

Tweets from 7th set of 100 posts in S4ME thread: Michael Sharpe skewered by @JohntheJack on Twitter



strategist
Senior Member
(Voting Rights)

Messages: 496
Likes Received: 5,070

Interesting development



Carolyn Wilshire @wilshica

1 Jun

Replying to @profmsharpe @CMonaghanSNP

I see no statement anywhere in any of the PACE papers that factors other than cognitive, behavioural or emotional ones may be maintaining the illness. Or that such factors may limit improvement. If I have missed such a statement, can you remind me of it?



michael sharpe
@profmsharpe



I do agree that biological factors may limit improvement with behavioural treatment. Might I also suggest that it is in the nature of trial reports to report on what was done and the findings. How many drug trials say 'psychological factors may have limited improvement'.

11:50 AM - Jun 1, 2018

♥ 5 👤 See michael sharpe's other Tweets



We have to remember that what we observe is not nature in itself, but nature exposed to our method of questioning.

strategist, Jun 1, 2018 Report Bookmark

#618 Unlike + Multiquote Reply



Keela Too
Senior Member
(Voting Rights)

Messages: 317
Likes Received: 3,023
Location:
Sally Burch - Northern Ireland



michael sharpe @profmsharpe

1 Jun

Replying to @wilshica @CMonaghanSNP

I do agree that biological factors may limit improvement with behavioural treatment. Might I also suggest that it is in the nature of trial reports to report on what was done and the findings. How many drug trials say 'psychological factors may have limited improvement'.



Robert McMullen
@RobertHMcMullen



PACE CBT assumed that there is no "fixed disease pathology" which prevents recovery in ME/CFS patients.

qmul.ac.uk/wolfson/media/...

If the evidence suggested that that assumption may be wrong, did the authors not have a responsibility to make that clear?

Or have I misunderstood? pic.twitter.com/wOpNyl7paR

4:46 PM - Jun 1, 2018

Back

PACE-get-therapist-manual.pdf



activity, graded increases in activity, as with simple incremental pacing, and also directly addresses the participant's beliefs and fears about their symptoms and functioning. CBT differs from GET by directly targeting cognitions and related behaviours and it differs from APT by encouraging the participant to extend their physical functioning beyond their current ability.

Essence

The essence of CBT is helping the participant to change their interpretation of symptoms and associated fear, symptom focusing and avoidance. Participants are encouraged to see symptoms as temporary and reversible and not as signs of harm or evidence of fixed disease pathology. In this way it is anticipated that they will gain more control of their lives, as they, and not their symptoms, dictate what they do.



37



See Robert McMullen's other Tweets



I think this is a key point in the failings of the PACE authors.

Sally Burch
Blog "Just ME"

Keela Too, Jun 1, 2018 Edit Delete Report Bookmark

#620 + Multiquote Reply



Indigophoton

Senior Member
(Voting Rights)

Messages: 677

Likes Received: 7,245

Location: UK



michael sharpe

@profmsharpe



Replying to @MEwarrior_au

Do you really believe that the PACE trial was fraud? Could you defend that viewpoint in a public forum?

10:12 AM - Jun 1, 2018



See michael sharpe's other Tweets



I'd like to think MS was suggesting an Oxford union style debate here, or similar public discussion. We could field @Jonathan Edwards for the anti-PACE position vs Sharpe for the pro-PACE team... OK, it's probably not gonna happen, but it was a sweet idea for a moment 😊

Last edited: Jun 1, 2018

Indigophoton, Jun 1, 2018 Report Bookmark

#627 Like + Multiquote Reply



Keela Too

Senior Member
(Voting Rights)

Messages: 317

Likes Received: 3,023

Location: Sally Burch - Northern Ireland



It can't rain all the time @CounceSally1 Jun

Replying to @profmsharpe and 4 others

pic.twitter.com/gzWANscqcc



michael sharpe

@profmsharpe



Is that what that says. Really ? And furthermore it did not cause harm in the trial as harm carefully monitored. So please look again.

9:21 PM - Jun 1, 2018



See michael sharpe's other Tweets



I thought this was interesting. I understand that harm was not carefully monitored. Have there not been PACE trial participants stating that no interest was taken when they claimed to be deteriorating?

Sally Burch
Blog "Just ME"

Keela Too, Jun 2, 2018 Edit Delete Report Bookmark

#636 + Multiquote Reply



Esther12
Senior Member
(Voting Rights)

Messages: 1,599
Likes Received: 12,671

Sharpe now seems to be just tweeting random patients and telling them that he disagrees with how they're living their lives. Is this sort of thing normal on twitter?



Chronically Hopeful  **Char** @chronic_hopeful · 3h

Sat up in bed a few minutes to eat lunch. Sat upright rather than my usual reclined position, so I don't mess on myself... Heart rate promptly goes to 111! Lying down again, body slightly elevated for digestion now... #MEcfs #pwME #SevereME #MillionsMissing #CanYouSeeMEnow



michael sharpe
@profmsharpe

Follow

Replying to @chronic_hopeful

I disagree with that at least for PACE. Have a look yourself.

7:48 am - 2 Jun 2018

Esther12, Jun 2, 2018 Report Bookmark

#645 Like + Multiquote Reply



Liv aka Mrs Sowester
Senior Member
(Voting Rights)

Messages: 1,188
Likes Received: 8,328

Wow, passive aggressive tweeting at @Lucibee now



Lucibee @Lucibee

2 Jun

Replying to @profmsharpe @wilshica

So why didn't you correct @richardhorton1 when he stated that, "they were really stepping back and comparing two philosophies, not just two treatments, two philosophies of what chronic fatigue syndrome was."? @thelancet #PACEtrial



michael sharpe
@profmsharpe



Well I, unlike some who tweet about ME, I do not try to censor others views.

4:35 PM - Jun 2, 2018



See michael sharpe's other Tweets



Liv aka Mrs Sowester, Jun 2, 2018 Report Bookmark

#650 Like + Multiquote Reply



Barry

Senior Member
(Voting Rights)

Messages: 2,295
Likes Received: 14,761

Back

PACE-get-therapist-manual.pdf



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michael sharpe
@profmsharpe

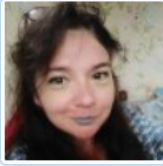
Follow

Replying to @CounceSally @RobertHMcMullen and 3 others

Is that what that says. Really ? And furthermore it did not cause harm in the trial as harm carefully monitored. So please look again.

1:21 pm - 1 Jun 2018

"Is that what that says. Really?"



Liv aka Mrs Sowester

Senior Member
(Voting Rights)

Messages: 1,188

Likes Received: 8,328

He's getting very defensive



Lucibee @_Lucibee

2 Jun

Replying to @profmsharpe and 3 others

So his views weren't informed by you or the other #PACEtrial investigators?

(And btw correcting is not censoring)



michael sharpe

@profmsharpe



No idea. Have you? Have you ever thought that some of these interactions sound like a heresy trial ?

5:04 PM - Jun 2, 2018



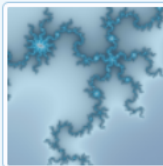
See michael sharpe's other Tweets



Which can only be a good sign.

Liv aka Mrs Sowester, Jun 2, 2018 Report Bookmark

#656 Like + Multiquote Reply



Lucibee

Senior Member
(Voting Rights)

Messages: 254

Likes Received: 2,622

Location: Mid-Wales

Aha!



Lucibee @_Lucibee

2 Jun

Replying to @profmsharpe and 3 others

Well, no, I don't. That's why I was asking. I did ask him, but he wouldn't say. I guess I'm just trying to understand why you are so determined to defend this trial when people have been harmed by it, that's all.



kd

@Kdcfsme



@Lucibee No one has been harmed by the trial, when CBT and GET are done safely as they were in PACE they do not harm anybody and often lead to improvement. How many doctors have even recognised that CFS/ME sufferers are genuinely ill, never mind developed useful treatments?

7:08 PM - Jun 2, 2018



See kd's other Tweets



Lucibee, Jun 2, 2018 Report Bookmark

#662 Like + Multiquote Reply

RESEARCH ARTICLE



Deconstructing post-exertional malaise in myalgic encephalomyelitis/ chronic fatigue syndrome: A patient-centered, cross-sectional survey

Lily Chu*, Ian J. Valencia[‡], Donn W. Garvert, Jose G. Montoya

Stanford ME/CFS Initiative, Division of Infectious Diseases and Geographic Medicine, Stanford University School of Medicine, Stanford, California, United States of America

[‡] Current address: Genentech, Inc., South San Francisco, California, United States of America

* lchu1@stanford.edu



Dr Mark Guthridge

@Dr_M_Guthridge



Exercise should not be recommended as a treatment for [#MECFS](#)

This large study found 90% of [#pwME](#) suffer a pathological worsening of physical and cognitive symptoms following exertion or exercise [#MyalgicE](#) [#PLOSONEbuff.ly/2xIT4kO](#)

11:00 AM - Jun 3, 2018

♡ 169 💬 119 people are talking about this



blueyoyoma @blueyoyoma

3 Jun

Replying to @Dr_M_Guthridge

I wonder how many years it will be until [@TheLancet](#) retracts the [#PACEtrial](#) & people like [@profmsharpe](#) have the humility to admit they pushed the wrong barrow. [#PACEtrial](#) looks like lasting longer than vaccines causing autism...



michael sharpe

@profmsharpe



Well. You are not going to be convinced I can see. Odd that folk want a trial to be retracted because they don't believe/like the results. and I expect you realise that there are many trials from several countries. But i dont expect you will change your mind.

6:43 PM - Jun 3, 2018

♡ 👤 See michael sharpe's other Tweets



He can't grasp that it's science, not belief nor dislike, that is driving the



Keela Too
Senior Member
(Voting Rights)

Messages: 317
Likes Received: 3,023

Location:
Sally Burch -
Northern Ireland

I'm not sure what he is up to really. There is no real substance to his replies, bar telling people to read papers of his. Pertinent questions are either sidestepped, ignored or derided.

Not sure it is worth trying to engage, but I tweeted this, because - well just because. . . The tweet above was talking of harms of aerobic exercise. Which he says trials don't show!



michael sharpe @profmsharpe

2 Jun

Replying to @FionaPWME and 2 others

Well trials don't. An interesting contradiction for someone to study.



Sally Burch

@KeelaToo



Really? Did the trials properly listen to patients? How closely did the trials look for harms? And what of charity surveys? Should the experiences of patients be routinely discounted? If so how can patients' subjective replies to trial questionnaires be taken seriously?

7:47 AM - Jun 3, 2018

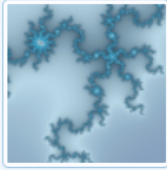
♥ 10 👤 See Sally Burch's other Tweets



Sally Burch
Blog "[Just ME](#)"

Keela Too, Jun 3, 2018 [Edit](#) [Delete](#) [Report](#) [Bookmark](#)

#684 [+ Multiquote](#) [Reply](#)



Lucibee

Senior Member
(Voting Rights)

Messages: 254

Likes Received: 2,622

Location: Mid-Wales

This is one of the things that most bothers me about PACE. That they would run a large randomised trial based on an unproven hypothesis, and one which they have not even designed the study to test.



Janelle Wiley @janwly

3 Jun

Replying to @janwly and 8 others

CBT focuses on ignoring symptoms (to increase activity) and GET focuses on increasing activity (while ignoring the inevitable symptoms). Two sides of the same coin.

Both explicitly assume there's no disease process causing said symptoms.



michael sharpe

@profmsharpe



Both are based on the hypothesis that biological factors might be at least partially reversible. Again starting to feel like a heresy trial here...

5:17 PM - Jun 3, 2018



See michael sharpe's other Tweets



and



Janelle Wiley @janwly

3 Jun

Replying to @janwly and 8 others

CBT focuses on ignoring symptoms (to increase activity) and GET focuses on increasing activity (while ignoring the inevitable symptoms). Two sides of the same coin.

Both explicitly assume there's no disease process causing said symptoms.



michael sharpe

@profmsharpe



Both assume the possibility that associated biological processes may be at least partially reversible. And that question is what the PACE trial aimed to test.

9:50 AM - Jun 3, 2018





See michael sharpe's other Tweets



I also conversed with this person - but it was the same reverse thinking. They can't seem to see that they are making very strong (and untested) assumptions about what is going on here.

Thread:


**Lucibee** @_Lucibee 3 Jun
Replying to @cfs_research and 7 others
Any advocacy effort is against CBT/GET research in #pwme, in whom we already know it is harmful. It is not against all research. Pts are left without tx options precisely bcs research has been too focussed in this area.


**CFS Research** @cfs_research
Except there is no evidence that it is harmful, if done correctly. We've had a massive long thread here, but no proof of harm. Yes, there are anecdotal reports (I've talked to many of them), so why can't we research this to improve treatment?
5:15 PM - Jun 3, 2018
1 Like See CFS Research's other Tweets

I can sort of see where they are coming from, but I passed through that phase too, and dismissed it after I realised that there is no evidence to confirm it, and that it runs counter to the vast majority of patient experience.

And this makes me especially cross:

**Lucibee**
Senior Member
(Voting Rights)
Messages: 254
Likes Received: 2,622
Location: Mid-Wales

**Lucibee** @_Lucibee 2 Jun
Replying to @profmsharpe and 3 others
Well, no, I don't. That's why I was asking. I did ask him, but he wouldn't say. I guess I'm just trying to understand why you are so determined to defend this trial when people have been harmed by it, that's all.

**kd** @Kdcfsme
@Lucibee No one has been harmed by the trial, when CBT and GET are done safely as they were in PACE they do not harm anybody and often lead to improvement. How many doctors have even recognised that CFS/ME sufferers are genuinely ill, never mind developed useful treatments?
7:08 PM - Jun 2, 2018
2 Likes See kd's other Tweets



Robert 1973
Senior Member
(Voting Rights)

Messages: 128
Likes Received: 1,897
Location: UK

Regardless of whether or not it is worth engaging with Prof Sharpe on Twitter, I think his second question is important, as it is one that many may ask and some may struggle to answer satisfactory:



Anton Mayer @MECFNews

1 Jun

Replying to @pechius and 4 others

It's just an ordinary placebo response that the authors refuse to interpret as such.



michael sharpe
@profmsharpe



But. First what do you mean by placebo? Second the PACE Trial compared 3 time and credibility matched interventions and got a differential response. Why ?

3:59 PM - Jun 2, 2018



See michael sharpe's other Tweets



I think I understand most of the reasons why the differences in responses do not provide reliable evidence of the effectiveness of CBT and GET but I would be interested to hear how others would answer this question, in particular [@Jonathan Edwards](#).

Robert 1973, Jun 4, 2018 [Report](#) [Bookmark](#)

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