

Consideration of Simon Wessely's letter to The Scotsman ("Research goes on")

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Professor Simon Wessely's response to Dr Margaret Cook's article merits, as ever, close scrutiny. In that response, he states "Margaret Cook's article 'ME sufferers have found enemy in Wessely' shows the real battle is not between myself and sufferers of ME but between your correspondent and the facts".

In the interests of accuracy, it may be worth considering some of those facts.

On 12 May 1994 Wessely gave the 9th Eliot Slater Memorial Lecture at The Institute of Psychiatry, London and his lecture was audiotaped by some members of the audience. That is a fact. The audiotape and transcript are still available. What he said (taken directly from his own working notes) must also be deemed to be "fact":

"I am going to talk not about an illness but about an idea. There is a phenomenon known as myalgic encephalomyelitis – or ME. ICD-10 now discourages its use. I will argue that ME is simply a **belief, the belief** that one has an illness called ME. Right from the start, ME has been identified with a refusal to accept the doctor's verdict. Neurasthenia was the disease of modern life --- so is ME. Does it really matter if the 5HT neurotransmitter is enhanced (that's CFS) or depressed (that's major depression)..... I will argue that this represents not the line between low and high cortisol responses, but the line between real and unreal illness. There is another condition with which ME might easily be confused – it is hysteria. The Royal Free disease itself is part of the world of myth. As Tony David (*a psychiatrist colleague of Wessely*) has said, it is the H word, never spoken, but always present. Organic diseases lose their credibility as their psychological causes are recognised. How do you prove that you are not hysterical? You must convince the doctor that you are really ill, so....the arm becomes more floppy, the leg weaker, yet what is the result of this--- it is (that) the neurologist, who is not a fool, is now convinced that the problem is functional. Now, how can you prove the doctor wrong? Well, the one thing you might not do is get better, since that might be interpreted as proof that it was all in the mind after all, (which) condemns the sufferer to a life time of non-recovery, if only to prove the doctor wrong (so) the (*laboratory*) test is crucial to respectability and legitimate occupation of the sick role".

In that lecture (which he called "Microbes, Mental Illness, the Media and ME: The Construction of Disease"), Wessely openly mocked and denigrated patients, even referring to a patient by name and ridiculing her. He emphasised that (quote) "doctors are still the main passport to acceptance and validation of suffering, not least because we control access to support and benefits. Doctors are entitled to express their scepticism about the status of the diagnosis and to suggest that these illnesses (ME and CFS) are already adequately covered in the psychiatric classifications. Each generation will find it necessary to discover its own ME".

The preceding year, Wessely and Tony David had published their views on ME (*Chronic Fatigue, ME, and ICD-10. David A, Wessely S. Lancet 1993;342:1247-1248*) in the

following terms: “The inclusion in the tenth revision of the International Classification of Diseases (ICD10) of benign myalgic encephalomyelitis as a synonym for postviral fatigue syndrome under Diseases of the Nervous System seems to represent an important moral victory for the self-help groups in the UK. Neurasthenia remains in the Mental and Behavioural Disorders chapter under Other Neurotic Disorders. Neurasthenia would readily suffice for ME. Applying more stringent criteria for CFS in the hope of revealing a more neurological subgroup succeeds only in strengthening the association with psychiatric disorders. We believe this latest attempt to classify fatigue syndromes will prevent many people from seeing the world as it actually is”. What is curious is that the inclusion of ME as a disease of the nervous system in the 1992 ICD-10 was not “an important moral victory” for anyone, for ME has been included in the ICD as a disorder of the nervous system since 1969.

And then there is Wessely’s inclusion of ME as a mental disorder in the first edition of the Guide to Mental Health in Primary Care produced by the UK WHO Collaborating Centre at the IOP and published by the Royal Society of Medicine: this directly led to the NHS Information Authority also listing CFS/ME as a mental disorder, but as a result of a two year battle by a few determined people unassociated with either of the two major UK ME charities, both the IOP and NHSIA have been obliged to accept that such a misclassification is in defiance of the WHO classification, as the WHO headquarters have stated in writing that it is at variance with the WHO’s position, so an erratum has been provided on the RSM’s website.

For the record, the second edition of the Guide to Mental Health in Primary Care is due in December 2003 and the section on “CFS” has been approved by Chris Clark (CEO of Action for ME, recently awarded significant funding by the government), Professor Tony Pinching (Medical Adviser to AfME) and Professor Leslie Findley. Tony Pinching is well-known for his published views on “CFS”, namely that “over-investigation can be harmful, causing (sufferers) to seek abnormal test results to validate their illness”; that “the essence of treatment is activity management and graded rehabilitation” and that the fatigue found in CFS is “not related to ongoing exertion”. (*Chronic fatigue syndrome. Anthony J Pinching. Prescribers’ Journal 2000;40:2:99-106*).

In his reply to Margaret Cook, Wessely refers to his 20 or so papers dealing with immunological aspects of “CFS” but fails to mention his other 180 or so papers claiming ME /CFS is a somatoform disorder. As far as his “immunological” papers are concerned, unlike other internationally esteemed ME/CFS researchers, Wessely’s results are often negative, thus, he claims, enhancing his own stance that there is nothing to find. One illustration of his view on the immunological aspect is unambiguous: “There lies at the heart of CFS not (an) immune disorder, but a distortion of the doctor-patient relationship”. (*Chronic fatigue syndrome: an update. Anthony J Cleare and Simon C Wessely. Update (Recent Advances); 14 August 1996 pp 61-69*). Anthony Cleare is a psychiatrist colleague of Wessely and was a member of the Key Group of the CMO’s Working Group on “CFS/ME”; together with Peter White, he was one of the five members of the psychiatric lobby who walked out because they wanted the report to conclude positively that CFS is a psychiatric disorder but the report left the issue open.

Wessely's view on the immunology of ME/CFS differs from that of greatly respected US immunologists such as Professor Roberto Patarca-Montero; it also differs from that of a group from Southampton University Hospital who have reported data that add weight to the concept (already supported by substantial evidence) that ME/CFS is a disease characterized by over-expression of genes which are known to be associated with immune system activation. The authors note the especially pertinent link with allergy, given that approximately 80% of these patients have allergies (*Identification of novel expressed sequences, up-regulated in the leucocytes of chronic fatigue syndrome patients. R Powell, S Holgate et al. Clin Exp Allergy 2003;33:1450-1456*). The use of the word "disease" by these distinguished authors is significant, because a "disease" is a disorder with a specific cause and is generally accepted by the medical community as a discrete entity which is not psychiatric in origin, whereas an "illness" or a "syndrome" is not generally so accepted.

As for his "powerful plea" for more research into CFS, Wessely sat on three Boards of the Medical Research Council for years and the only result was £2.6 million for yet more psychiatric studies which are to be aimed at attempting to strengthen the currently weak evidence that his "management" approach is the best approach. In addition, £8.5 million has been allocated by Government to implement Wessely's management strategies. There is no money for any research into the disrupted biology of ME.

It is hardly surprising that Wessely promotes cognitive behavioural therapy as the "evidence-based" management approach, since he is a member of the Supervisory Board and a Corporate Officer of PRISMA, a multi-national healthcare company working with insurance companies to arrange "rehabilitation" programmes for those with ME/CFS. PRISMA claims to be especially concerned with long-term disability from the perspective of government and the insurance companies. In his contribution to the UNUMProvident report "Trends in Disability 2002", Wessely's psychiatrist colleague and co-author Michael Sharpe states "Funding of rehabilitation by commercial bodies has begun in the UK (with organisations such as PRISMA) and is likely to continue". The ME community will recall Dr Sharpe's long association with UNUM (and that UNUM was a sponsor of the recent Labour Party Conference).

Simon Wessely publicly claims that Margaret Cook's article shows "the real battle is not between myself and sufferers of ME but between your correspondent and the facts", so let the facts speak for themselves.

Both Margaret Cook and The Scotsman deserve the thanks of those who have already suffered too much for too long, not only from the savage and harrowing disease of ME itself, but also from the wholly unnecessary additional burden imposed by all-powerful vested interests.