

The Saga of Science

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Today's Independent on Sunday publishes a letter signed by 27 medical professionals -- who may be described as supporters of the psychosocial model of ME/CFS -- in which they refer to the harassment of some researchers working in the field.

It is regrettable that the wholly unacceptable actions of a few people have not only undermined the efforts of those who, for many years, have sought to engage scientifically with proponents of the psychosocial model but have tarnished the reputation of all ME/CFS sufferers. Further, it has allowed a narrative to develop, namely that ME/CFS patients are prejudiced against psychiatry and are resistant to the possible role of psychological factors in their illness. A siege-like mentality has developed between patients and doctors and it is essential, if progress is to be made, to move beyond this impasse towards a constructive dialogue based on evidence, so that if the psychosocial model is found wanting, a commitment can be made to look for alternative causal mechanisms.

Much of the recent frustration has stemmed from the presentation of PACE Trial data in The Lancet (published online February 18 2011) and other journals. For example, in their accompanying editorial in The Lancet, Bleijenberg and Knoop wrote: "*PACE used a strict criterion for recovery...In accordance with this criterion, the recovery rate of cognitive behaviour therapy and graded exercise therapy was about 30%*", with another journal reporting "*a recovery rate of 30-40%*" (BMC Health Serv Res. 2011; 11: 217, three of the authors being signatories to the letter to the Independent on Sunday).

Both these reports are wrong, because no recovery data from the trial have been published, and although The Lancet's senior editor, Zoe Mullan, acknowledged this error and promised to publish a correction, to date (22 months after publication) no correction has been issued, allowing this misrepresentation to continue.

The above are but two of many well documented discrepancies surrounding the publication of selective results of the PACE Trial.

In their letter, the signatories say that the harassment: "*risks undermining research, preventing the development of new treatments and discouraging specialist clinicians from entering the field. We fear that this may have resulted in patients not receiving the best treatments or care*".

Quite apart from the fact that the signatories' favoured treatment may not be the best for people with ME/CFS, the signatories make no distinction between "extremists" and those who continue to present reasoned, evidence-based critiques of the psychosocial model. Moreover, they appear to have conflated criticism of a particular psychiatric theory with the wholesale rejection of psychiatry *per se*: being critical of certain psychiatrists' beliefs about the causation of ME/CFS is not the same as being anti-psychiatry.

The psychosocial model has been subject to challenge because when its predictions were tested empirically, such as in the FINE and PACE Trials, objective data from these trials show clearly that ME/CFS is not perpetuated by dysfunctional thinking and deconditioning as the model posits.

People are angry, but that's because a small group of psychiatrists who have consumed such a large share of research funding for twenty years have acted in a way that is perceived to be wholly unscientific ie. when the evidence (even from their own studies) shows their ideas to be wrong, they either ignore the evidence (eg. FINE), or appear to misrepresent it (eg. PACE), and the system which is meant to protect against this - academic peer review - has completely failed to prevent the dissemination of papers which contain egregious errors.

It is also the case that many patients and clinicians alike feel let down by the wider scientific community for not speaking out against apparent abuses of process such as the *post hoc* revision of primary outcome measures in the PACE Trial which made it possible for a participant to deteriorate after treatment but still be described as "recovered". Had such a situation applied in a drug trial there would, rightly, have been an outcry.

For the proponents of the psychosocial model to continue to ignore the biomedical evidence from world-class experts such as Drs Nancy Klimas, Mary Ann Fletcher, Anthony Komaroff, Kathy and Alan Light and Dan Peterson must surely conflict with a clinician's first duty to patients, as rejection of that evidence may carry the risk of iatrogenic harm.

As Professor Komaroff wrote in Nature Reviews Neuroscience, September 2011: *"Many of the documented abnormalities involve the central and autonomic nervous systems. In my experience, most sceptics are unaware of the extensive literature citing such abnormalities and become less sceptical upon reading it"*.

Professor Klimas was equally clear about those who dismiss the biomedical evidence, saying at the IACFSME Conference in September 2011: *"Look at the studies of many patients – and they tell you the same. It is not difficult. I mean immune findings in ME / CFS is proved. It is not controversial, and it is not just a hypothesis. There is immune activation, it is dysfunctional cells and a significant degree*

of malfunction of the immune system....I have no difficulty (saying) with great certainty that the immune system in ME/CFS is not working as it should".

Given the well-established body of biomedical evidence and the failure of CBT and GET to produce objective benefits, people diagnosed with ME/CFS (and the clinicians who support them) struggle to comprehend the continued propagation of the doctrine that they can be cured and be returned to employment by psychotherapy, when the evidence from the psychosocial studies shows this is not the case.

It is time for a more productive dialectic so that patients can receive treatment and support based on sound evidence and researchers can work without fear.