

Review of: "The Concept of ME/CFS"

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I thoroughly enjoyed reading this interesting report by Jonathan Edwards. The author provides a well-written report on ME/CFS and offers his view on various aspects of the disease. Without agreeing or disagreeing with the claims that were made, I tried to offer some counterclaims/queries to spark a scientific discussion:

It is good to see someone touching on nomenclature such as 'ME' and 'complex multisystem disorder' when there is no conclusive scientific evidence (say, for example, with tissue biopsies) to support these terms.

It feels like the author suggests that ME/CFS is a different entity, i.e., specified by PEM, than post-infective fatigue syndromes. Could the author elaborate on this distinction?

Should we consider post-viral fatigue syndromes as an entirely separate entity from post-viral ME/CFS? Or is post-viral ME/CFS still linked to post-viral fatigue syndromes, but does it encompass a more severe or distinct subgroup, for example?

I don't really follow your rationale on how the term ME/CFS provides a context for the clinical presentation of patients. In my opinion, it does not cover terms like PEM and POTS, and if PEM is truly the cardinal symptom of ME/CFS, should the name not reflect this symptom more clearly?

I like the paragraph on patient-initiated research and where it has brought the field. Are you at all afraid of a biased approach with these developments? Or do you feel the bias lies in the academic research that has been done up until then?

Could the author elaborate on psychological intervention studies after the PACE trial that found benefit for some patients? Could it not be of use for some patients on the fatigue spectrum?

Ref 17 does not scientifically support the strong claim that is made.

The author suggests specialised multi-disciplinary care for ME/CFS patients. Would specialised centres be an option? And would you say that these centres should specialise solely in ME/CFS or also in other adjacent syndromes like post-viral fatigue syndromes (given the recent surge in post-COVID cases)? Where does the GP come in, or does the author feel that ME/CFS (perhaps especially the severe cases) needs specialist care?

