Tweets from 15th set of100 posts in S4ME thread: Michael Sharpe skewered by @JohntheJack on Twitter



17 Jun

Well, my approach to the question of experimental design (and I consider trials to be a class of experiment) is Popper's critical rationalism. You have to design the experiment(s) with the express goal of trying to show how the theory may be wrong. (Counterintuitive, I know.)





In our response to #NICEguidelines in 2017 at @MEActNetUK we did look at Popper's falsification and this model. Though we came down on the other side that it is actually falsifiable and there is already enough evidence to refute it (see 1h, p12)meaction.net/wp-content/upl... pic.twitter.com/ebkA2Jvdny 9:39 AM - Jun 19, 2018

Whilst CG53 does not explicitly attribute any causal mechanism for CFS and ME, the main recommended treatment regimes of CBT and GET themselves necessarily imply that NICE supports the model that the illness is caused by illness beliefs and de-conditioning known as the CBT Model. It is important to understand that Cognitive Behaviour Therapy is not one monolithic structure but includes within it different approaches, models and disagreements (Westbrook, 2006). The regimes of CBT/GET used in most treatment trials for ME are not generic but are explicitly founded on these premises, which is known as the CBT Model of CFS/ME:

"The interventions with cognitive behavioral therapy and graded exercise therapy are based on a hypothesis that the disease is perpetuated by avoidance behavior and that symptoms are caused by a lack of filness. Although the Oxford school (CBT Model, PACE trial proponent researchers) have not described any underlying mechanisms, nor presented any evidence for the presumed causation, they refer to their hypotheses either as theories or models. This gives the impression of scientific support, which in fact does not exist." (Helmfrid, 2016)

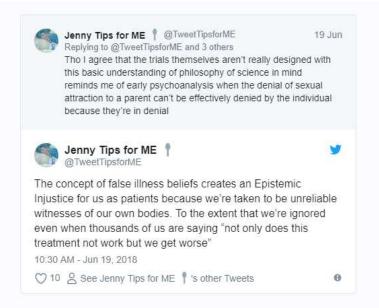
However, it is possible to imagine how this specific theoretical hypothesis can be effectively be refuted, so it is testable and falsifiable under the established Scientific Method (e.g. Popper 1963). Falsification would involve demonstrating that physical dysfunction in ME is not related to deconditioning; illness beliefs are not associated with activity levels and the treatments resulting from the model are ineffective or harmful. A competing model should also ideally be shown to better fit the data. We can demonstrate that each of these conditions apply.

1h.I Deconditioning: studies such as Vermeulen (2014) show that the problem in ME is not deconditioning. "The high increase of the cardiac output relative to the increase of oxygen uptake argues against deconditioning as a cause for physical impairment in these patients." (Vermeulen, 2014). Various 2-day CPET studies show a peculiar second day response, evidencing PEM (Institute of Medicine, 2015) rather than deconditioning. Many biomedical studies evidence bioenergetic difficulties incompatible with the concept of deconditioning as the cause (see 1e and 2b). Also, people who are deconditioned (perhaps from hospital admission) do not describe the experience of ME.

1h.ii Illness beliefs: a very recent study of 990 participants (defined under several case definitions) found that the theory did not fit the data, and was an especially poor fit for those

O 6 See Jenny Tips for ME 1 's other Tweets

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Of course the evidence to refute this model doesn't come from the PACE trial itself, so this isn't contradicting Mike Godwin, but it's relevant.

To read more see 1h, p12 of http://www.meaction.net/wp-content/...nse-to-proposal-to-not-update-CG53.pdf#page12

Last edited: Yesterday at 12:37 PM

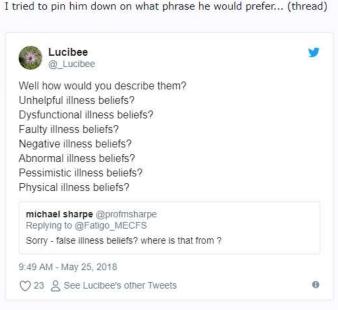
share a tip with me @TweetTipsforME and I'll retweet (as long as you don't make money from the advice and it doesn't sound dangerous of course!)

If you want to read my thoughts on life, Chronic Illness and so on follow my blog https://tipsforme.wordpress.com/

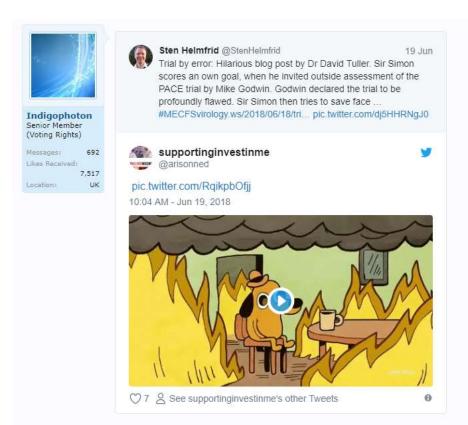
Jenny TipsforME, Yesterday at 12:26 PM Report Bookmark

#1404 Like + Multiquote Reply





comes from? Sharpe is claiming the PACE authors didn't use it, so who did?

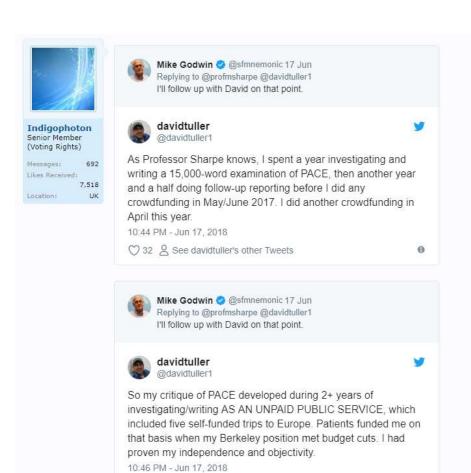


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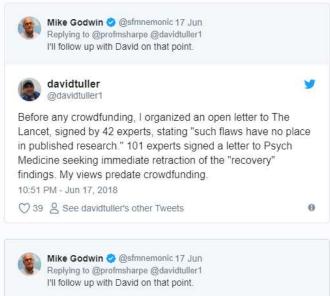
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♡ 35 & See davidtuller's other Tweets

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Liv aka Mrs Sowester Senior Member (Voting Rights)

Messages: 1,190 Likes Received: 8,382 Mike Godwin ②
@sfmnemonic

Trial By Error: Sir Simon Scores an Own Goal
virology.ws/2018/06/18/tri...
6:23 PM - Jun 19, 2018

◯ 192 ◯ 131 people are talking about this

Happy days!

Mike Godwin retweeted this,

Liv aka Mrs Sowester, Yesterday at 6:37 PM Report Bookmark

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Indigophoton Senior Member (Voting Rights)

Messages: 692 Likes Received: 7,518

UK

Robert McMullen
@RobertHMcMullen

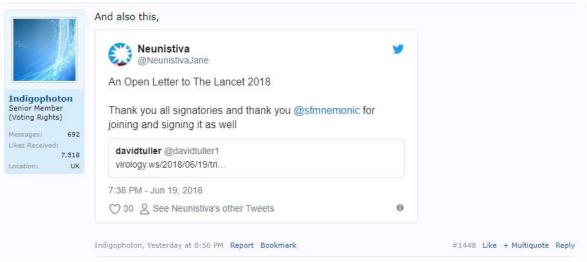
Great to see that Mike Godwin has signed this open letter calling on The Lancet to commission an independent re-analysis of the individual-level #PACEtrial data: virology.ws/2018/06/19/tri...

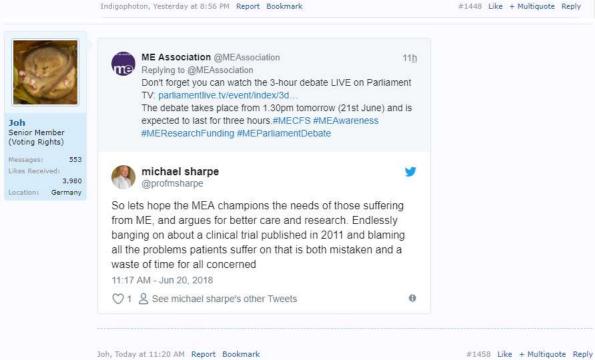
Thank you @sfmnemonic.
7:41 PM - Jun 19, 2018

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151 \Q 58 people are talking about this

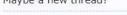
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Joh, Today at 2:23 PM Report Bookmark

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Liv aka Mrs Sowester Senior Member (Voting Rights)

1,190 Likes Received 8,382 How utterly crass and offensive of MS to post this in a thread that starts with a picture of Merryn Croft and a link to an article about her.



Liv aka Mrs Sowester, Today at 2:26 PM Report Bookmark

#1477 Like + Multiquote Reply

