Casanova et al. 2011). Then, after calculating the new recovery percentages with the 6MWDs, analyses could be performed to compare the means with predicted values.

Declaration of Interest

None.

References


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Letter to the Editor

Comments on ‘Recovery from chronic fatigue syndrome after treatments given in the PACE trial’

Important outcome data from the PACE trial (White et al. 2011) appears to be missing from the paper describing recovery in ME/CFS (White et al. 2013) and the participants do not appear to have been asked whether they had recovered as a result of receiving cognitive behaviour therapy (CBT), graded exercise therapy (GET) or Pacing.

The paper would have been improved had three specific markers of recovery been reported. First is the receipt of a state sickness or disability benefit. Claiming such a benefit indicates that the person is still ill and has not recovered. This data was included in the cost analysis study (McCrone et al. 2012) that reported: ‘Receipt of benefits due to illness or disability increased slightly from baseline to follow-up.’

Second is employment or education status. The recovery paper argues that ‘Return to work is not, however, an appropriate measure of recovery if the participant was not working before their illness and is influenced by other factors such as the job market.’ However, a sustained return to meaningful paid employment, or education, or the ability to do so, is an objective marker of recovery.

Third is ability to mobilize. Recovery in a condition whose cardinal clinical features relate to mobility – exercise-induced muscle fatigue and weakness – must be matched with an ability to mobilize in a normal and timely manner. The overall results for all the treatments in the PACE trial relating to changes in the six-minute walking test from baseline to 52 weeks do not represent a return to normal levels of activity. It can be seen that the figures for all the treatment groups at 52 weeks are below the 402 m reported to be present in patients with class 3 heart failure (Lipkin et al. 1986). So the results for those who had recovered – who should now be achieving a much higher distance – ought to have been included. In addition, the question could be raised as to how it is possible to meet the entry criteria for the PACE trial with a Short Form-36 physical function subscale score of 65 yet leave the trial as recovered with a lower score of 60.

The term ‘recovery’ implies a sustained return to symptom-free health with the ability to repeatedly and reliably participate in all aspects of normal life – employment, education, social activities, etc. Without this information it is difficult to conclude that these patients have in fact recovered.
Declaration of Interest
None.

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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
different 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; Treossters 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 par-
ticipants 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 par-
ticular 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