

## **Unanswered Questions: do inconsistencies matter in medicine?**

**Margaret Williams      10<sup>th</sup> September 2005**

Following recent posts about the intention of members of the Wessely School / One-Health company to persuade Government agencies to implement a national programme of cognitive behavioural therapy and graded exercise regimes for those with alleged “behavioural” disorders in which they include “CFS/ME” (see Co-Cure ACT: “Proof Positive?”: 2<sup>nd</sup> September 2005 and “More Proof Positive?”: 4<sup>th</sup> September 2005), there are numerous inconsistencies that seem to remain unaddressed by One-Health company lobbyists. They include (i) the irrationality of drawing conclusions across differing patient populations (for example, lumping together those with primary psychiatric disorder and those with primary organic disorder and then claiming that this amalgamation represents one single “behavioural” disorder); (ii) the absurdity of relying on assumptions as the basis for a compulsory management regime (for example, that ME/CFS patients obtain secondary gain); (iii) the divergent assertions about the efficacy of cognitive behavioural therapy; (iv) the inherent danger of applying a “one-size fits all” management policy to those with “CFS/ME” and (v) the opposing evidence of these psychiatrists’ intention to claim “CFS/ME” as a psychiatric disorder.

### **The irrationality of drawing conclusions across differing patient populations**

Although Wessely began attacking the validity of ME in 1987 (see, for example, “Mass Hysteria: Two Syndromes?” Wessely S. *Psychological Medicine* 1987;17:109-120), there is substantial evidence that since the creation of “CFS” in 1988 (“Chronic Fatigue Syndrome: A Working Case Definition”. Holmes et al. *Ann Int Med* 1988;108:387-389), Wessely and his colleagues have assiduously attempted to subsume ME within the heterogeneous label “CFS”, asserting that it is a functional somatic disorder (ie. a primary psychiatric disorder) whose sufferers must be made to alter their beliefs and behaviour (see <http://www.meactionuk.org.uk>) but it needs to be asked on what evidence One-Health company members rely that enables them to subsume the discrete entity ME into their own definition of “CFS/ME” when, by virtue of the criteria they used, most of their studies could not have included those with authentic ME?

Because of the irrationality of drawing conclusions across differing patients populations, in the first (1996) volume of “Denigration by Design?” (copies available at cost price from Mrs DM Jones, telephone 0208-554-3832) 34 questions were listed which it was believed Wessely should be required to answer; almost a decade later, most of those questions remain unanswered but are equally relevant and include the following:

1. On what grounds do Wessely et al justify their selection of patients for their studies when the criteria they use exclude the criteria necessary for a diagnosis of ME (which they now refer to as “CFS/ME”), for example, the Ramsay diagnostic triad? (see: *Myalgic Encephalomyelitis: A Baffling Syndrome with a Tragic Aftermath*. A. Melvin Ramsay. Published by the UK ME Association, November 1981)
2. Why do Wessely et al ignore the world-wide literature on the severity and chronicity of ME?

3. What are their views on the fact that patients with ME are not permitted to donate blood, whereas patients with a psychiatric diagnosis are not excluded?
4. In how many of their patients have they requested tests of vestibular function, of pancreatic exocrine function, of liver function, of cardiac function and of levels of oxygenation, perfusion and pulsilities; in how many patients have they asked for measurement of patients' CD4:CD8 ratio; of IgG3 levels; of circulating immune complexes and of NK cells; what percentage of their patients have abnormal vascular changes and what percentage of their patients have undergone nuclear medicine imaging studies?
5. Where is their evidence of secondary gain in ME patients who they claim have "adopted the sick role"?

The answers to these questions are important: without answers, why are people trained in other professional disciplines to make factual observations and to collect and analyse data taking Wessely School psychiatrists' studies seriously?

### **The absurdity of relying on assumptions as the basis for a compulsory management regime**

On the issue of secondary gain, in 1996 the question was asked why Wessely never addresses the losses sustained by those with ME/CFS: "Why does (Wessely) assume that there are invariably benefits in the sick role? If he wishes to claim there are benefits (which he does), then he needs to ascertain in each individual case that patients *are* benefiting from adopting the sick role for what they can get out of it: this needs to be proved before it can be stated as fact. No expensive tests would be required to ascertain whether or not patients do benefit in any way, and this should not be stated as a universal fact merely on Wessely's assertion that it is so".

What "secondary gain" can possibly compensate for the loss of health, employment, financial security, social life and – far too often – loss of home, partner, family and friends? If "adopting the sick role" brings people with ME/CFS to the point of such despair that they consider or commit suicide, how can it be thought to be "rewarding"?

However, as was shown in "Proof Positive?", Wessely and his co-lobbyists still seem to hold the same beliefs because Professor Michael Von Korff said: "If we start with the assumption that (these patients) are motivated largely by secondary gain ....". To depend on such an assumption defies logic, so the question therefore needs to be repeated: where are the published studies which demonstrate that such patients obtain secondary gain? As Von Korff made plain, the psychiatrists' view is an assumption -- with much being built on it -- but assumptions are hardly "evidence-based medicine" upon which Wessely et al claim to place such store.

### **Divergent assertions about the efficacy of CBT**

The documented inconsistencies about the efficacy of cognitive behavioural therapy (CBT) seem to present another paradox: in his "Reply to our critics" that followed the publication of the paper "Randomised controlled trial of patient education to encourage graded exercise in chronic fatigue syndrome" by Pauline Powell, Richard Bentall, Fred Nye and Richard

Edwards (BMJ 2001:322:387) in which the authors – all of whom could be regarded as being supportive of “Wessely School” beliefs about “CFS/ME” -- cite Sharpe’s 1996 BMJ paper, Richard Bentall asserted: “There is now a consistent and impressive body of evidence that shows that psychological interventions that facilitate a graded return to normal activity are effective in many cases of CFS”. (eBMJ: 27<sup>th</sup> February 2001).

What seems to have been overlooked is that although Sharpe contributed much of the cited (allegedly supportive) literature, Sharpe himself substantially undermined it by stating on 3<sup>rd</sup> November 2000: “There is a tendency for the difference between those receiving CBT and those receiving the comparison treatment to diminish with time due to a tendency to relapse in the former” (see: <http://www.cfs.inform.dk>). Curiously, in the same document Sharpe referred to a five-year follow-up study of CBT as showing “some persistent benefit”.

It is important to be aware that the authors of the study to which Sharpe referred conceded that CBT “has been shown to improve functional impairment for up to 8 months after treatment” and state about the efficacy of CBT that “observed gains may be transient”. The conclusion was: “It seems that once therapist contact ended at six months after treatment, some patients may have become vulnerable to relapse”, so (unsurprisingly) the authors suggest that “It may be useful to extend the duration of treatment to include more attention to core beliefs that could leave patients vulnerable to relapse”. Crucially, the findings were that after five years, “almost one-half (of participants) still fulfilled the criteria for chronic fatigue syndrome” (“Long-Term Outcome of Cognitive Behaviour Therapy Versus Relaxation Therapy for Chronic Fatigue Syndrome: A 5-Year Follow-Up Study”. Alicia Deale, Trudie Chalder, Simon Wessely et al. Am J Psychiatry 2001:158:2038-2042).

Of more relevance is by what reasoning a management regime that delivered “some” benefit lasting for only six months can be deemed to be cost-effective to the extent that it is being promoted as the national management regime of choice for the much-abused sufferers of ME/CFS. Is this the calibre of “evidence” that One-Health members will rely on to convince the Establishment that they are right?

It is not only Sharpe but also Wessely himself who has conceded the limited efficacy of CBT: in his editorial “Chronic Fatigue Syndrome – Trials and Tribulations” (JAMA: 19<sup>th</sup> September 2001:286:11) Wessely stated that CBT and graded exercise are only “modestly effective” and that neither is “remotely curative”; one wonders why he confided this insight to a leading American journal, while he continues to withhold it from the readership of the BMJ and from Government policy-makers.

### **The inherent danger of applying a “one size fits all” policy of management in ME/CFS**

Of note is that the same Richard Bentall referred to above (professor of experimental clinical psychology at the University of Manchester) is on record as stating: “The idea that there is a clear division between ‘mad’ and ‘sane’ is resulting in the mass-application of treatments which, while benefiting some, are very harmful to others”; of significance in relation to ME/CFS is that he also said that identifying and addressing the problems the sufferer, rather than the psychiatrist, perceives is far more scientific, humane and effective than a blanket diagnosis (Madness of labelling mental illness. Michelle Roberts. BBC News health reporter; BBC 2<sup>nd</sup> September 2005, 23:50 GMT).

Are Bentall's two quotations consistent in relation to ME/CFS, especially as those with ME/CFS are indeed the subjects of "blanket diagnosis" (ie. somatisation disorder) by One-Health company members and are also subject to the mass application of CBT and graded exercise and it is beyond dispute that the problems identified by patients with ME/CFS are not only not addressed but are comprehensively ignored by One-Health company psychiatrists?

Yet again, it needs to be asked why there is special pleading in relation to ME/CFS?

### **The opposing statements from One-Health company members concerning the intention of psychiatry to claim "CFS/ME" as a psychiatric disorder**

It seems unequivocal from what was disclosed in "Proof Positive?" that the psychiatric lobby believes "CFS/ME" to be a somatisation disorder. It is widely understood that this psychiatric lobby is intent on the creation of a new category for "somatisation" disorders in the next edition of International Classification of Diseases (ICD-11) into which category "CFS/ME" will be placed, as proposed by Professor Mike Sharpe (see "Sinister Science": Co-Cure:ACT 6<sup>th</sup> June 2004). Sharpe believes that this new category should accommodate "behavioural" disturbances such as CFS/ME: "The ambitious programme to prepare for the forthcoming DSM-V and ICD-11 offers an opportunity to reconsider somatoform disorders" (see: British Journal of Psychiatry 2004:184:465-467).

This seems inconsistent with the written assurances from Wessely, who in November 2001 wrote to a correspondent: "I am aware that some people see (the inclusion of ME as a mental disorder in the WHO Guide to Mental Health in Primary Care) as a plot for WHO to surreptitiously switch CFS/ME from neurological to psychiatric. I can tell you that is nonsense. I am afraid there is no conspiracy to claim CFS/ME for psychiatry". In a second letter, Wessely re-iterated his earlier assurances: "I know one or two people detect a plot by psychiatry to claim CFS/ME for itself --- I promise you that the idea is preposterous. If the real issue is that this is all a sinister plot to get CFS transferred into the clutches of psychiatry --- forget it".

How do such assurances match the facts?

As Wessely et al seem intent on enticing the Chancellor of the Exchequer and the policy-makers with a national programme of CBT for those with "CFS/ME" that is promised to save money (presumably by removing patients from State benefits, after which what subsequently happens to them is of little interest to this cabal), should someone not tell them that the psychiatrists' own existing evidence is already clear that such programmes do not deliver lasting improvement? The policy-makers are unlikely to save money in the long-term by allowing themselves to be indoctrinated by One-Health company members, especially as any such claim seems to be based on nothing more than unsustainable assumption and assertion.

It would surely be more cost effective to fund appropriate research into causation, ie. biomedical research that stands a realistic chance of delivering actual treatment that leads to what sufferers regard as the ultimate goal – a cure.