hooper and Margaret Williams 22nd July 2011

In her BMJ editorial in which she referred to “myalgic encephalitis” instead of the correct term “myalgic encephalomyelitis” (Ending the stalemate over CFS/ME: BMJ 2011:342:d3956), Fiona Godlee described the disagreement between the biomedical and psychosocial schools of thought about ME as “*an unproductive standoff in which...all progress is being stifled by increasingly aggressive intimidation of researchers*”.

The “*unproductive standoff*” certainly existed and may be said to be the result of 25 years of inflexible arrogance by “*overly powerful psychiatrists who hold key positions in medicine, research, media gatekeeping and government policy...suppressing the argument that ME may be biomedical rather than psychiatric*” (Let psychiatric and biomedical lobbies be heard equally in CFS/ME research; Caroline Davis: BMJ 2011:343:d4544).

Following her editorial, Godlee published a letter from Professor Peter White (Chief Principal Investigator of the notorious PACE Trial) in which he was joined by Alastair Miller (medical advisor to the charity Action for ME) and by paediatrician Esther Crawley (renowned for her belief in the Lightning Process in the management of ME) in which they decried the need for adequate assessment of patients with ME as being “*a significant burden*” on both patients and doctors.

When did careful assessment of sick people stop being part of the practice of medicine, particularly when the disorder in question is known to be both complex and chronic? The answer seems to be that it was when Wessely School psychiatrists and others who work for the insurance industry became the arbiters of what constitutes disease or disability.

In their published letter, White et al use inverted commas when referring to “*symptoms*” of ME such as “*ataxia*” and “*palpitations with cardiac arrhythmias*” and “*loss of thermostatic stability*”, denoting their dismissal of such symptoms as genuine components of ME; indeed, White et al go on to refer to the assessment of “*too many symptoms of dubious validity*”.

Godlee also afforded a platform for psychiatrist Alastair Santhouse (who, with Esther Crawley, was a member of the Guideline Development Group that produced the NICE Clinical Guideline on “CFS”) to reject valid criticisms of the PACE Trial (“*the sound rebuttal by the Medical Research Council and the Lancet to allegations that the PACE trial was in some way improper should be proof enough*” – BMJ 2011:343:d4550).

However, a positive step has just been taken towards resolving the “standoff”.

Not only were researchers from 13 countries including the UK not intimidated by their patients with ME, they have now produced International Consensus Criteria specifically for ME (ME: International Consensus Criteria; Bruce M Carruthers et al; Journal of Internal Medicine: Accepted Article: doi:10.1111/j.1365-2796.2011.02428.x).

Between them, the international panel have about 400 years of both clinical and teaching experience of ME; they have authored hundreds of peer-reviewed publications and they have diagnosed or treated approximately 50,000 (fifty thousand) ME patients.

The abstract is clear: “*In view of more recent research and clinical experience that strongly point to widespread inflammation and multisystemic neuropathology, it is more appropriate and correct to use the term ‘myalgic encephalomyelitis’ (ME) because it indicates an underlying pathophysiology. It is also consistent with the neurological classification of ME in the World Health Organisation’s International Classification of Diseases (ICD G93.3)*”.

The expert authors explain that the purpose of developing the latest international criteria was to base them on current knowledge of ME that reflects the complex symptomatology and they have

produced guidelines which *“promote optimal recognition of ME by primary care physicians and other health care providers”*.

The authors point out that ME *“is a complex disease involving profound dysregulation of the central nervous system and immune system, dysfunction of cellular energy metabolism and ion transport, and cardiovascular abnormalities”*.

They note that the use of overly inclusive criteria in research has included people who do not have ME and that this leads to *“biased research findings, inappropriate treatments, and waste(d) scarce research funds”*.

The International Consensus Criteria are soundly supported by research and are based on 123 cited references; the authors note that broadly based studies show a lack of objective findings and state that *“the primary goal of this consensus report is to establish a more selective set of clinical criteria that would identify patients who have neuroimmune exhaustion with a pathological low threshold of fatigability and symptom flare in response to exertion”*.

The authors are explicit: *“Pain and fatigue are crucial bioalarm signals that instruct patients to modify what they are doing in order to protect the body and prevent further damage. Post-exertional neuroimmune exhaustion is part of the body’s global protection response and is associated with dysfunction in the regulatory balance within and between the nervous, immune and endocrine systems, and cellular metabolism and ion transport”*.

The panel members consider the neurological impairments including structural and functional abnormalities seen on neuroimaging studies in ME; they address the immune impairments including decreased natural killer cell signalling and function; abnormal growth factor profiles; decreased neutrophil respiratory bursts with a shift towards a Th2 profile; chronic immune activation with increases in inflammatory cytokines, pro-inflammatory alleles, chemokines and T lymphocytes, and dysregulation of the antiviral ribonuclease L (RNaseL) pathway.

They consider the evidence of profound energy impairment and poor cardiac performance and they note the possible involvement of altered control and reduced cortisol production during and after exercise.

They note the evidence of abnormal blood pressure regulation and the measurable vascular abnormalities that suggest the brain is not receiving sufficient circulating blood volume when the patient is upright and that this is intensified when standing in one place such as in a grocery checkout line.

The authors discuss the clinical application of their criteria, as well as paediatric considerations and research applications.

The authors conclude that they *“believe the International Consensus Criteria will help clarify the unique signature of ME”* and they state unambiguously that *“individuals meeting the International Consensus Criteria have myalgic encephalomyelitis and should be removed from the Reeves empirical criteria and the National Institute for (Health and) Clinical Excellence (NICE) criteria for chronic fatigue syndrome”*.

This approach could not be more different from that used by Professor White in the PACE Trial, in which he used the intentionally broad Oxford criteria that do not discriminate between ME and chronic medically unexplained fatigue.

The adoption of these international diagnostic criteria would ensure that future studies are investigating people with well-defined ME and would thus satisfy one of the biggest complaints from within the ME community (ie. that previous studies have not been looking at a homogeneous group of ME patients). It would certainly be a positive step towards resolving the standoff between science and psychiatry.