

Dear NIH P2P Panel Members,

In my prior comment, I had asked that the Panel consider a) excluding trials, like the 2011 UK PACE trial, that employ Oxford criteria, when making conclusions about treatment for US CFS patients, who are diagnosed using Fukuda criteria, which involves more than fatigue, and b) incorporating more of AHRQ's statement about the limitations and weaknesses of graded exercise therapy (GET) trials including poor reporting about/ recognition of the harms of GET. (p. 85-86 of the Systematic Review)

Lo and behold, just when I thought I had finished my comments to the Panel this week, out comes another paper from the PACE trials concluding that ME/CFS patients would get better if only they stopped believing, exaggerating, or fearing their body's negative responses to exercise and activity.

[http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(14\)00069-8/abstract](http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(14)00069-8/abstract)

As usual the media onslaught starts:

a) <http://www.economist.com/news/science-and-technology/21639438-controversial-trial-mysterious-disease-continues-yield-insights-fear>

"Questions had been designed to measure established psychological factors that might serve to mediate the various treatments; for example, whether a respondent agreed with the statement, "I am afraid that I will make my symptoms worse if I exercise" fell into the category of fear avoidance. Other categories included avoiding embarrassment, focusing on symptoms (thinking frequently about the illness and its effects) and catastrophizing (believing things were worse than they really were)."

b) <http://www.medicalnewstoday.com/articles/287972.php> -

"one of the most important elements of improving physical function in patients with chronic fatigue syndrome is using therapy to reduce fear that exercise will worsen rather than improve symptoms."

c) <http://www.exchangemagazine.com/morningpost/2015/week2/Wednesday/15011410.htm> -

"Reducing fear avoidance beliefs key to improving symptoms and reducing disability in chronic fatigue syndrome"

Neither the study authors nor the media articles point out that Oxford, not the Fukuda criteria used internationally, were used in PACE. And certainly, no one points out the multiple problems with the PACE trial or other GET studies that AHRQ did. No one even bothers to mention that there is scientific evidence that some ME/CFS patients' bodies respond negatively to activity/ exercise and that they're not imagining or exaggerating symptoms. (<http://www.ncbi.nlm.nih.gov/pubmed/19855350>) Never mind that some ME/CFS patients were former, even Olympic-level or professional, athletes that, contrary to fearing exercise, enjoyed it and regret not being able to do it anymore despite their best efforts. It came out of Lancet so it must be true!

Instead, the overarching message is that all ME/CFS patients need to do to get better is to ignore their symptoms and increase their activity or exercise. If you were a healthcare professional reading these articles, wouldn't you too conclude that patients are "lazy, deconditioned, and disability-seeking" (ES-4, Line 65) or that the illness is psychological/ psychiatric in etiology and thus treat "patients with disdain, suspicion, and disrespect" (ES-4, Line 66-67) or psychiatric medications?

These types of articles come out regularly about ME/CFS and makes it much harder for patients to gain understanding or for research to progress. Even clinicians and researchers face this prejudice. Dr. Ian Lipkin, a prominent professor at Columbia University known for his work with SARS and West Nile virus and who has accumulated millions of dollars in NIH grants over his career, told the ME/CFS community that one reasons his grant application examining the microbiome's role in ME/CFS was rejected was because one grant reviewer viewed ME/CFS as a psychological illness. (You can ask Dr.Lipkin personally to confirm this story.) NIH grant reviewers/ Institute directors and staff may hold the same biases as the general medical/ scientific community.

It's good that the Panel reinforces the message that ME/CFS is not a "psychological illness in etiology" (Line 92) but it would be even better if that message was accompanied by action. The Panel recommends that Oxford be discontinued due to its non-specific nature. By including trials that use Oxford in its assessment of treatment, the Panel contradicts its own recommendation and inadvertently contributes to the view that all patients need to do is exercise. Exclude the trials including Oxford OR at least conduct a sensitivity analyses with and without Oxford trials. Incorporate more of AHRQ's critique in your final report. This will help patients more than just asserting that it is not a psychological illness. It's just like the rest of life: actions matter more than words.

Thanks for reading this.