

Tweets from 15th set of 100 posts in S4ME thread:
Michael Sharpe skewered by @JohntheJack on Twitter



Mike Godwin @sfmneonic

17 Jun

Replying to @profmsharpe and 2 others

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.)



Jenny Tips for ME @TweetTipsforME



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 fitness. 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

6 See Jenny Tips for ME's other Tweets

 **Jenny Tips for ME**  @TweetTipsforME 19 Jun
 Replying to @TweetTipsforME and 3 others
 Tho I agree that the trials themselves aren't really designed with this basic understanding of philosophy of science in mind reminds me of early psychoanalysis when the denial of sexual attraction to a parent can't be effectively denied by the individual because they're in denial

 **Jenny Tips for ME**  @TweetTipsforME 
 The concept of false illness beliefs creates an Epistemic Injustice for us as patients because we're taken to be unreliable witnesses of our own bodies. To the extent that we're ignored even when thousands of us are saying "not only does this treatment not work but we get worse"
 10:30 AM - Jun 19, 2018
 10 ❤️ 10 👤 See Jenny Tips for ME's other Tweets ⓘ

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



Lucibee
 Senior Member
 (Voting Rights)
 Messages: 265
 Likes Received: 2,752
 Location: Mid-Wales

any, in a sort of general way he been wondering where the phrase 'false illness beliefs' comes from? Sharpe is claiming the PACE authors didn't use it, so who did?

I tried to pin him down on what phrase he would prefer... (thread)

 **Lucibee** @_Lucibee 
 Well how would you describe them?
 Unhelpful illness beliefs?
 Dysfunctional illness beliefs?
 Faulty illness beliefs?
 Negative illness beliefs?
 Abnormal illness beliefs?
 Pessimistic illness beliefs?
 Physical illness beliefs?

michael sharpe @profmsharpe
 Replying to @Fatigo_MECFS
 Sorry - false illness beliefs? where is that from ?

9:49 AM - May 25, 2018
 23 ❤️ 👤 See Lucibee's other Tweets ⓘ

Lucibee, Yesterday at 2:15 PM [Report](#) [Bookmark](#)

#1416 Like + Multiquote Reply



Indigophoton
Senior Member
(Voting Rights)

Messages: 692
Likes Received: 7,517
Location: UK



Sten Helmfrid @StenHelmfrid

19 Jun

Trial by error: Hilarious blog post by Dr David Tuller. Sir Simon scores an own goal, when he invited outside assessment of the PACE trial by Mike Godwin. Godwin declared the trial to be profoundly flawed. Sir Simon then tries to save face ...
[#MECFsvirology.ws/2018/06/18/tri...](#) [pic.twitter.com/dj5HHRNgJ0](#)



supportinginvestinme

@arisonned



[pic.twitter.com/RqikpbOfjj](#)

10:04 AM - Jun 19, 2018



7 See supportinginvestinme's other Tweets

Indigophoton, Yesterday at 2:26 PM [Report](#) [Bookmark](#)

#1418 [Like](#) [+ Multiquote](#) [Reply](#)



Indigophoton
Senior Member
(Voting Rights)

Messages: 692
Likes Received: 7,518
Location: UK



Dr Keith Geraghty

@keithgeraghty



Anyone following recent tweets by PACE lead author Prof M. Sharpe and Prof S. Wessely's defence of PACE will see their replies are starting to evoke images of a mad hatters tea party - bizarre forgetfulness on who did what, when. Ship captains and HQ Rear Admiral are all at sea.

5:58 PM - Jun 18, 2018

127 50 people are talking about this



Indigophoton, Yesterday at 4:00 PM [Report](#) [Bookmark](#)

#1424 [Like](#) [+ Multiquote](#) [Reply](#)



Indigophoton
Senior Member
(Voting Rights)

Messages: 692

Likes Received: 7,518

Location: UK



Mike Godwin  @sfmneonic 17 Jun
Replying to @profmsharpe @davidtuller1
I'll follow up with David on that point.



davidtuller
@davidtuller1



As Professor Sharpe knows, I spent a year investigating and writing a 15,000-word examination of PACE, then another year and a half doing follow-up reporting before I did any crowdfunding in May/June 2017. I did another crowdfunding in April this year.

10:44 PM - Jun 17, 2018

 32  See davidtuller's other Tweets



Mike Godwin  @sfmneonic 17 Jun
Replying to @profmsharpe @davidtuller1
I'll follow up with David on that point.



davidtuller
@davidtuller1



So my critique of PACE developed during 2+ years of investigating/writing AS AN UNPAID PUBLIC SERVICE, which included five self-funded trips to Europe. Patients funded me on that basis when my Berkeley position met budget cuts. I had proven my independence and objectivity.

10:46 PM - Jun 17, 2018

 35  See davidtuller's other Tweets



 **Mike Godwin**  @sfmnemonic 17 Jun
Replying to @profmsharpe @davidtuller1
I'll follow up with David on that point.



 **davidtuller**
@davidtuller1 

Before any crowdfunding, I organized an open letter to The Lancet, signed by 42 experts, stating "such flaws have no place in published research." 101 experts signed a letter to Psych Medicine seeking immediate retraction of the "recovery" findings. My views predate crowdfunding.

10:51 PM - Jun 17, 2018




 39  See davidtuller's other Tweets 

 **Mike Godwin**  @sfmnemonic 17 Jun
Replying to @profmsharpe @davidtuller1
I'll follow up with David on that point.

 **davidtuller**
@davidtuller1 

Contrary to what Professor Sharpe might believe, debunking PACE was not my career goal. I crowdfunded so I could continue this investigation only because Professor Sharpe, his colleagues and the journals refuse to acknowledge the obvious issues with their work.

10:53 PM - Jun 17, 2018

 69  See davidtuller's other Tweets 

Indigophoton, Yesterday at 4:17 PM [Report](#) [Bookmark](#)

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Liv aka Mrs Sowester
Senior Member
(Voting Rights)

Messages: 1,190
Likes Received: 8,382

 **Mike Godwin**  @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!

Liv aka Mrs Sowester, Yesterday at 6:37 PM [Report](#) [Bookmark](#)

#1435 [Unlike](#) [+ Multiquote](#) [Reply](#)



Indigophoton
Senior Member
(Voting Rights)

Messages: 692
Likes Received: 7,518
Location: UK

Mike Godwin retweeted this,

 **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

 151  58 people are talking about this 

Indigophoton, Yesterday at 8:55 PM [Report](#) [Bookmark](#)

#1447 [Like](#) [+ Multiquote](#) [Reply](#)



Indigophoton
Senior Member
(Voting Rights)

Messages: 692
Likes Received: 7,518
Location: UK

And also this,



Neunistiva
@NeunistivaJane



An Open Letter to The Lancet 2018

Thank you all signatories and thank you @sfmnemonic for joining and signing it as well

davidtuller @davidtuller1
virology.ws/2018/06/19/tri...

7:38 PM - Jun 19, 2018

♡ 30 👤 See Neunistiva's other Tweets

Indigophoton, Yesterday at 8:56 PM Report Bookmark

#1448 Like + Multiquote Reply



Joh
Senior Member
(Voting Rights)

Messages: 553
Likes Received: 3,980
Location: Germany



ME Association @MEAssociation

11h

Replying to @MEAssociation

Don't forget you can watch the 3-hour debate LIVE on Parliament TV: parliamentlive.tv/event/index/3d...

The debate takes place from 1.30pm tomorrow (21st June) and is expected to last for three hours. #MECFs #MEAwareness #MEResearchFunding #MEParliamentDebate



michael sharpe
@profmsharpe



So lets hope the MEA champions the needs of those suffering from ME, and argues for better care and research. Endlessly banging on about a clinical trial published in 2011 and blaming all the problems patients suffer on that is both mistaken and a waste of time for all concerned

11:17 AM - Jun 20, 2018

♡ 1 👤 See michael sharpe's other Tweets

Joh, Today at 11:20 AM Report Bookmark

#1458 Like + Multiquote Reply



Joh
Senior Member
(Voting Rights)
Messages: 553
Likes Received: 3,980
Location: Germany

@Robert 1973 Great idea. 😊

MillionsMissing Deutschland



MillionsMissing Deutschland @MMissingGermany 28 May

»Sobald alle Fakten der #PaceTrial Studie bekannt sind, wird diese sich als einer der größten Medizinskandale des 21. Jh. herausstellen. «bit.ly/2qJUwOj #ME #MEcfs #MillionsMissing @jensspahn @DHAEV_Sprecher @BMG_Bund @BAEKaktuell @BMBF_Bund @rki_de @LutzStroppe pic.twitter.com/M5wlr1PL0V



michael sharpe
@profmsharpe

Really ? Have you read the paper? or just copying with others have said?
kind regards

8:10 AM - May 29, 2018

See michael sharpe's other Tweets

Maybe a new thread?

Joh, Today at 2:23 PM Report Bookmark

#1476 Like + Multiquote Reply



Liv aka Mrs Sowester
Senior Member
(Voting Rights)
Messages: 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.



ME Association @MEAssociation 11h

Replying to @MEAssociation
Don't forget you can watch the 3-hour debate LIVE on Parliament TV: parliamentlive.tv/event/index/3d...
The debate takes place from 1.30pm tomorrow (21st June) and is expected to last for three hours. #MEcfs #MEAwareness #MEResearchFunding #MEParliamentDebate



michael sharpe
@profmsharpe

So lets hope the MEA champions the needs of those suffering from ME, and argues for better care and research. Endlessly banging on about a clinical trial published in 2011 and blaming all the problems patients suffer on that is both mistaken and a waste of time for all concerned

11:17 AM - Jun 20, 2018

See michael sharpe's other Tweets

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

#1477 Like + Multiquote Reply



Cheshire
Senior Member
(Voting Rights)

Messages: 504
Likes Received: 5,943

What is he talking about?



michael sharpe
@profmsharpe



So here is a challenge for ME activism:
Can you articulate what treatment you want as opposed to what you don't want?
Can you offer a positive vision for care as opposed to negativity about previous research?

5:47 PM - Jun 20, 2018

♡ 4 💬 19 people are talking about this



Cheshire, Today at 5:51 PM Report Bookmark

#1485 Like + Multiquote Reply



Indigophoton
Senior Member
(Voting Rights)

Messages: 692
Likes Received: 7,520
Location: UK



michael sharpe @profmsharpe

1h

So here is a challenge for ME activism:
Can you articulate what treatment you want as opposed to what you don't want?
Can you offer a positive vision for care as opposed to negativity about previous research?



Ollie Cornes 🇪🇺
@ollie72



That's easy... one shown to be effective in a decent-sized, blinded clinical trial with objective biomedical outcome measures, with an acceptable cost and risk profile and ideally advance identification of any subgroup most likely to receive benefit.

6:15 PM - Jun 20, 2018

♡ 5 👤 See Ollie Cornes 🇪🇺's other Tweets



New

Indigophoton, 52 minutes ago Report Bookmark

#1493 Like + Multiquote Reply