

## The PACE trial: It's time to broaden perceptions and move on

Keith J Petrie<sup>1</sup> and John Weinman<sup>2</sup>

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### Abstract

The continued critiques of the PACE trial highlight how differing beliefs about the causes of chronic fatigue syndrome still influence how scientific studies in this area are accepted and evaluated. Causal beliefs about chronic fatigue syndrome and a modern version of Cartesian dualism are important in understanding the reaction to the PACE trial. The continued debate on the PACE trial seems to miss the fact that science is incremental. An unfortunate outcome of the PACE controversy and intimidation of researchers may be less research in the area. It is time to move on from criticism and collect more data on effective treatments.

### Keywords

cause, chronic fatigue syndrome, cognitive behaviour therapy, graded exercise therapy, illness perception

The controversy over the PACE trial (White et al., 2011) including the recent critique by Geraghty (2016) highlights how differing beliefs about the causes of chronic fatigue syndrome (CFS) still influence how scientific studies in this area are accepted and evaluated. The PACE trial was started in 2005 and the trial was published in *The Lancet* 6 years ago. The study's findings that cognitive behaviour therapy and graded exercise can moderately improve outcome in CFS created a storm of criticism led mainly from patient groups attacking the study's findings (*The Lancet*, 2011) and even the researchers themselves (Hawkes, 2011; *The Guardian*, 2011).

The criticism over the past 6 years has continued and include the recent critique by Geraghty (2016) who has strongly challenged the study's findings. He has criticised the PACE trial for their reporting of treatment effectiveness, the definition of recovery and for the fact that the data are not freely available. These issues and other points raised have been responded to by the PACE authors in detail in

this journal (White et al., 2016). They have also previously answered a number of similar rounds of critiques (Sharpe et al., 2016; Wessely, 2015; White et al., 2016).

The reactions to a trial that identified helpful treatments for a chronic and severely disabling condition contrast markedly with other physical illnesses and highlight the suspicion of patients with CFS towards any psychological interventions for CFS. In our experience as health psychologists, patients with other illnesses such as cancer, renal disease, heart disease or chronic respiratory problems are usually very keen to adopt psychological interventions that can

<sup>1</sup>University of Auckland, New Zealand

<sup>2</sup>King's College London, UK

#### Corresponding author:

Keith J Petrie, Department of Psychological Medicine, Faculty of Medical and Health Sciences, University of Auckland, Private Bag 92019, Auckland 1142, New Zealand.

Email: kj.petrie@auckland.ac.nz

reduce fatigue, improve functioning and well-being. Indeed for these disorders a common complaint is that psychological support and interventions are not readily available.

Patient beliefs about CFS and in particular causal beliefs about the illness are clearly important in understanding the reaction to the PACE trial. As Geraghty (2016) states in the conclusion to his critique: 'Many CFS patients reject the theoretical rationale for the use of CBT and GET. PACE-Gate exposes the long-running acrimony between doctors and patient groups over the cause of the illness and the most appropriate approaches to treatment' (p. 6). This is really the key issue behind the criticisms of the PACE study and antagonism towards the study's authors. There is a strong resistance by some people who have CFS to any psychological interpretations or interventions, which are at variance with the way they view their illness.

Causal beliefs are an important factor in the way patients understand their illness. Causal beliefs provide a basis for patients to understand how their illness developed and, most importantly, these beliefs point towards treatments that make sense for controlling the condition (Petrie and Weinman, 2012). Common causal beliefs held by CFS patients highlight a viral explanation for the illness or personal susceptibility to developing CFS through a weakened immune system. These causal beliefs tend to point patients towards looking for biological therapies that can control the virus responsible or bolster personal immunity. Other forms of treatment do not fit so comfortably into the patient's view of their illness. Psychological interventions and graded exercise especially contrast with these beliefs. The use of exercise when someone feels fatigued is counterintuitive to the common sense model of CFS. Exercise and psychological therapies may also highlight for patients their experiences of stigma they have felt from other people's responses or explanations for their condition.

Another aspect of people's causal beliefs about illness is that they often demonstrate a modern-day version of Cartesian dualism and a

rather crude division between mind and body. Thus, for the same illness, people may believe strongly in either a physical or a psychological cause, sometimes in a rather simplistic way. In reality, most diseases are caused and perpetuated by a complex mix of behavioural and physical factors and hence will be best managed by a range of treatments (e.g. lifestyle change, self-management and medication). A failure to appreciate this may inevitably result in sub-optimal management and poorer outcome.

Geraghty (2016) comments that the majority of patients with CFS are pragmatic and aware of the lack of an agreed cause for their condition but then cites Green et al. (2015) that 'an increasing amount of research points to immune and cellular alterations as important clues'. However, the Green et al. paper is not an overview of the evidence base but a set of recommendations from a working group on key directions for future research, including the need for biologically based studies as well as more treatment trials.

The continued debate on the PACE trial seems to miss the fact that science is incremental. One study rarely has all the answers, especially for a heterogeneous and complex condition such as CFS. Over time more research is published and greater clarity emerges from the evidence on whether there is support for these treatments. The important issue is whether CBT and graded exercise improve the lives of patients with CFS.

Currently, the weight of evidence would seem to support these treatments. A recent Cochrane review of exercise therapy for CFS, which included eight studies and data from 1581 participants, concluded that 'patients with CFS may generally benefit and feel less fatigue following exercise therapy and found no evidence that exercise therapy may worsen outcomes'. The PACE study provides important evidence that CBT may be a useful treatment option for patients with CFS but clearly more good quality research is needed. A recent review of cancer-related fatigue also found that exercise and psychological interventions, and both used in combination, were effective, and

recommended that clinicians should prescribe exercise and psychological therapy for cancer-related fatigue (Mustian et al., 2017).

The unfortunate outcome of the continued controversy about the PACE trial and intimidation of researchers in the CFS field has increased the likelihood of deterring quality researchers from working in the area. Who would want to set up a scientific base camp in an area where you will get continuously attacked should your research findings or clinical trials support an unpopular treatment? The opportunity cost of continuous criticism of the PACE trial over 6 years ago is likely to be a considerable reduction in researchers wanting to research to further understand CFS or do further treatment trials.

There is so much more research work to do in CFS. As well as finding out what treatments work best with what types of illness, how treatments are best delivered with new mobile technologies and via the Internet and how existing treatments can be improved to reduce the morbidity from this disabling condition. The PACE trial has made a start. It is time to move on and time for researchers to continue adding to the evidence base in order to increase our understanding of the condition and the most effective treatments.

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