

Leeds BABCP conference: workshop on emotion processing in chronic fatigue syndrome - current CBT treatment results (2nd post – 27.06.12)

In yesterday's post, I described the pre-workshop publicity for this day on treatment of chronic fatigue syndrome. How did I find the workshop in actual practice? Well, I enjoyed meeting Trudie Chalder. She came across as very alive, friendly, bright, knowledgeable. Great. And her two decades or so of dedicated exploration of Chronic Fatigue Syndrome is so impressive ... one of those research journeys that I find it heart-warming to look at. For me the workshop itself was a bit of a funny mix. In the morning session we were given an overview/update on chronic fatigue syndrome and its standard CBT treatment. Although this wasn't maybe what most workshop participants had come for, I found it the most useful section of the day (particularly as I've thought and read more about it subsequently). I do know a fair amount about standard CBT for chronic fatigue, but revisiting this territory underlined a series of factors I hadn't really taken on board before.

We were each given a big 125 slide handout - more than covering what we talked about over the course of the day. It was very useful. If I was being a little picky, I would point out that some slides don't give a reference to the linked research they are highlighting (or get the reference wrong). I personally sometimes find this a bit maddening & time consuming (as I do the detective work to try to dig out the source material). So, for example, Trudie said that 25% of the population feels tired all the time and that 10% of GP patients present with fatigue as principle symptom. Apparently this makes fatigue the second most common symptom in primary care (after headache). I'm not sure where she got her 25% "tired all the time" figure from. Her own 1994 survey - "Population based study of fatigue and psychological distress" - found that 18.3% of respondents "reported substantial fatigue lasting six months or longer". Subsequent work seems to have found prevalence rates more in line with her 1997 study - "The prevalence and morbidity of chronic fatigue and chronic fatigue syndrome: A prospective primary care study" - which reported "The point prevalence of chronic fatigue was 11.3%, falling to 4.1% if comorbid psychological disorders were excluded. The point prevalence of chronic fatigue syndrome was 2.6%, falling to 0.5% if comorbid psychological disorders were excluded." I know that it's easy to descend into semi-obsessive definitional discussions in these prevalence estimates, but what's clear is that fatigue problems are very common.

Trudie went on to talk about standard CBT and GET (graded exercise therapy) interventions for chronic fatigue. Outcomes are helpful but only quite moderately so. The major paper here is the multi-authored White et al study, that Trudie & colleagues had published in the Lancet last year - "Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial" (you may need to register & sign in, but this paper is then freely accessible in full text). Comparisons were made between specialist medical care (SMC) on its own or with additional adaptive pacing therapy (APT) or with additional CBT or with additional GET. Participants were selected "in accordance with Oxford criteria for chronic fatigue syndrome. These criteria require fatigue to be the main symptom, accompanied by significant disability, in the absence of an exclusionary medical or psychiatric diagnosis (psychosis, bipolar disorder, substance misuse, an organic brain disorder, or an eating disorder) ... Other eligibility criteria consisted of a bimodal score of 6 of 11 or more on the Chalder fatigue questionnaire and a score of 60 of 100 or less on the short form-36 physical function subscale. 11 months after the trial began, this requirement was changed from a score of 60 to a score of 65 to increase recruitment."

The therapist & participant treatment manuals are freely downloadable. Participants received up to 15 sessions of therapy - 4 at weekly intervals, 10 at fortnightly intervals, and a 15th session three months after the 14th. The outcome was that additional APT seemed to add nothing useful to SMC on its own, but additional CBT or GET resulted in somewhat less fatigue and disability than just SMC on its own. More

specifically, fatigue scores on the Chalder fatigue questionnaire (range 0 - 33) at baseline, 12 weeks (mid-therapy), 24 weeks (post-therapy) & 52 weeks were for additional CBT 27.7, 23.6, 21.5 & 20.3; for GET 28.2, 22.8, 21.7 & 20.6; while additional APT & SMC on its own were very similar at 28.5/28.3, 24.2/24.3, 23.7/24.0 & 23.1/23.8. Interesting stuff. Participants were achieving a 4 or 5 point fatigue improvement with CBT or GET at 12 weeks, increasing to a 6 or so point improvement (a bit over 20%) by the end of therapy (at 24 weeks) with some minor further improvement leading to a 27% or so level of benefit on fatigue scores at one year. Another way of looking at it is to note that a large community sample of the general population averaged 14.2 on the same fatigue questionnaire i.e. in broad terms a shift from a score of 28 to 20 leaves the trial participants nearly 60% of the way down to the community sample level of about 14 on the fatigue scale. So we can be both encouraged (significant change is achievable in this very difficult to treat chronic disorder) and disappointed (only a little more than 25% better after a year).

For my own work as a therapist, I note that 1.) 20% improvement on the Chalder fatigue questionnaire after 14 sessions (6 months) of therapy is currently a very reasonable outcome to aim for with CBT or GET - better than this and the therapy is going particularly well. It's worth noting that Trudie commented that one may well be able to achieve fuller recovery more regularly with younger sufferers, although one might need to keep going for quite a long time & family involvement may well be useful (involvement of significant others may help too with adults). 2.) It's sensible to use the current 11-item version of the Chalder scale when assessing fatigue - downloadable here both as a Word doc and as a PDF file. 3.) Partly because change in fatigue is likely to be fairly slow, it may be sensible to only assess fatigue with the Chalder scale pre-therapy, after about 12 weeks and again after about 24 weeks. Repeated sessional assessment as I have tended to do in the past could lead to frustration at the understandably slow rate of change. 4.) Encouraging & monitoring increases in activity are central to this therapy approach. See the GET manual for more information on exercise assessment and the CBT manual or books like Trudie's "Overcoming chronic fatigue: a self help guide" for more general comments. Cella, Sharpe & Trudie published a paper last year - "Measuring disability in patients with chronic fatigue syndrome: reliability and validity of the Work and Social Adjustment Scale" - highlighting the potential value of the widely used WSAS as a disability measure in chronic fatigue (and as a tool to help in discussion of activity targets). Initial WSAS scores in two fatigue cohorts treated at specialist centres were 27.2 (SD 6.3) and 26.9 (SD 8.5). The scores decreased significantly in severity and did so at approximately the same (fairly slow) rate that the Chalder Fatigue scores decreased - with the final WSAS ratings getting to the high teens by one year follow-up. Interestingly correlation with objective measures of physical activity improvement (e.g. walking & step tests) was only weak, highlighting how disability assessment is likely to be quite strongly coloured by factors like anxiety & depression. The WSAS is downloadable from the "Increasing access to psychological therapies (IAPT) outcomes toolkit" page of this website, where you'll also find other helpful measures. 5.) Still on this theme of allowing enough time for changes to develop, I notice that - in contrast to most CBT trials on anxiety and depression - after the first four sessions, appointments to treat chronic fatigue syndrome moved to fortnightly (rather than weekly). 6.) It might seem that GET (graded exercise therapy) is a much easier therapy to use than full-blooded CBT (just as behavioural activation is a simpler treatment than full CBT when treating depression). This is true, but not as true as it initially looks - see the freely downloadable treatment manuals to get a better idea of what's involved in GET. Overall though, you can see why it's so important to improve on these outcomes (25% fatigue reduction at one year) currently typically achieved with CBT or GET. Hence the developments explored in the second half of this workshop described in "Leeds BABCP conference: workshop on emotion processing in chronic fatigue syndrome - new ways to improve outcomes? (3rd post)".
