The Views of Dr. Simon Wessely on M.E.: Scientific Misconduct in the Selection and Presentation of Available Evidence?

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It is widely acknowledged in the peer-reviewed medical literature that patients with myalgic encephalomyelitis (M.E.), otherwise known as chronic fatigue and immune dysfunction syndrome (CFIDS) or chronic fatigue syndrome (CFS), suffer from an organic illness which is not psychological or psychiatric in origin. Persons with M.E. are particularly vehement on this point because they know from experience that selective symptoms which point to an organic etiology are simply ignored by many in the medical community because of ignorance or bias. One of the prime offenders in this category is the British psychiatrist Dr. Simon Wessely.

It is very distressful that Wessely appears to be quite unstoppable in his blind determination to claim that M.E./CFIDS is nothing more than a primary psychiatric disturbance. The only United Kingdom government-funded research on M.E./CFIDS has been a small grant from the Medical Research Council, which went toward Wessely's research into the psychiatric aspects of M.E./CFIDS. In addition, Wessely has a seemingly unassailable influence on the U.K. Department of Health and the Department of Social Security, and the misinformation he is propagating is causing immeasurable risk and hardship to sufferers of M.E./CFIDS.

His influence does not stop at the U.K. border, however. Wessely has recently been in the United States doing his utmost to alter the Centers for Disease Control and Prevention (CDC) criteria for CFS by trying to get the case definition turned wholly away from an organic etiology. All M.E./CFIDS patients should be adequately informed about the nature and extent of the damage Wessely has done to them and to the image and public perception of this condition by his many publications in the medical literature. We know that the accuracy of his quotations is not an issue, as all have been published by Wessely and his close associates.

"Maladaptive Coping Strategies"

Despite his claim that he does not want to get into the 'organic' versus 'functional' argument (1), Wessely has done perhaps more than anyone else to fan this particular flame. He believes that M.E. (or CFS as he prefers to call this disease) is merely one end of a continuum of "tiredness" as experienced by everyone at some stage in their lives, and that the prognosis of those who succumb to M.E. may "depend on maladaptive coping strategies"(2). In other words, Wessely seems to be saying that M.E. is nothing more than an attitude problem experienced by suggestible people who are poor copers and who see the label of M.E. as an easy escape route from life's problems. Wessely compares M.E. with neurasthenia, the late 19th century psychiatric disorder.

He writes that neurasthenia "provided the most respectable label ... one which conferred many of the benefits ... and fewest of the liabilities ... associated with illness. ... There is little evidence of any change in the current era [of M.E.]. Unfortunately and probably due to the input of doctors like Wessely, M.E. definitions have recently centered on the symptom of fatigue instead of on the original definition by Ramsay, which focused on the rapid muscle fatigue after minimal exertion. Fatigue is too vague and common a symptom on which to base any definition, but it fits the aims of psychiatrists like Wessely who want to link M.E. with depression.

Wessely's Scientific Methods

Wessely is a most prolific author, and to support his own views on the nature of M.E. he relies heavily on his own opinions; for instance, in his chapter in a recent neurological textbook (4) he uses no less than 31 self-references. Most mainstream medical journals will permit no more than two self-references in an article.

The extrapolations which Wessely makes from his own research findings simply do not carry the weight to support his conclusions. For the most part it seems he has reached his conclusions before generating his data. One of his studies included only 47 patients, yet from this small sample Wessely's major conclusion is that "an alternative hypothesis is that all cases of CFS can be explained by disorder of mood" (5). In truth, this trial is too small to be of any practical use and, by his own admission, his methodology was flawed. Therefore his conclusions are baseless and arbitrary. Even so, this study continues to be quoted by Wessely as a paper of substance in the M.E./CFS literature, as it was published in the prestigious Journal of Neurology, Neurosurgery and Psychiatry. This would undoubtedly convey considerable acumen if one of his colleagues had not let it be known that most of the reviewers for this journal are closely connected with Wessely and that Wessely himself is the referee on M.E. for this journal (although he would not have been permitted to review his own work). We understand that he also holds this position for the British Medical Journal, The Lancet and various other peer-reviewed journals.

The Referees' Role

Normally, the identity of referees who perform peer-reviews is never revealed, but there has been such concern over the abuse of the referees' power to wield undue influence that Professor Peter Sleight, head of cardiology at the John Radcliffe Hospital in Oxford, stated "Peer review is 50 percent garbage, 50 percent malice and 10 percent good advice" at a recent Royal Society of Medicine meeting (6). Professor Sleight went on to claim that "many [referees] actually steal data and hold up publication while they publish it as their own research."

The role of referee on any particular subject carries enormous responsibility because he or she decides what gets published and what gets rejected. If the journals are flooded with enough articles which reinforce concepts of a particular disease, and when many of the articles have been written by a single author, then two things happen. One is that the ideas and conclusions repeatedly put forth gradually become accepted as facts; the other is that the prolific author becomes thought of as an "expert" merely by virtue of the sheer volume of his or her published works. It would then be natural for such a prolific author to be sought out as the expert of choice by lawyers, for instance. Professor Sleight told the Royal Society of Medicine meeting that for his part, he prefers writing his own detailed press-releases rather than relying on the discredited peer-review system (6).

Railroading the Opposition

Of more importance than his own personal views about M.E. is Wessely's treatment of other people's genuine research into M.E.: he repeatedly ignores, dismisses or trivializes any evidence which does not accord with his own views. When he reviews the M.E. literature, he makes factual errors (which lend support to his own theories) and he distorts other people's accounts. For example, in one article (7), Wessely reduced the duration of the 1955 Royal Free Hospital epidemic from the actual three months by claiming that it lasted from one day to one month. He bases one argument on a 1970 review of this epidemic written by McEvedy and Beard (8), who claimed that this outbreak was simply mass hysteria, even though they had only reviewed old case notes and failed to interview a single patient. Wessely states that McEvedy and Beard felt that the use of the name "benign myalgic encephalomyelitis" in this epidemic served to reinforce the outbreak. However, that name was not even coined until 1956, well after the end of the outbreak, so it is unlikely that it could have influenced the course of the epidemic. Further, there is no such reference by the original authors in the McEvedy and Beard paper.

More recently, when discussing the persistence of viruses, Wessely writes that even if a virus manages to evade the host response, "the immune system still responds in such a fashion as to indicate the presence of the virus. Evidence of any of these processes has not been provided in CFS"(9). The fact that Wessely chose to ignore the extensive evidence found by Landay, et al.(10); Klimas, et al. (11); Morrison, et al. (12); Chao, et al. (13); Jones, et al. (14) and Buchwald, et al.(15) does not mean that there is none, it only means that Wessely, as usual, restricts his references to a biased and personal selection of the evidence which is available.

This is but further evidence that Wessely continues to dismiss the findings of other M.E. researchers which clearly give credence to the organic etiology of this disease; in the past he has dismissed such findings as 'artifacts,' presumably because the findings do not fit his own model in any way. It is known that Wessely has

refused to acknowledge other researchers' results, claiming that those results were simply caused by "interpreter bias," and that all laboratory data is meaningless because it is open to subjective interpretation (16). It is surely noteworthy that Wessely consistently fails to admit the duplicity of his stance, since most psychiatric diagnoses are made on the subjective opinion of the psychiatrist.

A report commissioned by an M.E. patient association found that one of Wessely's primary dismissal techniques is to claim that the evidence in favor of organic causation relied on "sophisticated" techniques like polymerase chain reaction (PCR) and MRI scans. This report found that most of Wessely's articles do not present a balanced or accurate picture of the literature on M.E./CFS.

Wessely's Words

In order to lend support to the above observations, we have reprinted a selection of quotes from Wessely's own published work below.

1. *David AS, Wessely S, Pelosi AJ: Postviral fatigue syndrome: time for a new approach. British Medical Journal 5 March 1988:696-699.*

"Future investigations and clinical practice must take into account the similarities between the symptomatology of the post-viral fatigue syndrome and that of common psychiatric disorders in the community."

2. *Wessely S: What your patients may be reading. British Medical Journal 1989;298:1532-3.*

"Beard and Mitchell have returned to obscurity, but their disease is back with a vengeance. My local bookshop has just given M.E. the final seal of approval, its own shelf."

"... a little more psychology and a little less T cells would be welcome ..."

3. *Wessely S, David A, Butler S, Chalder T: Management of the chronic (postviral) fatigue syndrome. Journal of the Royal College of General Practitioners: 1989;39:26-9.*

"Many patients referred to a specialized hospital with chronic fatigue syndrome have embarked on a struggle. This may take the form of trying to find an acceptable diagnosis, or indeed, any diagnosis. One of the principal functions of therapy at this stage is to allow the patient to call a halt without loss of face."

"[M.E. patients are in] a vicious circle of increasing avoidance, inactivity and fatigue."

"... there is no clinical evidence that allergies exist in anything but a small number of sufferers, and their existence may be coincidental."

4. *Wessely S, Powell R: Fatigue syndromes: a comparison of chronic "postviral" fatigue with neuromuscular and affective disorders. Journal of Neurology, Neurosurgery and Psychiatry 1989:52.*

"Seventy two percent of the CFS patients were cases of psychiatric disorder."

"Any abnormalities in muscle structure or function may ... result from physical inactivity."

5. *Wessely S: Chronic fatigue and myalgia syndromes. In N. Sartorius, et al. (eds.) Psychological Disorders in General Medical Settings. Hogrefe & Huber: 1990.*

"Most CFS patients fulfill diagnostic criteria for psychiatric disorder."

"Other symptoms include muscle pain and many somatic symptoms, especially cardiac, gastrointestinal and neurological. Do any of these symptoms possess diagnostic significance? The answer is basically negative."

"... this suggests that, despite frequent claims to the contrary, these are not immuno-deficiency syndromes, nor is active viral infection a likely factor."

"The description given by a leading gastro-enterologist at the Mayo Clinic remains accurate: 'the average doctor will see they are neurotic and he will often be disgusted with them'. "

"... it is of interest that the 'germ theory' is gaining popularity ... at the expense of a decline in the acceptance of personal responsibility for illness. Such attribution conveys certain ... benefits in other words, there is avoidance of guilt and blame."

"It is this author's belief that the interaction of the attributional, behavioral and affective factors is responsible for both the initial presentation to a physician and for the poor prognosis."

6. *Wessely S, Thomas PK: The chronic fatigue syndrome myalgic encephalomyelitis or postviral fatigue. In C. Kennard (ed): Recent Advances in Clinical Neurology no.6. Churchill Livingstone: 1990;85-132.*

"A number of patients diagnosed as having ... myalgic encephalomyelitis were examined ... by one of the authors of this chapter. ... In many of them the usual findings of simulated weakness were present."

"... many physicians may not be familiar with the range and severity of the symptoms of major depression."

"The epidemic may have resulted from a combination of altered medical perception and a floating numerator."

"... efforts are often made to over-interpret laboratory findings."

"Over-enthusiastic espousal of new illness ... can be ... harmful. It may legitimize some of the maladaptive behavior already described."

Note: In the above article, Wessely uses 31 self-references throughout his text.

7. *Powell R, Dolan R, Wessely S: Attribution and self esteem in depression and chronic fatigue syndromes. Journal of Psychosomatic Research 1991; 34:6:665-673.*

"... this research shows that in ... CFS [compared to depression, the patients] experience less guilt ... such an external style of attribution has certain advantages; external attribution also protects the patient from being exposed to the stigma of being labelled psychiatrically disordered ... [and] may lead to helplessness ... and diminished responsibility for one's own health. ... Our results are close to those predicted by the 'learned helplessness' theory of depression."

"Such 'inappropriate' referrals to physicians can lead to extensive physical investigations that may then perpetuate the symptom patterns of physical attributions."

8. *Wessely S: Editorial. Journal of Neurology, Neurosurgery and Psychiatry 1991;54:669-671.*

"Studies of dynamic muscle function have demonstrated essentially normal muscle strength, endurance and fatiguability, other than as a consequence of physical inactivity."

9. *Butler S, Chalder T, Ron M, Wessely S: Cognitive behavior therapy in chronic fatigue syndrome. Journal of Neurology. Neurosurgery and Psychiatry 1991;54:153-158.*

"Continuing attribution of all symptoms to a persistent 'virus' ... preserves self-esteem."

10. *David AS, Wessely S, Pelosi A: Chronic fatigue syndrome: signs of a new approach. Brit J Hosp Med 1991;45:158-163.*

"Having established the high prevalence of psychiatric disorder, particularly affective disorder, in patients with CFS ..."

"Given the well-known links between ... depression and the immune system, it is not surprising that a host of immunological abnormalities continue to be reported in association with CFS."

"Although there were preliminary well-publicized reports ... of increased levels [of interleukin 1] in the serum of some CFS patients, this could be accounted for by elevation known to rise following exertion in normal, unfit subjects."

"The study established that the injunction to rest ... is rarely in the patients' best interests." (*Note: Wessely was referring to his own study.*)

"The importance of psychiatric illness in CFS is now clear."

11. *Wessely S: The psychological basis for the treatment of CFS. Pulse of Medicine 14 Dec 1991,58.*

"The prognosis may depend on ... maladaptive coping strategies ... and the attitude ... of the medical profession."

12. *Lewis G, Wessely S: The epidemiology of fatigue: more questions than answers. Journal of Epidemiology and Community Health 1992;46:92-97.*

"We suggest that many patients currently labelled as having 'CFS' ... may lie at the extreme end of a continuum that begins with the common feeling of tiredness."

"Studies usually find a high prevalence of psychiatric disorder amongst those with CFS, confirming that physicians are poor at detecting such disorders."

13. *Wessely S: Chronic fatigue syndrome: current issues. Reviews in Medical Microbiology 1992;31211-216.*

"Validation is needed from the doctor ... once that is granted, the patient may assume the privileges of the sick role (sympathy, time off from work, benefits, etc.)."

14. *Howard LM, Wessely S: The psychology of multiple allergy. British Medical Journal 25 Sept 1993; 307:747-748.*

"Many people present to their doctors with multiple unexplained symptomatology which they attribute to allergy. ... Those at the extreme end of this range often attract a diagnosis of total allergy syndrome, multiple chemical sensitivity or environmental illness diagnoses that most allergists or immunologists repeatedly reject. ... If the problem is not one of allergy then what are the possible causes? Research has shown the relevance of psychological disorder."

"A recent study ... confirmed that ... psychological symptoms were a central component of chemical sensitivity."

"Inherent in the concept of allergy is the avoidance of any blame. Sufferers from allergies feel no guilt about their condition and are not subject to any moral sanction."

"Sufferers from mysterious conditions that lie outside conventional medical practice no longer consider themselves to be oppressed by spirits and demons but by mystery gases, toxins and viruses. This is particularly visible in the changing nature of mass hysteria."

15. *David A, Wessely S: Chronic fatigue, M.E. and ICD 10. The Lancet 13 Nov 1993;1247-8.*

"The inclusion in the tenth revision of the International Classification of Diseases (ICD 10) 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 self-help groups in the UK. ... it is unlikely to lead to advances in our understanding of the condition. ... The nineteenth century term neurasthenia remains in the Mental and Behavioral 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 that this latest attempt to classify fatigue syndromes will prevent many people from seeing the world as it actually is."

16. *Pawlikowska T, Chalder T, Wallace P, Wright DJM, Wessely S: Population based study of fatigue and psychosocial distress. British Medical Journal 19 March 1994;308:763-766.*

"In recent years, fatigue has attracted renewed attention, largely because of the prominence given to the chronic fatigue syndrome ... the infective characteristics may, however, be the result of referral patterns and illness behavior and not intrinsically related to the chronic fatigue syndrome."

"The chronic fatigue syndrome ... may represent a morbid excess of fatigue rather than a discrete entity. ... The definition may have arisen as a result of referral patterns to specialists."

"Numerous ... studies have found associations between chronic fatigue syndrome and psychiatric diagnoses muscle pain was also related to psychological morbidity."

17. *MacLean G, Wessely S: Professional and popular views of chronic fatigue syndrome. British Medical Journal 19 March 1994;308:776-777.*

"We have found that the British media tend to favor an organic cause for the syndrome. ... Much of the press coverage of the chronic fatigue syndrome shows a lack of understanding of psychological medicine and its practitioners."

In conclusion, Wessely continues to ignore or dismiss the massive world-wide evidence of organic abnormality in M.E., presumably because the findings of M.E./CFIDS researchers and the evidence which has now been accumulated conflict with his own model of this disease. Through his modification of scientific data, Wessely is waging a war against the thousands who live and work daily with this devastating condition. This can only be judged as scientific misconduct.

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