Behavioural and Cognitive Psychotherapy, 1999, 27, 249–260
Cambridge University Press. Printed in the United Kingdom

Clinical Section

THE TREATMENT OF WHEELCHAIR-BOUND CHRONIC FATIGUE SYNDROME PATIENTS: TWO CASE STUDIES OF A PRAGMATIC REHABILITATION APPROACH

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Abstract. Chronic fatigue syndrome is a disabling condition characterized by persistent mental and physical fatigue. Its aetiology is controversial, and it has been attributed to both physical and psychological causes. Previous controlled trials with ambulatory patients have shown that a proportion of CFS patients respond to cognitive-behaviour therapy. In this paper, we report two case studies of patients who are wheelchair-bound, who have been treated by a pragmatic intervention designed to increase activity and challenge dysfunctional illness beliefs. The patients received 60 and 55 contacts with the therapist, some of which were face-to-face and some of which were by telephone. At the end of treatment, the patients experienced clinically significant reductions in fatigue, were not using wheelchairs, showed an increase in occupational and social functioning and were leading relatively independent existences.

Keywords: Chronic fatigue syndrome, wheelchair bound, psychological treatment, case studies.

Introduction

Epidemiological studies show that up to 3% of the population fulfil recently agreed criteria for chronic fatigue syndrome or CFS (Wessely, Chalder, Hirsch, Wallace, &

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Wright, 1997). CFS is defined as persistent disabling fatigue of at least 6-months duration which is exacerbated by exertion and which cannot be explained by any identifiable medical cause (Sharpe et al., 1991). In addition to fatigue, CFS patients often complain of malaise, muscle pain, headaches, dizziness, disturbances of mood and sleep, impaired memory and cognitive difficulties. A small proportion may experience such a drastic reduction in physical functioning that they become bed and wheelchair-bound. This severe physical limitation with consequential feelings of loss of control can have very distressing personal, social and economic consequences.

The aetiology of CFS remains a matter of controversy. Extensive research has failed to find any serious underlying pathological process. However, since the majority of CFS symptoms are somatic, many patients attribute their condition to an underlying physical cause and are disinclined to accept a psychological explanation for their experiences. Attributing symptoms to solely external physical factors has been found to be a strong predictor of poor prognosis (Sharpe, Hawton, Seagrott, & Pasvol, 1992).

Circadian rhythm desynchronization has been observed in CFS patients (Williams et al., 1996). Other findings, particularly a high incidence of sleep abnormalities (Fischler et al., 1997) and deficiency of cortisol production (Cleare et al., 1995), are consistent with the hypothesis that CFS patients suffer from a physiological dysregulation, which effects both physical and mental functioning. The subsequent reduction in activity levels results in severe cardiovascular and muscular deconditioning. On this view, symptoms of CFS are precipitated by any disruption to life (for example, following physical illness or psychosocial stressors) sufficient to produce a marked and persistent decrease in activity together with desynchrony of the circadian rhythm. It has further been hypothesized that the syndrome is maintained by illness beliefs, which encourage avoidance of activity and poor sleep hygiene (Wessely, Butler, Chalder, & David, 1991).

The effectiveness of treatments for CFS is consistent with this hypothesis. Two randomized clinical trials of cognitive-behaviour therapy together with graded exercise have obtained positive outcomes, with as many as 70% of those who complete the treatment showing clinical improvement (Sharpe et al., 1996; Deale, Chalder, Marks, & Wessely, 1997). The cognitive-behavioural components of these interventions have focused on challenging patient's beliefs about avoidance of activity.

Traditional cognitive-behavioural therapy is expensive to deliver, and carries the risk of deterring patients who are often fearful of contact with mental health workers. We have therefore developed a pragmatic rehabilitation programme for CFS which includes elements of CBT (particularly challenging of illness beliefs) but which is briefer, and which is focused on a psychophysiological formulation of patients' difficulties. This intervention involves educating patients about the physical and psychological effects of physical deconditioning, circadian dysrhythmia and anxiety, and correcting inaccurate illness beliefs. The patient is then encouraged to accept the rationale of a graded exercise programme. In this paper, we describe the treatment of two patients using this approach. These patients have been confined to bed or a wheelchair for most or all of the time. We are aware of no previous studies in which non-ambulatory patients with CFS have been offered any kind of outpatient psychological treatment.

Case study 1: Ms A

History and initial assessment

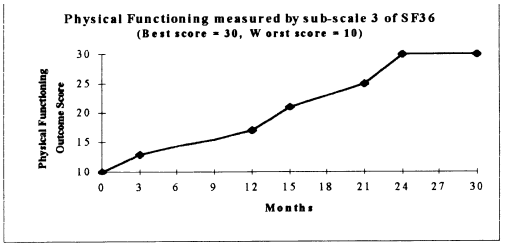
Ms A was a 16-year-old woman living with her parents, who had a six-year history of "recurrent infections" that included shingles, flu and recurrent tonsillitis. The onset of CFS was not clearly defined but was estimated to precede treatment by at least 27 months. Increasingly frequent episodes of sore throat and myalgia were ascribed to "tonsillitis" or "school phobia" by a family doctor. During these episodes she slept or rested in the day until returning to school and often felt tired for prolonged periods.

At 15 years of age, Ms A left school and briefly worked in a bakery before attending a full-time college course in drama. During this period her grandfather became seriously ill, her father had an emergency admission to hospital, and her brother divorced; these were experienced as significant life events. At college Ms A suffered from increasing fatigue and poor concentration and worried about her ability to cope with exams. However, she maintained an active social life outside college and attended a gym. After becoming ill with tonsillitis, she returned to college before making a full recovery and was sent home. She switched between activity and rest depending on her symptoms. At this time, Ms A's symptoms intensified. Her overriding complaint was of profound fatigue and she also experienced severe headaches. She became wheelchair-bound and because of intense fatigue she rested for 4 months in a horizontal position, during which time she was fed and toileted by her mother. Later she recalled catastrophic thoughts during this period (e.g. "I was going to die because my symptoms were so intense") which were exacerbated by the lack of any medical explanation for her symptoms ("Maybe I've got a new disease and they don't know how to cure me").

Ms A was referred to a hospital medical clinic specializing in CFS. A consultant physician (RHTE), diagnosed CFS based on the Oxford criteria (Sharpe et al., 1991). Prior to treatment, Ms A was assessed using validated self-report measures: the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), a fatigue scale (Chalder et al., 1993), the sleep problem questionnaire (Jenkins, Stanton, Niemcryk, & Rose, 1988), the physical functioning scale of the SF36 (Ware & Sherbourne, 1992), the London handicap scale (Harwood, Gompertz, & Ebrahim, 1994) and the Clinical Global Impressions scale (Guy, 1976). These assessments were repeated at regular intervals during the 2 years of treatment (see Figure 1). At initial assessment Ms A reported moderate level of clinical anxiety and depression. She scored maximum limitation for physical functioning, maximum score for fatigue, maximum score for muscle pain on a visual analogue and her score for sleep problems was close to maximum. On the London handicap scale she reported a disability score of 35%, with 100% representing no disability.

Treatment and outcome

Ms A was treated by PP over 60 sessions over 2 years, 43 of which were by telephone contact averaging approximately 20 minutes, and the remainder of which were one-hour face-to-face clinic appointments (total therapy time = approximately 32 hours). Treatment consisted of the pragmatic rehabilitation approach outlined above. In order to engage the patient in a successful therapeutic relationship, therapy initially focused

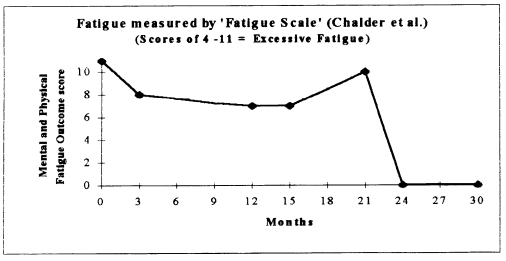


Physical Functioning Scores
Best score = 30 Worst score = 10

0mths	3mths	12mths	15mths	21mths	24mths	30mths
10	13	17	21	25	30	30

Cumulative Change

0	3	7	11	15	20	20

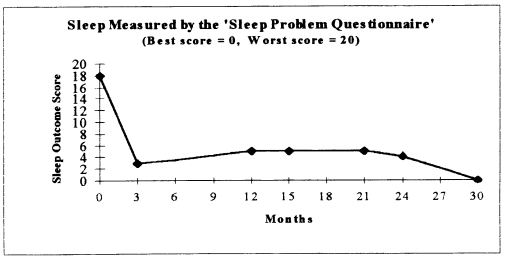


Mental & Physical Fatigue Scores
Scores of 4 to 11 = Excessive fatigue

0mths	3mths	12mths	15mths	21mths	24mths	30mths
11	8	7	7	10	0	0

Cumulative Change

0	-3	-4	-4	-1	-11	-11

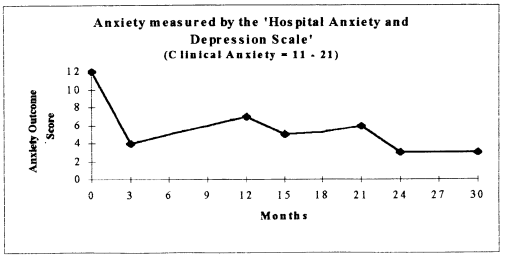


Sleep Scores
Best score = 0 Worst score = 20

0mths	3mths	12mths	15mths	21mths	24mths	30mths
18	3	5	5	5	4	0

Cumulative Change

0	-15	-13	-13	-13	-14	-18

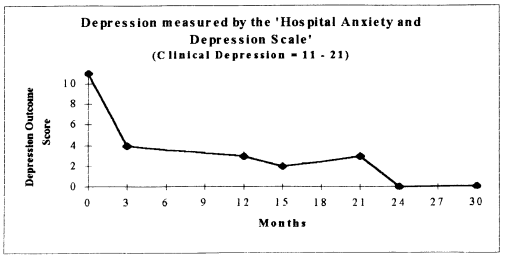


Anxiety Scores
11 to 21 = Clinical Anxiety

0mths	3mths	12mths	15mths	21mths	24mths	30mths
12	4	7	5	6	3	3

Cumulative Change

0	-8	-5	-7	-6	-9	-9



Depression Scores
11 to 21 = Clinical depression

0mths	3mths	12mths	15mths	21mths	24mths	30mths
11	4	3	2	3	0	0

Cumulative Change

0	-7	-8	-9	-8	-11	-11

Figure 1. Patient Ms A

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on addressing the patient's overwhelming physical perception of the illness. Ms A was given physiological explanations for her symptoms, supported by medical research that was presented verbally and supported by an educational pack. This included information about physical deconditioning, circadian desynchronization, and the effects of anxiety on the body. This information provided a rationale for a graded exercise programme. As treatment progressed the rationale was reiterated and an attempt was made to help Ms A become aware of the role played by psychosocial and personality factors that perpetuated her condition. Ms A's mother attended treatment sessions and was encouraged to constructively support Ms A at home.

Early exercises involve sitting, standing, and walking for increasing lengths of time. These were later followed by increasing time on an exercise bike and a step-up programme. Ms A was encouraged to avoid sleeping in the day and was asked to keep a daily diary of activities. She was given audiocassette relaxation tape to help her minimize any anxiety associated with her condition.

By exploring Ms A's fears about her symptoms the therapist was able to identify dysfunctional illness beliefs that had resulted in unhelpful coping. Ms A thought that a tumour could have caused her headaches. When she got chest pain she thought she was having a heart attack. She was extremely frightened of these symptoms. She believed that activity was harmful and, because rest appeared to relieve her symptoms, had avoided activities over a period of time. These beliefs had been supported by her mother and by literature supplied by the ME support group to which Ms A belonged.

The diagnosis of CFS was for Ms A, "A huge relief. It was an acknowledgement that I was suffering. I wasn't a fraud; there was something up. Also I didn't need to worry anymore because it wasn't a tumour". As can be seen from Figure 1, this was reflected in a marked reduction in her anxiety and depression scores at 3 months. Clarifying inaccurate illness beliefs with straightforward physiological explanations allowed Ms A to change her beliefs and appreciate the need to modify her behaviour ("My attitude has completely changed, I don't fear ME now. I know its not life-threatening"). The effects of "symptom watching" were discussed. Ms A was encouraged to generate alternative situational attributions for symptoms and to use distraction techniques.

During treatment Ms A suffered two set backs. The first was at 2 months, when the therapist was on holiday. Ms A was beginning to feel improvement when she, "Overdid it and the programme went off the rails". However, she was able to re-establish her exercise programme at a level at which she felt in control. The second and more severe setback occurred 8 months into the programme as a result of an influenzal illness. Following this, she rapidly deteriorated. She was unable to continue her exercises, and became depressed ("I took myself off into my room and didn't want to know. I wanted to die"). It took 4 months for Ms A to regain the level of exercise that she had performed immediately prior to the viral illness. Motivational interviewing techniques (Miller & Rollnick, 1991) were used to encourage Ms A. The patient's satisfaction with her current state of health was explored and compared with her premorbid state of health. Any discrepancies were amplified to encourage dissatisfaction and initiate change.

During treatment Ms A became increasingly competent in controlling her condition ("I've managed to accept the symptoms and that I have to go through a certain amount

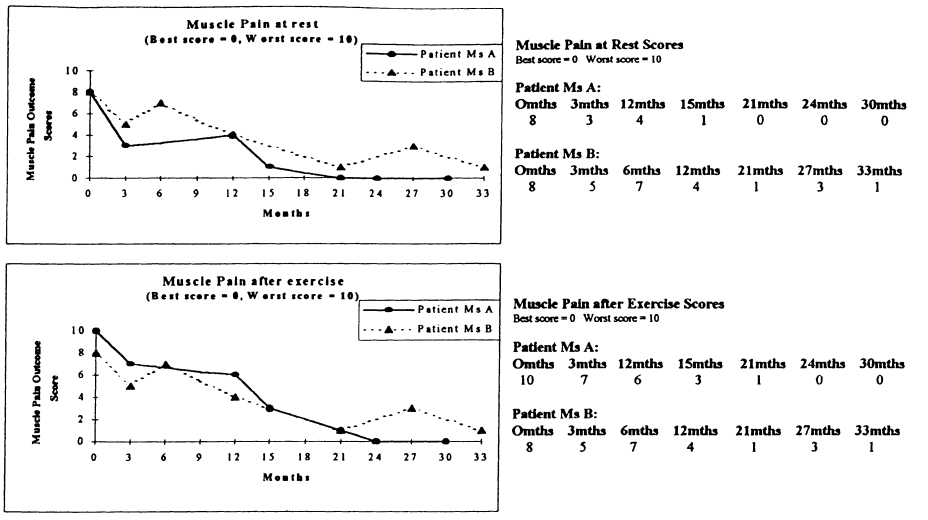

Figure 2. Muscle pain levels Ms A and Ms B prior to and following intervention

of pain to get better''). Over the later months of the programme, she recognized her physical achievements, which boosted her confidence and mood, leading to a further improvement in her exercise and consequential overall improvement in CFS symptoms. Ms A completely abandoned her wheelchair at 15 months. At 21 months, she was resuming challenging and stressful activities, which she had not performed since the diagnosis of CFS. These included singing and music lessons, regular socializing, coping with hospital visits to her ill father and supporting her mother. This demanding and, at times, stressful period was accompanied by an increase in fatigue. However, Ms A coped successfully, reporting that the fatigue was different in nature to that previously experienced during CFS, and attributed it to her circumstances.

The substantial reduction in Ms A's CFS symptoms is shown in Figure 1. In addition, her muscle pain dropped sharply, as shown in Figure 2. On the London handicap scale her score had substantially improved to 85%. After 24 months on the programme Ms A reported that she was 'Very much better'' on the Clinical Global Impression scale and was no longer in receipt of state disability benefits. Six months after completion of treatment her score on the London handicap scale was 100%, indicating no disabilities. She is now pursuing a musical career.

Case 2: Ms B

History

Ms B was a 25-year-old single French woman living with friends who cared for her. Her childhood was unhappy because of intense parental control; Ms B had frequent medical attendances that were dismissed as unnecessary. At 20 years of age, in an attempt to be free of family control, she moved to England. She worked as a school's computer technician and was very active. However, she reported that making so many

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changes in her life so quickly was very stressful and financially difficult. She worked long hours in a physically demanding role for her church. During this period Ms B was becoming increasingly tired and coped by sleeping after work and having weekend bed rest. She was isolated with little social support, which has been suggested to be a predisposing factor to this condition (Lewis, Cooper, & Bennett, 1994).

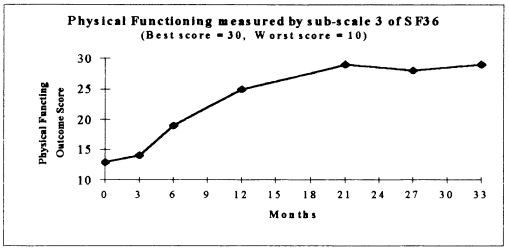
The onset of CFS was estimated to precede treatment by 50 months. Ms B had a viral infection following which she became active and "overpushed" herself. Suddenly she became "unusually tired", was overwhelmed by fatigue and pain, and collapsed. She was referred to several psychiatrists over the following 3 years, adding to her fears that she was not receiving appropriate medical attention (e.g. "I was terrified because I knew it was physical. I couldn't work out what was wrong with me. Nobody had examined me properly, I thought they'd missed something"). She was told she was tired because she was depressed and advised to become more active.

In an attempt to build up stamina, Ms B reported overdoing strenuous activities, which exacerbated her condition. She tried to endure her symptoms but became increasingly convinced that her problem was not just depression and that, "There was something physically wrong with me". Her intense myalgia forced her to give up church activities. Eventually, she had to give up work because of her profound fatigue. She was a member of a ME support group and received literature advocating rest. She therefore alternated between activity and rest depending on her symptoms. Some days she could not move and felt "paralyzed"; this was relieved by prolonged rest. She had catastrophic thoughts (e.g. "I believed I was going to die because I felt so ill"). Unable to care for herself because of severe fatigue she moved in with friends. For 3 years Ms B was completely bedridden and, "lost all track of time".

She was referred to the same hospital team as Ms A and was diagnosed with CFS using the Oxford criteria (Sharpe et al., 1991). She was in receipt of antidepressant medication from her GP, which she had taken for the previous 4 years. Prior to treatment she was assessed by the validated self-report questionnaires used in case study 1, which were repeated at regular intervals during the 27 months of treatment. At initial assessment Ms B reported non-significant levels of clinical anxiety and depression, and her score on the SF36 indicated severe physical limitation. She reported a maximum score for fatigue, muscle pain and her sleep problem score was close to maximum. The London handicap scale indicated a disability score of 38%.

Treatment and outcome

Ms B was treated by PP over 55 sessions over a period of 27 months, 53 of which were by telephone contact averaging approximately 26 minutes, and two of which were one hour face-to-face clinic appointments (total therapy time = 25 hours). Treatment consisted of the pragmatic rehabilitation approach described in case study 1. Therapy initially focused on addressing Ms B's intensely physical perception of her "illness". Physiological explanations for her symptoms, delivered verbally and supported by an educational pack, provided the rationale for a graded exercise programme similar to that described in case study 1. Ms B received little support from any significant person during treatment.

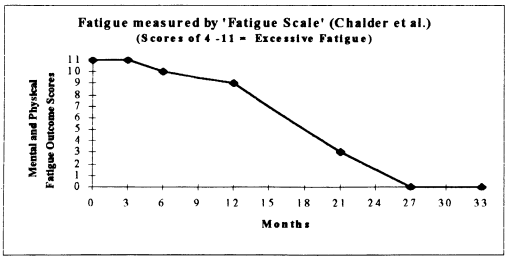


Physical Functioning Scores
Best score = 30 Worst score = 10

0mths	3mths	6mths	12mths	21mths	27mths	33mths
13	14	19	25	29	28	29

Cumulative Change

0	1	6	12	16	15	16

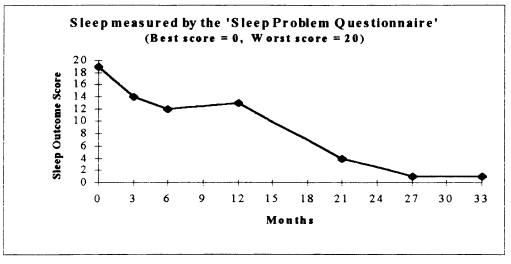


Mental & Physical Fatigue Scores
Scores of 4 to 11 = Excessive fatigue

0mths	3mths	6mths	12mths	21mths	27mths	33mths
11	11	10	9	3	0	0

Cumulative Change

0	0	-1	-2	-8	-11	-11

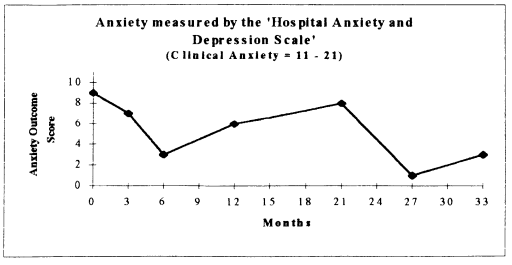


Sleep Scores
Best score = 0 Worst score = 20

0mths	3mths	6mths	12mths	21mths	27mths	33mths
19	14	12	13	4	1	0

Cumulative Change

0	-5	-7	-6	-15	-18	-19

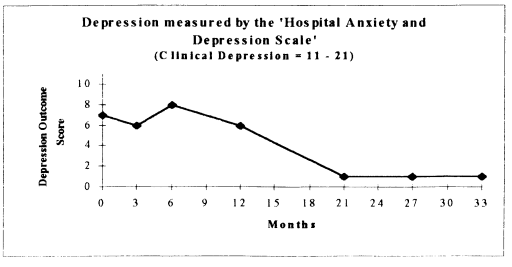


Anxiety Scores
11 t0 21 = Clinical Anxiety

0mths	3mths	6mths	12mths	21mths	27mths	33mths
9	7	3	6	8	1	3

Cumulative Change

0	-2	-6	-3	-1	-8	-6



Depression Scores
11 to 21 = Clinical depression

0mths	3mths	12mths	15mths	21mths	24mths	30mths
7	6	8	6	1	1	1

Cumulative Change

0	-1	1	-1	-6	-6	-6

Figure 3. Patient Ms B

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It was found that dysfunctional illness beliefs and the absence of appropriate medical advice had resulted in unhelpful coping behaviour, which was perpetuating her condition. She believed that a virus had caused "something in my body not to work properly", and that her severe palpitations were a sign of abnormal cardiac function. She was "terrified, tense and having spasms at night". Ms B spent most of the day sleeping or resting in bed and avoided activity in order to conserve enough energy for breathing and other vital functions.

As Ms B believed that previous medical investigations had been inadequate, the medical investigation conducted by the consultant physician had special significance for her. She was reassured by the tests, including a heart investigation, which showed no abnormalities. However, she had mixed emotions about her diagnosis ("Before I thought I was mad, then when they said ME, I was angry because nobody had believed me. I was also relieved because there was something up but I wasn't going to die"). A reduction in B's anxiety score was observed at 3 and 6 months.

With encouragement and the frequent reiteration of the treatment rationale, Ms B began to take control of her exercise programme. Her understanding of CFS was extended to include the harmful effects of excessively monitoring symptoms. This was a complicated issue for Ms B, who reported sensitivity to bodily symptoms associated with irritable bowel syndrome, wheat allergy and painful periods. She reported high expectations of her body and was therefore encouraged to realistically attribute fluctuations in symptoms to circumstances.

At about 6 months into the programme she ceased using a wheelchair but was still limiting her activity. At 9 months she stated, "I find it quite frightening that I'm getting better". At this stage of treatment Ms B was no longer in receipt of disability benefits. She resumed her church activities and went on holiday. At about 21 months into the programme she decided to move from her carer's accommodation into her own flat. During this period her anxiety increased. She felt unemployable as her previous training was outdated and parental pressure to resume her career caused her distress. However, by the end of treatment she was voluntarily teaching French, expanding her church role and seeking part-time employment.

The considerable reduction of Ms B's CFS symptoms is shown in Figure 3. In addition, there was a reduction in Ms B's muscle pain (Figure 2). On the London handicap scale her disability score had improved to 65%. After 27 months on the programme Ms B reported she was "Very much better" on the Clinical Global Impression scale. Six months after completion of treatment her scores on repeated outcome measures indicated that improvements have been maintained and the London handicap scale score had improved to 72%.

Discussion

We have described two uncontrolled case studies in which non-ambulatory patients with chronic fatigue syndrome were treated using a pragmatic rehabilitation approach. Both patients responded well to therapy. Outcome assessments of subjectively experienced fatigue, physical limitation, sleep problems and muscle pain showed a substantial reduction using validated measures. The most obvious indication of treatment success

was that neither patient needed a wheelchair nor walking aids once recovered and was no longer in receipt of disability benefits.

This was an uncontrolled study and the results must therefore be interpreted cautiously. However, it seems unlikely that the observed improvements were due to spontaneous resolution as studies indicate that, untreated, the prognosis is poor (Joyce, Hotopf, & Wessely, 1997). The suggestion that improvement in CFS was due to therapists' time and attention is unsupported by the results of two previous trials (Deale et al. 1997; Fulcher & White, 1997) which controlled for such factors. No other therapeutic intervention took place during treatment suggesting that improvement can be accredited to the intervention alone. However, confirmation of this is currently being addressed in a further similar study using a multiple baseline design.

Duration of treatment was longer than in two previous studies of cognitive behavioural therapy for ambulatory CFS conducted by Sharpe et al., 1996, (16 weekly sessions) and Deale et al., 1997 (13 weekly or fortnightly, mean therapist time was 15 hours). However, this was necessary in view of the severity of the patients' condition.

The delivery of treatment by telephone was a deliberate part of the treatment rationale. Initially, it enabled severely compromised patients to engage in therapy without the excessive demands of hospital attendance. The ability of the patient to conduct and monitor their own treatment is also encouraged, increasing their responsibility for and control over their condition.

Physical symptoms are ambiguous and subjective, open to a wide variety of interpretations, some of which may be inaccurate (Pennebaker, 1982). Both patients' hypotheses about the meaning of symptoms resulted in misinterpretations of the possible effects of symptoms on their bodies. As increased activity was associated with an exacerbation of threatening symptoms Ms A and Ms B limited their physical functioning in order to relieve symptoms and prevent deterioration of their assumed underlying pathology. The findings of this study are therefore consistent with previous observations that catastrophic interpretations in CFS patients are related to higher levels of fatigue as well as greater physical and social disability (Petrie, Moss-Morris, & Weinman, 1995). Prolonged avoidance of activity led to psychological distress and increased physiological deconditioning in Ms A and Ms B, resulting in intense symptoms at progressively lower levels of exertion, which reinforced their illness beliefs. Our findings accord with those of Ray, Jefferies, and Weir (1995) in that attempting to maintain activity was associated with less functional impairment, while accommodating to the illness was positively related to impairment.

Previous studies have noted the difficulty of engaging CFS patients in treatment, and the high risk of refusal (Butler, Chalder, Ron, & Wessely, 1991). The basic rationale of the pragmatic treatment approach is to draw together all the information regarding predisposing and perpetuating factors of CFS, and present this to the patient in a logical and acceptable package, thus minimizing the likelihood that the treatment will be rejected. As most patients see their condition in mainly physical terms, initial discussion of symptoms and treatment is conducted using an almost completely physical model of illness. (This process was probably facilitated by locating the treatment programme in a medical clinic.) For this reason, an important component of this form of therapy is the confirmation of the diagnosis and exclusion of other serious medical conditions by an experienced physician. Once this has been carried out, the therapist

can then reassure and explain the symptoms of CFS in terms of maladapted physiology, thereby challenging the patient's previously held inaccurate illness beliefs and unhelpful illness behaviour.

Once successfully engaged in treatment, patients can be made aware of the psychosocial and personality factors that predispose to and perpetuate their condition. (Discussion of these factors earlier in therapy would probably be met by resistance.) These may include significant stressful events such as those that appeared to play a role in the development of Ms A and Ms B's conditions. Such stressful life events have previously been noted in the histories of CFS patients (Salit, 1997), as has the perfectionist, pressurized life-style also observed in Ms A and Ms B (Lewis et al., 1994; Magnusson et al., 1996; Ware, 1993).

To summarize, the outcomes from these case studies support previous findings that suggest that psychological interventions targeted at challenging illness beliefs and increasing activity can significantly improve the well-being of CFS patients, and indicate that this kind of intervention may be effective even with severely disabled patients. Given the success of recent clinical trials of psychological interventions for CFS (Sharpe et al., 1996; Deale et al., 1997), future research might focus on establishing the most cost-effective method of delivering treatment, and determining whether particular subgroups of CFS patients respond to particular methods.

Acknowledgements

We are grateful to the Linbury Trust for supporting this research with a grant to Professor Bentall. We are also grateful to the Royal Liverpool University and Broadgreen Hospitals Trust, and to the Department of Medicine, Liverpool University, for their assistance.

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