## **Faculties Failure?**

## Margaret Williams 25<sup>th</sup> May 2008

There can be few in the international ME/CFS community, either researchers or sufferers, who are not profoundly dismayed at yet another article co-authored by Professor Simon Wessely that fails to distinguish between patients with "chronic fatigue" and those with "chronic fatigue syndrome".

His article "Physical or Psychological – a comparative study of causal attribution for chronic fatigue in Brazilian and British primary care patients" (Acta Psychiatr Scand May 2008: doi:10.111/j.1600-0447.2008.01200.x) fails to distinguish between "chronic fatigue" and "chronic fatigue syndrome", the latter also being referred to as "myalgic encephalomyelitis".

For peer-reviewers of a highly-rated journal such as Acta Psychiatrica Scandinavica (which has an impact factor of 3.857, this being a high score, since 90% of journals score less than 1 on impact rating) to have allowed such blatant misrepresentation to have escaped censure is alarming.

It is a matter of record that when serious errors and misrepresentations in his published articles (which, when challenged, even Wessely himself cannot rationally condone) have been pointed out to him and to Editors, Wessely blames his peer-reviewers. One instance of this occurred in 1997 in relation to his article in the Quarterly Journal of Medicine ("The prognosis of chronic fatigue and chronic fatigue syndrome: a systematic review". Joyce J, Hotopf M, Wessely S. Q J Med 1997:90:223-233), the many flaws of which were exposed by Dr Terry Hedrick (a research methodologist) in a bullet-proof analysis that was published in Q J Med 1997:90:723-725. To quote Hedrick: "Patients' beliefs in organic bases for their illnesses may be more accurate than anything else we have to offer at this time. Not only did the Joyce et al article fail to summarize the psychiatric literature accurately, it omitted discussion of the many avenues now being explored on the organic underpinnings of (ME)CFS".

This is not an isolated example of Wessely blaming his peer-reviewers. There have been others, for example, when UK medical statistician Professor Martin Bland from St George's Hospital Medical School, London, pointed out significant statistical errors in a paper by Wessely and Trudie Chalder, saying that Wessely's findings were "*clearly impossible*", Wessely absolved himself from any blame.

Bland was robust: "*Potentially incorrect conclusions, based on faulty analysis, should not be allowed to remain in the literature to be cited uncritically by others*" (Fatigue and psychological distress. BMJ: 19<sup>th</sup> February 2000:320:515-516). Wessely was compelled to acknowledge on published record that his figures were incorrect: "We have been attacked by gremlins. We find it hard to believe that the usually infallible statistical

reviewers at the BMJ could have overlooked this and wonder, totally ungallantly, if we can transfer the blame to the production side".

Will Wessely once again try to blame his peer-reviewers for this latest confusion and absolve himself from any blame? By what mental mechanism does he continue to dissociate himself from the fact that his personal belief that ME/CFS is a behavioural disorder is unsupported by hard evidence? Is he unmoved by the body of irrefutable evidence that has shown him to be wrong? That body of evidence is not going to go away. Why does he continue to deny it?

How often must it be pointed out that it was in 1990 that the American Medical Association made it plain that "chronic fatigue" and "chronic fatigue syndrome" are not the same? The AMA statement said: "A news release in the July 4 packet confused chronic fatigue with chronic fatigue syndrome; the two are not the same. We regret the error and any confusion it may have caused".

And yet --- eighteen years later --- here we have Wessely and his co-authors still using the terms "chronic fatigue" and "chronic fatigue syndrome" and "myalgic encephalomyelitis" synonymously.

Does this not amount to scientific misconduct?

The title and the abstract of his latest paper refer to "chronic fatigue" but the text refers to chronic fatigue syndrome and ME.

Given the fact that "chronic fatigue" is not synonymous with ME/CFS, the authors cannot possibly be talking about patients with ME/CFS, yet they claim to be doing so: "*Chronic fatigue syndrome (CFS), sometimes also known as myalgic encephalomyelitis (ME)....*".

Once again, this is in rank defiance of the World Health Organisation's International Classification of Diseases (ICD-10, 1992), which classifies "fatigue" quite separately from "ME/CFS"; moreover, the WHO has provided written clarification that it is not permitted for the same disorder to be classified to more than one rubric. "Fatigue" is classified as a mental disorder whilst ME/CFS is classified as a neurological disorder.

Why is Wessely continually permitted to defy such international taxonomic principles?

Unsurprisingly, this latest paper is replete with self-references.

In it, Wessely states emphatically: "British primary care patients with unexplained chronic fatigue were more likely to attribute their fatigue to physical causes than their Brazilian counterparts".

Wessely acknowledges that: "The study participants were not randomly selected representative samples from the healthcare seeking population" yet his conclusion is categoric: "Causal attribution influences symptom experience, help-seeking behaviour and prognosis in chronic fatigue syndrome".

Wessely states: "Less explored is a possible variation in causal attribution between sociocultural settings and to what extent physical attribution – consistently associated with a poor prognosis of CFS – is enhanced by sociocultural variables more frequently observed in Western affluent countries such as the UK. These include the sociopolitical debate about the nosological status of CFS in general and for disability benefits in particular".

Somewhat unexpectedly, Wessely concedes that "*CFS is officially endorsed as a medical condition in the UK*", citing "A report of the CFS/ME working group: report to the Chief Medical Officer of an independent working group". Hutchinson A. cited 2007 September 23 (i.e. the Report to the CMO). This is notable, given that the original report of  $11^{\text{th}}$  January 2002 specifically omitted to accept the WHO classification of ME/CFS as a neurological disorder.

If Wessely concedes that CFS is officially endorsed as a medical condition in the UK, why does he refer to it as "unexplained chronic fatigue (UCF)", which is a WHO classified mental disorder?

It is a straight-forward enough concept, so once again it has to be asked what is it about this concept that Wessely seems so continually unable or unwilling to understand?

In this latest paper, patients in the study with unexplained chronic fatigue were identified using the Chalder Fatigue Questionnaire, which is said to identify substantial "chronic fatigue" lasting six months or more. How this matches the criteria for ME/CFS such as the 2003 Canadian definition by Carruthers et al is not explained. The authors state: "*The questionnaires were read out to illiterate (Brazillian) participants. Those who fulfilled criteria for CFS were then asked to answer questions on causal attribution, duration of fatigue, and the Centre for Disease Control and Prevention (CDC) 1994 case definition of CFS*".

Furthermore, the authors state that they relied upon "an estimated prevalence of chronic fatigue" and on an "assumed prevalence of UCF".

Despite a study cohort that seems to be a conglomeration of ill-defined participants, Wessely et al state: "More widespread awareness of CFS/ME in the UK may lead to a greater likelihood of British patients viewing their fatigue via a biomedical perspective than their counterparts in Brazil. In the UK, most media and self-help material provided by patient organisations are more likely to promote physical rather than psychological explanations (and) the health care system, which labels fatigue as a medical condition, may further reinforce this tendency".

No reference is provided to support the assertion that the UK health care system labels "fatigue" as a medical condition.

The authors state: "Social support provided in a way which fosters dependency can help maintain chronic fatigue (and) there is an association between 'secondary gain' and health outcomes (in) functional somatic syndromes".

Wessely et al supply no references to support their claim, and seem to ignore the fact that both the Canadian and Australian guidelines reject such a notion.

Despite Wessely's acknowledgement that there was a high non-response rate in the UK ("Approximately 30% of the eligible patients in the UK did not complete phase 2 in comparison with only 6% in Brazil), the conclusion is that "The higher availability of sick leave / sickness benefit because of CFS in the UK may both contribute to and reflect the greater 'legitimisation' of chronic fatigue as a medical disorder. The findings of this study lend some support to the evidence on the important role of sociocultural factors in shaping illness attribution and perception around chronic fatigue and chronic fatigue syndrome".

It cannot be emphasised enough that "unexplained chronic fatigue" is not the same as ME/CFS.

At the Second World Congress on CFS and related disorders held in September 1999 in Brussels, Dr Daniel Peterson from the US said that ten years ago (i.e. in 1989), he believed that (ME)CFS would be resolved by science, but that he had now changed his mind and believed that it could only be resolved by politics.

It is politicians whom Wessely advises on "CFS/ME" and it is politicians who implement his advice, without seeming either to be aware of or to care about the enormous body of scientific evidence demonstrating that Wessely is simply wrong to lump "chronic fatigue" with ME/CFS as a single entity.

Can it be right that politicians should now control the science of medicine?

Wessely seems to think so. His latest paper seems to be saying that if Social Security benefits are stopped, patients will stop having ME/CFS.

This contradicts the NICE Guideline on "CFS/ME" that was published in August 2007, which clearly said that it was the doctor's job to support "CFS/ME" patients in obtaining benefits.

It seems that Wessely disagrees.