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Dr Kerr and Post Infectious Stress Syndrome.

By Lara

Dr Jonathan Kerr has become a prominent researcher over the last several years in the field of ME/CFS (or CFS/ME as he prefers to call it). Many have applauded him and he holds centre stage this year at the Invest In ME (IiME) conference, due to take place in London later this month. In the opinion of many, Kerr is a relative hero to the ME/CFS cause.

But this man is not without his controversies. In 2005, he shocked many when he co-authored a paper with Prof Simon Wessely, attributed by many to be the man ultimately responsible for the devastating misrepresentation and ill treatment of ME/CFS sufferers everywhere. Wessely is infamous for his attack on ME sufferers at the 9th Eliott Slater lecture in 1994 when he stated that ME was nothing more than an illness belief. His tyranny continued unabated as he pioneered GET/CBT psychosocial approaches for 'treating CFS/ME'. As the final insult in 2007, his face smiled out at us from the slick pages of the 'Outlaw' insurer UNUM's CMO Report. In his article in this report on Collusion (no: doctors and patients, not Wessely and UNUM), he explained how a psychological diagnosis would be too offensive to many patients and that labels such as Fibromyalgia Syndrome (FMS) were often used as 'euphemisms'. He did not have to reference any work to back this up nor explain that there were strongly opposing views.

Likewise, Wessely mused that anti-depressants (known to cause worsening mitochondrial function) were often prescribed for sleep and pain, not the relief of the real problem - psychological stress. His discussion explains how in his view the use of euphemisms and collusion can help to make the (tricyclic antidepressant) pill easier to swallow as it were, (at least before the metabolic slow-down and worsening of symptoms kicks in). The wording was startlingly similar to that now apparently euphemistically used in the CFS//ME NICE Guidelines. So it appears that it took Wessely less than 15 yrs to cement his hideous psychological dogma into place for CFS/ME and has undoubtedly saved governments, insurers and pharmaceutical companies' worldwide money equivalent to that of a small country's GDP. Meanwhile he and his troop of psychiatric buddies have made a fortune out of the situation. The last thing we need is for him to be given more help – especially not from someone who can tightly sew his views into an apparent 'biomedical' model which can then be delivered more acceptably to the 'CFS/ME' patient population.

So what was our 'hero' Dr Jonathan Kerr doing publishing papers with Wessely and other psychiatric favourites back in 2005? And now in his latest publication he places psychological stress, rather than the more euphemistic 'stressors' (e.g. either physical or psychological stress) at the root of post-infectious complications ('chronic fatigue') in patients with a history of infection with Parvovirus B19. Yet again, this study of Kerr's uses the ever elastic Fukuda criteria to select the patient cohort. This was bothersome even back in 2005 when many were singing the praises of the Canadian Guidelines but Kerr's studies did not attempt to use them or modify other existing criteria to incorporate a better neurological focus in the patient group. [See full text: *Preexisting Psychological Stress Predicts Acute and Chronic Fatigue and Arthritis following Symptomatic Parvovirus B19 Infection*, Kerr et al]

The language in the paper is also of great cause for concern. The core of patient advocates in the ME/CFS community globally have consistently criticised the psychiatric lobby for slipping between the terms 'Chronic Fatigue' which can be applied in its own right as a (mental health) diagnosis and 'Chronic Fatigue Syndrome' which according to the Word Health Organisation International Classification of Diseases Chapter 10 (ICD-10), code G93.3 is a neurological disease synonymous with Myalgic Encephalomyelitis (ME). Yet Kerr's paper does exactly that. He also oddly refers at one point to 'Idiopathic CFS/ME'. Is there any such thing? If so what is its ICD-10 Code? It sounds startlingly similar to Idiopathic Chronic Fatigue (ICD-10 F48). Kerr then draws in selectively chosen research references that claim that glandular fever (EBV) is reactivated by stress. At this point one wonders, what exactly is Kerr doing? Is

he deliberately building a case for stress as the cause of the initial 'viral trigger' and the more stressed the person, the more likely he/she is to develop CFS/ME? Should we therefore rename it Post-Infectious Stress Syndrome? I cannot help but think that Kerr is taking it with his latest offering.

As other advocates have pointed out, the paper is in any case based on a decade old study, with only 5 of the 39 patients going on to develop 'CFS/ME', 3 of whom actually improved when given a physical treatment - intravenous immunoglobulin therapy. Considering this and the small numbers involved, it is analytically and scientifically ludicrous to suggest that the study is predictive of a correlation between stress and CFS/ME or anything else for that matter.

His earlier paper from 2007 - the gene study which elucidated seven genomic subtypes got us quite excited. But at the same time uneasy because some of the most upregulated genes (up to 47 fold) involving neurodevelopmental and mitochondrial functions did not appear to be highlighted for future study or for design of therapeutic targets, at least not in the text of that paper. Other research is currently screaming out that mitochondrial genes and dysfunctions which may be inherited, exacerbated or caused by environmental toxins, vaccines and/or infections may be playing a major role in ME/CFS and other neurological or neurodegenerative diseases. So why is Dr Kerr, having found a genetic link in his own studies, not prioritising these areas? Why is old research on stress being published first when patients have already found that psychosocial therapies do not work? Where is the relevance to the majority of ME/CFS sufferers? Will it simply be claimed in the end that the gene expression is ultimately a cascade caused by psychological stress? I sincerely hope not – but I think that Kerr's wording and research directions now must be eyed with much more caution. They have the power to do untold damage to sufferers and the horrible irony being that patients helped to fund his work!

One thing is for sure – suggesting that 'CFS/ME' is all down to 'Stress-Infections-Genes' certainly detracts from the 'Environment-Infections-Genes' hypothesis and lets every institution causing the changes to the environment royally off the hook. Furthermore, insurance companies (such as UNUM and others) whose policies do not pay out for 'stress-based conditions' for longer than a year or two (if at all) also win hands down. This situation is just impossible to rationalise and sadly, I cannot see that this piece of Kerr's research is any better than that of the Wessely School's – in fact, the latter will use it to vindicate themselves.

If patients are not convinced that there is a problem with Kerr now, try to imagine scenarios where his latest paper would help you. You are going down for another fraught meeting with your local GP. Are you going to go in there and wave this paper at him/her stating see I have a real, physical illness after all? Please take it seriously and treat me appropriately. No! Because the word 'STRESS' would simply jump off the page at the doctor and referral for CBT/GET and amitriptyline script gladly pressed into your trembling hands. Likewise, how will Dr Kerr's work stop patients from being inappropriately sectioned and mistreated?

I sincerely hope that subsequent papers and presentations from Dr Kerr will allay these concerns and that he will be able to provide more insight into the upregulation of mitochondrial and neurodevelopmental genes in 'ME/CFS' patients. This is where more research input is desperately needed and therapies required. I would strongly recommend to patients that they watch him very closely and make sure that they are getting what they need and what they paid for. Patients and advocates have fought very hard not to be labelled with 'stress' and we certainly do not want it indelibly stamped on by someone whom we funded and whom is supposed to be firmly on our side.

References

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