Response to allegations that "Sinister Science?" is disseminating misinformation

Margaret Williams 11th June 2004

Usually I do not enter into dialogue with those who instantly criticise whatever I write. This is because it is always the same small number of people and because they rarely make valid and constructive points but are, I believe, simply seeking to establish their own superior knowledge and status in the ME/CFS world, which is seen by others as being damaging to the ME community.

People are, of course, entitled to criticise but if they do, it is important that their criticisms are valid and accurate. This being so, I draw to the attention of these crusading critics the following points.

In a posting dated 6th June 2004, a critic asserted with apparent authority:

- (with reference to the new CFS centres of expertise being "headed up exclusively by psychiatrists"): **"This is not the case. The centres are not being headed up exclusively by psychiatrists".**

This complainant has apparently failed to notice that it was not I who made this statement; I merely quoted from an official letter in my possession from the Department of Health, which does state exactly what was quoted in the article.

In the same post, the critic commented:

- (with reference to the rhetorical question asking if those with other neurological disorders such as MS would be compelled to undergo mandatory psychological assessment before receiving medical care): **"Is anyone suggesting this other than this writer? I think not. Those with multiple sclerosis and other accepted neurological disorders may have been classed as having unexplained illness in the past but not now. A red herring".**

This seems to reveal that this complainant has little working knowledge of the difficulties still experienced by those presenting with early symptoms of MS and by those suffering from other neurological disorders, where dismissal of symptoms as psychiatric by physicians is not rare . The UK MS Society has confirmed that unfortunately it can often take more than five years to get a diagnosis of MS, and in one case known to me it took sixty years: a woman of 80 has had symptoms since her 20s but has only just been definitively diagnosed. Misattribution of neurological symptoms is notoriously common in medicine, not only in ME but also in other disorders, and my question was why should there be special pleading for psychological assessment only in the case of ME patients? The complainant has not provided an answer.

Again in the same post, the critic stated:

- **"The Oxford criteria does** *(sic)* **not exclude those with ME, but does exclude those with other neurological disorders such as MS, Parkinsons etc. This is what should be expected. Another false "fact" circulating at the moment".**

If the ICD, the UK Department of Health ***and*** the UK WHO Collaborating Centre at the Institute of Psychiatry all agree and confirm that the correct classification for ME/CFS is neurological (as stated in the letter of 11th February from the Health Minister Lord Warner to the Countess of Mar), and if the Oxford criteria state that ***"Certain patients should be excluded from the definition. They include patients with proven organic brain disease. Suggested comparison groups include patients with neuromuscular disorder"***, by what logic can those with a classified neurological disorder (in whom neuro-imaging studies have now demonstrated significant neurological abnormalities and abnormal values) be included in the MRC CFS trials that will use the Oxford criteria that exclude them from entry into those trials?

Once more in the same post, the critic stated:

- (with reference to the rhetorical question asking if the rapier-sharp investigative media are being effectively controlled by sinister science): **"The powers- that-be may be trying to control the media, but what of the ME lobby? Some may think that the investigative media are being controlled by those claiming to be the voice of the Patients/Carers. A case of the kettle calling the tea-pot?"**

I assure this particular critic and everyone else that I do not claim to represent anyone and I certainly have no influence upon the media; my only aim is to bring matters of significant concern about the misrepresentation of ME/CFS to the attention of those who persist in ignoring the international evidence that ME/CFS is not a behavioural problem but a devastating and often life-long organic disorder involving all the major systems of the body.

<u>The issue of fibromyalgia being included in the MRC trials on a CFS population</u>

In response to those who seem not to understand why the issue of the inclusion of fibromyalgia in the CFS trials by the MRC is contentious, the following information may provide clarification.

It seems that the intentional heterogeneity of the prospective study population for the MRC CFS trials is based solely on the assumption by Simon Wessely and his close-knit psychiatric lobby that "medically unexplained" physical symptoms which they believe "cannot be explained in terms of a conventionally defined medical disease" are simply a single, unified syndrome: these psychiatrists postulate that all "medically unexplained" syndromes are like the elephant to the blind man ---simply different parts of the same

animal. Wessely et al believe that this particular elephant is in reality a psychiatric disorder which they prefer to call a "functional somatic syndrome". The diverse syndromes said by this group of psychiatrists to form part of their elephant include tension headache, irritable bowel syndrome, premenstrual syndrome, atypical chest pain, globus hystericus, repetitive strain injury, fibromyalgia, chronic fatigue syndrome, food allergy and multiple chemical sensitivity. Wessely et al believe that the existence of such distinct syndromes is "largely an artefact of medical specialisation" and that such syndromes "are associated with unnecessary expenditure of medical resources". (*see* Functional somatic syndromes: one or many? S Wessely, C Nimnuan, M Sharpe. *Lancet 1999:354:936-939*).

The beliefs of these psychiatrists are a legitimate concern, not least because medical science has now demonstrated that key elements of serotonin signalling are changed in people with irritable bowel syndrome and it is no longer regarded as a psychological or social disorder because it has been shown to be due to altered gut biochemistry. (*see* Researchers Identify Molecular Aberration in IBS Patients. October 2003. *Medscape*).

Equally, in 2001 Germany officially recognised multiple chemical sensitivity and MCS is now classified in the International Classification of Diseases where it is referenced to code T78.4 (a pre-existing code for allergies) in the section on injuries and poisonings.

Many disagree with what they consider to be the over-simplistic stance of Wessely et al, not least on the grounds that there is a significant difference between "chronic fatigue" (as seen in many psychiatric disorders) and "post-exertional muscle fatigability" (the absolutely cardinal feature of ME). "Fatigue", as confirmed in JAMA in July 1990 ("American Medical Association issues correction") is not the same as the chronic fatigue syndrome. It is a matter of continuing concern that this distinction is consistently disregarded by Wessely and his group, who focus on "fatigue" as a continuum of "tiredness" to the virtual exclusion of more prominent symptoms that dominate ME/CFS but not other non-specific states of "chronic fatigue".

In respect of the MRC CFS trials, there are known and established differences between FM and ME/CFS and many believe that the FM community and the ME/CFS community have a right to know why patients suffering from both disorders are to be amalgamated in the MRC trials that claim to be studying "CFS".

Likewise, an explanation is required as to why GPs are suddenly to be offered financial incentives to identify and refer people with FM to the new CFS centres specifically so that such patients can be entered into the MRC studies of "CFS".

It is a matter of record that Whiting et al expressly excluded FM studies from the systematic review of the literature that was commissioned by the Policy Research Programme of the Department of Health and carried out by the Centre for Reviews and Dissemination at the University of York for the CMO's Working Group on CFS, the results of the systematic review being intended to underpin the conclusions of that report (namely that cognitive behavioural therapy, including graded exercise regimes, is the

management of choice for patients with chronic fatigue syndrome). The systematic review is unequivocal: **"Studies including patients with fibromyalgia were not selected for the review"**; why, therefore, and on what evidence, was it decided to include patients with FM in the subsequent MRC trials of CBT on a CFS population? (*see* Interventions for the Treatment and Management of Chronic Fatigue Syndrome. Penny Whiting et al. *JAMA 2001:286:11:1360-1368*).

Of foremost significance is the fact that fibromyalgia is classified as a distinct entity in ICD-10 at section M79.0 under Soft Tissue Disorders and it is not permitted for the same condition to be classified to more than one rubric, since ICD categories are mutually exclusive.

The literature itself is quite clear about this distinction, stating that up to 70% of those with ME/CFS have *concurrent* FM, and those who have both FM *and* ME/CFS have worse physical functioning than those who have ME/CFS alone.

Some illustrations from the literature make these distinctions clear:

1991: in spite of some overlap, FM and ME/CFS do not represent the same syndrome. (Primary fibromyalgia and the chronic fatigue syndrome. AJ Wysenbeek et al *Rheumatology Int 1991:10:227-229*)

1996: "**fibromyalgia appears to represent an additional burden of suffering amongst those with (ME)CFS**" (Fibromyalgia and Chronic Fatigue Syndrome – similarities and differences. Dedra Buchwald and Deborah Garrity. *Rheum Dis Clin N Am 1996:22:2:219-243*)

1997: levels of somatomedin C are lower in FM patients but higher in ME/CFS patients (Somatomedin C (insulin-like growth factor) levels in patients with CFS. AL Bennett, AL Komaroff et al. *J psychiat Res 1997:31:1:91-96*)

1998: "**recent studies suggest that (co-existent FM and (ME)CFS) may bode much more poorly for clinical outcome than CFS alone. In contrast to (significantly) elevated CBG (cortisol binding globulin) levels in patients with CFS, no differences were observed in FM patients. Differences in secretion of AVP may explain the divergence of HPA axis function in FM and (ME)CFS"** (Evidence for and Pathophysiologic Implications of HPA Axis Dysregulation in FM and CFS. Mark A Demitrack and Leslie J Crofford. *Ann New York Acad Sci 1998:840:684-697*)

1998: there is no evidence for elevated Substance P in patients with ME/CFS, whereas levels are elevated in patients with FM (CFS differs from FM. No evidence for altered Substance P in cerebrospinal fluid of patients with CFS. Evengaard B et al *Pain 1998:78:2:153-155*)

2001: patients with FM are NOT acetylcholine sensitive (Investigation of cutaneous microvascular activity and flare response in patients with fibromyalgia. AW Al-Allaf,

F Khan, J Moreland, JJF Belch. *Rheumatology 2001:40:1097-1101*)
2004: patients with ME/CFS ARE acetylcholine sensitive (Acetlycholine mediated vasodilatation in the microcirculation of patients with chronic fatigue syndrome.
VA Spence, F Khan, G Kennedy, NC Abbot, JJF Belch *Prostaglandins, Leukotrienes and Essential Fatty Acids 2004:70:403-407*)

2003: endothelin-1 is RAISED in fibromyalgia (Increased plasma endothelin-1 in fibromyalgia syndrome. Pache M, Ochs J et al *Rheumatology 2003:42:493-494*)

2004: endothelin-1 is NORMAL in ME/CFS (Plasma endothelin-1 levels in chronic fatigue syndrome. Kennedy G, Spence V, Khan F, Belch JJF *Rheumatology 2004:43: 252-253*)

Finally, consultant rheumatologists who have sufficient experience with both syndromes have observed clinically that in FM, the muscle pain is helped by gentle stretching and exercise, whereas in ME/CFS, exercise makes muscle pain worse.

If the Oxford criteria are to be used for the MRC "CFS" trials, on what logic (other than a pre-determined agenda) can patients with FM, a completely separate disorder, be intentionally included from the outset?

Equally, I still am unable to understand how any "secondary analysis" using ***any*** supplementary criteria can identify those whom the trial entry criteria have already excluded by definition.

Perhaps those who are so keen to criticise and so eager to engage in destructive disparagement would be kind enough to provide the answer.

Margaret Williams
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