



M.E. Analysis – Evaluating the results of the PACE study

a project supported by Phoenix Rising

5. We must find the factors that identify those patients who benefit from these therapies (more)

It is entirely reasonable to speculate that any patient with ME/CFS could have an additional psychological component that adds to her or his difficulties, just like patients with any other long-term chronic disabling illness. In the past there has been much emphasis on the idea that these components are the major, if not the sole causes of ME/CFS, but the evidence from the PACE trial clearly suggests that the average contribution that they make to the severity of the illness is small. The report states that there was no significant difference in the pattern of results of those meeting international criteria, those meeting the London criteria, and those meeting the depressive disorder criteria, which suggests that the extent of these psychological components is not specific to any one of these diagnoses.

The animated graphic in section 3-details emphasises that it is likely that, for the majority of patients, these psychological components are small, with just a few (say 2 in 15) for whom the component is significant. Until the individual data is available, speculation is difficult, but the weak average effect certainly casts major doubt on the present psychological model. Of course, it is also possible that the patients who improved simply had a spontaneous remission, which is not unknown, especially in people who are within the first year of having ME/CFS (although it is hard to find any reliable data on this).

A study in 2001 by Ridsdale et al. found that counselling was as effective as CBT in reducing symptoms of fatigue in patients. Their patients had lower average baseline scores on the Chalder Fatigue scale than those in the PACE trial (and it must be emphasised that only a quarter of them met research criteria for chronic fatigue syndrome). In the PACE trial, the patients in the group who only had 4 or 5 sessions of Specialist Medical Care recorded greater average improvement than the extra improvement "added on" by the 12 or so extra therapy sessions of CBT or GET. The obvious question to ask is, what form of help did the SMC sessions give to the patients? Without a control group, it is impossible to assess how much was caused simply through familiarisation with the system. Equally, the help with pain control and sleep would have produced benefits. But if those patients who showed the greatest overall improvement in the GET and CBT groups matched the profile of those in the SMC group who also showed the greatest improvement, it would suggest that these improvements were not due specifically to GET or CBT, but to something that they, SMC and counselling have in common.

In 2002, a report published in the British Journal of Psychiatry by Bentall et al. found that patients who were members of a support group showed less improvement to the treatment given than those who were not members of a support group. They then made the illogical conclusion that membership of a support group probably caused poor motivation and resistance to the therapies. Of course, the exact opposite picture of support groups is also possible from the same data – that membership of a self help group had already taken these patients part-way down the route to improvement leaving less to be done, and this conclusion would now, in the light of the results in the PACE trial of the SMC groups, seem to be the more rational one. It is unfortunate that prejudice against such groups clearly coloured the conclusion.

One of the factors that causes so much disquiet amongst patients with ME/CFS is that CBT and GET are assumed to be relevant to everyone without there being a specific attempt to measure their individual need. It has been suggested many times that many patients with ME are resistant to a diagnosis of psychiatric illness (e.g. an interview with Prof Wessely on the Today programme). We feel that this is not the case, but the problem lies in the fact that such a diagnosis is not made, but is simply assumed.

Often, when considering whether an approach is reasonable, it is illuminating to transpose it into a very different situation. We all know that there are a few people who frequent doctors' surgeries for trivial reasons. Let's give this a name – Doctor Dependency Syndrome – and suggest that it is the result of inappropriate levels of sympathy being given by a doctor. We will devise an appropriate training sessions for doctors on that basis – Gradational Empathy Training – carry out a few tests on small numbers of volunteer

doctors, and assess its effectiveness by means of questionnaires about their attitudes at the start and the end of the course. If the results show a statistically significant improvement in doctors' attitudes (but not necessarily in the number or frequency of DDS visits), then the training will be rolled out across the country for all doctors who have patients with DDS, and will entail a series of afternoon monthly sessions run by counsellors trained to deliver this treatment. Now the big question: Would the response of doctors be more or even less enthusiastic than the response of ME/CFS patients to the assumption, without a specific diagnosis, that they have psychological problems?

It is time that such assumptions came to an end.