

PACE is dead, long live PACE?

To whom it may concern,

In my view, in relation to the PACE trial into 'Chronic Fatigue Syndrome/Myalgic Encephalomyelitis'[1] (published by The Lancet) and some subsequent supportive publications, it is timely for the scientific community and interested observers to consider three questions and revisit some previously published material for possible answers.

The first question is, just why do certain UK psychiatrists apparently refuse to adhere to WHO disease taxonomy, as per ICD-10-G93.3 neurological ME/PVFS and ICD-10-F.48.0 psychiatric FATIGUE SYNDROME respectively, by erroneously conflating what the WHO and an increasing body of biomedical evidence rightly separate? (That, according to some such psychiatrists, 'CFS/ME' is allegedly and primarily both physical and psychiatric and that most illnesses are comprised of both such primary components is often cited as justification: an unlikely assertion if, for example, applied to lung-cancer or HIV/AIDS. Like cancer and AIDS patients, ME sufferers do not object to secondary/co-morbid psychiatric complications being addressed for what they are. They do however object to primary physical illness being misrepresented and mistreated as psychiatric. Such misrepresentation of primary physical illness in the case of cancer and AIDS would rightly be dismissed as ludicrous by most informed people and ditto should be the case for neurological ME/Postviral Fatigue Syndrome categorised by the WHO in ICD 10, G93.3.)

Perhaps in no small part the answer is to be found in earlier published comment. In this case the 2006 UK Parliamentarian Group on the Scientific Research into ME (GSRME) which, in connection with such psychiatrists' role in advising the UK Department of Work and Pensions (the DWP was one of the major funders of the PACE study) on ME/CFS, cautioned:

“There have been numerous cases where advisors to the DWP have also had consultancy roles in medical insurance companies. Particularly the Company UNUM Provident. Given the vested interest private medical insurance companies have in ensuring CFS/ME remain classified as a psychosocial illness there is blatant conflict of interest here. The Group find this to be an area for serious concern and recommends a full investigation of this possibility by the appropriate standards body. It may even be that assessment by a medical ‘expert’ in a field of high controversy requires a different methodology of benefit assessment.”

- GSRME Report, Page 30. See:

www.erythos.com/gibsoninquiry/index.html

The second question is, how on earth does so much psychiatric 'research' that is poorly-conceived, of questionable-quality and undertaken by investigators with demonstrable conflicts of interest receive so much funding and peer-reviewed journal exposure?

Again, in no small part, perhaps the explanation is to be found in earlier published comment. In this case taken from the introductory summary of Professor Bruce Charlton's 2008 peer-

reviewed paper entitled 'Zombie Science – a sinister consequence of evaluating scientific theories purely on the basis of enlightened self-interest':

"Although the classical ideal is that scientific theories are evaluated by a careful teasing-out of their internal logic and external implications, and checking whether these deductions and predictions are in-line-with old and new observations; the fact that so many vague, dumb or incoherent scientific theories are apparently believed by so many scientists for so many years is suggestive that this ideal does not necessarily reflect real world practice. In the real world it looks more like most scientists are quite willing to pursue wrong ideas for so long as they are rewarded with a better chance of achieving more grants, publications and status."

"The classic account has it that bogus theories should readily be demolished by sceptical (or jealous) competitor scientists. However, in practice even the most conclusive 'hatchet jobs' may fail to kill, or even weaken, phoney hypotheses when they are backed-up with sufficient economic muscle in the form of lavish and sustained funding. And when a branch of science based on phoney theories serves a useful but non-scientific purpose, it may be kept-going indefinitely by continuous transfusions of cash from those whose interests it serves. If this happens, real science expires and a 'zombie science' evolves."

In seeking examples of such 'zombie science', in my opinion, few contenders can match the recent UK PACE trial study by Professor Peter White et al published in The Lancet this February that was rightly, and eruditely, criticised by Professor Malcolm Hooper. Outside of the usual supporters, The Science Media Centre and what many would regard as misinformed converts, PACE is widely viewed as a disgrace: having conflated illness rightly separated by the WHO, having effectively ignored a large body of biomedical evidence, having used unscientific and disingenuous patient selection criteria, and having almost exclusively employed subjective and highly unreliable measurement techniques. See:

<http://www.meactionuk.org.uk/COMPLAINT-to-Lancet-re-PACE.htm>

With PACE etc in mind, Professor Charlton's 'Zombie Science' critique paper is well worth reading in full. The reference & link for the full text of the paper is: Professor Bruce Charlton – Zombie Science – a sinister consequence of evaluating scientific theories purely on the basis of enlightened self-interest, Medical Hypotheses (2008) 71 327-329, DOI: 10.1016/j.mehy.2008.05.018:

<http://medicalhypotheses.blogspot.com/2008/07/zombie-science-dead-but-wont-lie-down.html>

If the psychiatrists involved in the PACE trial were serious about science, and genuinely believed ME was maintained by fear of activity and muscle deconditioning as they assert, they would have exclusively used rigorous and internationally accepted patient selection criteria to ensure their study was beyond reproach. They did not. If they were serious about science they would have applied objective assessment criteria to properly informed patients. They did not. In my view, PACE represents a gross abuse of the scientific process and a gross abuse of ME patients. Ditto for much of the largely rhetorical and uncritical literature supportive of PACE that, unlike the many patient protestations such as this article, find their way into the so-called scientific literature. From its inception, PACE was roundly and eruditely criticised as being seriously flawed, that it was publicly funded amounts to a gross abuse of millions of pounds of UK taxpayers' money.

In terms of the real-world clinical setting amongst real-world ME patients, I believe the full scientific evidence-base shows that PACE CBT/GET will ultimately contribute nothing positive[2,3]. It will not improve ME patient function in the medium to long term, if at all, and will eventually be seen by most as having been dead on arrival and a complete waste of money: Zombie therapies based upon Zombie science. Moreover, I believe that most of the

PACE Principal Investigators actually know this. If so, my third question is what then could be the real purpose of PACE? Professor Charlton's following observation seems to me to answer that question perfectly:

"If zombie science is not scientifically-useable – what is its function? In a nutshell, zombie science is supported because it is useful propaganda to be deployed in arenas such as political rhetoric, public administration, management, public relations, marketing and the mass media generally. It persuades, it constructs taboos, it buttresses some kind of rhetorical attempt to shape mass opinion. Indeed, zombie science often comes across in the mass media as being more plausible than real science; and it is precisely the superficial face-plausibility which is the sole and sufficient purpose of zombie science."

In my opinion PACE is an issue for more than just ME patients. It is an affront to British science and to British society.

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ENDNOTES:

[1] Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial; PD White et al; published online, The Lancet, February 18, 2011 DOI:10.1016/S0140-6736(11)60096-2.

[2] For example, a recent large scale randomised controlled trial demonstrated exactly that: Núñez M, Fernández-Solà J, Nunez E, Fernandez-Huerta JM, Godás-Sieso T, Gomez-Gil E. (2011) Health-related quality of life in patients with chronic fatigue syndrome: group cognitive behavioural therapy and graded exercise versus usual treatment. A randomised controlled trial with 1 year of follow-up. Clinical Rheumatology. 2011 Jan 15. (E-publication ahead of print).

[3] As Professor Komaroff rightly stated back in 2006:

"...there are now over 4,000 published studies that show underlying biomedical abnormalities in patients with this illness. It's not an illness that people can simply imagine that they have and it's not a psychological illness. In my view, that debate, which has waged for 20 years, should now be over."

Professor Anthony Komaroff, Harvard Medical School: Speaking at the USA Government CDC (Centers for Disease Control and Prevention) press conference on 3 November 2006:

<http://www.cdc.gov/media/transcripts/t061103.htm>

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The above is the text emailed by Anglia ME Action to The Lancet, The Royal Colleges and Newspapers on 28 April 2011. This document is available online at:

www.angliameaction.org.uk/docs/PACE-Zombie-Science.pdf