Author's response to reviews

Title: The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers

Authors:

Luis Nacul (luis.nacul@lshtm.ac.uk)
Eliana M Lacerda (eliana.lacerda@lshtm.ac.uk)
Peter D Campion (p.d.campion@hull.ac.uk)
Derek F Pheby (derekpheby@btinternet.com)
Maria L Drachler (jcdc.leite@googlemail.com)
Jose C Leite (jcdc.leite@googlemail.com)
Fiona Poland (F.Poland@uea.ac.uk)
Amanda Howe (Amanda.Howe@uea.ac.uk)
Shagufta Fayyaz (Shagufta.Fayyaz@lshtm.ac.uk)
Mariam Molokhia (Mariam.Molokhia@kcl.ac.uk)

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Author's response to reviews: see over
Dear Dr Reeve,

Thank you very much for your letter following review of the paper. We are pleased to enclose a further version of the manuscript (with track changes) addressing the comments received. We hope this will meet your satisfaction and look forward to seeing it published by this reputable journal.

Yours sincerely,

Dr Luis Nacul (on behalf of the authors)

Response to reviewers’ reports

Reviewer – J. Reeve

“I do wonder if the stated 'need' to combine 'objective measures' with SF36 needs further justification. Would this enhance our capacity to address the illness burden/disability experienced by patients and carers?”

Answer – We agree further justification was required and amended the last sentence of the Conclusions to that effect.

Reviewer: Jin-Mann Lin

Major Compulsory Revisions:

“The authors have added some description in case ascertainment; however, it is not really clear how they applied the three case definition criteria. For example, while applying CDC-1994 how many subjects had at least 4 CFS accompany symptoms lasting >= 6 months, not alleviated by rest, substantial reduction in activities, etc. It was suggested providing a table with such kind of information across three criteria in Appendix so that readers can visualize how the criteria actually applied.”

A – All the subjects who complied with the CDC-1994 criteria had unexplained fatigue for 6 months or more, accompanied by at least 4 from the eight symptoms required in the CDC-1994 criteria definition. We have added an Appendix with 2 tables, one explaining the criteria and the other with frequency of symptoms according to criteria.

Minor Essential Revisions:

“Page 10. In the first sentence for the “Study size” section, it indicated that “43” named carers while n=44 listed in several places of Table 1. Please clarify this.”

A – Thank you for pointing this, as it gave us the opportunity to make corrections that would otherwise go unnoticed. This discrepancy occurred because we had excluded one ‘carer’ - as it is stated in the 2nd paragraph of the Results section (between brackets), but the analysis with the inclusion of this carer still inadvertently appeared in parts of the text and tables. The extra case was a professional nurse, who was not part of the group of carers we focused on in the study, namely the unpaid, non-professional
carers, usually family members and/or close friends. We carefully revised the analyses, and changes were made accordingly in the text and tables 6, 7, 8 and Figures 2a and 2b. These changes, however, were very small and did not alter the interpretation of results. We also noted that in Table 1 there was a typo in the total carers of individuals who complied with the Canadian criteria; the total is 32 instead of 43, and we corrected that.

“Page 10. In Line #5 of the Results section, the authors stated “The median age of onset of symptoms was 41.5 years..., corresponding to a median duration of fatigue of 10 years...” Please describe how the age of onset of symptoms was defined. Is it the onset of fatigue? Or the onset of CFS illness or some specific symptoms?”

A – The age of onset, was related to the time when the subjects started presenting significant tiredness/fatigue (i.e. not explained by excessive exercise or work and that did not go away completely after rest), which persisted until the time of the study. Subjects that had reported this and other symptoms (required in the study case definitions) have stated in years and months how long their symptoms had been present for. From this data, the date of onset was derived. We have explained this in the first paragraph of the Results section.

Table 5. The n’s listed in the current version of the manuscript were slightly different from the previous version. The number of patients with Canadian diagnostic criteria was 96 in the current Table 5 whereas it was 95 in the previous version. Please clarify this. In the current Table 1, 166 patients met CDC-1994 criteria. Does this mean that 96 patients with Canadian criteria (also met CDC-1994) plus 70 patients met CDC-1994 only? Please clarify this.”

A – There was a typo in the previous version, which was corrected. The number of cases complying with the Canadian criteria was 96, from these 88 also complied with the CDC-1994 criteria. Therefore, we compared the first group with that formed by the 70 cases that conformed to the CDC-1994 criteria only.

“Page 16. “Study strengths and limitations”, line #4, “The response rate for carers was nor particularly high”. “nor” could be a typo?”

A – Yes, it was, thank you. Typo corrected.