RESPONSE TO WESSELY'S ARTICLE IN JRSM MAY 2003 ISSUE

Malcolm Hooper Eileen Marshall Margaret Williams

Contact address: Malcolm Hooper, Emeritus Professor of Medicinal Chemistry, Department of Life Sciences, University of Sunderland, SR2 7EE, UK

Reading with familiar heartsink and increasing incredulity the latest re-run of Wessely's personal philosophy about "CFS", all of which he has published before ad nauseam, 2,3,4,5,6,7,8,9 one wonders yet again at the apparent determination of editors of UK medical journals (including the editor of the JRSM) to favour the fallacious psychiatric paradigm of "CFS" propagated by Wessely et al.

One is repeatedly struck by Wessely's apparent inability to keep up-to-date with the current science which has been published on ME/CFS, as he seems so intent on ignoring the ever-increasing body of evidence from international centres of excellence for a variety of biomarkers for ME/CFS. From even a quick search of the literature, it is obvious that these exist for not only neurological deficits, as demonstrated by nuclear medicine techniques such as SPECT, PET, MRI and MRS scans (which demonstrate cerebral hypo-perfusion, changes in glucose metabolism, brain abnormalities and biochemical disturbances), but also for endocrine dysfunction (disturbance of the HPA axis), immune dysfunction (evidence of an unusual and inappropriate immune response) and vascular disturbance (evidence of disrupted biology of blood vessel endothelium), together with evidence of mitochondrial abnormalities in muscle.

Why are editors so eager to afford these psychiatrists a seemingly ever-open page to propound a primary psychiatric aetiology for ME/CFS, thereby failing to offer their readers a balanced presentation of international biomedical evidence that ME is a biological disorder, ¹⁰ including the evidence which lead Professor Paul Levine from the Viral Epidemiology Branch, Division of Cancer Aetiology, National Cancer Institute, Bethesda, Maryland, USA to state as long ago as 1994 that "the spectrum of illnesses associated with a dysregulated immune system must now include CFS". ¹¹ It is irrational to persist in ignoring or dismissing the work of such world-class experts in the disorder.

In all other disciplines except psychiatry, rigorous standards of evidence-based knowledge inform the clinician's judgment but in psychiatry alone it is the personal interpretation, beliefs and bias of the individual psychiatrist which prevail unchallenged by the establishment, as is undoubtedly the case with ME and "CFS"

Until editors acknowledge what is happening, in particular that the term "CFS" means different things to different people (to the international research community, CFS equates with ME ¹², but to certain UK psychiatrists including Wessely, CFS equates with somatisation disorder – which Wessely now decrees is to be known as 'medically unexplained symptoms' or MUS according to this latest article in the

JRSM), those editors ill-serve both the scientific and clinical communities, let alone the patients, the alleviation of whose suffering used to be paramount in medicine but which now seems to have been replaced by the dictates and corporate interests of multi-national industries who dominate and control not only governments but medical and research institutions and whose life-blood is profit. ¹³

Publication bias needs to be dealt with if psychiatry is to become more 'evidence-based': the continued existence of publication bias represents an abuse of the trust that patients give and is essentially a form of scientific misconduct ¹⁴ about which editors need to be keenly mindful.

For example, in our own lifetime psychiatrists used to refer to multiple sclerosis as "hysterical paralysis" but HHV6 DNA has now been clearly demonstrated in oligodendrocytes, lymphocytes and microglia of MS lesions, which means that they could be the target of the immune response. ¹⁵ Are editors these days unaware that in 1942, psychiatrists confidently asserted that people who developed Parkinson's Disease (PD) were individuals who had histories of an insecure childhood and who exhibited poor adjustment to previous stresses? ¹⁶ And have editors forgotten that in 1948, it was psychiatrists who described Parkinson's Disease as "an illness of the ambitious, moralistic man", concluding (*sic*) that the intention tremor was the manifestation of strong internal conflict caused by the wish to masturbate in a person who believed that to do so was morally wrong. ¹⁷

Psychiatrists' dominance over PD patients and their claims that it was a "psychosocial" disorder ceased abruptly with the discovery in the 1950s of the role of neurotransmitters and the knowledge that in PD there is a deficiency of dopamine in the corpus striatum.

We believe that it is Wessely himself (and not the patients as he so endlessly asserts) who does not see the world as it actually is. 18¹ The evidence provided by his published works and the many published criticisms of his work is that he consistently ignores, trivialises or dismisses all the scientific, clinical and laboratory evidence that does not accord with his personal beliefs, which we believe supports the contention that he is himself guilty of doing exactly what he accuses patients of doing succumbing to self-delusion, dysfunctional thinking and false Notwithstanding, he is / has been an adviser to the DSS (now the DWP); he is adviser to the MOD and has recently acted against Gulf War veterans in a court case concerned with compensation; he has been a member of three Boards at the MRC and he and his psychiatrist colleagues have just been awarded £2.6 million by the MRC plus £8.3 million by Government to try and "strengthen" the very weak evidence that cognitive behavioural therapy (CBT) actually works for those with "CFS", despite the mounting evidence that such interventions are actively harmful for many patients with ME/CFS.

When will UK editors wake up and realise that they are being fed an endless diet of deceit and mischaracterization of the facts about ME by Wessely et al? ^{19,20}

For those who believe that they have the prerogative to define reality, editors' continued collusion in publication bias serves to augment their delusions and ideals, notwithstanding that those ideals do not represent good science and are actively harming sufferers in many practical ways, including the refusal and withdrawal of previously awarded state benefits from those with ME/CFS; difficulties amounting to the impossibility of obtaining insurance benefits; difficulties in obtaining necessary early retirement on health grounds; unfit patients being forced to return to work (notably those in responsible professional posts such as teachers, and especially doctors and nurses, where mistakes can be life-threatening to others); inappropriate treatment (including the threat of and the being sectioned under the Mental Health Act if patients decline or refuse psychiatric interventions); withdrawal of cover by private health insurance companies (who exclude "psychiatric" illness from eligibility); inappropriate and dismissive attitudes of doctors, with increasing numbers of patients being removed from a GP's list for no valid reason; special problems for children and young people with ME; lack of appropriate NHS provision and care; high rates of suicide in those with ME. A detailed and fully referenced dossier documenting all this has been presented to the CMO.

As long as the collusion of UK editors with such scientific misconduct continues unchecked, progress towards accurate assessment and realistic prospects of treatment for those with ME/CFS will remain impossible.

References

- 1. Medically unexplained symptoms: exacerbating factors in the doctorpatient encounter. LA Page S Wessely JRSM 2003:96:223-227
- 2. Old wine in new bottles. Simon Wessely. Psychological Medicine 1990:20:35-53
- 3. Chronic fatigue and myalgia syndromes. Wessely S. In: Psychological Disorders in General Medical Settings ed: N Sartorius et al. Hogrefe & Huber 1990
- 4. The chronic fatigue syndrome—myalgic encephalomyelitis or postviral fatigue. Wessely S, Thomas PK. In: Recent Advances in Clinical Neurology No.6 ed: C Kennard, Churchill Livingstone 1990
- 5. The psychological basis for the treatment of CFS. Wessely S. Pulse of Medicine 14 December 1991:58
- 6. Chronic fatigue syndrome: current issues. Wessely S. Reviews in Medical Microbiology 1992:3:211-216
- 7. Professional and popular views of chronic fatigue syndrome MacLean G, Wessely S. BMJ 19 March 1994:308:776-777
- 8. Psychiatry in the Allergy Clinic: nature and management of patients with non-allergic symptoms. LM Howard and S Wessely Clinical & Experimental Allergy 1995:25:503-514

- 9. Denigration by Design? Vol I [1987-1996] and Vol II [1996-1999]: more illustrations of what Wessely has actually stated about patients with "ME" and "CFS" in his published works (available at cost price from DM Jones on 0044 + (0)208-554-3832)
- 10. The Biology of the Chronic Fatigue Syndrome. Anthonly L Komaroff. Am J Med 2000:108:99-105
- 11. Summary and Perspective: Epidemiology of Chronic Fatigue Syndrome. Clin Inf Dis 1994:18: (Suppl 1):S57-S60
- 12. WHO ICD 10: G.93.3, 1992
- 13. Politics isn't Working: the End of Politics. Channel 4 documentary by Cambridge academic Noreena Hertz, 13 May 2001 8pm
- 14. Publication bias and the integrity of psychiatric research. SM Gilbody, F Song: Psychological Medicine 2000:30:253-258
- 15. Human herpesvirus 6 genome and antigen in acute multiple sclerosis lesions. Andrew D Goodman et al J Inf Dis 2003:187:1365-1387
- 16 Physical, Psychiatric and Psychometric Studies of Post-Encephalitic Parkinsonism. Shaskan D, Yarnell H and Alper K; Journal of Nervous and Mental Disease 1942:96:652-662
- 17. Psychodynamics in Parkinsonism. Booth G; Psychosomatic Medicine 1948:10:1-14
- 18. Chronic Fatigue Syndrome, ME, and ICD 10. David A, Wessely S, Lancet 1993:342:1247-1248
- 19. Chronic Fatigue Syndrome. TE Hedrick. QJM 1997:90:723:727
- 20. The Royal Colleges' Report on CFS: Insidiously Biased and Potentially Harmful. Terry Hedrick. CFIDS Chronicle 1997:10:1:8-13