

Clinical Section

In-Patient Treatment of Chronic Fatigue Syndrome

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A cognitive behavioural model for the development of chronic fatigue syndrome (CFS) is outlined. Six patients with CFS are described who were treated as in-patients using cognitive behaviour therapy. Treatment consisted of graded consistent exposure to activity and cognitive restructuring. Substantial improvements were made in all but one patient up to three months after discharge.

Introduction

In recent years attention has been focused on a particular group of fatigued patients; those with severe fatigue affecting both physical and mental functioning, associated with substantial physical disability. Such patients are described as having myalgic encephalomyelitis, post viral fatigue syndrome or chronic fatigue syndrome (CFS). The latter term is preferred because it is purely descriptive and makes no assumptions about aetiology (Fukada et al. and the International Study Group, 1994; Holmes et al., 1988; Sharpe et al., 1991).

A host of specific physical and psychological causes have been implicated in CFS. However, because of the subjective, heterogeneous nature of CFS it is likely that a complex interaction of physiological, cognitive, behavioural and affective factors are responsible for its development and maintenance. A cognitive behavioural model takes into account such factors and points towards effective treatment. A randomized controlled trial recently concluded that cognitive behaviour therapy led to a reduction in functional impairment and improvement in fatigue in out-patients with

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CFS (Sharpe et al., 1996). To date, little attention has been paid to those who need in-patient treatment.

The purpose of this paper is to briefly describe a cognitive behavioural model of CFS and to report six severe cases of CFS taken from a larger sample of patients described elsewhere (Butler, Chalder, Wessely and Ron, 1991; Wessely and Powell, 1989). They merit separate description since the severity of their symptoms necessitated in-patient treatment.

Cognitive behavioural model of chronic fatigue syndrome

The literature suggests that pre-morbid personalities of patients with chronic fatigue syndrome are characterized by a marked hyperactivity or workaholism and achievement orientation, perfectionism and high standards for work performance (Houdenove, Onghena, Neerincx and Hellin, 1995; Salit, 1985; Surawy, Hackmann, Hawton and Sharpe, 1995; Ware and Kleinman, 1992). Patients' pre-illness lifestyles have typically consisted of prolonged striving in order to achieve the personal high standards they have set for themselves. Failure to meet these standards results in the person feeling dissatisfied. Achievements seem to have an all or nothing quality about them and patients report an inability to enjoy whatever they are doing unless they are doing it well. These harsh personal expectations place an enormous burden on the individual, so much so that when an acute illness is experienced and the person is unable to perform to the usual high standard, he/she believes that something must be wrong.

Set in this context, delayed recovery from an infection, for example, may be the "straw that breaks the camel's back". Although there is little evidence that common viruses can cause a chronic fatiguing illness (Wessely et al., 1995) one recent study showed an association between Epstein Barr virus and delayed recovery six months after onset (White et al., 1995). It is likely, however, that once several years have past, factors other than the virus would be influencing the pattern of symptoms.

At the time of infection it is pertinent to rest in response to symptoms of fatigue, but if the patient is still fatigued and resting six months later, then it is reasonable to consider the contribution of factors other than the initial virus in the continuing illness.

Why might patients be resting six months after the onset of the symptoms? People generally use rest as a strategy for reducing symptoms. However, in some a reduction of symptoms does not occur. The symptoms persist and the person, understandably, continues to rest. Slowly, a reduction and avoidance of activities takes place for fear of bringing about a worsening of symptoms. Sharpe, Hawton, Seagrott and Pasvol (1992) found that avoiding exercise predicted disability in patients with CFS while Ray, Jefferies and Weir (1995) found an association between functional impairment and accommodating to the illness.

A number of studies have demonstrated that making physical illness attributions for fatigue predicts degree of disability in patients with CFS (Chalder, Power and Wessely, 1996; Sharpe et al., 1992; Vercoulen et al., 1996; Wilson et al., 1994). Many patients may believe the viral infection that triggered off the illness in the first place

is a persistent one, and that this accounts for their ongoing fatigue. As viruses are potent, uncontrollable, aversive, frightening and untreatable, feelings of being out of control are experienced (Helman, 1978; Powell, Dolan and Wessely, 1990; Chalder et al., 1996). This can be compounded by the advice given to sufferers. Some patients believe, and have been told, that they have a neuromuscular disease. Consequently, they worry about the risk of causing further muscle damage. This is an understandable response to the presence of myalgia, but it may not be an accurate attribution. Although some studies have suggested muscle abnormalities in CFS, the general consensus is that neuromuscular function is normal in sufferers (Lloyd, Hales and Gandevia, 1989; Lloyd, Gandevia and Hales, 1991; Riley, O'Brien, McCluskey, Bell and Nicholls, 1990; Stokes, Cooper and Edwards, 1988).

A further cognitive factor in CFS is that many patients, in an effort to control and reduce symptoms, often by adjusting activity levels, become hypervigilant and oversensitized to bodily sensations. This "symptom focusing" may serve to exacerbate unpleasant sensations (Warwick and Salkovskis, 1990) and has been shown to be associated with fatigue in patients with CFS (Ray et al., 1995).

In summary then, symptoms are perpetuated by physical illness attributions, unhelpful cognitions and schemas relating to perfectionism and avoidant coping strategies.

Subjects

All the patients had been extensively investigated by neurologists, and organic pathology had been excluded as a cause for their symptoms. Their care was then transferred to the Department of Psychiatry and the cognitive behavioural psychotherapy service. Patients were further assessed by a psychiatrist, using both standardized interviews and questionnaires (see Wessely and Powell, 1989). Psychiatric diagnosis was established by Research Diagnostic Criteria (RDC) (Spitzer, Endicott and Robbins, 1978). All patients thought they had ME, attributed their symptoms to an ongoing viral infection, and were members of the ME Association.

Case 1

This 43 year old married woman with two teenage children had a two year history of fatigue. Until the onset of her problem which started with a viral illness she had worked full time as a shop assistant. When first seen she was only able to walk within the confines of her home with the aid of a stick. When walking she dragged her right foot. She was unable to carry out any household chores and spent most of the day resting. As a result of her illness she had become socially isolated. In addition to profound physical and mental fatigue which was exacerbated by activity, she experienced frequent headaches. She was not depressed but described symptoms of autonomic anxiety. She believed her symptoms were caused by ongoing organic pathology despite negative neurological investigations. Previous treatment included a six month course of physiotherapy. There was no previous history of psychiatric disorder. She fulfilled RDC for minor depression.

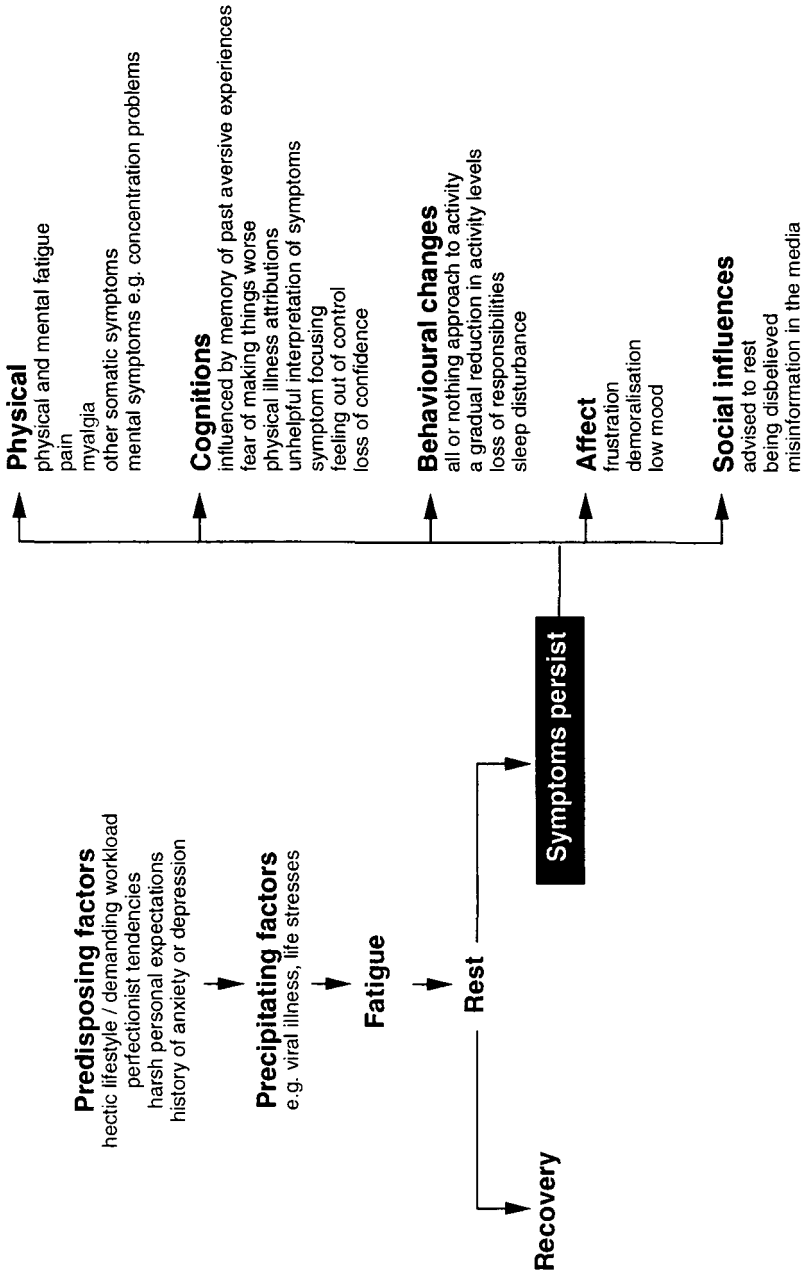


FIGURE 1. Model of chronic fatigue syndrome

Case 2

This 44 year old unemployed man had a five year history of an inability to walk because of lower limb weakness and poor co-ordination. Following a viral illness he went on to develop fatigue, abdominal pain and diarrhoea. His main complaints were physical and mental fatigue, accompanied by muscular and joint pain. He was unable to carry out any activities and needed help to wash and dress. He fulfilled RDC for major depression, and had mild hypertension. He had a previous psychiatric history of depression and psychosis which had been treated with antidepressants, major tranquillizers and ECT.

Case 3

This 25 year old single unemployed woman had a five year history of fatigue. She had been confined to bed for two years, getting up for the purpose of toileting only. She believed light and dust would aggravate her condition and therefore the windows of her bedroom were sealed and curtains were permanently drawn. She fulfilled RDC for major depression. She was living in a therapeutic community and required total care provided by other residents and staff. The move to a community home had been necessary because of her poor physical and mental condition. She had been told by a senior doctor in a self-help organization that she would be permanently disabled and would require long term care. She did not have a previous history of psychiatric disorder.

Case 4

This 42 year old married health visitor with two teenage children had a two year history of fatigue and muscle pain. Onset was associated with an influenza type illness accompanied by a busy stressful lifestyle. As a result of her fatigue she was confined to bed and slept for the greater part of the day. She fulfilled RDC for major depression and phobic disorder. Past treatments included homeopathy, acupuncture and spiritual healing. There was no previous history of psychiatric disorder.

Case 5

This 44 year old single woman had worked as a solicitor prior to her illness. She had been ill for three years and her main problems consisted of fatigue, muscle pain, and shortness of breath which became worse on physical and mental effort. She was unable to walk more than a few yards, was unable to cook, shop and maintain her home. In response to her difficulties she had moved back to the parental home. She fulfilled RDC for major depression but was unable to acknowledge she was depressed and attributed her difficulties to an ongoing viral illness. She had a history of depression at the age of 24 for which she had received psychotherapy.

Case 6

This 50 year old married man with a lifelong history of somatic complaints had a five year history of fatigue. His main presenting complaints were fatigue, weakness,

muscle twitching, blurred vision and concentration difficulties accompanied by the fear that activity of any sort would cause him harm. He constantly sought reassurance as to whether his symptoms were due to a yet undiscovered serious illness. He spent the majority of the day resting. He was severely depressed and prior to his admission he had made a suicide attempt. He fulfilled RDC for major depression and somatization disorder.

Method

Assessment and rationale

Treatment began with a detailed assessment that included a cognitive behavioural analysis of the main problem as identified by the patient. During assessment the foundations of the therapeutic alliance were established. Care was taken to establish an accepting, empathic relationship and to acknowledge the reality of the patients' distress and symptoms. It was important to allow expression of dissatisfaction with previous medical advisors, many of whom were perceived as disbelieving of the genuineness of patients' symptoms.

The rationale explaining the onset and maintenance of the principal problem was discussed in detail with the patient incorporating all aspects of the model described earlier. The therapist discussed with the patient the negative results of tests and investigations emphasizing that this did not detract from the reality of their physical symptoms. It was explained how taking a rigidly dichotomous view of illness contrasting organic and psychological was unhelpful and that a pragmatic approach was important whatever the cause. Watts (1982) summed this up by stating "The aim in working with disease should not be to move the patient from a belief in an organic aetiology to belief in a psychological one. This would not only be an unrealistic aim, it would usually represent one distortion of reality with another."

Once a treatment plan had been outlined the patient was asked to give feedback on their understanding of the approach and the therapist made a formal offer of a course of treatment. Patients were invited to discuss reservations or concerns about treatment at this stage.

Measures

Measures were given before and after the main intervention and at follow-up. Problems and targets were defined by the patient in collaboration with the therapist. A problem definition involved a succinct statement of the problem, taking into consideration cognitive, behavioural and physiological factors, for example, "difficulty in walking more than 20 yards owing to fatigue and muscle pain accompanied by the fear of making myself worse". Targets involved a behavioural description of long term goals, for example, "to be able to walk a mile a day without undue fatigue". These were rated on a nine point scale (0–8), the highest score representing the greatest degree of difficulty (Marks, 1986).

The Social Adjustment Questionnaire measured degree of handicap in relation to work, home, social leisure activities and private leisure activities, again on a nine

point scale (Marks, 1986). The Fear Questionnaire, which was devised for use in phobic disorders and primarily measures avoidance and dysphoria (Marks and Mathews, 1979) and the short form of the Beck Depression Inventory were also used (Beck, Rush, Shaw and Emery, 1979). A fatigue scale, (Chalder et al., 1993) assessed the severity of physical and mental fatigue. All measures were given pre- and post-treatment and at follow-up.

Treatment

Patients were initially treated on a neuro-psychiatric ward for between three and eight weeks. Mean therapist treatment time was 10.5 hours (range 7–15 hours). The therapist attended ward meetings in order to ensure that the team was aware of the treatment approach. After discharge from hospital, patients were seen for out-patient follow-up appointments. Mean total, in- and out-patient therapist time, was 14.6 hours (range 9–17). Five patients were depressed and were treated with a tricyclic anti-depressant (dothiepin; doses ranging from 50–150mg daily according to tolerance).

All patients received advice on graded consistent exposure to activity, facing the avoided activity in pre-planned steps of increasing difficulty. Goals were initially set at a level that was acceptable to the patient and achievable. For example, it was agreed that Case 4 should get out of bed for five minutes every hour. The aim of this negotiated goal setting was to maximize the chance of success, thereby increasing patients' confidence in the approach. An increase in activity levels was delayed until the previous activity could be performed without undue physical difficulty. Emphasis was placed on breaking the association between experiencing symptoms and stopping activity. As tolerance to symptoms improved, behavioural goals were stepped up. Before discharge from hospital most patients remained out of bed during the day, and were able to walk for at least fifteen minutes outside the hospital three times a day. Goals were gradually increased until the patient had reached the longer term targets initially agreed upon at assessment.

Planned rest was also an important part of the programme. Patients were reminded that, like activity, rest was to be regulated, taken at set times, for set durations, rather than in response to symptoms. As far as possible patients were encouraged to sleep at night rather than during the day in response to tiredness, and were told that any sleep taken during the day would be likely to result in insomnia. Care was taken to ensure that patients were actively involved in setting their own goals and they were encouraged to keep to them as far as possible. They were asked to keep a record of the activities undertaken and symptoms experienced. These records were then used as a basis for discussion in sessions with the therapist.

Patients' significant others were given detailed information about treatment and in two instances relatives were asked to act as co-therapists.

Two of the patients sought reassurance about the significance of symptoms, and their fears as to the consequences of increasing activity levels. Because of the consequences of reassurance seeking behaviour, the unhelpful nature of reassurance seeking was discussed with the patient (Warwick and Salkovskis, 1985). They were

then asked not to seek reassurance and were told that such requests would be met with a standard response in the form of a question "looking back to our earlier discussions about treatment what do you think my answer might be?" Whilst in hospital, patients came into contact with many health professionals. The entire health care team were therefore made aware of the importance of not giving reassurance, and were asked to give responses such as, "I am not able to discuss this with you; perhaps you should talk to your therapist about it."

The occurrence of negative thoughts, for example "If I go for a walk today then I'll feel worse and will not be able to do anything tomorrow", often hampers progress. Patients were therefore taught to monitor their negative automatic thoughts, to recognize the link between thought and behaviour and to generate more helpful alternatives (Beck et al., 1979).

In the course of treatment, particularly prior to discharge, the therapist discussed with the patient how to manage "setbacks" such as an apparent inexplicable exacerbation of symptoms. Patients were told that "setbacks" were inevitable, and that these should be prepared for systematically. They were encouraged to draw up a plan of action using principles they were already familiar with. General problem solving skills were taught and individual patients were encouraged to examine their previous lifestyles with a view to altering expectations of themselves and making appropriate changes if necessary for the future.

Many of the patients expressed concern about the difficulty of explaining to relatives and friends how improvement could be possible after a long period of disability due to an illness which they had previously been told was untreatable. Ways in which an explanation could be given and possible answers to difficult questions were examined. The therapist acknowledged that a return to health could in itself cause potential problems such as having to resume responsibilities about which they might feel ambivalent or fearful. Attempts were made to discuss such concerns openly.

Results

After treatment, five cases were much improved (1-4 and 6), with reductions in fears and avoidance and improvement in work and social functioning. There was a reduction in depression and fatigue scores. Four of the five cases who had improved at discharge maintained their gains to 3 month follow-up. Case 6 showed a moderate increase on some measures at 3 month follow-up as compared to discharge (see Tables 1 and 2).

The progress of Case 5 was hampered by treatment resistant depression. Furthermore, although she had accepted the offer of treatment, she was reluctant to accept the treatment model. The patient discontinued treatment at discharge from hospital but agreed to complete the questionnaires on request.

The pattern of change in patients who completed follow-up is shown in Figure 2.

TABLE 1. Results of main problem; main target; global social adjustment

Case no.	Problem (0-8)				Target (0-8)				Social adjustment (0-32)			
	B	P	1	3	B	P	1	3	B	P	1	3
1	7	2	1	0	8	2	0	0	27	5	2	0
2	7	1	0	0	8	1	0	0	31	6	11	
3	8	2	1	0	8	4	2	1	32	10	13	13
4	8	1	1	1	8	4	2	0	19	4	0	1
5	8	7			8	4			32	29		
6	8	3	3	3	8	2	3	4	26	9	10	13

B = Before treatment; P = Post treatment; 1 = 1 month follow-up; 3 = 3 month follow-up

TABLE 2. Results of Fear Questionnaire, Beck Depression Inventory, Fatigue Scale (to 3 months follow-up)

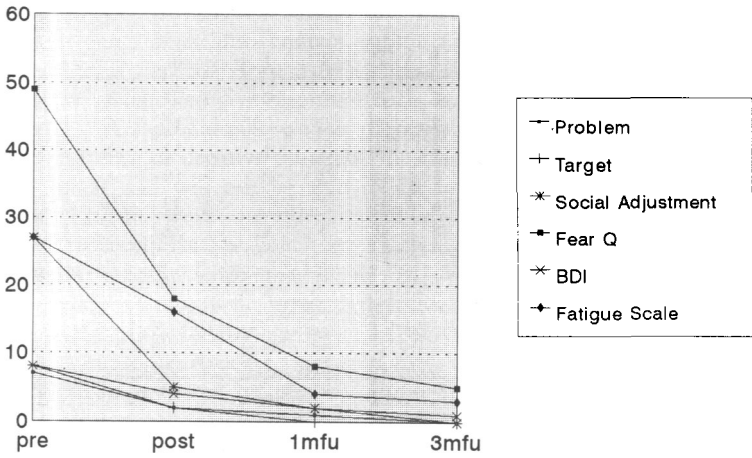
Case	Fear Questionnaire (0-120 global phobia)				Beck Depression Inventory (0-39)				Fatigue Scale (0-44)			
	Pre	Post	1mfu	3mfu	Pre	Post	1mfu	3mfu	Pre	Post	1mfu	3mfu
1	49	18	8	5	8	4	2	1	27	16	4	3
2	39	16	13	13	7	6	0	0	31	1	1	1
3	36	33	22	28	17	9	3	6	33	8	5	16
4	8	3	0	0	8	1		0	23	10	8	8
5	60				30	25			31			
6	74	28	46	47	27	16	7	9	34	4	12	4

Discussion

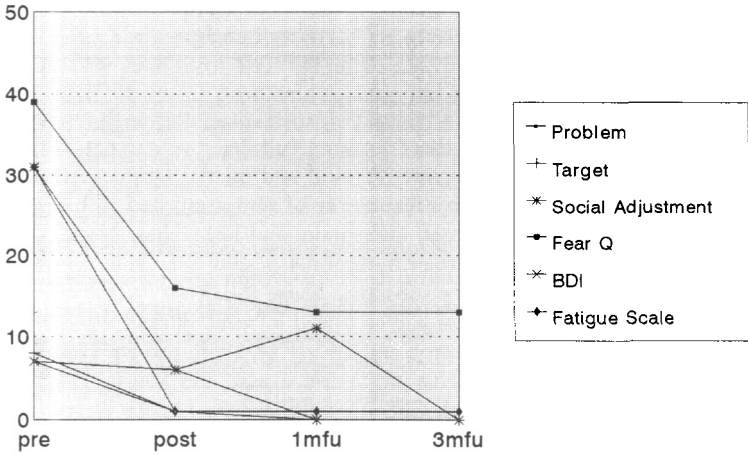
From a descriptive point of view these patients fulfilled the current criteria for chronic fatigue syndrome; all had severe physical and mental fatigue. All reported that even minor exertion brought on a recurrence of symptoms and all had multiple somatic symptoms such as sore throat, chest pain, and headaches. None had been given an adequate explanation for their symptoms despite intensive investigation, and none suffered from psychosis or substance abuse (Sharpe et al., 1991). Finally, five out of six stated that their illness had followed a "viral" illness.

The overlap between major depression and CFS (Ray, 1991) and between somatization disorder and CFS (Katon, Buchwald, Simon, Russo and Mease, 1992) is now well known. Thus many patients with CFS also fulfil criteria for depression (Levine, Kreuger and Straus, 1989; Behan, More and Behan, 1991). At present no definitive diagnosis can be established as both categories remain operational rather than aetiological constructs. We elected to accept the label of CFS, as patients were comfortable with it. In terms of treatment, we used cognitive behavioural interventions which are widely used for conditions such as depression and chronic pain but adapted them for the problems peculiar to CFS.

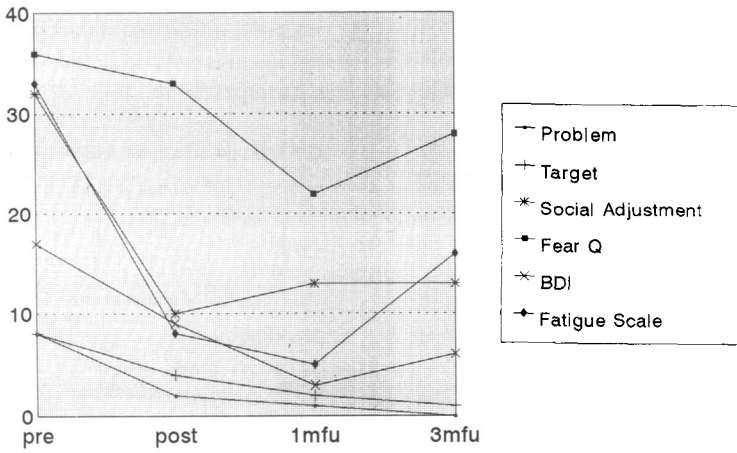
FIGURE 2. Pattern of change in five severe cases of CFS



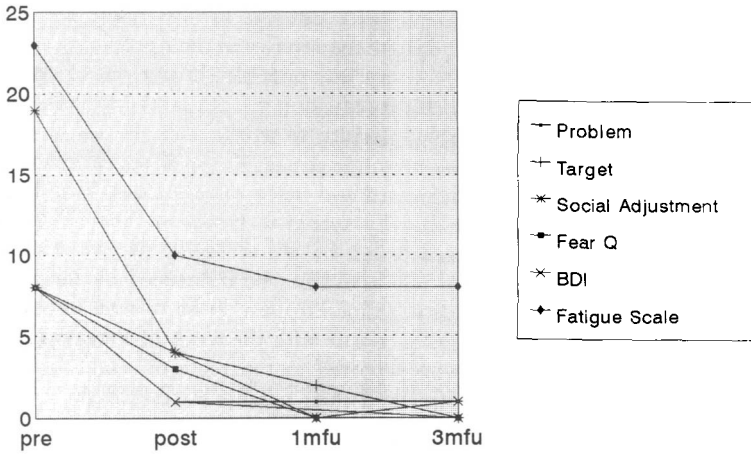
CASE 1. Main problem and target, total social adjustment, Fear Q, BDI, Fatigue Scale



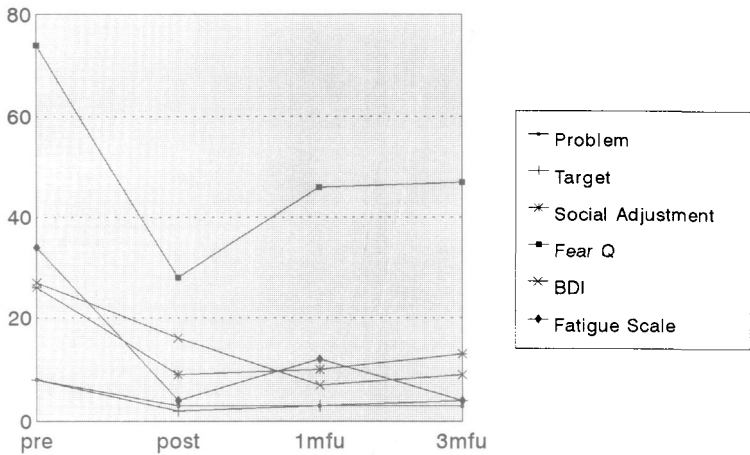
CASE 2. Main problem and target, total social adjustment, Fear Q, BDI, Fatigue Scale



CASE 3. Main problem and target, total social adjustment, Fear Q, BDI, Fatigue Scale



CASE 4. Main problem and target, total social adjustment, Fear Q, BDI, Fatigue Scale



CASE 5. Main problem and target, total social adjustment, Fear Q, BDI, Fatigue Scale

The case series we report was not part of a randomized controlled trial and the results should therefore be interpreted with caution. However, the results show, that for the patients described here, despite the severity of their problems, substantial improvement and even complete recovery was possible. In five out of six patients there was an improvement in mood and a reduction in both disability and symptoms of fatigue. Patients 1 and 4 were able to return to work.

There are several possible reasons why one patient dropped out of treatment and failed to do well. First, she was depressed and failed to respond to anti-depressant medication. Second, although she initially agreed to treatment, she did not accept the model of the problem presented to her by the therapist. She was fixed in her belief that the illness was physical and could not be influenced by therapy. Individuals' beliefs about the nature of the illness appear to be of vital importance in CFS. It is noteworthy that our results concur with the work of Vereker (1992) and Rikard-Bell and Waters (1992) who reported that parents of children with CFS responded less favourably to treatment if their parents attributed the problem to organic factors.

It is unclear whether recovery was related to therapist time, specific techniques or anti-depressants. However, the improvements were unlikely to be due to chance alone as the average length of illness prior to referral was three years, after which spontaneous improvement is exceptional (Behan and Behan, 1988; Sharpe et al., 1992). It also seems unlikely that antidepressants alone were sufficient to account for the dramatic improvement made by most of the patients.

The cost-effectiveness of treatment for patients who have chronic disabilities is

receiving increasing attention (Shaw and Creed, 1992). Improvements in health care have occurred with the advent of cognitive behavioural treatment programmes for problems associated with functional disabilities. This should lead to a reduction in long term costs to the health service (Cott, Anchel, Goldberg, Fabich and Parkinson, 1990). Without effective treatment patients with CFS may receive unnecessary investigations, and continue to require a range of services few of which lead to clinical improvement.

In conclusion, we have shown that despite the severity of both symptoms and disability, substantial improvements can be made in CFS sufferers who require inpatient treatment. Future research should concentrate not only on elucidating bio-psycho-social causes for the problem, but should also take a pragmatic approach to management which aims at lessening disability.

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