



However CFS is operationalised young people's perspectives are important

Trudie Chalder¹ · Sheila Ali¹ · Mary Burgess² · Lucy Adamczyk¹

Received: March 12, 2019 / Accepted: March 20, 2019 / Published online: April 1, 2019
© Springer Science+Business Media, LLC, part of Springer Nature 2019

We would like to thank authors Twisk (2019) and Tack (2019) for taking the time to respond to our article (Ali et al. 2019) which focused on young people with severe chronic fatigue syndrome, the majority of whom were using a wheelchair or some form of assistive equipment.

In our study we recruited young people with self-reported chronic fatigue syndrome (CFS) and examined whether a range of factors predicted fatigue, social adjustment and school attendance cross sectionally and at follow up. We did not select patients according to the Oxford criteria as suggested by Twisk (2019). Participants had to have self-reported CFS. All but one stated that their diagnosis had been confirmed by a health professional. We also assessed how many met the Oxford criteria (Sharpe et al. 1991), although this cannot be used as a proxy for a clinical diagnosis. In any case there is a lack of consensus about how the illness should be operationally defined. We used the term “ME” as many of the participants identified themselves as having “ME” rather than CFS. It was not within the scope of the paper to address the issue of whether CFS and “ME” are the same condition.

Thank you for pointing out that fear avoidance beliefs were not associated with fatigue at time 2. There was a typographical error in the abstract. Fear avoidance beliefs only predicted fatigue cross sectionally at time 1 but more

importantly did predict social adjustment (degree to which the individual participates in life) at follow up.

Our study did not set out to test the effectiveness of an intervention. We reported on how many participants said they had had cognitive behaviour therapy (CBT) or graded exercise therapy (GET). However, we used a crude measure of treatment access and the study only took place over a period of 4–9 months, meaning we cannot make any assumptions about treatment effectiveness. Neither can we make any claims about safety or deterioration on the basis of these results. As noted in the paper, the young people may have needed more time away from school/work to attend appointments, and this may explain why access to treatment was associated with lower work/school attendance.

The evidence for CBT and GET for moderately affected young people with CFS has been reviewed by others. CBT provided the best evidence for reducing fatigue and increasing school attendance while GET resulted in some fatigue reduction (Smith & Crawley, 2013). We suggested that the potential efficacy of CBT for severely affected adolescents is based on very small-scale studies (Burgess et al., 2019). Adequately powered, randomised controlled trials are clearly needed. However, we believe it is important that young people are not left untreated with no hope of change. We are open to any ideas about how these young people can be helped to gain health and independence. The idea that nothing can be done to help people with CFS must surely be challenged.

✉ Trudie Chalder
trudie.chalder@kcl.ac.uk

¹ Department of Psychological Medicine, Institute of Psychiatry, Psychology and Psychiatry, King's College London, London, UK

² South London and Maudsley NHS Trust, London, UK

Compliance with ethical standards

Human and animal rights and Informed consent All procedures followed were in accordance with ethical standards of the responsible committee on human experimentation (institutional and national) and

with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

References

- Ali, S., Adamczyk, L., Burgess, M., & Chalder, T. (2019). Psychological and demographic factors associated with fatigue and social adjustment in young people with severe chronic fatigue syndrome/myalgic encephalomyelitis: A preliminary mixed-methods study. *Journal of Behavioural Medicine*. <https://doi.org/10.1007/s10865-019-00010-x> (Epub ahead of print).
- Burgess, M., Lievesley, K., Ali, S., & Chalder, T. (2019). Home-based family focused rehabilitation for adolescents with severe Chronic Fatigue Syndrome. *Clinical Child Psychology & Psychiatry*, 24, 19–28. <https://doi.org/10.1177/1359104518794764>
- Sharpe, M., Archard, L. C., Banatvala, J. E., Borysiewicz, L. K., Clare, A. W., David, A., et al. (1991). A report-chronic fatigue syndrome: Guidelines for research. *Journal of the Royal Society of Medicine*, 84(2), 118–121.
- Smith, S. N., & Crawley, E. (2013). Is there effective behavioural treatment for children with chronic fatigue syndrome/myalgic encephalomyelitis? *Archives of Disease in Childhood*, 98(7), 561–563.
- Tack, M. (2019). Fear avoidance in CFS/ME: Invalid results. *Journal of Behavioural Medicine*. <https://doi.org/10.1007/s10865-019-00033-4>.
- Twisk, F. (2019). Cognitive-behavioural and graded exercise therapies for chronic fatigue (syndrome) are associated with lower levels of work/school attendance. *Journal of Behavioural Medicine*. <https://doi.org/10.1007/s10865-019-00032-5>.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.