Professor Sir Simon Wessely – Right or Wrong?

Margaret Williams 28th October 2013

When a professional person – especially a doctor – has repeatedly been shown to be wrong in their professional judgment and, as a direct consequence, people have been harmed, that doctor should surely be held personally responsible and accountable: in such circumstances legitimate criticism should not be dismissed as an *ad hominem* (personal) attack.

Following the award of the inaugural John Maddox Prize to psychiatrist Professor Sir Simon Wessely for his alleged *"courage"* in *"standing up for science"* and for promoting "*sound science*" about ME/CFS in the face of "*hostility*" in doing so, a letter published on 13th January 2013 by the Countess of Mar, Professor Malcolm Hooper and Dr William Weir in The Independent on Sunday was explicit that criticism of Wessely's hypothesis about ME/CFS is scientifically legitimate:

"*Scientific understanding always depends upon sound evidence….For scientific understanding to prevail, the extensive biomedical evidence-base of ME/CFS must now be recognised by all researchers in the field. The idea that ME/CFS is due to a dysfunctional psyche is a hypothesis without an evidence-base. The Maddox Prize was therefore awarded to the defender of an hypothesis with no evidence-base rather than to someone who was upholding true scientific inquiry. Personal attacks against Professor Sir Simon Wessely do not advance the cause, but it is scientifically legitimate to direct criticism at the hypothesis both he and Professor White* (chief Principal Investigator of the MRC's PACE trial on ME/CFS) *continue to espouse".*

It has been shown time and again that Professor Sir Simon's published assertions about disorders such as ME/CFS, fibromyalgia, Gulf War Syndrome, the Camelford drinking water poisoning, and interstitial cystitis are simply wrong. Merely stating so is likely to result in yet more claims by him of "harassment" and "attack" upon him but, in the words of Professor Martin Bland, one of the UK's leading medical statisticians, it is important that false information should not remain on the record to be quoted uncritically by others: "*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: 19th February 2000:320:515-516). Wessely's "incorrect conclusions", however, remain in the literature to be cited uncritically by others and therefore may result in iatrogenic harm.

ME/CFS

For over 25 years Wessely's dismissal and rejection of the biomedical evidence on ME has continued unabated, even though there is substantial evidence of on-going inflammation throughout the body; systems prominently affected are the central and autonomic nervous systems, the immune system and the cardiovascular, endocrine, gastro-intestinal and musculoskeletal systems.

Unscientifically, he conflates ME, CFS, PVFS and chronic "fatigue" into what he refers to as "CFS". This has become a waste-basket label, with 40% of those afforded it subsequently being shown to have other diagnoses (J R Coll Physicians Edinb, 2010:40(4):304-307).

Despite the extensive biomedical evidence that shows him to be wrong, Wessely is certain that he is right: he believes that ME/CFS is a behavioural disorder that should be managed with *"cognitive restructuring"* specifically designed to convince sufferers that they are not physically sick.

Indeed In October 2003, in a frenzied attack on people with ME and on those scientists and clinicians who regard it as an organic disorder, Wessely raged that those who disagree with him and believe ME to be an organic disorder (to whom he referred as *"the radicals"*) are *"crazy"* and that they are *"engaged in fantasies, lies and gross distortions".* He wrote that the *"radicals"* are left *"fighting yesterday's battles"* (seemingly because he believes he has established that ME does not exist except as a false illness belief), that they need a *"reality check"* and that *"their behaviour is outrageous"*(private communication; available to Medical Defence Union lawyers on legitimate request).

Ten years later, his views have not progressed in line with the advancement of medical science: at a medical meeting in March 2013 held in Bristol, Wessely informed attendees that ME has been caused almost entirely by what he called the *"shockingly"* negative way in which some ME charities, in particular the ME Association, portray it as a viral illness, saying that this has harmed patients as it encourages them to focus too much on symptoms and to be fearful of activity, resulting in a vicious cycle of deconditioning. Making no distinction between chronic "fatigue" and ME/CFS, doctors were assured by Wessely that all patients with CFS would benefit from the same management regime, namely behavioural therapy and exercise (Research in Chronic Fatigue Syndrome – ups and downs; Bristol Medico-Chirurgical Society; 13th March 2013: approved as a Continuing Medical Education module).

The continued propagation of such erroneous beliefs is a matter of significant concern because of their potential harm to very sick people, so it may be appropriate to re-consider the evidence that proves Professor Sir Simon to be wrong about four other issues as well: fibromyalgia, Gulf War Syndrome, the Camelford poisoning tragedy, and interstitial cystitis.

Fibromyalgia

As with ME/CFS, Simon Wessely believes that fibromyalgia (FM) is a functional somatic disorder (Lancet 1999:354:936-939), despite the fact that FM is formally classified in the World Heath Organisation's ICD-10 at M79 as a soft tissue disorder. FM was officially recognised as a syndrome on 1st January 1993 by the WHO as a result of the Copenhagen Declaration (Consensus Document on Fibromyalgia: The Copenhagen Declaration 1992). It is a systemic disorder and affects not only the muscles – including the heart – but also the gut and immune system, and these are all recognised features of FM.

Israeli researchers have pointed out that FM is believed to be the result of a central nervous system malfunction and emphasised that: *"many of the differential diagnoses can be excluded by means of an extensive clinical examination and patient history*" (Autoimmun Rev 2012 Jun:11(8)585-588), but Wessely advises against extensive clinical examination, claiming that it supports patients' false beliefs that they are physically ill.

Whilst Wessely has not changed his position that fibromyalgia is but one part of a unified functional somatic syndrome, medical science has shown that in fibromyalgia, there is objective evidence of:

· abnormal nerve fibres in the skin, showing enlarged Schwann cells which relay information from tissues to brain and produce cytokines, resulting in pain (Clin Rheumatol 2008:27:407-411)

· central nervous system malfunction which increases pain transmission and perception (Autoimmun Rev, June 2012)

· autoimmune thyroid disease being highly associated with fibromyalgia (J Rheumatol, June 2012)

· overlap with inflammatory back pain (Clin Exp Rheumatol, August 2012)

· interstitial cystitis and irritable bowel syndrome as co-morbidities (Front Neurosci, August 2012)

· altered cerebral blood flow dynamics with an enhanced haemodynamic response (Psychosom Med, Sept 2012)

· self-management programmes being ineffective (BMC Musculoskelet Disord, September 2012)

· inflammatory dysregulation (Neuroimmunomodulation, Sept 2012)

· neuromuscular fatigue and lowered exercise capacity (Arthritis Care Res, September 2012)

· mitochondrial dysfunction (Antioxid Redox Signal, Sept 2012)

· small-fibre polyneuropathy with evidence of nerve loss (American Neurological Association 137th Annual Meeting in partnership with the Association of British Neurologists; Abstract W1409; 7-9thOctober 2012)

· abnormally high muscle membrane conduction velocity (Clin Exp Rheumatol 2012: November 22)

· FM commonly occurring in patients with autoimmune disorders such as lupus, Sjogren's Syndrome and rheumatoid arthritis (BMC Clinical Pathology, 17th December 2012:12:25)

· aberrant expression of immune mediators (cytokines), with impairment of cell-mediated immunity, providing evidence that FM is an immunological disorder which occurs independently of any subjective features (BMC Clinical Pathology, 17th December 2012:12:25)

· hearing difficulties, hair loss and easy bruising (Clin Exp Rheumatol 2012:30:S88-S93)

· impaired small-fibre function, pointing towards a neuropathic nature of pain in FM (http://brain.oxfordjournals.org/content/early/2013/03/09/brain.awt053.short)

· biochemical differences (changes in tryptophan catabolism pathway) that are quite distinctive from those found in osteoarthritis or rheumatoid arthritis (Analyst Issue 16, 2013)

· a mismanaged blood flow and low levels of inflammation, with a unique peripheral neurovascular pathology consisting of excessive peptidergic sensory innervation of cutaneous arteriole-venule shunts (AVS) in the skin of FM patients confirmed by multimolecular immunocytochemistry, with blood flow dysregulation as a result of excessive innervation to AVS contributing to widespread deep pain and fatigue (Pain Medicine: June 2013:14:6:895-915)

· heart rate variability (HRV) aberrances, indices of increased sympathetic activity and a blunted autonomic response to stressors (Semin Arthritis Rheum 2013:6th July)

In addition to these demonstrable abnormalities, there is no objective link to psychiatric disease in fibromyalgia (BMC Clinical Pathology 2012:12:25) and furthermore, there is evidence that the use of antidepressants in long-term treatment of fibromyalgia resulted in a worse impact of the disease on patients' daily lives, with worsened quality of life and deterioration in long-term management (Clin Pract Epidemiol Ment Health 2013:9:120-124).

Evidentially, Wessely's aberrant belief that fibromyalgia is but one component of a single functional somatic syndrome has been vitiated and he has been proved wrong.

Gulf War Syndrome

Simon Wessely was knighted in the 2013 New Year Honours List for his work on "military health"; he is civilian psychiatric advisor to the UK Ministry of Defence where, despite his having no case definition of Gulf War Syndrome (GWS), he has consistently denied its existence, ascribing it to "*stress of combat"* and to a *"belief"* of exposure to a chemical attack (Lancet: 16th January 1999:353:169-178). Despite having been funded to the tune of $1 million by the US Pentagon, Wessely and his co-psychiatrist Professor Anthony David (both described as "*specialists in unexplained syndromes"*) definitively concluded that exposure to chemical weapons was not the cause of Gulf War veterans' health problems (US cash for study of Gulf victims. Jeremy Laurence. Independent: 4" June 1997).

Sixteen years later, Wessely's view apparently still pertains throughout the UK Ministry of Defence.

In contrast, US scientists have shown that Gulf War veterans' chronic ill-health is indeed linked to toxic causes and it is clear that Gulf War Illness/Syndrome cannot be associated with stress or any psychiatric disorder: it is associated with poisoning by the cholinesterase inhibitors sarin and organophosphates (these being known neurotoxins which give rise to multi-system illness) combined with the effect of pyridostigmine bromide which acts synergistically with them (US Congressionally Mandated Report of the Research Advisory Committee on Gulf War Illness – Findings and Recommendations; 13th June 2012).

Further, a large study led by Robert Haley, Professor of Internal Medicine and Chief, Division of Epidemiology, University of Texas Southwestern Medical Centre, confirmed cholinergic dysfunction in affected Gulf War veterans (Archives of Neurology, 26 November 2012: 1-10). The authors concluded: "*Autonomic symptoms are associated with objective, predominantly cholinergic autonomic deficits in the population of Gulf War veterans"*, with affected veterans displaying orthostatic intolerance, secretomotor dysfunction, upper gastrointestinal dysmotility, sleep dysfunction, urinary dysfunction and autonomic diarrhoea.

As Haley pointed out: "*It takes this out of the realm of psychological illness into the realm of a brain illness"* (Gulf War Illness linked to Cholinergic Abnormalities. Pauline Anderson: Medscape 26 November 2012).

The statistics show that almost one third of UK troops who were deployed or were prepared for deployment to the Gulf (which equates to between 13,250 and 15,900 previously fit and healthy personnnel) remain chronically sick. Death statistics from GWS are impossible to obtain because once the sick Gulf War veterans have left the armed forces, they are passed to the care of the NHS and no extant medical records for service personnel are made available to the NHS – they have been either destroyed or retained by the MoD. (It is notable that in 1997, Wessely forecast that Gulf War veterans' *"contemporary records…may be difficult to obtain"*: BMJ 1997:314:239-240).

Thus convincing evidence exists that proves Wessely is wrong in asserting that Gulf War Syndrome does not exist and that veterans' ill-health is merely the result of their own misperceptions.

<u>The Camelford water poisoning tragedy</u>

Wessely not only denies the existence of ME and of Gulf War Syndrome: he has denied that residents of Camelford were poisoned by aluminium sulphate. In July 1988, 20 tonnes of aluminium sulphate were accidentally pumped into the drinking water supplies of the small town of Camelford in Cornwall. It was reported that in the Camelford catastrophe, seven people died; 25,000 suffered serious health effects, and 40,000 animals were affected. (Dr Douglas Cross. The Ecologist:1990:20:6:228-233). Five years later, an article by Bernard Dixon entitled "Still waters" was published in the BMJ (5th August 1995: 311:395); it informed readers that: "*mass hysteria was largely responsible for the furore*". Dixon's article was based on a 1995 "re-assessment" of the Camelford incident by psychiatrists Anthony David and Simon Wessely which was published in the Journal of Psychosomatic Research (1995:39:1-9*)*. Dixon noted that David and Wessely had found that anxiety was the cause of the symptoms and that there was no evidence of long-term adverse effects on health as a consequence of the drinking water contamination.

However, David and Wessely's confident assertion that mass hysteria and/or anxiety were responsible for the supposed suffering of those in the Camelford area at the time of the incident has been shown to be wrong. Paul Altman et al showed that Camelford residents who were exposed to aluminium sulphate-contaminated drinking water suffered considerable damage to cerebral function which was not related to anxiety, and that there was objective evidence of organic brain damage compatible with the known effects of exposure to aluminium (BMJ 1999:319:807-811). Altman et al reported that previous psychological studies on victims of the Camelford incident which concluded that: *"the perception of normal and benign somatic symptoms (physical and mental) by both subjects and health professionals was heightened and subsequently attributed to an external cause, such as poisoning"* were demonstrably erroneous.

Twenty-five years after the catastrophe, the UK Government apologised to those affected "*unreservedly"* for the way in which the incident was dealt with at the time (BBC News Cornwall, 19th September 2013).

It remains to be seen if Simon Wessely will also apologise unreservedly to those whom he denigrated by dismissing their symptoms as anxiety. Quite how hair, skin and nails turning blue, and bone biopsies showing stainable aluminium over six months later could possibly be due to anxiety has not been explained by Wessely.

Again, Wessely has been proved wrong in ascribing serious and chronic physical ill-health to aberrant perception not only by those afflicted but also by those medical professionals who supported them.

Interstitial cystitis

In 2009 the BMJ carried a well-structured Clinical Review of interstitial cystitis/bladder pain syndrome (Serge Marinkovic et al: BMJ 2009:339:337-342) in which the authors provided a compelling case – based on evidence of bladder epithelial damage and related blood vessel transitions activating mast cells and generating an autoimmune response – of likely autoimmune causation.

At once Wessely sprang into action, rejecting outright any autoimmune or allergic component and noting the association with chronic fatigue syndrome, asserting that there was *"good evidence"* for the role of psychological factors in both the aetiology or maintenance of both conditions and stating that physical pathology cannot fully account for the symptoms(http://www.bmj.com/cgi/eletters/339/jul31_2/b2707#218935). He criticised Marinkovic for resisting in his review his (Wessely's) own proposition that they are simply part of one functional somatic syndrome in which psychological factors contribute to the aetiology and for omitting to mention that psychological interventions (CBT) deserve a place in any review of the disorder (seehttp://www.meactionuk.org.uk/Interstitial_cystitis_and_Chronic_Fatigue_Syndrome.htm).

In 2012 it was established that patients with interstitial cystitis/painful bladder syndrome demonstrated measurable systemic dysfunction, with central and autonomic nervous system disorders and high rates of syncope as well as gastrointestinal dysfunction (Chelimsky G et al. Front Neurosci 2012:6:114: Epub 10 August 2012).

In October 2013, researchers again proved Wessely wrong (Jiang Y-H et al; Increased Pro-Inflammatory Cytokines, C-Reactive Protein and Nerve Growth Factor Expression in Serum of Patients with Interstitial Cystitis/Bladder Pain Syndrome: PLoS ONE 8(10): e76779. doi:10.1371/journal.pone.0076779).They demonstrated increased pro-inflammatory cytokine/chemokine (IL-1ß, IL-6, TNF-α and IL-8) expression in the sera of IC/BPS patients, implying not only mast cell activation but also that other inflammatory mediators play important roles in the pathogenesis, and supporting the fact that interstitial cystitis/bladder pain syndrome is now considered a chronic inflammatory disease.

Conclusion

Wessely's attempts to re-classify as a single somatoform disorder various disparate physical syndromes have failed. As the Countess of Mar et al so concisely commented, the Maddox Prize was *"awarded to the defender of a hypothesis with no evidence-base rather than to someone who was upholding true scientific inquiry".* There are many who maintain that, contrary to *"standing up for science"*, the award to Wessely militates against medical science and actively devalues it.