Declaration of Interest

None.

References


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Letter to the Editor

Response to correspondence concerning ‘Recovery from chronic fatigue syndrome after treatments in the PACE trial’

The definition of recovery from any chronic illness is challenging. We therefore agree with Cox (2013) and Courtney (2013) that no single threshold measurement is sufficient; this is why we measured several domains of improvement and combined them into a composite measure of recovery (White et al. 2013). Shepherd (2013) suggests asking patients whether they recovered as a result of [our italics] receiving a treatment; we did not ask this since it is not possible for individuals to ascribe change to one particular source in exclusion from all others, such as regression to the mean or external factors. Maryhew (2013) suggests self-ratings may be biased when participants cannot be masked to treatment allocation; this may be true, but is inconsistent with cognitive behaviour therapy (CBT) being more effective than adaptive pacing therapy (APT) when treatment expectations were significantly lower before treatment (White et al. 2011).

We dispute that in the PACE trial the six-minute walking test offered a better and more ‘objective’ measure of recovery, as suggested by Agardy (2013), Maryhew (2013), and Shepherd (2013). First, recovery from chronic fatigue syndrome (CFS), which is defined by a patient’s reported symptoms, is arguably best measured by multiple patient-reported outcome measures, rather than a single performance test. Second, and importantly, there were practical limitations to our conduct of the walking test. Due to concerns about patients with CFS coping with physical exertion, no encouragement was given to participants as they performed the test, by contrast to the way this test is usually applied (Guyatt et al. 1984; American Thoracic Society, 2002). Rather than encouragement, we told participants, ‘You should walk continuously if possible, but can slow down or stop if you need to.’ Furthermore we had only 10 metres of walking corridor space available, rather than the 30–50 metres of space used in other studies; this meant that participants had to stop and turn around more frequently (Guyatt et al. 1984; Troosters et al. 1999; American Thoracic Society, 2002), slowing them down and thereby vitiating comparison with other studies. Finally, we had follow-up data on 72% of participants for this test, which was less than for the self-report measures (White et al. 2011).

Economic data, such as sickness benefits and employment status, have already been published by McCrone et al. (2012). However, recovery from illness is a health status, not an economic one, and plenty of working people are unwell (Oortwijn et al. 2011), while well people do not necessarily work. Some of our participants were either past the age of retirement or were not in paid employment when they fell ill. In addition, follow-up at 6 months after the end of therapy may be too short a period to affect either benefits or employment. We therefore disagree with Shepherd (2013) that such outcomes constitute a useful component of recovery in the PACE trial.

We agree with Carter (2013) that there is a difference between sustained recovery and temporary remission; this is why we were careful to give a precise definition of recovery and to emphasize that it applied at one particular point only and to the current episode of illness (White et al. 2013).

Despite the complexities of measuring recovery, we believe that our approach of using multiple self-report measures provides a reasonable approach to inform clinicians’ and patients’ choice between available...
treatments. The findings from the PACE trial are clear; however we measured recovery, CBT and graded exercise therapy (GET) were more likely to lead to recovery, when added to specialist medical care (SMC), compared to either adding APT or SMC alone. Recovery after SMC alone, using our composite criteria, was only 7%—the same as that without treatment (Cairns & Hotopf, 2005)—whereas three times as many (22%) recovered after receiving CBT or GET. The PACE trial has shown that both CBT and GET are moderately effective, safe, cost-effective, and are more likely to lead to recovery (White et al., 2011, 2013; McCrone et al. 2012). These treatments should now be routinely offered to all those who may benefit from them (Crawley et al. 2013).

Declaration of Interest

Declaration of Interest is as stated in White et al. (2013).

References


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