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# **Doctor of Clinical Psychology Degree**

**\* This volume was submitted in partial fulfillment  
of the degree of Doctor of Clinical Psychology**

**An Exploration of Activity, Fatigue and Mood in Chronic  
Fatigue Syndrome**

**& Research Portfolio (Volume 1)**

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Submitted in partial fulfilment towards the degree of Doctorate in Clinical Psychology,  
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**August 1998**

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# **VOLUME 1**

**SMALL SCALE SERVICE RELATED PROJECT**

**Evaluation of an Opt-in System in Primary Care**

*Target Journal: Clinical Psychology Forum  
(see Appendix 1 for Submission Notes)*

# Evaluation of an opt-in system in primary care

## INTRODUCTION

Non-attendance of patients has long been an issue for clinical psychologists. Various authors have associated it with decreased therapist morale (Hughes, 1995) and wasted therapist time (Startup, 1994), time that could be used to decrease the lengthy waiting lists which burden most psychology services (DCP, 1993).

Non-attendance and early treatment terminations are estimated to account for between 25 and 40 per cent of all outpatients referred to clinical psychology services (Markman and Beene, 1990; Trepka, 1986, respectively). Hughes (1995) estimates that, in British clinical psychology services, approximately one third of patients terminate treatment early. First appointment non-attendance predicts a likelihood of subsequent second appointment non-attendance (Weighill, Hodge and Peck, 1983). A potentially effective method of increasing first appointment attendance is to ask patients to "opt-in" to treatment. Anderson and White (1995) found the use of an opt-in system in primary care clinics decreased the first appointment "did not attend" (DNA) rates from 25 to 3 per cent. Another promising method is to prepare patients for psychological input by providing information about the role of the psychologist and the service they provide. Webster (1992) found the use of information leaflets at a day centre psychology service reduced first appointment DNAs from 43 to 18 per cent and also improved patient satisfaction with the session itself. Spector (1988) reported that combination of opt-in system and information leaflets reduced a first appointment DNA rate from 35 to 12 per cent.

The present study aimed to evaluate a system of opt-in and information provision in reducing first appointment DNAs in comparison with a similar primary care clinic without an opt-in system, i.e. with a "conventional" referral system.

The Renfrewshire Clinical Psychology Department was requested to set up a special primary care service funded directly by the Scottish Office. It was to run in a town which had not previously had a local primary care psychology service. The funding was initially for one year only and it was deemed the ideal opportunity to pilot a new system of referral in which the GP was involved with both information provision and an opt-in system. In this system the GP gave the potential clinical psychology patient an information leaflet and a "consultation request form". The information leaflet was entitled "The Bishopton Stress Clinic" and contained information under the headings: who can be helped, what kind of help patients might receive, results of treatment, patient involvement, what is a clinical psychologist, and how to get, cancel and change appointments. The consultation request form simply required the patient to fill in sections giving their name, address and signature. It also allowed them to add some information about their problem, should they wish. The GP also explained briefly why a referral to the clinical psychologist might be of benefit. Next the patient was required to fill in the request form and return it to their GP in their own time, it was then sent by the GP, with a covering referral letter, to the clinical psychology department. On receipt of the referral letter and completed form, the patient was then placed on the waiting list and was usually seen within the next three or four weeks.

## **METHODOLOGY**

As this service was new, it was not possible to compare the DNA rates of the group using the opt-in system with data prior to the introduction of the system, as has been done by other authors (e.g. Anderson and White, 1995). Instead it was necessary to find a similar primary care service with which to make the comparison. This was not feasible within the department as the new service had a minimal waiting list whereas other department primary care clinics had relatively long waiting lists. As waiting list length is likely to be linked with increased first appointment DNAs (Anderson and White, 1995), it was necessary to obtain data from a different Clinical Psychology Department. It was hoped that in this way a comparative group could be found, i.e. a group with similar waiting times and similar sociodemographics, but without any form of opt-in system (the conventional referral group).

The opt-in group consisted of 61 referrals from the 12 month period (July 1995 to June 1996) to the new clinic in Renfrewshire. The conventional referral group consisted of 115 referrals from a three year period (March 1993 to March 1996) to a primary care clinic in Ayrshire (a longer time period was used to give a larger number and thus allow for more robust statistical comparisons to be made). All patients were between the ages of 16 and 65 inclusive. All were first referrals to the psychology service. The two areas were also considered to be similar enough in socio-economic terms. According to the most recent census data (Crown census, 1991), the opt-in group had a three per cent unemployment rate and the conventional referral group had a four per cent unemployment rate (where "unemployment" is defined as claiming unemployment benefit only and does not include those claiming income support, disability allowance or retired individuals).

For each patient, data was collected on age, sex, waiting time and diagnosis or "reason for referral". This last variable was used to assess whether GPs in both areas were referring similar types of problem. The coding system used was that of the Renfrewshire psychology department, and for the purposes of analysis, coding of problems was condensed into three simple categories: (1) anxiety disorders (i.e. generalised anxiety disorder, panic attacks, phobias, post traumatic stress disorder and obsessive compulsive disorder, as grouped by the DSM-IV, 1994); (2) depression; and, (3) "other", essentially non-affective disorders (such as grief, eating disorders and neuropsychological assessment)

## **RESULTS**

### *Comparison of opt-in sample and conventional referral sample*

Age, sex, waiting times and reason for referral for each of the two groups are described in table 1.

.....  
*Insert Table 1. About Here*  
.....

Independent t-tests showed that there were no significant difference between groups for waiting time ( $t=1.05$ ,  $df=174$ ,  $p = n.s.$ ) or age ( $t=1.05$ ,  $df=174$ ,  $p = n.s.$ ). Chi-square test on sex and reason for referral also demonstrated no significant differences between the groups ( $\chi^2=1.146$ ,  $df=1$ ,  $p = n.s.$ ;  $\chi^2=0.399$ ,  $df=2$ ,  $p = n.s.$ , respectively).

Thus the two groups were noted to have very similar mean ages and age ranges. Both groups had greater numbers of women referred than men. Waiting time means also appeared similar although the conventional referral group had a more variable range of waiting times. Both groups had very similar percentages of anxiety disorders, depression and "other" reasons for referral

The above analysis demonstrated that the selected conventional referral group was similar to the opt-in group. This allows a comparison of DNA rates between the two referral systems to be completed. See table 2.

.....  
*Insert Table 2. About Here*  
.....

Defining "contact" as either attending or cancelling an appointment, there was no significant difference between groups (group ( $\chi^2=0.034$ ,  $df=1$ ,  $p = n.s.$ ). Defining "attendance" as attending an appointment, i.e. neither cancelling nor DNAing, again no significant difference was found between the groups ( $\chi^2=0.537$ ,  $df=1$ ,  $p = n.s.$ ).

## DISCUSSION

The results of this study indicated that the opt-in system group was not significantly different from the conventional referral system group in terms of frequency of first appointment DNAs.

### *Why did the opt-in system not decrease DNA rates?*

As mentioned in the introduction, previous studies have supported the efficacy of opt-in systems in reducing first appointment DNA rate (Anderson and White, 1995; Spector, 1988). However, Markman and Beeney (1990) found that an opt-in system did not affect first appointment DNA rates. Perhaps the reason for this discrepancy between the above studies is due, in part, to first appointment DNA rates prior to an opt-in system being introduced. Anderson and White (1995) found this to be 25 per cent and, Spector (1988), 35 per cent. However, Markman and Beeney (1990) noted a DNA rate of only 15 per cent before the opt-in system was introduced. In the present study, the conventional referral group had first appointment DNA rate of only 7.4 per cent.

Such a low DNA rate suggests that the conventional referral group used in this study may be different from the groups reported in previous studies. The comparison group in this study was obtained from a trading agency. This factor may have played some part in the low DNA rate observed in this group. Perhaps, because the trading agency had recently formed and had been in contact with many local GPs to explain their role, referrals may have been more appropriate. The agency certainly emphasised the importance of providing an acceptable service to GPs and had contracted to stay within an average waiting time of nine weeks. It is possible that these actions made local GPs more “psychologically aware” and thus they made more appropriate referrals, which might have resulted in greater first appointment attendance.

In both groups patients waited for approximately four weeks before being seen. It would appear that both the opt-in and the conventional groups had shorter waiting times than the norm (DCP, 1993). Geekie (1995) reported a typical primary care waiting list as being 15 weeks and the DCP report (1993) noted the most common waiting time nationally to be 17 to 26 weeks. In the Anderson and White study, waiting time was 26

weeks. It is suggested that, if a patient has to wait a long time for a first appointment, their situation might change in a number of ways, which might affect whether they attend their first appointment. For example, their problem may have improved during the wait, they may have gained help or support from other sources or they may have lost motivation, resulting in their not wishing intervention.

Also, both groups in the present study appeared to have come from areas of relatively low unemployment and, by implication, higher socio-economic status. Weighill, Hodge and Peck (1983) noted that socio-economic status was related to broken appointments and self-termination of treatment.

*So when would an opt-in system be of use?*

From the literature and from the above results, there would appear to be times when the use of an opt-in system would be especially efficient. In particular, it seems that such a system might be of much benefit when;

1. waiting lists are long,
2. DNA rates are high,
3. clinics cover areas with higher levels of deprivation.

Any combination of these three factors might warrant an opt-in system. When waiting lists are short (e.g. less than six weeks), there may be no advantage in using an opt-in system.

## **CONCLUSION**

In certain services and clinics, opt-in systems may be very effective in reducing first appointment DNA rates. However, an opt-in system may not be necessary when waiting times are short and DNA rates are low. An opt-in system is an additional administrative burden and this hidden cost cannot be ignored. Nevertheless, opt-in systems such as the one used in this study, may be less of a burden than clinical psychology driven opt-in systems due to the extent of GP involvement.



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Table 1: Comparison of samples: Age, sex, waiting times and reason for referral

		<b>Opt-in referral system</b>	<b>Conventional referral system</b>
Age (years)	<i>mean</i>	39.03	37.09
	<i>range</i>	17 - 63	17 - 64
Sex (%)	<i>males</i>	39.3	31.3
	<i>females</i>	60.7	68.7
Waiting time (weeks)	<i>mean</i>	4.34	3.92
	<i>range</i>	1 - 8	0 - 14
Reason for referral (%)	<i>anxiety</i>	57.4	55.2
	<i>depression</i>	23.0	21.0
	<i>"other"</i>	19.7	23.8

Table 2: Attendance at first appointment: Opt-in system v conventional referral system

<b>First appointment</b>		<b>Opt-in referral system</b>	<b>Conventional referral system</b>
Attended	n (%)	52 (85.2)	87 (80.6)
Cancelled	n (%)	4 (6.6)	13 (12.0)
DNA (no contact)	n (%)	5 (8.2)	8 (7.4)

# **MAJOR RESEARCH PROJECT LITERATURE REVIEW**

## **Activity, Fatigue And Mood In Chronic Fatigue Syndrome: A Review**

*Target Journal: Journal of Psychosomatic Research  
(see Appendix 2 for Instructions to Authors)*

# **ACTIVITY, FATIGUE AND MOOD IN CHRONIC FATIGUE SYNDROME: A REVIEW**

Running Head: Activity, Fatigue and Mood in CFS: A Review

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# **Activity, Fatigue and Mood in Chronic Fatigue Syndrome: A Review**

*Abstract - The role of psychological and behavioural factors in the aetiology and symptomatology of chronic fatigue syndrome (CFS) has recently been recognised in the literature. Theoretical models of CFS emphasise that activity levels, perception of fatigue and low mood are important in this syndrome. Studies of these three factors in CFS are therefore reviewed, and it is suggested that much of the past literature in this area has used experimental designs and methods which have yielded contradictory findings. In particular, several studies have used retrospective, self-report measures of activity, which have been found to be unreliable in this patient group. The use of concurrent, subjective ratings and objective measurements of the factors is suggested for future research. This approach also allows diurnal variability of the factors to be investigated, which is felt to be another important but under-researched area in CFS.*

*Keywords: Activity; Chronic fatigue syndrome; Fatigue; Mood.*

## **INTRODUCTION**

Chronic fatigue syndrome (CFS) is a condition defined, most prominently, by the presence of persistent and disabling fatigue which is out of proportion with the sufferer's level of activity or exertion. Fukuda, Straus, Hickie et al. (1), from the American Centre for Disease Control, define the condition by the presence of fatigue lasting for six or more consecutive months for which no other underlying or contributing medical or psychiatric condition can be found. In addition, four or more of the following symptoms must be present for six months or more: impaired memory or concentration, sore throat, tender lymph nodes, muscle pain, joint pain, headaches, un-refreshing sleep, and post-exertion malaise. Another operational definition, recommended by the Royal Colleges of Physicians, Psychiatrists and General Practitioners, is that proposed by Sharpe, Archard, Banatvala et al. (2). This definition

focuses on similar criteria to that of Fukuda et al. and also provides guidelines for research. Prior to 1991 other definitions of CFS existed which, in clinical terms, were more than satisfactory. However, as research criteria they were a little broader than has been recommended recently, thus the methodology of earlier research should be viewed cautiously.

Since CFS has only relatively recently been acknowledged as a disorder by medical and allied professions, it is surprising how prevalent it is currently thought to be. Using the recommended criteria above, the population point prevalence of CFS is estimated to be approximately 0.6 per cent in primary care (3).

#### *Theories of the aetiology and pathogenesis of CFS*

Numerous theories regarding the aetiology and pathology of CFS have been suggested over the last ten years or so, though few of these have been convincingly supported by the literature. These theories have included:

1. Viral infections as a cause (4, 5, 6) or a trigger (7) for CFS.
2. Muscle dysfunction as the cause of fatigue (8, 9, 10).
3. Immune system depression (11, 12, 13, 14) or activation (15) as a cause.
4. Neuro-anatomical (16) or neuro-endocrinological (17, 18) changes resulting in fatigue.
5. Psychological difficulties (19, 20, 21) presenting as a fatigue syndrome.

As noted in the report by the National Task Force on CFS (22), “Chronic fatigue syndromes often do not fit neatly into the conventional view that disease is either physical or psychological” (p. 2).

The report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners (23) notes as part of its conclusion:

*“There is no evidence that infections have a primary causal role in the vast majority of cases, although they appear to precipitate the disorder in some. Previous personality factors and premorbid distress appear to be more important than common viral infection per se. They may also play an important part in perpetuating disability.*

*“The evidence for structural or functional abnormalities of brain or muscle or for a disturbance of endocrine or immune function as primary aetiological factors in CFS is currently weak.” (p. 37)*

Thus the report emphasises and acknowledges the large part played by psychological factors in the symptomatology of CFS.

It is the intention of this review to investigate the literature relating to activity levels, perceptions of fatigue and low mood in sufferers of CFS. Few studies simultaneously address these specific aspects of the CFS experience, as a consequence, the literature regarding important theoretical models of CFS will be reviewed initially, followed by the literature on each separate factor. Finally, the few papers which address these or similar variables simultaneously will be discussed.

## **COGNITIVE BEHAVIOURAL MODELS OF CFS**

Wessley, David, Butler and Chalder (24) theorised that a number of factors interact in CFS, perpetuating and maintaining symptoms. These include; patients' beliefs of physical illness, resultant decreases in activity, which lead to deconditioning, and depression, with its concomitant behaviours. They postulated the existence of a vicious circle in which the CFS sufferers attributed all their symptoms to a disease and avoided activity in order to avoid symptoms, thereby exacerbating both depression and deconditioning and hence increasing fatigue and weakness and perpetuating symptoms.

This theory was further developed by Surawy, Hackmann, Hawton and Sharpe (25). They identified the key clinical features of CFS as coming under the headings of; symptoms, illness beliefs, behaviour and emotion. The identified symptoms were; physical and mental fatigue, muscle pain and symptoms associated with sympathetic nervous system activity. Illness beliefs centred around attribution of symptoms to disease, fear of exacerbating symptoms and concerns about lost performance. Behaviours tended to be avoidance of activity and fluctuation between activity and inactivity. Finally, associated emotions were identified as frustration and a reduction in



the expression of anxiety and depression, despite the presence of symptoms typically associated with anxiety and depression. Surawy et al also attempted to explain the onset or precipitation of CFS in cognitive terms. They noted that certain aetiological factors were commonly observed in the history of CFS sufferers. Notably premorbid personality characteristics such as being “hard-working and achievement oriented” and a tendency to “bottle up” emotions. There was also a commonality about the events surrounding the onset of the illness, including chronic pressures to perform, life events and symptoms of acute illness. It is proposed by this paper that once the symptoms of fatigue are established they are perpetuated by various cognitive, behavioural, physiological and social factors (figure 1).

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*Insert Figure 1. About Here*  
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Fry and Martin (26) reviewed the area and proposed a development of the model emphasising the role of cognitive processes in enhancing the perception of symptom severity and hence perpetuating illness beliefs. This model explicitly presents the theoretical inter-relationships of fatigue, mood and activity. See figure 2.

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*Insert Figure 2. About Here*  
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This model was based on the evidence reviewed by Fry and Martin that, in CFS, fatigue is neither peripheral; e.g. muscular or neuromuscular; nor central, e.g. neuroendocrinological. Rather, fatigue is viewed as being a cognitive phenomenon brought about due to perceptual distortions and resultant changes in affect.

Support for such a cognitive behavioural model of CFS might be extrapolated from the relative success of cognitive behavioural therapy (CBT) as a treatment or management of CFS. Such treatment aims to help the patient re-evaluate his understanding of his illness and find more appropriate behavioural methods for dealing with it. Sharpe,

Hawton, Simkin et al (27) undertook a randomised control trial of CBT, in conjunction with standard medical care. Experimental subjects, who received 16 weekly sessions of CBT, showed significantly superior outcome measures with 73% achieving a satisfactory outcome at 12 months from the start of the study, compared to 27% of the control group. These results are supported by other similar studies, such as Wessley, David, Butler and Chalder (24) and Butler, Chalder, Ron and Wessley (28) but are not unequivocal (29, 30). Nevertheless, the report by the joint working party of the Royal Colleges (23) concludes that, as a treatment for CFS, CBT is a promising and cost-effective approach.

## **ACTIVITY IN CFS**

As noted above, fatigue, illness beliefs and perceptions in CFS invariably impact on the sufferer's behaviour, often resulting in decreased levels of day-to-day activity. Leisure pursuits, socialising and working are all frequently reported by CFS sufferers to be adversely affected by their illness. Many report avoiding activities due to anxiety about the consequences of "overdoing it" and, as a result, become deconditioned and more disabled. The subjects of rest, exercise and activity in CFS are surrounded by misconceptions and apprehensions for both the CFS patient and the clinician.

### *Rest*

It is widely accepted that "rest", particularly bed-rest, has many adverse consequences (31, 32). Saltin, Blomquist, Mitchel et al. (33) measured a 30% loss of aerobic capacity in just three weeks of bed-rest in trained individuals. The Royal Colleges report states that, from the available evidence, rest is contraindicated in CFS and very recently Sharpe and Wessely (34) emphatically titled a report on the issue; "Rest has no place in treating chronic fatigue". However, for a variety of reasons, CFS sufferers may have treated their symptoms using long periods of bed-rest and over-sleeping. Vercoulen et al. (35) note that, although there was no difference in total sleeping time during the night between CFS patients and healthy subjects, the CFS group did spend more time asleep or resting during the day. The consequences of such behaviour is frequently deconditioning of muscles resulting in further fatigue.

### *Exercise*

There are many studies looking at exercise in CFS sufferers. A recent review by McCully, Sisto and Natelson (36) concluded that CFS patients were not significantly weaker nor more impaired than controls and that any reports of reduced exercise capacity in CFS is likely to be due to deconditioning as a result of the severe reductions in activity levels reported by CFS patients, as opposed to being part of an illness pathology.

There is literature which supports the use of graded exercise programmes in the treatment of CFS. For example Fulcher and White (37) tested the efficacy of a graded aerobic exercise programme compared to a relaxation and flexibility programme. They found fatigue, functional capacity and fitness were significantly improved after exercise relative to flexibility training.

It would generally appear from the literature that the exercise capacity of people with CFS is not significantly different from normal given their levels of activity and rest. Their perceptions of exercise, however, are quite different. Despite showing normal muscle physiology before and after exercise, their perception of effort during exercise has been shown to be significantly raised (38). There is evidence that these perceptions are centrally, rather than peripherally, mediated. Stokes, Cooper and Edwards (39) proposed that this central process involves a decreased threshold for sensations coming from peripheral receptors in the body. Fischler, Dendale, Michiels et al (40) note from their exercise study that CFS subjects are less tolerant and more avoidant of exercise. Interestingly, they also note that, in accordance with cognitive-behavioural models, perceptions of fatigue and effort are associated with increased functional disability in everyday living.

Taking the concept of altered effort perception in CFS a step further, Lawrie (41) argues that CFS could be viewed as primarily a disturbance in the perception of effort. He suggests that, from a neuropathological point of view rather than cognitive, the perception of effort in CFS is similar to a disturbance sometimes seen after brain lesions affecting motor areas. Hence patients with CFS would have to devote greater

attention to both motor output and sensory input during activity, resulting in increased perception of effort and decreased tolerance of activity.

### *Day-to-day Activity*

Literature regarding day-to-day, functional activity levels in people with CFS is quite sparse. That which exists tends to concern itself with retrospective reports of activity levels or self reports of general functional ability.

Vercoulen, Swanink, Fennis, et al. (42) attempted to identify dimensions of CFS. Avoidance of activity and functional impairment in daily life were among those identified. They noted that 93% of patients reported severe impairment in daily life because of their complaints and only 4% did not report avoiding some degree of physical activity. Ray, Weir, Stewart et al. (43), using an illness management questionnaire, identified four main coping factors which predicted the variance of functional impairment, anxiety and depression. The coping factor “maintaining activity”, as would be expected, was found to correlate negatively with impairment and illness accommodation and correlate positively with anxiety and denial. However, as Ray et al. noted, a prospective design would be needed to clarify causality. Smets, Garssen, Bonke and de Haes (44) compared CFS patients with a variety of other groups including cancer patients, soldiers in training and junior doctors. They found that, on self-reported measures of physical activity, the CFS group reported significantly lower levels than the other groups and on measures of physical and mental fatigue, the CFS group had significantly higher scores than the other groups.

The three studies discussed above all used subjective, self-reporting methodologies. Studies which use objective measures to assess physical activity levels in CFS are rare. Fry and Martin (45) investigated the perceptions of children with CFS and their parents’ perceptions. They asked the children and their parents to report current activity levels and desired and expected future activity levels. In addition they used an ambulatory monitoring system to measure daily activity over a three day period. Interestingly, Fry and Martin found that self-reports of activity levels from both children with CFS and their parents under-estimated the actual level of activity. Also, despite the criteria that children with CFS should have fatigue severe enough to interfere with normal activities,

there was no significant difference between the monitored levels of activity between the CFS and “normal” controls. It would appear, therefore, that retrospective self-reports of activity, as used previously (42, 43, 44), may not be true representations of the level of activity being undertaken by this population. Fry and Martin suggested that both the parents and the children in their study showed idiosyncratic cognitive processes which may play a role in the maintenance of the illness. These idiosyncratic cognitions may not be totally dissimilar in nature to those expressed regarding ability to exercise in CFS, i.e. although there is no objective evidence of pathophysiological reasons for being unable to exercise, CFS sufferers often report severe difficulties.

Despite using a self-report measure, Stone, Broderick, Porter, et al. (46) found activity levels in CFS sufferers to be similar to that of controls. Instead of using a retrospective measure, Stone et al used a momentary assessment technique in which subjects were randomly prompted by a palm-top computer to detail activity, fatigue and affect. In this way any possible retrospective biases and cognitive distortions could be minimised. A similar type of assessment technique was used by Packer, Foster and Brouwer (47) although they did not apply such technologically advanced equipment. Instead, they simply requested CFS subjects to record their primary activity each half hour for forty-eight hours. Each activity was also rated for fatigue, pain, enjoyment and perceived difficulty. Essentially, they reported that the CFS group rested more and spent less time in ‘productive activities’ i.e. work and household activities, than a healthy control group.

A recently published study by Vercoulen, Bazelmans, Swanink et al. (48) looked specifically at the efficacy of retrospective self-report measures of activity in CFS sufferers. They were able to confirm that simple self-observations made at the time correlated much more highly with actual measured activity levels than retrospective self-reports of general levels of activity. They also found a significant difference in objectively measured levels of activity between CFS subjects and a control group. This is in contrast to both Fry and Martin and Stone et al.’s findings above. Thus there exists some inconsistency in the research findings regarding day-to-day activity levels in CFS sufferers.

## **MOOD IN CFS**

Depression and anxiety are by far the most common reported concurrent, diagnosable psychopathologies in CFS. It is estimated that approximately half of individuals seen in primary or specialist care with a diagnosis of CFS fulfil the criteria for an affective disorder, even disregarding the symptom of fatigue (49, 50). Only about one-quarter to one-third of people who fulfil the criteria for CFS do not fulfil any criteria for psychiatric disorders (49). However, this tells us nothing of causality.

Ray (21) notes that there are four main interpretations of the role of affective disorders in CFS:

1. The symptoms of CFS are a manifestation of psychological distress.
2. The rate of affective disorders in CFS may be inflated by the fact that the somatic complaints characterising it are also criteria for depression.
3. The affective disorders observed in CFS may result directly from pathological processes whose aetiology is distinct from that of a major affective disorder.
4. The affective state of patients with CFS is a reaction to the symptoms and consequences of CFS.

The joint report of the Royal Colleges (23) suggests that the shared origin theory (number 3) is most appealing and they dismiss the reverse causality theory (number 4) in most cases. This is due to the results from studies comparing CFS with other chronic and disabling illnesses which find CFS sufferers to have very elevated rates of psychiatric disorders. They acknowledge that anxiety and depression are the “strongest risk factors so far identified for CFS” but suggest that any simple equation with a psychiatric disorder (number 1) is also erroneous. It would appear that there can be a variety of mechanisms responsible for the mood status of an the individual with CFS and researchers and clinicians should bear this in mind.

Assessment of mood in CFS can be complicated by the prevalence of the many physical symptoms that the syndrome shares with depression, most notably fatigue. Many well

validated and reliable measures of mood emphasise physical symptoms, for example, the Beck Depression Inventory (BDI) (51) contains questions relating to fatigue and health. What is more, it is possible that mood would vary in line with symptoms, so a one-off assessment using only a retrospective questionnaire might not yield as stable results as repeated measures of mood. This technique was used by Marshall, Watson, Steinberg et al (52) who repeated the Positive and Negative Affect Schedule (PANAS) each day of their study schedule and found lower levels of positive affect in their CFS group compared to a healthy control group.

### *Diurnal Patterns*

On a moment-to-moment or day-to-day basis, mood is likely to subtly alter in response to minor changes in thoughts, behaviour, physiological or social events. These changes are unlikely to be clinically significant in themselves but will affect an individual's quality of life and may, over the longer term, impact on overall state of mind.

Wood, Magnello and Sharpe (53) investigated the changes of perceived energy and mood in CFS on an hour to hour basis. They found significantly higher levels of negative affect for the CFS group compared to a normal control group, using the Hospital Anxiety Depression Scale (Zigmond and Snaith, 1983) and visual analogue scales. They noted that energy levels and positive affect were highest in the late morning and lowest first thing in the morning and last thing at night.

As well as measuring activity, Stone et al. (46) examined fatigue and mood in CFS patients. They found changes in mood during the course of a day with subjects feeling more negative earlier in the day and positive feelings increasing during the course of the day. Unlike Wood et al. they did not observe significant differences in the overall level of positive and negative affect between the CFS and non-chronically ill control group.

Thus it would appear that mood in CFS sufferers has been documented to vary during the course of a day. However the few available papers on this topic do not clarify the nature, direction and extent of these variations.

## **FATIGUE IN CFS**

It is self-evident that a diagnosis of “chronic fatigue syndrome” can only be made in the presence of the key feature of prolonged, chronic fatigue. Sharpe et al. (2) speak of CFS as being “a syndrome characterised by fatigue as the principle symptom”. Fukuda et al. (1) note that the “chronic fatigue” within the syndrome is “defined as self-reported persistent or relapsing fatigue lasting for six or more consecutive months.”. According to a review of the literature (55) 100 per cent of CFS patients report symptoms of fatigue. The fatigue reported, however, is not constant and, like mood, it can be seen to vary over the course of a day.

Wood et al. (53) observed that CFS sufferers report significantly lower levels of physical and mental energy than either recovered CFS sufferers or a control group. They note also that the normal diurnal pattern of energy is maintained, although at a lower overall level, with the highest level of energy being reported between waking and noon.

Consistent with Wood et al., Stone et al. (46) showed the CFS group to be more tired and less aroused than the control group. The fatigue experienced by the CFS group had a U-shaped function, being worse first thing in the morning and late in the evening.

According to Fry and Martins’ model (figure 2), fatigue not only varies diurnally, but is affected by cognitions and activity. In their review, paper they argue that the fatigue in CFS is not purely a physiological phenomenon and cannot be explained purely in terms of an organic dysfunction, either peripheral or central. Instead they emphasise the role of beliefs and cognitions about desired and expected abilities and the subsequent impact these cognitions have on mood, and hence fatigue and activity levels.

## **SIMULTANEOUS INVESTIGATIONS OF ACTIVITY, FATIGUE AND MOOD**

It would appear that there are few published studies investigating two or more of the above factors simultaneously in CFS. The paper by Stone et al. (46), mentioned



frequently above, measured these variables simultaneously and used advanced statistics to ascertain the correlations between them. The details of the assessment tools used, however, were not made very clear and it does not appear that all the measures used were standardised. Despite this, the Stone et al. paper used a very elegant momentary assessment technique, as detailed in the activity section of this review. In this way moment to moment changes in mood, fatigue and activity were ascertained without the problems seen in other studies which have used retrospective, self-report measures.

Stone et al. noted that CFS subjects' changes in affect over the day were independent of activity. There was no evidence that the CFS subjects' experience of fatigue decreased their level of activity, though the researchers noted a modest degree of correspondence between fatigue and mood. Similarly, Wood et al. (53) noted that correlations between physical and mental energy and positive affect were significant, although correlations with negative affect were not. This relationship between energy and mood was noted to be the same for CFS patients as for the control subjects.

Stone et al also reported that level of activity or type of activity did not appear to be related to mood in chronic fatigue. Nevertheless, they noted that, in the normal population, social activities were associated with positive affect relative to work or occupational activities.

Morriss, Wearden and Battersby (56) measured fatigue and depression simultaneously in CFS and simply concluded that these measures were significantly elevated for their CFS group compared to control subjects.

## **CONCLUSION**

The area of activity, fatigue and mood in CFS is an important one. Among other things, a better understanding of these factors could help CFS sufferers manage their symptoms more effectively. Much work has been completed in these areas which gives a degree of insight into how these variables might be affected in CFS. Furthermore, a model of CFS has been proposed by Fry and Martin which suggests the sorts of changes which

might be expected in these factors in an individual suffering from CFS. To date, it appears that there has been no published research investigating this model more fully and thus it would seem appropriate to suggest that future research might ask questions based on examining aspects of such a theoretical model. In particular, the literature to date has not effectively explored the effects of CFS on normal day-to-day activity. As a result, the review of this area of the literature in particular could be said to be somewhat inconclusive.

Research into the areas of activity, fatigue and mood requires that researchers choose their methods carefully. As discussed above, certain types of self-report methodologies are apparently prone to yielding inaccurate results due to the cognitive idiosyncrasies of CFS patients. Ecological momentary assessment (EMA), in which subjects report their behaviour, perceptions or affect in the here and now, may be an effective way to avoid this problem. Stone and Shiffman (57) report EMA to be a more accurate and valid way to assess situational subjective states than retrospective self reports, but, when using momentary assessment techniques, a balance must be found between gathering huge amounts of raw data from subjects, thus requiring a lot of commitment from them, and losing valuable information due to coding and data aggregation at an early stage.

With regard to the assessment of activity, probably the most reliable method of approaching the area is by using objective measures to minimise self-report distortions. However, as Vercoulen et al (48) note, the next best option is to use a method which requires subjects to give “here and now” self-reports of activity as opposed to retrospective self-report.

In summary, there is no doubt that, over the years, many valuable studies have been completed looking at the various cognitive, behavioural and emotional aspects of CFS. Nevertheless, in the areas of activity, fatigue and mood, there are still many questions to be answered and future research in these areas needs to address these questions using carefully chosen, comprehensive methods.

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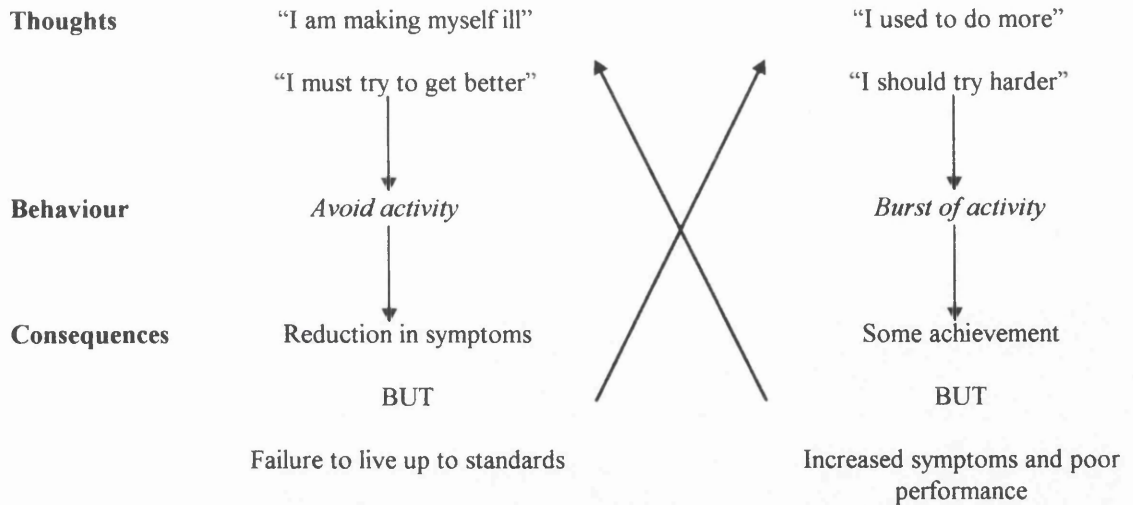


Figure 1. Cognitive model of the perpetuation of CFS (Surawy et al., 1995)

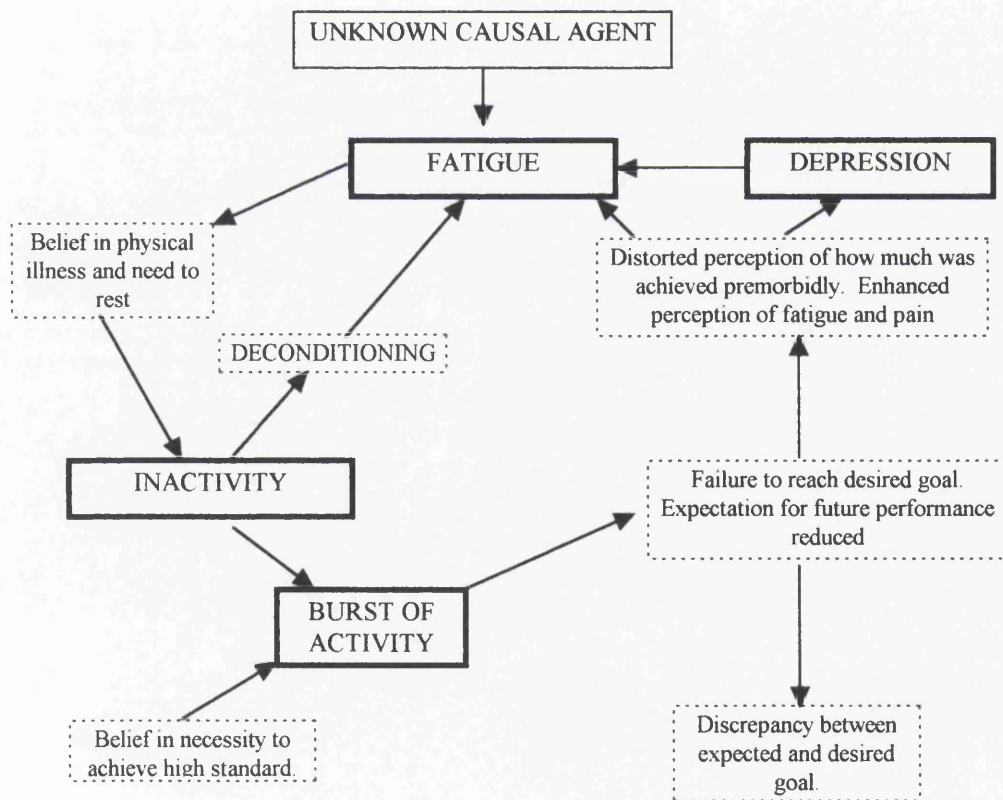


Figure 2. Cognitive model of the perpetuation of CFS (Fry and Martin, 1996)

# **MAJOR RESEARCH PROJECT PROPOSAL**

## **An Exploration of Activity, Fatigue and Mood in Chronic Fatigue Syndrome**

*Prepared in accordance with guidelines in the D. Clin. Psy. Handbook, based on the application for a mini-project grant in Health Services Research (see Appendix 3).*

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## **TITLE**

# **An Exploration of Activity, Fatigue and Mood in Chronic Fatigue Syndrome**

## **SUMMARY**

Chronic Fatigue Syndrome (CFS) is a debilitating illness. Despite a good deal of research in recent years, there is still little decisive evidence regarding its aetiology and research on treatment outcome is similarly inconclusive. The key symptom of CFS; fatigue, has previously been treated by prescribing rest for lengthy periods of time. Activity avoidance over a long time, however, will result in a deterioration of fitness, CFS symptoms subsequently occurring at progressively lower levels of exertion. CFS sufferers are noted to show high co-morbidity of psychiatric disorders, depression in particular. Levels of everyday activity in CFS sufferers, and their subsequent relationship to mood and the key symptom of fatigue, have not been studied in detail.

Research investigating the area of activity, fatigue and mood in CFS is sparse and only one detailed theoretical model of these relationships appears to exist, that of Fry and Martin (1996). There is no published research based on this model. Thus an observational study is proposed. The aim of this study will be to examine the above variables using a prospective momentary assessment technique and taking an objective measure of activity. As exploratory research, the initial proposal is simply to compare CFS subjects with 'healthy' matched controls, before then examining changes in the variables over the course of a day and briefly examining the relationships between measures.

It is intended that subjects participating in this study will be recruited from CFS sufferers attending the clinic of Dr Todd (Consultant in Infectious Diseases), Monklands Hospital. The control group will be recruited from Health Board staff and families.

## INTRODUCTION

Chronic Fatigue Syndrome (CFS) is the preferred term for a group of symptoms, the most prominent of which is a chronic and incapacitating fatigue for which no obvious organic cause can be found (Lietch, 1994). Other terms often used to denote the syndrome include: epidemic neuromyasthenia; myalgic encephalomyelitis (ME); post-viral fatigue syndrome; and "Royal Free" disease. Though the case definition for the diagnosis of CFS has been tightened in recent years, it remains, in practice, a diagnosis by exclusion when no other medical or psychological explanation for the symptoms can be found (Clements, 1993). The cause and mechanisms of CFS are unclear but, as noted in the report by the National Task Force on CFS (1994), "Chronic fatigue syndromes often do not fit neatly into the conventional view that disease is either physical or psychological" (p. 2)

The report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners (1996) noted as part of its conclusion:

*"There is no evidence that infections have a primary causal role in the vast majority of cases, although they appear to precipitate the disorder in some. Previous personality factors and premorbid distress appear to be more important than common viral infection per se. They may also play an important part in perpetuating disability.*

*"The evidence for structural or functional abnormalities of brain or muscle or for a disturbance of endocrine or immune function as primary aetiological factors in CFS is currently weak."*(p. 37)

Hence the report emphasises and acknowledges the large part played by psychological factors in the symptomatology of CFS.

CFS has no specific treatment. The interpretation of treatment outcome study results is hampered by the fact that a variety of diagnostic criteria exists to describe the syndrome. Pharmacotherapy, physiotherapy and psychotherapy, among others, have been studied as treatments ( the results are reviewed by, among others, Blondel and Shafran 1993), but it would appear that no single treatment provides a "cure" for CFS. However, evidence exists to suggest that cognitive behaviour therapy can provide some help in managing the symptoms.

In the normal population it is well documented that moderate activity can have beneficial effects on mood (see review by Yeung 1996). The rapid and detrimental effects of even short periods of bed rest on physical fitness have also long been documented (Asher, 1947; Greenleaf and Kozlowski, 1982). Individuals with CFS have frequently reported resting for many days or even months which is likely to cause major muscle wasting, deconditioning and loss of stamina. The result of this is that even minor, day to day activities may cause severe fatigue. It is felt that deconditioning and subsequent fatigue are likely to impact on mood. Whether it be cause or effect, co-morbid depression is noted to regularly accompany CFS (Wessley and Powell, 1989; David, 1991).

Fry and Martin (1996) emphasised the role of cognitive processes in enhancing the perception of symptom severity and hence perpetuating illness beliefs. Their model explicitly presents the theoretical inter-relationships of fatigue, mood and activity. See figure 1.

.....  
*Insert Figure 1. About Here*  
.....

This model is based on the review of evidence, which suggested that fatigue is neither peripheral, e.g. muscular or neuromuscular, nor central, e.g. neuroendocrinological. Rather, fatigue is viewed as being a cognitive phenomenon brought about due to

perceptual distortions and resultant changes in affect. There has, to date, been no published study providing empirical evidence to support this model.

## **AIMS AND HYPOTHESES**

This observational study aims to empirically explore key phenomena of CFS, particularly concentrating on altered behaviour, feelings of fatigue and low mood. It is proposed that the study will investigate objective levels of activity and prospective measures of fatigue and mood in a group of individuals referred to a CFS outpatient clinic. These measures will be compared with those of a group of 'healthy' control subjects matched for age, sex and occupational activity at time of observation.

### **Research Questions**

1. Does a difference exist between diagnosed CFS sufferers and matched controls in terms of:
  - i. day-to-day physical activity?
  - ii. fatigue?
  - iii. mood ?
  
2. Do differences in diurnal variation exist in CFS compared with matched controls in terms of:
  - i. day-to-day physical activity?
  - ii. fatigue?
  - iii. mood ?
  
3. What are the basic relationships between:
  - i. day-to-day physical activity?
  - ii. fatigue?
  - iii. mood ?

## **PLAN OF INVESTIGATION**

### **Design and Procedure**

An observational study is proposed, in which high quality data will be collected in the form of objective and subjective measures. The design proposed, is intended to incorporate both within and between subjects elements. Activity, fatigue and mood measures in CFS and control groups will be quantitatively and qualitatively described, and differences between groups and at different times of the day will be described and discussed. Relationships between variables will be briefly examined.

### **Subjects and Recruitment**

All subjects will be between the ages of 16 and 65. CFS patients will be recruited from a medical out-patient clinic by Dr Todd, who will confirm that all subjects have CFS which conforms to the American Centre for Disease Control criteria (Fukuda, Straus, Hickie et al., 1994). Patients who do not meet this research criteria will not be included in the study. Those patients interested in participating will be given an information sheet and have an opportunity to discuss the study with the researcher before signing a consent form.

Matched control subjects will be recruited from local Health Board staff and their families by word of mouth and notice boards if necessary. These control subjects will be provided with information as above.

Ten to fifteen subjects will be recruited to each group. The nature and time constraints of the study do not permit greater numbers.

### **Measurements**

The following measures will be taken;

1. Mood will be measured using the Hospital Anxiety and Depression Scale - HADS (Zigmond and Snaith, 1983), which will be completed in order to give an approximate measure of affective disturbance at the time of first interview.



2. Fatigue at the time of first interview will be measured using an appropriate, validated scale, such as the Fatigue Scale developed by Chalder, Berelowitz and Pawlikowska (1993).

3. A 48 hour objective measure of activity will be taken using an ambulatory monitoring system ('Actiwatch'). This device is wire-free and is the size and weight of a standard wrist watch. It is manufactured by Cambridge Neurotechnology and is often used in clinical practice as a method of objectively assessing and monitoring behaviour.

4. Subjects will be asked to fill out a 48 hour record of activity, fatigue and mood. The exact nature of this diary will be decided by a pilot study. Ideally the diary should be filled in once every waking hour for the 48 hour sample. Activity could be coded to make this task easier. Fatigue and mood would theoretically be measured on an hourly basis using a very simple numerical scale.

Table 1 details the stages of subject participation

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*Insert Table 1. About Here*  
.....

### **Settings and Equipment**

It is intended that the subjects be interviewed at Dr Todd's outpatient clinic, Monklands Hospital, preferably directly after their appointment with him thus avoiding the need for another journey to the hospital.

The equipment to be used will be the aforementioned questionnaires and Actiwatch with an appropriate computer package for the analysis of data collected using this instrument.

### **Pilot of 48 Hour Diary**

The diary will be piloted on a small group of individuals. In particular the layout and ease of completion of the 48 hour hourly record will be investigated as it is recognised that compliance and accuracy of recording will be influenced by subject perception of this tool. Open interviewing and subsequent discourse analysis could be used to this end.

### **Data Analysis**

Each subject's data will be coded initially to ensure confidentiality and will be appropriately stored. Actiwatch data will be downloaded to the data storage and analysis programme on a computer in the Department of Psychological Medicine at Gartnavel Royal Hospital. The Actiwatch data will be corrected and coded for statistical purposes then transferred into SPSS for Windows spreadsheets for statistical analysis.

Data will be described and frequency distributions viewed to ensure appropriate statistical tests are chosen. The small numbers of subjects in each group and the types of measures taken, make it likely that non-parametric tests will be appropriate. Given the matched design, tests for related samples will generally be used. Statistical tests are likely to be two-tailed as predictions about direction of difference are not being made, the exception being when evaluating measures of fatigue, as these are predicted to be higher in CFS subjects.

### **PRACTICAL APPLICATIONS**

It is hoped that this research will help provide information which will allow further understanding of the key factors of activity, fatigue and mood in CFS sufferers. Such a contribution would be expected to aid future study of this field by suggesting areas which might benefit from research of a more experimental type. It is also possible that implications for individual treatments could be generated by this research.

## **TIMESCALES**

**Summer 1997 (July to September)** - Collection of pilot study data and subsequent analysis will be completed with an appropriate number of subjects. During this time a full literature review will be completed and submitted. Any necessary changes to the study design resulting from the pilot or literature review will then be made. Also ethical approval from Monklands Ethics of Research Committee will be sought.

**October 1997 to March 1998** - Data collection for the study proper. During this period it is expected that one day per week will be used solely to collect data.

**March 1998 to June 1998** - Data analysis and first draft of project write-up will be completed.

## **ETHICAL APPROVAL**

An ethics application based on this proposal will be submitted to the appropriate group. It is hoped that approval will be obtained with relative ease, given that this study uses wholly non-invasive and non-threatening techniques and adds the benefit to the participants of receiving personalised information on their symptoms and information on symptom management, which might not otherwise be provided. It is also considered that clinicians dealing with the individual cases might find the objective information gathered useful for planning intervention and monitoring treatment efficacy.

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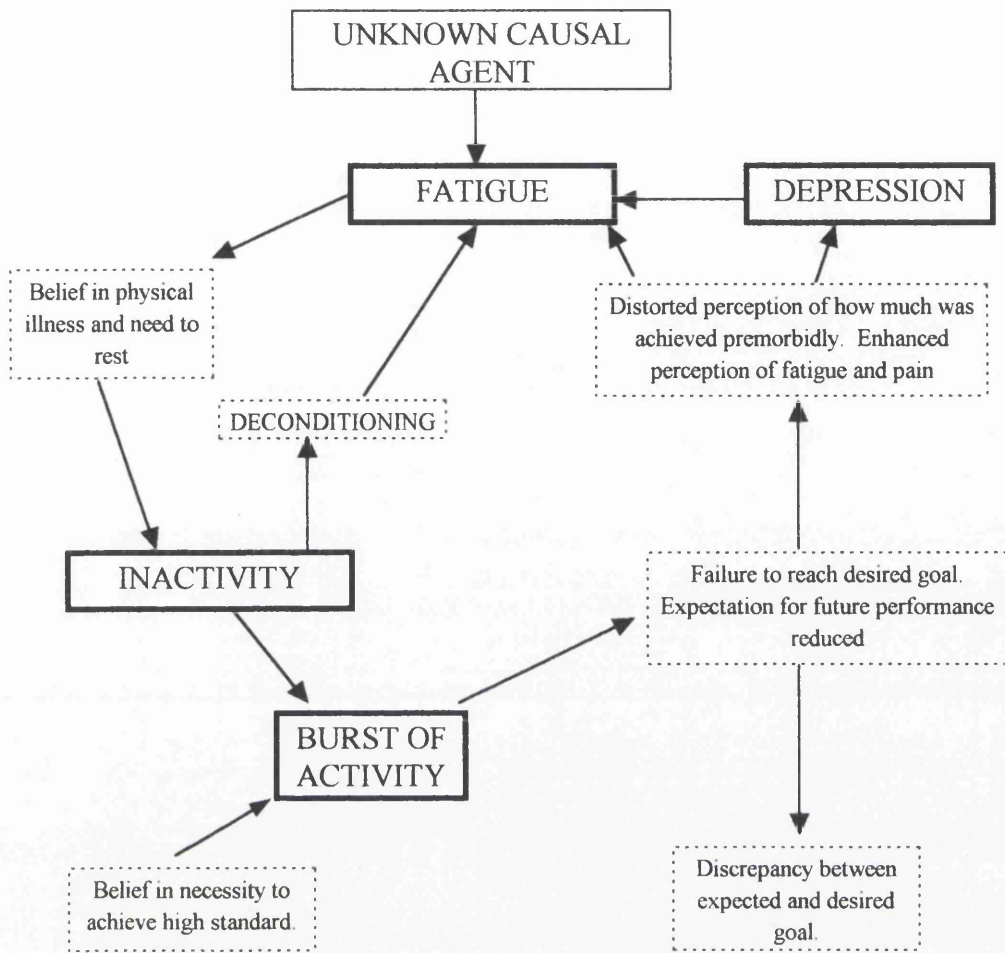


Figure 1: Cognitive model of the perpetuation of CFS (Fry and Martin, 1996)

*Table 1: Summary of participation stages*

<p>Prior to Participation</p>	<p>The CFS patient attends the consultant and is given the "usual" assessment. If the patient fulfils the criteria, the consultant will provide information on study and study handout. The patient may then choose to discuss participation with researcher and may decide to sign the consent form and take part, in which case the initial meeting will take place then and there, or an arrangement will be made to meet with the subject at the out-patient clinic at a more convenient time.</p>
<p>Initial Meeting</p>	<p>The subject will complete the HADS and Fatigue Scale. The protocol for use of the actiwatch and completion of the diary will be explained. Brief training for the rating and differentiation of mood and fatigue will be provided, problems or queries regarding procedure will be discussed, and a time agree for the return of the Actiwatch and diary.</p>
<p>48 Hour Period</p>	<p>Subjects are then to go about their normal daily routines but record all their activities on an hourly basis using activity codes, and also rate their subjective level of fatigue and mood hourly also. The subject will then return the Actiwatch and diary to out-patients in the envelope provided</p>
<p>Feedback to Subjects</p>	<p>All CFS subjects will then receive individual feedback on their mood, fatigue, activity and sleep measures (taken from diary and Actiwatch data). Patients will also be provided with an information pack designed to help them manage their CFS.</p>

# **MAJOR RESEARCH PROJECT PAPER**

## **An Exploration of Activity, Fatigue and Mood in Chronic Fatigue Syndrome**

*Research  
Supervisor:* Professor C.A. Espie,  
Dept of Psychological Medicine,  
University of Glasgow.

*Field  
Supervisor:* Dr A. Todd,  
Dept of Infectious Diseases,  
Monklands Hospital.

*Target Journal: Journal of Psychosomatic Research  
(see Appendix 4.1 for Instructions to Authors)*



# **AN EXPLORATION OF ACTIVITY, FATIGUE AND MOOD IN CHRONIC FATIGUE SYNDROME**

Running Head: Activity, Fatigue and Mood in CFS

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# **An Exploration of Activity, Fatigue and Mood in Chronic Fatigue Syndrome**

*Abstract - Previous studies of activity, fatigue and mood in chronic fatigue syndrome (CFS) have used diverse methodologies, often implementing retrospective, subjective measurements. Recent literature has suggested that such methods may not yield accurate representations of the experience of CFS. This study, therefore, attempts to apply scientific method to this complex and subjective field by making use of an objective measure of activity in conjunction with concurrent, hourly self-ratings of fatigue and mood states. The results indicate that the CFS subjects (n = 10) are significantly different from the healthy matched control group with regard to activity, fatigue and mood variables. Investigations of diurnal patterns and interrelationships of the measured variables, show that the CFS group possess a different pattern of daily activity and different variable interrelationships to those found in the matched controls. These findings, and their implications for future research, are discussed.*

*Keywords: Activity; Chronic fatigue syndrome; Fatigue; Methodology; Mood.*

## **INTRODUCTION**

Chronic fatigue syndrome (CFS) is a condition of severe disabling fatigue. This fatigue has been suggested to result in decreased physical activity in CFS sufferers, thus leading to deconditioning (1).

In a number of studies, a positive relationship between physical activity and mood has been documented, as reviewed by Dubbert (2). Reports of an association between low levels of activity and fatigue also exist (3). Finally, there is much literature investigating CFS sufferers' ability to exercise, as reviewed by McCully, Sisto and Natelson (4). However, explorations of day-to-day activity in CFS are scarce, particularly those which objectively measure "normal", everyday activities.

Fry and Martin (5) proposed a model of CFS in which the key symptoms of inactivity, perceptions of fatigue and low mood were described and their relationships suggested.

In most of the research into fatigue or mood in CFS, retrospective self-report methodologies have been used. Subjects are typically requested to rate their fatigue or mood over some reasonably long time period (for example, days or weeks). Stone, Broderick, Porter, et al.(6) noted that both passive and active distortions may operate in retrospective assessments of fatigue and mood. They therefore recommend that other assessment techniques, such as moment-to-moment reporting, are utilised. This type of assessment has the additional benefit of providing data on the variations of fatigue and mood over the course of a day. Stone et al (6) noted that CFS subjects reported increased fatigue in the morning and evening and improving mood over the course of the day. Woods, Magnello and Sharpe (7) noted maximum energy levels and positive mood in CFS subjects between 10 and 12 o'clock in the morning. These two studies noted similar variation of fatigue over the day, with fatigue being greatest first thing in the morning and in the evening. These studies did not document similar diurnal patterns of mood.

Fry and Martin (8) and Vercoulen, Bazelmans, Swanink et al (9) suggested that cognitive distortions also occur in the reporting of activity levels in CFS. Both groups noted that actual activity levels were significantly different from perceived or reported activity levels. These are the only studies to date to have measured objective levels of day-to-day activity in CFS. Unfortunately, the results of these two studies are somewhat contradictory. Fry and Martin found that 19 children with CFS showed no significant difference in activity level compared to age and sex matched "healthy" controls, whereas Vercoulen et al reported their adult CFS group (n = 51) had significantly lower recorded levels of activity than age and sex matched "healthy" controls. Both studies used similar activity monitors worn on the ankle. This method of monitoring activity has been shown to provide highly reliable data (10), and close correlations with energy expenditure have been reported (11). It is particularly suited to non-intrusive monitoring of day-to-day activity levels as monitors are small and can be worn nearly all of the time. In the Fry and Martin study (8) activity was recorded over three days

and in the Vercoulen et al. study (9), recordings were made over 12 days. Fry and Martin did not use measures of raw activity data in their comparison, rather they reported each subject's percentage of sampled epochs over a specific activity threshold. In contrast, Vercoulen et al. reported a mean activity value for each subject. These methodological differences could have accentuated the discrepant results. Finally, the discrepancy in findings between these two studies may have been due to a difference in the behaviour of children with CFS to that of adults with CFS.

A more detailed review of the literature surrounding this area can be found in Verity (1998) - (previous section of this thesis). Based on this review, the current study aimed to examine the key variables of; activity, fatigue and mood in CFS. For the reasons discussed above, this study used an objective measure of activity in conjunction with a prospective, momentary assessment technique, similar to that used by Stone et al. (6).

This study attempted to answer the following questions: (a) What are the differences in prospective fatigue and mood ratings between CFS subjects and matched "healthy" control subjects? It was expected that fatigue ratings would be greater in the CFS group, and it was more tentatively hypothesised that mood would be lower in CFS subjects. (b) Is objectively measured physical activity lower in subjects with CFS than in controls? It was thought that this was likely to be the case. (c) Are there differences between the CFS and control groups in levels of physical activity and prospective ratings of fatigue and mood at different times of the day? Fatigue was expected to be higher in the morning and evening, although the direction of variations in activity and mood over time were not predicted. (d) What are the relationships between activity, fatigue and mood? The extent and directions of relationships were not predicted, but instead were to be explored.

## **METHOD**

### *Subjects*

The study was of matched-pairs design. Ten CFS patients (5 male and 5 female) were recruited from a medical out-patient clinic by the consultant in infectious diseases (ID)

dealing with their case. For inclusion, subjects were confirmed by the consultant to be suffering from CFS, using the research criteria defined by the American Centre for Disease Control (12) (A summary of this criteria can be viewed in Appendix 4.2). For inclusion, subjects were also to be aged >15 to <65 years old. The average age in the CFS group was 36.5 years old ( $\pm 8.9$  years). Subjects reported having been symptomatic for an average of 48.5 months (range 6-196 months  $\pm 56.5$ ). Each of the 10 CFS subjects was matched with a healthy control subject for age, sex and occupational activity at time of recording (table 1 gives descriptive details of the two groups).

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*Insert Table 1. About Here*

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### *Instrumentation*

Wrist actigraphy was produced using the AW2 model of Actiwatch manufactured by Cambridge Neurotechnology Ltd. This device was considered superior to those used in previous studies due to its small size (27 x 26 x 9mm), ultra light weight (16g) and design making it as comfortable and unobtrusive to wear as a wrist watch. The Actiwatch utilises an accelerometer to monitor the occurrence and degree of motion. The piezo-electric sensor integrates the degree and speed of motion to produce the activity counts that are recorded. Each Actiwatch had been programmed with a calibration coefficient to normalise data between watches. The recording epoch length was set to 0.5 minutes, which allowed 48 hours of actigraphy to be recorded. This was considered the optimum length of time for recording activity, as subjects also had to complete an hourly diary of fatigue and mood. Subjects were required to wear the Actiwatch on their non-dominant wrist throughout the recording period to ensure consistency. The AW2 Actiwatch model had an event marker button which, when pressed by the subject, marked the time and date on the record. The watch was only to be removed when bathing to prevent damage by water.

Stored data, including the subject's personal code, start and stop time, sampling interval, actigraphic counts and details of events marked, were downloaded onto an IBM compatible personal computer and analysed. Using the rhythmwatch/ sleepwatch

programme, a total activity score for each hour per subject could be then calculated. This was transferred directly onto a Windows Excel spreadsheet. It was then corrected for the short periods of missing data which related to the watch being removed for showers etc.. The data, having been corrected by averaging activity over the rest of the hour, were subsequently transferred from the Excel spreadsheet onto the statistics package - Statistics Package for Social Sciences (SPSS).

### *Measures*

Before the 48 hour activity recording was started, subjects completed questionnaires for the purpose of describing group characteristics:

1. Hospital Anxiety Depression Scale (HADS) - Zigmond and Snaith (13). This 14 item scale assessed both anxiety and depression and was felt to be appropriate for assessment of this population as it has limited interference from physical illnesses.
2. The Fatigue Scale - Chalder, Berelowitz, Pawlikowska, et al. (14). This 18 item scale was used to assess both physical and mental aspects of fatigue.

### *48 Hour Diary*

During the period of actigraph recording, subjects kept a brief hourly record of their activity, mood and fatigue. Each time they completed the diary they were asked to event mark their actigraph record so degree of adherence to the hourly diary could be ascertained. This was found to be satisfactory in both CFS and control groups.

Because of the necessity for reasonable compliance to instructions and minimal diary interference in normal day-to-day activities, three different types of activity diary were piloted on a group of eight healthy subjects. The three types were:

1. Hourly diary, activity coded using numbers 1 to 8 and an activity key;
2. Hourly diary, activity not coded, instead space left to detail activity;
3. Diary to be filled in retrospectively only three times a day, activity not coded.

Of the eight pilot subjects, six expressed a strong preference for the hourly coded form of the diary. Suggestions for clarification of instructions regarding coding of activities and wording of instructions were taken into account in the final form of the diary. The codes used are presented in table 2. (The diary used can be viewed in Appendix 4.3).

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*Insert Table 2. About Here*  
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Mood and fatigue ratings were to be made at the same time as activity was noted down. For these, a 1 to 5 Likert scale was used and a key given for the meaning of each number as it pertained to each variable. For example, for fatigue, 1 = “not fatigued” and 5 = “exhausted”. Training was given at the initial meeting between subject and researcher to ensure that the subject understood and could distinguish between the variables.

### *Procedure*

Out-patients received an information leaflet (Appendix 4.4) about the CFS study and were asked by the ID consultant if they were interested in taking part. Those interested discussed the protocol with the researcher and signed a standard consent form (Appendix 4.5). Subjects then completed the HADS and Fatigue Scale and were given further information on wearing the Actiwatch and completion of the 48-hour diary. The Actiwatch was programmed to start recording from 6pm that night. Due to the timing of the ID clinic the 48 hour period for CFS subjects always started at 6pm on a Thursday. In return for their participation, the CFS subjects received individual feedback and an information pack on managing chronic fatigue and related problems. This was based on information provided in Chalder (15). Permission was gained from the author to use the information in this way.

Control subjects were recruited by word of mouth from Health Service personnel and their families, the procedure above was followed. Six control subjects were recorded over the same period (Thursday 6pm to Saturday 6pm). The other four were recorded over the weekend so as to minimise the effects of occupational activity on their record as they were matched with non-working CFS subjects.

### *Statistical Analysis*

Statistical analysis was carried out using SPSS for Windows (Version 6.1). All statistical tests were performed two-tailed at the 5% level of significance, with the exception of fatigue measures which were tested one-tailed.

The Actiwatch data were aggregated by subject to the level required for the analysis. That is, hourly totals and forty-eight hour totals were calculated for each subject.

Frequency distributions were examined and a non-normal distribution was found. Thus the Wilcoxon matched-pairs signed-ranks test was used to compare between the groups on measures of activity, fatigue and mood. Hourly self-ratings of fatigue and mood were transformed to mean ratings for each 6 hour portion of the day per subject. Friedman tests were used to compare differences in activity, mood and fatigue ratings at these different times. Correlations were computed between the main variables using Spearman's rank correlations.

## **RESULTS**

### *Group Differences in Initial Questionnaire Results*

As can be seen in table 3, the CFS group reported significantly higher levels of anxiety ( $p = 0.012$ ,  $z = -2.505$ ) and depression ( $p = 0.005$ ,  $z = -2.829$ ), assessed by the HADS, than the matched control group. The CFS group's depression score remained significantly higher when scores from the statement 'I feel as if I am slowed down', were removed from their HADS results.

As was predicted, the CFS group also reported significantly higher levels of fatigue (as assessed by the Fatigue Scale).

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*Insert Table 3. About Here*  
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### *Group Differences in Individual Total Activity*

The quality and type of data generated by this study's methodology meant that there were several possible ways in which it could be aggregated for analysis. The most global method was to use a total activity count for each subject. Figure 1 provides a graphical representation of total activity count, during the 48 hour recording period, for each individual, displayed in matched pairs.

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*Insert Figure 1. About Here*  
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A two-tailed Wilcoxon matched-pairs signed-ranks test showed no significant difference in activity when aggregated into individual totals ( $p = 0.093$ ,  $z = -1.682$ ). Inspection of the graph revealed a great deal of variability in total activity counts in both the CFS and control groups.

### *Group Differences in Hourly Activity*

An alternative, and more specific, method by which activity counts may be aggregated is on an hourly basis. This method makes better use of the quality of data collected. Total activity level per hour was found to be significantly lower for the CFS group than for the control group ( $p < 0.001$ ,  $z = -3.846$ ). It can be seen from table 4 that the median hourly activity of the CFS group was approximately 25% less than that of the control group.

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*Insert Table 4. About Here*  
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Hourly levels of objective activity can be viewed in the first graph of figure 2. It can be seen that the control group showed higher peaks of activity and, although the groups became active at about the same time of day, the control group seemed to maintain activity for longer and at a higher level. This was particularly apparent in the afternoon

(hours 18 to 24 and 42 to 48 correspond to the period midday to 6pm) and evening (hours 1 to 6 and 25 to 31 are the period of 7pm to midnight). (Activity levels of each matched pair over the 48 hour period can be viewed in Appendix 4.6)

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*Insert Figure 2. About Here*  
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#### *Group Differences in Reported Hourly Fatigue, Mood and Rest*

Aggregation of the hourly self-report data on fatigue and mood, to give global, individual totals, was felt to be inappropriate as the effects of diurnal variation would be lost. Thus hourly levels of fatigue and mood, aggregated by group, were analysed. A graphical representation of these measures can be viewed in figure 2.

As expected, mean hourly ratings of fatigue were significantly higher in the CFS group ( $p = 0.002$ ,  $z = -2.803$ ), with ratings of these subjects typically twice as high as those of the controls. Mean hourly ratings of mood were also found to be significantly greater in the CFS group ( $p = 0.005$ ,  $z = -2.803$ ), with higher mood scores relating to increased low mood.

Finally, in the coded activity diary, CFS subjects reported spending significantly more time resting and sleeping during the 48 hour recording period than the control subjects ( $p = 0.018$ ,  $z = -2.374$ ). Detailed comparisons of sleep patterns in these groups will form the basis of a future report. (See Appendix 4.7 for future use of data set).

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*Insert Table 5. About Here*  
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#### *Diurnal Variation in Activity, Fatigue and Mood*

Having explored the differences between CFS subjects and matched controls in terms of global and hourly activity, fatigue and mood. The question of altered diurnal patterns of these variables was subsequently addressed. The 48 hour recording period was,

therefore, divided into six-hour sections. Morning was defined as 7am to midday; afternoon as 1pm to 6pm; and evening as 7pm to midnight. Because most subjects were asleep during the 1am to 6am period, this time was not included in analysis. As the data from each time period were taken from both the days recorded, a total of 12 data points were available for analysis.

Total group hourly activity and mean group hourly self-ratings of fatigue and mood were calculated. The difference between the groups on activity, fatigue and mood variables was evaluated using a Friedman's one way analysis of variance (ANOVA) comparing the three different periods.

The CFS subjects activity was found to be significantly different from that of the control group ( $p < 0.001$ ,  $\chi_r^2 = 16.666$ ,  $df = 2$ ). Post-hoc testing using the Wilcoxon matched-pairs signed-ranks test revealed that there were significant differences in activity between all three time periods. See table 6.

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*Insert Table 6. About Here*  
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Analysis of differences between the group ratings for both fatigue and mood showed no significant difference over time (fatigue;  $p = 0.272$ ,  $\chi_r^2 = 2.600$ ,  $df = 2$ ; mood;  $p = 0.067$ ,  $\chi_r^2 = 5.400$ ,  $df = 2$ ).

#### *Intercorrelations Between Activity, Fatigue and Mood*

Having investigated daily variations in the patterns of activity, fatigue and mood, the final research question to be addressed was that of intercorrelations of these variables. In order to achieve this it was decided to again maximise the quality of the data by completing analysis of hourly aggregations of activity, fatigue and mood. Spearman's rank correlations were used to explore the interrelationships of these key variables.

In the control group, a significant negative correlation was found between activity and fatigue ( $p = 0.003$ ,  $r = -0.463$ ). The relationships between mood and activity and mood

and fatigue, in the control group, were not found to be significant ( $p = 0.389$ ,  $r = 0.144$ ;  $p = 0.757$ ,  $r = 0.052$ , respectively).

The correlation between activity and fatigue, found to be highly significant in the control group, was not significant in the CFS group ( $p = 0.311$ ,  $r = 0.174$ ). However, the correlation between mood and fatigue ratings were highly significant ( $p < 0.001$ ,  $r = 0.572$ ). There was no significant correlation found between mood and activity in the CFS group ( $p = 0.150$ ,  $r = 0.245$ ).

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*Insert Table 7. About Here*  
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#### *Stepwise Multiple Regression*

The correlations completed above were simple, bi-variate analyses of the data. They could not explain the possible predictive interrelationships of these variables. Thus, the next logical step was to attempt to examine which variables predicted fatigue in the two groups. This was achieved using step-wise multiple regression. Fatigue was taken as the dependent variable and mood and activity were entered as the independent variables. A dummy variable of time code, which represented the time periods in which data were recorded, was also entered as an independent variable.

For the CFS group, step-wise multiple regression demonstrated that only mood was a significant predictor of fatigue ( $p = 0.002$ ,  $F_{(1, 34)} = 10.754$ ,  $\text{Adj } R^2 = 0.218$ ,  $\beta = 0.490$ ). This indicates that self-rated mood explained a significant amount of the variance of fatigue. However, the objective measure of activity did not explain a significant proportion of the variance of fatigue.

For the control group, step-wise multiple regression demonstrated that only the objective measure of hourly activity emerged as a significant predictor of fatigue ( $p < 0.001$ ,  $F_{(1, 36)} = 15.296$ ,  $\text{Adj } R^2 = 0.279$ ,  $\beta = -0.546$ ). The relationship between activity and fatigue was inverse in nature.

Thus these analyses confirmed the impression given by the simple bi-variate analyses.

## DISCUSSION

### *Level of Physical Activity and Rest*

The present study demonstrated that the CFS group had a lower hourly level of activity and also reported spending more hours resting, than the healthy matched controls. These findings support some past findings regarding activity and rest in CFS (9, 16). However, the significant difference between the CFS and control groups' activity levels was dependent on the method of data aggregation. This suggests that the method by which objective measures of activity are aggregated, is important. When activity was chunked into total *individual* scores, as oppose to total *hourly* scores, the difference between the CFS and control groups was not found to be significant. The only two previous studies of objective activity in CFS (8, 9) apparently used just one overall activity score per subject. Fry and Martin (8), who had a smaller subject group ( $n = 19$ ), found no significant difference, whereas Vercoulen et al. (9), using a subject group of 51, noted a significant difference ( $p < 0.05$ ). The current study's finding of no significant difference when the data is aggregated into total per subject, may be due to low numbers of subjects, although an alternative explanation might be that CFS affects certain individual's behaviour more than others. It can be noted in figure 1 that there is a very wide variation in total activity scores, with several CFS subjects showing a slightly higher level of activity over the 48 hour period than their matched control.

### *Mood and Fatigue*

In both the retrospective questionnaires completed initially (the fatigue scale and the HADS), and in the hourly self-ratings of mood and fatigue, significant differences were noted between the groups. As predicted, the CFS subjects were very much more fatigued than the control group. There was also a highly significant difference between the groups on all measures of mood, with the CFS group being significantly lower in mood (hourly self-ratings) and exhibiting more depressed and anxious symptomatology (HADS scores). Vercoulen et al (17) concluded that low levels of physical activity in

their CFS patients were not attributable to depressive symptomatology. This may also be the case with the CFS subjects in this study.

### *Variation in Activity*

It can be seen from the first graph in figure 2 that, during the morning period of both of the recorded days, both the CFS and control groups' total hourly activity levels increased rapidly and appeared relatively similar. The CFS subjects' activity peaked in the morning on both days; 10 am on the first day (a Friday) and midday on the second day (a Saturday), whereas the peak for the control group appeared more variable. During the afternoon time period the total hourly activity recorded became more dissimilar, as the control group's total activity continued to increase on the first afternoon recorded, whereas the CFS group's appeared to decrease after the morning peak. The control group's activity on the second afternoon decreased only slightly relative to that of the CFS group. Finally, during both evening periods recorded, the CFS group could be observed to have had a much lower total activity than the control group.

These observations were confirmed by statistical analysis comparing differences in the two groups' activity at different times of day. It could be seen that the CFS group was most different from the control group during the evening compared to the morning, with the comparison between afternoon and morning also being very significant. The comparison between afternoon and evening was also significant but to a lesser degree. Thus the CFS group had an overall pattern of activity which was only similar to that of the control group during the morning. The activity level then seemed to tail off after midday and became progressively more different from that of the control group. There appear to be no other studies to date which have observed this pattern of activity in CFS patients.

However, a note of caution must be added to the activity findings in general, due to the fact that four of the control subjects were recorded over the weekend. This was done in order to minimise the effects of occupational activity, as they were matched with non-working CFS subjects, however, it may have resulted in a slightly different pattern of

activity than would be expected for the non-working, healthy population during the week. For example, rising later in the morning and staying active later into the evening.

#### *Variation in Fatigue and Mood Self-Ratings*

The second and third graphs in figure 2 plot the hourly mean ratings of mood and fatigue in the CFS and control groups. It was observed that mood appeared relatively constant for both groups, the CFS group having a higher hourly rating (i.e. lower mood) than the control group. Although on the first morning recorded, mood rating in the CFS group seemed to start high (i.e. increased reports of low mood) and decrease slightly during the day, this pattern was not observed on the second morning. Fatigue ratings remained reasonably constant over the whole day in the CFS group. This pattern of fatigue was slightly different from that of the control group. It was noted that the control group's fatigue ratings remained stable through most of the day before sharply increasing late in the evening.

Statistical analysis of these variations, however, found no significant difference in the patterns of either mood or fatigue in the CFS group compared to controls. This is in contrast to the findings of Stone et al. (6) that diurnal patterns of fatigue and affect were different in CFS subjects compared to the control group. However, the findings from this study are similar to those of Wood et al (7). They reported that the pattern of diurnal energy, which might be presumed to be inversely related to fatigue, in CFS subjects was similar to that of controls.

#### *Intercorrelations and Multiple Regression of Activity, Fatigue and Mood*

The results from the Spearman's rank correlations and step-wise multiple regression were interesting in that they demonstrated differences between the groups in the relationships found between the variables. Two particular differences were noted:

1. The relationship between fatigue and mood.

In the CFS group, a strong positive correlation was noted between self-rated fatigue and mood. Regression analysis demonstrated that only self-ratings of mood could significantly predict self-ratings of fatigue. Fatigue and mood ratings were made simultaneously at the end of each hour when subjects were asked to rate how they felt at

that very moment. The positive relationship found suggested that, for the CFS group, mood and fatigue were very closely coupled, with low mood predicting increased fatigue. An alternative explanation might be that the CFS subjects had difficulties differentiating these states, and thus the data from the mood and fatigue scales were essentially measurements of the same thing. However, as all subjects were trained regarding the distinguishing of feelings of fatigue from those of low mood, the latter explanation is perhaps less likely to be the case.

Positive correlation between momentary reports of mood and fatigue has been previously noted by Stone et al (6). However, Woods et al. (7, 18) found no relationship between low mood and fatigue in either CFS subjects or healthy volunteers. It is likely that the results of this study are more robust than previous similar studies, given the methodology used and the strength of correlation found.

## 2. The relationship between activity and fatigue.

A strong negative correlation was found between objective hourly activity and fatigue ratings in the control group only. As fatigue was to be rated at the end of each hour, it is logical to assume that increased activity was leading to decreased fatigue in this group. This assumption was supported by the regression analysis. There was no significant relationship between fatigue and activity in the CFS group. However, the relationship found in the control group is supported, to an extent, in the literature on exercise and arousal (19), although, of course, the measured activity was general, day-to-day activity rather than exercising per se.

## CONCLUSION

In summary, this study has taken a new approach to looking at activity, fatigue and mood in CFS. Activity was measured objectively, a method only used in two previous studies of this patient group. Also, mood and fatigue were rated by subjects on an momentary, prospective basis, every hour. Again, this is a method which has been used very infrequently in the past, despite evidence to suggest retrospective self-ratings made by CFS sufferers may be affected by cognitive distortions (8).



The group of CFS subjects in the present study showed significantly more psychopathology, in the form of raised HADS scores and higher hourly self-ratings of low mood, than the control group. As expected, they also reported higher levels of fatigue. Their activity level was seen to be significantly lower than that of the control group when analysed on an hourly basis. Analysis confirmed that during the afternoon and evening periods of the day, the CFS subjects showed a different activity pattern to that of the controls. This difference in the activity patterns of CFS patients has not been noted previously and may reflect an important underlying aspect of the syndrome. The relationships between activity, fatigue and mood were found to be different in the CFS group compared to the control group. Specifically the strong relationship that exists between mood and fatigue, found only in the CFS group, may suggest a pathological process. As might the lack of the negative relationship between activity and fatigue, which was found to be very strong in the matched control sample. These findings might benefit from further investigation in the future.

The analysis of hourly data, rather than aggregated global data, is thought to be an important methodological feature of this study. This approach appears to maximise the value of the data and allows micro- rather than macro-presentations to be observed. It is possible that aggregating this type of data would introduce unnecessary error as it might even out hourly variation which is in itself an important feature. These observations may also be important for clinicians seeking to understand an individual's presentation. Perhaps asking a CFS sufferer for a general or global report of symptoms and behaviour would lead to misrepresentation of the more specific variations found on a momentary basis.

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Table 1: Age, sex and duration of illness in CFS group and matched control group

	CFS Group	Control Group
Number	10	10
Female:Male	5:5	5:5
Age (mean $\pm$ SD)	36.5 ( $\pm$ 8.9)	33.4 ( $\pm$ 7.9)
Age range	24 - 53	27 - 53
Duration CFS (months, mean $\pm$ SD)	48.5 ( $\pm$ 56.5)	N/A

Table 2: Activity codes used in 48-hour diary

ACTIVITY	CODE
sleeping	0
resting - sitting or lying down, relaxing e.g. reading, watching TV, chatting with friends at home	1
active in or about the house e.g. personal grooming, dressing, cooking, eating, housework, DIY, gardening	2
active 'housework' outside the house e.g. shopping, driving etc. related to normal housekeeping	3
light occupational activities e.g. at work - mainly sitting, and work related activities, e.g. driving to work	4
heavy occupational activities e.g. at work - standing, lifting, physical jobs	5
exercise - activities in which the intention is to increase stamina, fitness or health e.g. walking, running, exercise classes, muscle toning exercises	6
socialising outside house e.g. at friend's, cinema, café, restaurant, and other leisure activities e.g. travelling, sight seeing, visiting a museum	7
<i>other or not sure</i> - if you are unsure which code is correct for the activity you were engaged in, please write what you were doing in the space provided on the activity sheet and code it 8	8

Table 3: Group differences in initial questionnaire results using the Wilcoxon Matched-pairs Signed-ranks Test (2-tailed except for fatigue scale)

	CFS Group (mean $\pm$ SD, median)	Control Group (mean $\pm$ SD, median)	probability	z-score
HADS-Anxiety	12.9 $\pm$ 4.7, 13.0	4.9 $\pm$ 2.7, 4.5	0.0122	-2.5054
HADS-Depression (total)	10.0 $\pm$ 3.8, 10.0	1.8 $\pm$ 2.2, 1.0	0.0047	-2.8290
HADS-Depression (statement removed)	7.6 $\pm$ 3.4, 8.0	1.0 $\pm$ 1.6, 0.5	0.0048	-2.8233
Fatigue Scale	13.5 $\pm$ 0.8, 14.0	4.1 $\pm$ 4.4, 2.5	0.0038	-2.6703

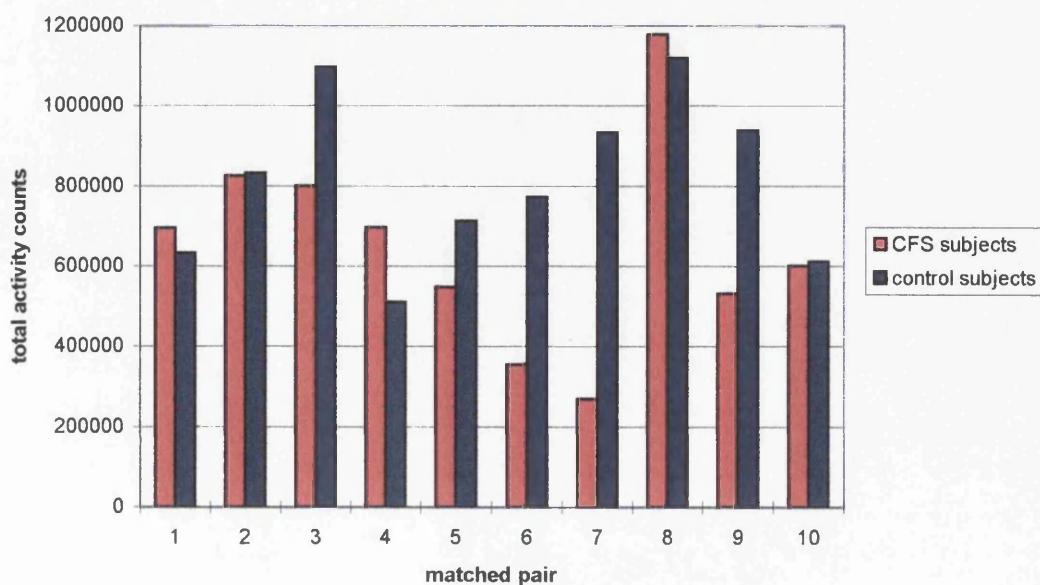
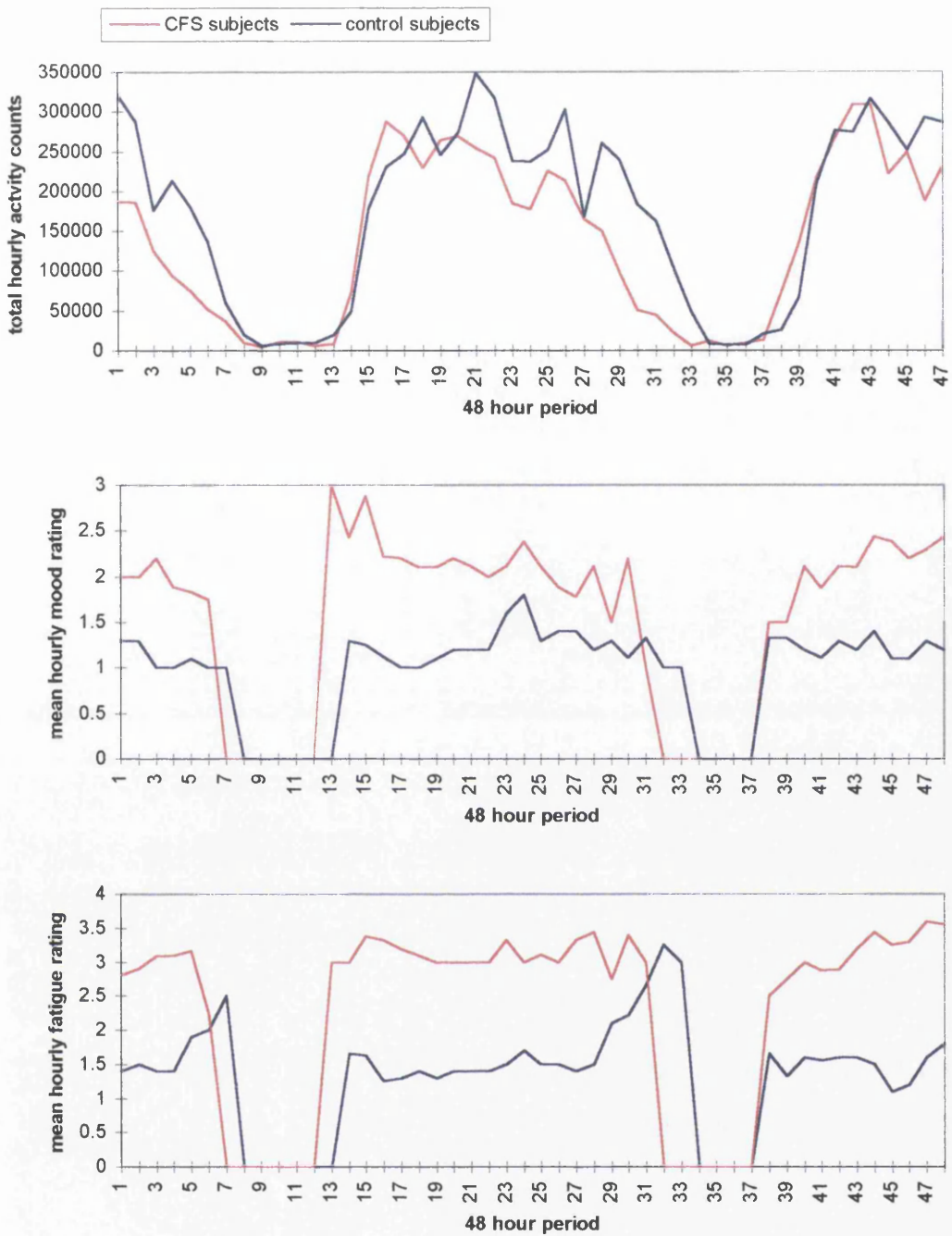


Figure 1: Total activity during the 48 hour period: displayed in matched pairs

*Table 4: Group differences in hourly activity using the Wilcoxon Matched-pairs Signed-ranks Test (2-tailed test)*

	CFS Group	Control Group	probability	z-score
Mean hourly activity	141488.0	176991.7		
Standard deviation	± 104064.9	± 115356.4	0.0002	-3.8462
Median hourly activity	157735.5	211439.0		



Morning (7am to midday)	= hours 13-18 and 37-42
Afternoon (1pm to 6pm)	= hours 19-24 and 43-48
Evening (7pm to midnight)	= hours 1-6 and 25-30

Figure 2: Variation in hourly activity, fatigue and mood over 48 hour period



Table 5: Group differences in reported hourly fatigue, mood and rest; analysed using the Wilcoxon Matched-pairs Signed-ranks Test(2-tailed except for fatigue rating)

	CFS Group (mean ±SD)	Control Group (mean ±SD)	Probability	z-score
Mean hourly rating - fatigue	3.2 ± 0.9	1.6 ± 0.3	0.0025	-2.8031
Mean hourly rating - mood	2.2 ± 0.9	1.2 ± 0.3	0.0051	-2.8031
Hours reported resting	10.4 ± 4.1	6.5 ± 3.1	0.0463	-1.9928
Hours reported resting plus sleeping	28.8 ± 4.8	22.6 ± 4.1	0.0176	-2.3736

Table 6: Post-hoc Wilcoxon matched-pairs signed-ranks testing of activity difference between groups, during morning, afternoon and evening.

	Morning	Afternoon
Afternoon	p = 0.0060, z = -2.7456	
Evening	p = 0.0022, z = -3.0594	p = 0.0342, z = -2.1181

Table 7: Intercorrelations of hourly activity and fatigue and mood ratings

	CFS group		Control group	
	Activity	Fatigue	Activity	Fatigue
Fatigue	p = 0.311, r = 0.1738		p = 0.003, r = -0.4629	
Mood	p = 0.150, r = 0.2449	p = 0.000, r = 0.5720	p = 0.389, r = 0.1440	p = 0.757, r = 0.0518

**CLINICAL CASE RESEARCH STUDY 1 (abstract)**

**Avoidance of Trauma Exposure in the Treatment of Post-Traumatic Stress Disorder**

*Target Journal: Journal of Behaviour Therapy and Experimental Psychiatry  
(see Appendix 5 for Instructions to Authors)*

## **Abstract**

*Prolonged exposure to memories of the traumatic event is generally considered to be an essential component in the treatment of post-traumatic stress disorder (PTSD). Unfortunately, some patients may find it difficult to engage in this type of treatment. This study investigates the efficacy of treatment which addresses only secondary depression and anxiety in an individual with PTSD following rape. Prolonged exposure to memories of the trauma were avoided during treatment. Instead, general cognitive-behavioural treatment for anxiety and depression was used. The results indicate that, for the individual concerned, avoidance of prolonged exposure in treatment did not prevent some improvement in the anxiety and depression symptoms that were secondary to PTSD. However, the PTSD phenomenology itself was not seen to change substantially.*

*Keywords: Anxiety, Avoidance, Depression, Exposure, Post-Traumatic Stress Disorder.*

**CLINICAL CASE RESEARCH STUDY 2 (abstract)**

**Collaborative Empiricism in the Treatment of Chronic Pain:  
A Case Study**

*Target Journal: Journal of Pain and Symptom Management  
(see Appendix 6 for Instructions to Authors)*

## **Abstract**

*Chronic pain, and its accompanying beliefs and behaviours, may be associated with anxiety, depression and low self-efficacy. This paper discusses the process of treatment for an individual with chronic pain. In this case study, collaborative empiricism was used, with the patient and therapist working together to gain a better understanding of the patient's unique experience. A warm, empathic therapeutic relationship, together with appropriate structure and support in treatment, allowed the patient to implement changes in behaviour which consequently altered her pain experience, anxiety and depression.*

*Key-words: Anxiety, Chronic Pain, Collaborative Empiricism, Depression, Self-Efficacy.*

**CLINICAL CASE RESEARCH STUDY 3 (abstract)**

**Deterioration of cognitive function in an individual with Velo-  
Cardio-Facial Syndrome and associated psychosis**

*Target Journal: Neurocase  
(see Appendix 7 for Instructions to Authors)*

## **Abstract**

*Velo-cardio-facial syndrome (VCFS) is a common multiple anomaly syndrome generally resulting from deletions within chromosome band 22q11. The incidence of schizophrenia and other psychiatric illnesses is increased in VCFS relative to the general population. Very little literature exists regarding cognitive function in this syndrome, in particular changes in intellectual ability over the course of time are rarely discussed. This report explores the neuropsychological profile a young woman with VCFS and chronic schizophrenia. The results of this current assessment are compared with those from past assessments of this individual and the changes in cognitive function over time are discussed.*

*Keywords: Cognitive Function, Neuropsychological Assessment, Pharmacotherapy, Schizophrenia, Velo-Cardio-Facial Syndrome.*

## APPENDICES

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## **APPENDIX 1**

### **SUBMISSION NOTES FOR CLINICAL PSYCHOLOGY FORUM**

#### **Clinical Psychology Forum**

Clinical Psychology Forum is designed to serve as a discussion forum for any issues of relevance to clinical psychologists. The editorial collective welcomes brief articles, reports of events, correspondence, book reviews and announcements.

#### **Notes for contributors**

Articles of 1000-2000 words are welcomed. Shorter articles can be published sooner. Send two copies of your contribution, typed and double spaced. Contributors are asked to keep tables to a minimum, to ensure that all references are complete and accurate, and to give a word count. News of Branches and Special Groups is especially welcome.

Language: contributors are asked to use language which is psychologically descriptive rather than medical and to avoid using devaluing terminology; i.e. avoid clustering terminology like “the elderly” or medical jargon like “person with schizophrenia”. If you find yourself using quotation marks around words of dubious meaning, please use a different word.

Articles submitted to **Forum** will be sent to members of the Editorial Collective for refereeing. They will then communicate directly with the authors.

## APPENDIX 2

### INSTRUCTIONS TO AUTHORS FOR THE JOURNAL OF PSYCHOSOMATIC RESEARCH

#### Journal of Psychosomatic Research

Affiliated to the International College of Psychosomatic Medicine

#### Instructions to Authors

Papers must be written in English. They will be acknowledged on receipt, and then reviewed. The decision on acceptance will usually be conveyed to the authors within two months.

**Full Length Papers.** Full length research papers will not normally be more than 4000 words in length and will preferably be shorter. Submission of a paper to the *Journal of Psychosomatic Research* will be held to imply that it represents original research not previously published (except in the form of an abstract or preliminary report), that it is not being considered for publication elsewhere, and that if accepted by the *Journal of Psychosomatic Research* it will not be published elsewhere in the same form in any language without the consent of the Publisher. Major papers of topical content will be given priority in publication.

**Short Reports.** The Journal welcomes short reports, which may be either preliminary communications or brief accounts of original research. Case reports will be published only if they illustrate important issues. The text must not exceed 1500 words. Short reports will normally be published more quickly than full length papers.

**Editorials.** The Editors welcome suggestions for editorials which give personal and topical views on subjects within the Journal's area of interest. They should not normally exceed 1500 words.

**Review Articles.** Review papers are normally 4000-5000 words. Authors are advised to consult one of the Editors with an outline before submitting a review.

**Letters to the Editors.** These normally refer to articles previously published in the Journal. The Editors are also willing to consider letters on subjects of direct relevance to the Journal's interest.

**Book Reviews.** These are normally submitted by the Book Review Editors, but they welcome suggestions of books for review.

**Other Papers.** The Editors welcome suggestions for other types of papers, such as conference reports, accounts of major research in progress and interviews with senior research workers. These should not be submitted without prior consultation.

## Manuscript Requirements

Manuscripts should conform to the uniform requirements known as the 'Vancouver style' (International Committee of Medical Journal Editors. Uniform requirements for manuscripts submitted to biomedical journals. *N Engl J Med* 1997; 336:309-315). The Editors and Referees attach considerable importance to a succinct and lucid prose style and well organized tables. Authors whose native language is not English are advised to seek help before submission. Statistical procedures should be clearly explained.

Manuscripts should be typed with wide margins, double-spaced on one side of standard A4 or 8.5" x 11" paper. The format should be as follows:

*Title page.* This should contain (a) the title of the article; (b) a short running head; (c) name of department where the work was conducted; (d) names of the each author with highest academic degree; (e) name, address, phone and fax of author responsible for correspondence and to whom requests for reprints should be addressed; (f) up to six keywords should be listed in alphabetical order after the abstract. These terms should optimally characterize the paper.

*Abstract.* This should not exceed 150 words.

*Text.* This should be divided into sections with main headings: Introduction, Method, Results and Discussion. Accepted papers will usually be between 2000 and 4000 words in length.

*Acknowledgments.* These must include mention of any source of funding outside the basic funding of the host institution.

*References.* These should be numbered consecutively in the text in the order in which they are first mentioned and be so denoted in the list. Their form should be that adopted by the US National Library of Medicine, as used in the Index Medicus and as recognized in Uniform Requirements:

1. Ingham JC, Miller P McC. Self-referral to primary care: symptoms and social factors. *J Psychosomatic Res* 1986;30:49-56.
2. Berkenbosch F. Corticotrophin-releasing factor and catecholamines: a study on their role in stress-induced immunomodulation. In: Schneiderman N, McCabe P, Baum, A, eds. *Perspectives in behavioral medicine*. Hillsdale, New Jersey: Erlbaum 1992:73-91.

*Tables.* Each should be on a separate sheet, numbered consecutively in Roman numerals.

*Figures* A glossy photograph or clear ink drawing of each should be sent. Each figure should be numbered on the back and the top should be marked. A photocopy should be attached to each copy of the manuscript. Captions should be on a separate sheet. The number of illustrations should be kept to a minimum. Color illustrations are not normally acceptable. Authors may be asked to support the costs of color reproduction.

*Letters to the Editors.* Letters should not exceed 1000 words and, where appropriate, must begin with the reference to the published article about which the author is commenting.

Authors are encouraged to submit a computer disk (5.25" or 3.5" HD/DD disk) containing the final version of their papers along with the final manuscript to the editorial office. Please send disk only after manuscript has been accepted for publication. Please observe the following criteria: (1) Specify what software was used, including which release (e.g., WordPerfect 6.0); (2) Specify what computer was used (either IBM compatible PC or Apple Macintosh); (3) Include both the text file and ASCII file on the disk; (4) The file should be single-spaced and should use the wrap-around end-of-line feature (i.e., no returns at the end of each line). All textual elements should begin flush left, no paragraph indents. Place two returns after each element such as title, headings, paragraphs, figure and table callouts, etc.; (5) Keep a back-up disk for reference and safety.

### **Submission Of Manuscripts**

Each manuscript should be accompanied by a covering letter in which: (1) all authors must give signed consent to publication; (2) relationship of the submitted paper to any other published, submitted or proposed papers reporting the same study is explained. Three high quality copies are required. Authors from the United Kingdom and the remainder of Europe should send manuscripts to DR. RICHARD MAYOU, University Department of Psychiatry, Warneford Hospital, Warneford Road, Oxford OX3 7JX, UK. Authors from North America, Australia and the Far East should send manuscripts to DR. COLIN SHAPIRO, Department of Psychiatry, University of Toronto, The Toronto Hospital, ECW-3D, 399 Bathurst Street, Toronto, Ontario, Canada M5T 2S8; (416) 603-5388; FAX (416) 603-5036.

Rejected manuscripts and correspondence will be destroyed six months after receipt.

### **Proofs and Reprints**

The corresponding author will receive page proofs for checking. Corrections must be restricted to printing errors. Any other alterations may be charged to the author.

**Reprints may be ordered when the proofs are returned.**

### **APPENDIX 3**

#### **FORMAT BASED ON APPLICATION FOR A MINI-PROJECT GRANT IN HEALTH SERVICES RESEARCH (SOHHD)**

- 1.1 Applicants – names and addresses including the names of co-workers and supervisor (s) if known.
- 1.2 Title – no more than 15 words.
- 1.3 Summary – No more than 300 words, including a reference to where the study will be carried out.
- 1.4 Introduction – of less than 600 words summarising previous work in the field, drawing attention to gaps in present knowledge and stating how the project will add to knowledge and understanding.
- 1.5 Aims and hypothesis to be tested – these should wherever possible be stated as a list of questions to which answers will be sought.
- 1.6 Plan of investigation – consisting of a statement of the practical details of how it is proposed to obtain answers to the questions posed. The proposal should contain information on Research Methods and Design i.e.
  - 1.6.1 Subjects – a brief statement of inclusion and exclusion criteria and anticipated number of participants.
  - 1.6.2 Measures – a brief explanation of interviews/ observations/ rating scales etc. to be employed, including references where appropriate.
  - 1.6.3 Design and Procedure – a brief explanation of the overall experimental design with reference to comparisons to be made, control populations, timing of measurements, etc. A summary chart may be helpful to explain the research process.
  - 1.6.4 Settings and equipment – a statement on the location(s) to be used and resources or equipment which will be employed (if any).
  - 1.6.5 Data analysis – a brief explanation of how data will be collated, stored and analysed.
- 1.7 Practical applications – the applicants should state the practical use to which the research findings could be put.
- 1.8 Timescales – the proposed starting date and duration of the project.
- 1.9 Ethical approval – stating whether this is necessary and, if so, whether it has been obtained.

## APPENDIX 4.1

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*Figures* A glossy photograph or clear ink drawing of each should be sent. Each figure should be numbered on the back and the top should be marked. A photocopy should be attached to each copy of the manuscript. Captions should be on a separate sheet. The number of illustrations should be kept to a minimum. Color illustrations are not normally acceptable. Authors may be asked to support the costs of color reproduction.

*Letters to the Editors.* Letters should not exceed 1000 words and, where appropriate, must begin with the reference to the published article about which the author is commenting.

Authors are encouraged to submit a computer disk (5.25" or 3.5" HD/DD disk) containing the final version of their papers along with the final manuscript to the editorial office. Please send disk only after manuscript has been accepted for publication. Please observe the following criteria: (1) Specify what software was used, including which release (e.g., WordPerfect 6.0); (2) Specify what computer was used (either IBM compatible PC or Apple Macintosh); (3) Include both the text file and ASCII file on the disk; (4) The file should be single-spaced and should use the wrap-around end-of-line feature (i.e., no returns at the end of each line). All textual elements should begin flush left, no paragraph indents. Place two returns after each element such as title, headings, paragraphs, figure and table callouts, etc.; (5) Keep a back-up disk for reference and safety.

### **Submission Of Manuscripts**

Each manuscript should be accompanied by a covering letter in which: (1) all authors must give signed consent to publication; (2) relationship of the submitted paper to any other published, submitted or proposed papers reporting the same study is explained. Three high quality copies are required. Authors from the United Kingdom and the remainder of Europe should send manuscripts to DR. RICHARD MAYOU, University Department of Psychiatry, Warneford Hospital, Warneford Road, Oxford OX3 7JX, UK. Authors from North America, Australia and the Far East should send manuscripts to DR. COLIN SHAPIRO, Department of Psychiatry, University of Toronto, The Toronto Hospital, ECW-3D, 399 Bathurst Street, Toronto, Ontario, Canada M5T 2S8; (416) 603-5388; FAX (416) 603-5036.

Rejected manuscripts and correspondence will be destroyed six months after receipt.

### **Proofs and Reprints**

The corresponding author will receive page proofs for checking. Corrections must be restricted to printing errors. Any other alterations may be charged to the author.

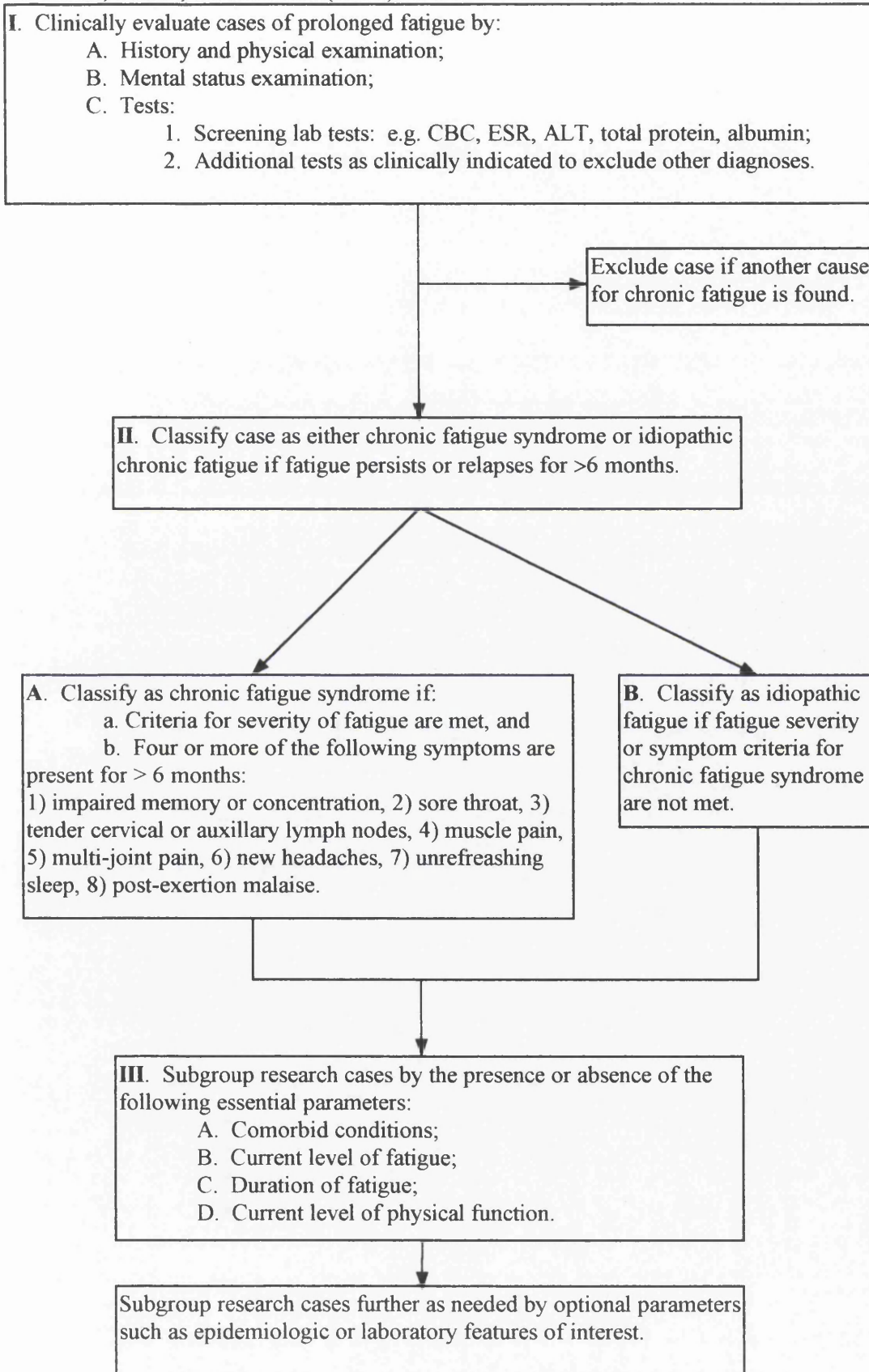
Reprints may be ordered when the proofs are returned.



## APPENDIX 4.2

### DIAGNOSTIC CRITERIA FOR CHRONIC FATIGUE SYNDROME

Fukuda, Straus, Hickie et al. (1994)



## APPENDIX 4.3

### DAILY ACTIVITY DIARY

Name \_\_\_\_\_ Date of Birth \_\_\_\_\_

#### DAILY INSTRUCTIONS

The actiwatch that you have been given is set to start recording at 6.00pm Thursday. You will notice that the activity diary also starts at 6.00pm. Therefore your first entry to your diary should be at 7.00pm and each hour after that for the next 48 hours, except when you are asleep.

You should try to carry the daily activity diary with you at all times and complete it each hour, if possible. Each time you complete the diary please press down firmly on the “marker” button on the actiwatch. This allows me to know the exact time at which you are filling in the diary.

If for any reason you cannot complete the diary one hour, or if you forget, please think back to what you were doing at that time. If you can *clearly* remember what you were doing and *exactly* how you felt, then fill it in. However, if you are not *totally sure*, leave it blank. It will be more useful to have a half-filled but totally accurate diary than one in which lots of guesses are made.

When filling in the daily activity diary, please refer to the codes below. If you are not sure what code is correct for a particular activity please write the activity in the space provided and code it as 8.

ACTIVITY	CODE
sleeping	0
resting - sitting or lying down, relaxing e.g. reading, watching TV, chatting with friends at home	1
active in or about the house e.g. personal grooming, dressing, cooking, eating, housework, DIY, gardening, working at home	2
active ‘housework’ outside the house e.g. shopping, driving etc. related to normal housekeeping	3
light occupational activities e.g. at work - mainly sitting, and work related activities, e.g. driving to work	4
heavy occupational activities e.g. at work - standing, lifting, physical jobs	5
exercise - activities in which the main intention is to increase stamina, fitness or health e.g. walking, running, exercise classes, etc.	6
socialising outside house e.g. at friend’s, cinema, café, restaurant, and other leisure activities e.g. travelling, sight seeing, visiting a museum	7
<i>other or not sure</i> - if you are unsure which code is correct for the activity you were engaged in, please write what you were doing in the space provided on the activity sheet and code it 8	8

In the MOOD box, please think about how your mood was at the end of that hour and place a number between 1 and 5 , where;

- 1 = fine
- 2 = a little low in mood
- 3 = quite low in mood
- 4 = very low in mood
- 5 = very depressed indeed

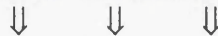
In the FATIGUE box, please think about how tired and fatigued you feel at the end of the hour. Place a number between 1 and 5 in the box, where;

- 1 = not fatigued
- 2 = a little fatigued
- 3 = quite fatigued
- 4 = very fatigued
- 5 = exhausted

When you turn out the light to go to sleep at night and on getting up in the morning, please press the actiwatch “marker” button firmly.

N.B. Although the actiwatch is water-resistant in theory, past experience has resulted in a recommendation that it be removed rather than allowed to get wet. Please take it off before showering, bathing etc.. Also, please remember to put it back on as soon as possible once dry.

**START OF 48 HOUR DIARY**



**Day 1 - 6pm to midnight**

Date \_\_\_\_\_

<b>HOUR</b>	<b>ACTIVITY CODE</b> (for 8 give details in last column)	<b>M</b>	<b>F</b>	<b>Written details of activity - if coded 8.</b>
		<b>O</b>	<b>A</b>	
		<b>O</b>	<b>T</b>	
		<b>D</b>	<b>I</b>	
			<b>G</b>	
			<b>U</b>	
			<b>E</b>	
6pm - 7				
7 - 8				
8 - 9				

9 - 10				
10 - 11				
11 - midnight				

**Day 2 - full 24 hours**

Date \_\_\_\_\_

<b>HOUR</b>	<b>ACTIVITY CODE (for 8 give details in last column)</b>	<b>M O O D</b>	<b>F A T I G U E</b>	<b>Written details of activity - if coded 8.</b>
midnight - 1am				
1 - 2				
2 - 3				
3 - 4				
4 - 5				
5 - 6				
6 - 7				
7 - 8				
8 - 9				
9 - 10				
10 - 11				
11 - midday				
12 midday - 1pm				
1pm - 2				
2 - 3				
3 - 4				

4 - 5				
5 - 6				
6 - 7				
7 - 8				
8 - 9				
9 - 10				
10 - 11				
11 - midnight				

**Day 3 - midnight to 6pm**

Date \_\_\_\_\_

<b>HOUR</b>	<b>ACTIVITY CODE (for 8 give details in last column)</b>	<b>M O D</b>	<b>F A I L U R E</b>	<b>Written details of activity - if coded 8.</b>
midnight - 1am				
1 - 2				
2 - 3				
3 - 4				
4 - 5				
5 - 6				
6 - 7				
7 - 8				
8 - 9				
9 - 10				

10 - 11				
11 - midday				
12 midday - 1pm				
1pm - 2				
2 - 3				
3 - 4				
4 - 5				
5 - 6				

If you have finished, please take a little time to think back over your hourly record of activity, fatigue and mood. Did you have any problems filling this in? YES / NO (please circle)

Also, did you have any problems using the actiwatch, such as remembering to wear it or using the marker button? YES / NO (please circle)

If YES, would it be all right for Kirsten Verity to contact you to discuss these problems? YES / NO

Now please remove the actiwatch and place it, and this diary, in the envelope provided. Please keep this envelope in a safe place until it is convenient for you to drop it off or for Kirsten Verity to pick it up. If you have problems with this, or any other part of the project, please contact Kirsten Verity on 01236 746 117 as soon as possible.

**Thank you very much for taking the time to take part.**

## APPENDIX 4.4

### INFORMATION SHEET FOR PATIENTS/ VOLUNTEERS IN A CLINICAL RESEARCH STUDY

**PROJECT TITLE:** ACTIVITY, FATIGUE AND MOOD IN CHRONIC FATIGUE SYNDROME

#### **Patient/Volunteer Summary**

You are being invited to take part in a study of Chronic Fatigue Syndrome (also called M.E. or Post-Viral Fatigue Syndrome). This study aims to find out how people with Chronic Fatigue Syndrome deal with their symptoms from one day to the next. In particular it will look at how normal, day to day activities make people with Chronic Fatigue Syndrome feel, both physically and mentally.

There is not very much known about how Chronic Fatigue Syndrome affects a person's behaviour and feelings. By taking part in this study you will be helping the medical profession understand more about Chronic Fatigue Syndrome which might in turn help them develop alternative ways to treat it.

**Your participation in this study is totally voluntary. Whether or not you decide to take part will have no effect on your treatment at all. You can withdraw from the study at any time without giving a reason and this will have no effect on your normal care.**

#### **What will happen if you agree to take part?**

*1. You will be asked to meet with Kirsten Verity, the researcher, at Dr Todd's out patient clinic. At the first meeting she will go over the details of the study again and answer any questions you might have about it. She will also ask you to fill in a consent form and two or three short questionnaires about how you feel at that time. This will probably take about half an hour.*

*2. You will then be shown an "actiwatch". This is a little device, about the same size as a wrist watch. You wear it on your wrist and it records how much activity you do. You will be asked to wear it for 48 hours.*

*3. During the 48 hours that you are wearing the actiwatch, you will also be asked to fill in a diary of what activities you are doing and how you feel at the time. This is the difficult bit because we ask that you fill in the diary on the hour, for every hour that you are awake during this time. The good news is that the diary is very easy to fill in and should not take more than 30 seconds each time you have to fill it in.*

*4. At the end of the 48 hour period you will be required to come back to the hospital to return the actiwatch. With your permission, Kirsten will contact you a few days later to ask you if you had any difficulties doing the above.*

*5. In order that you get something from helping us in this study, Kirsten will prepare an individual report for each person taking part in the study from their results. This will be sent to you after completion of the study and will have details about your level of activity, your mood and your sleep pattern. You will also be given an information pack about Chronic Fatigue Syndrome with suggestions about things that you can do which have helped other sufferers to cope with it in the past.*

If you would like to take part in the study you will need to fill in a consent form. You will be offered one by Kirsten Verity. Please read the form carefully, it should be signed by both yourself and the researcher.

If you are unsure whether you wish to take part in the study please feel free to discuss with Kirsten any questions or concerns you have about participating. You are under no obligation to take part in the study after talking to her.

**Thank you for your help.**



**APPENDIX 4.5**

**PATIENT OR VOLUNTEER CONSENT TO PARTICIPATE IN RESEARCH STUDY**

**Project Title:** Activity, Fatigue and Mood in Chronic Fatigue Syndrome

- You should have been given a complete explanation of the research in which you are being invited to take part, including details of the procedures and treatment you would undergo as part of the study.
- You should have had the opportunity to ask questions.
- You should have received the Information Sheet on the study which has been approved by Lanarkshire Health Board Ethics of Research Committee, which you should have read and should keep.
- There is no obligation to take part in the study and you need not give any reason if you do not wish to take part in the study.
- You may withdraw from the study at any time without the need to give a reason and without any effect on your normal care.

**Consent**

I ..... (name in block capitals)

of

.....

..... (address in block capitals)

agree to take part in this research project, the nature, purpose and possible consequences of which have been described to me

by ..... (name in block capitals)

If necessary, I may/may not (delete as applicable) be contacted at home by the researcher.

My telephone number is .....

Subject signature

..... dated .....

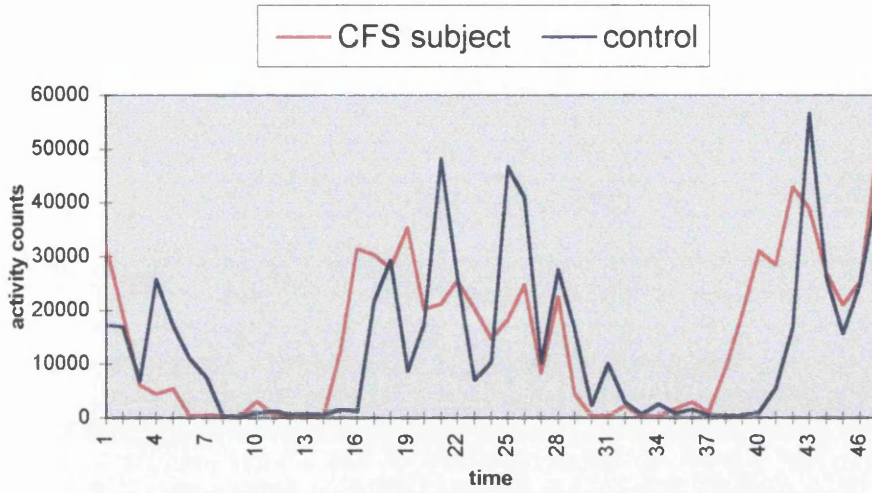
Researcher signature

..... dated .....

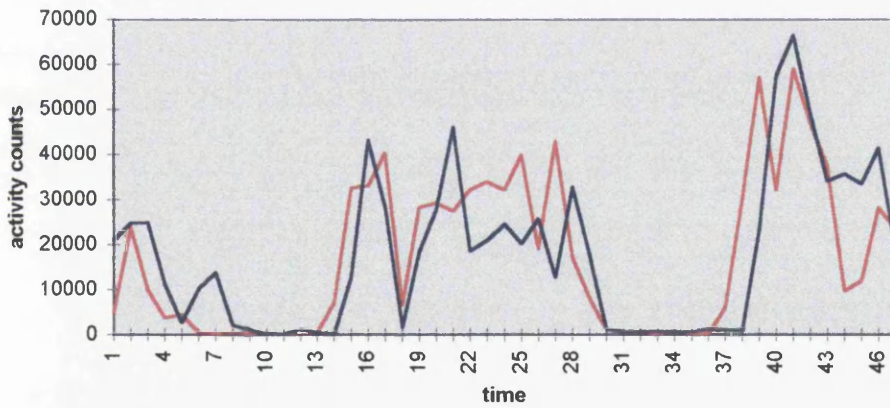
## APPENDIX 4.6

### MATCHED PAIRS - HOURLY ACTIVITY OVER 48 HOUR RECORDING PERIOD

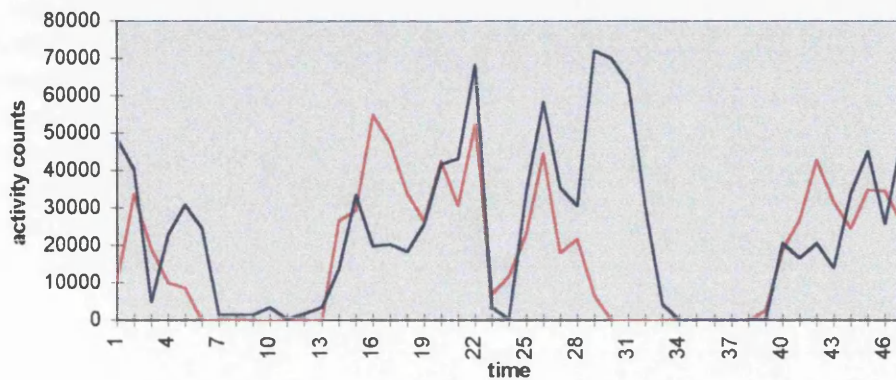
#### PAIR 1



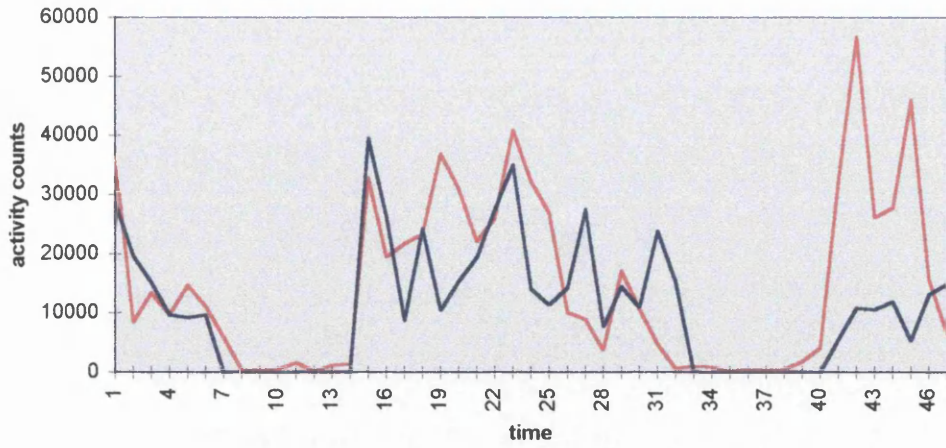
#### PAIR 2



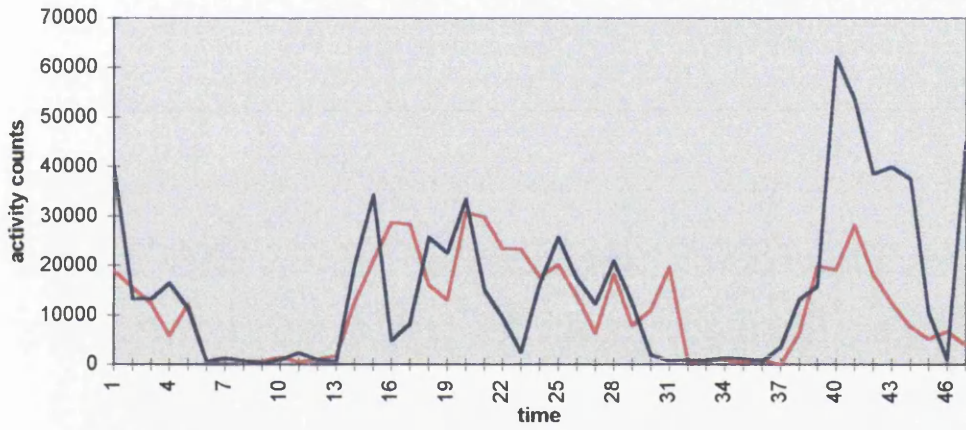
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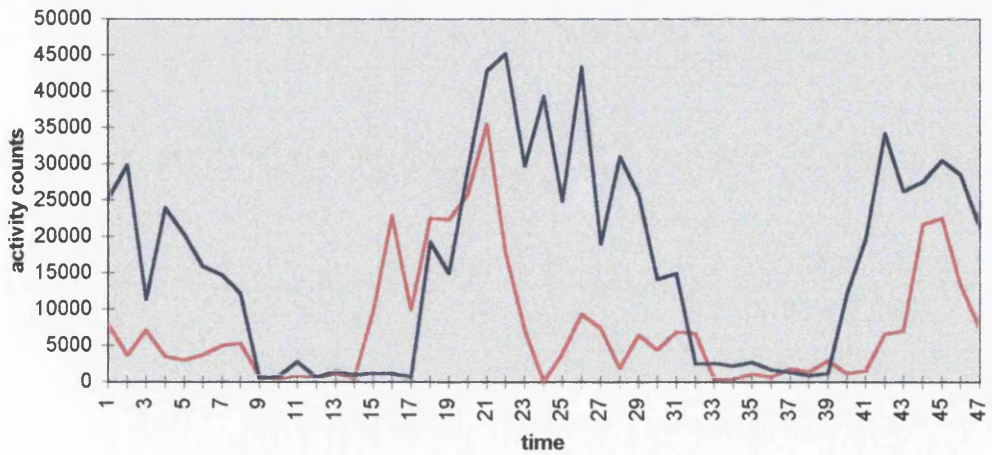
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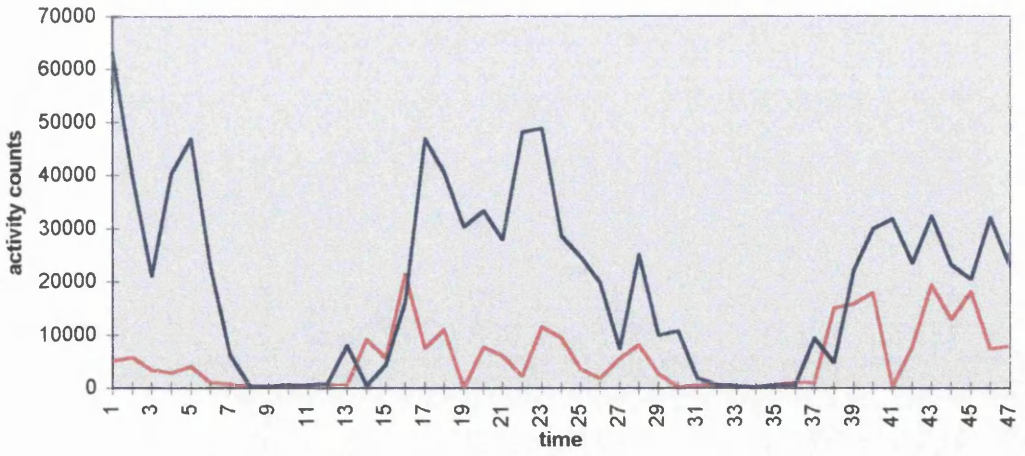
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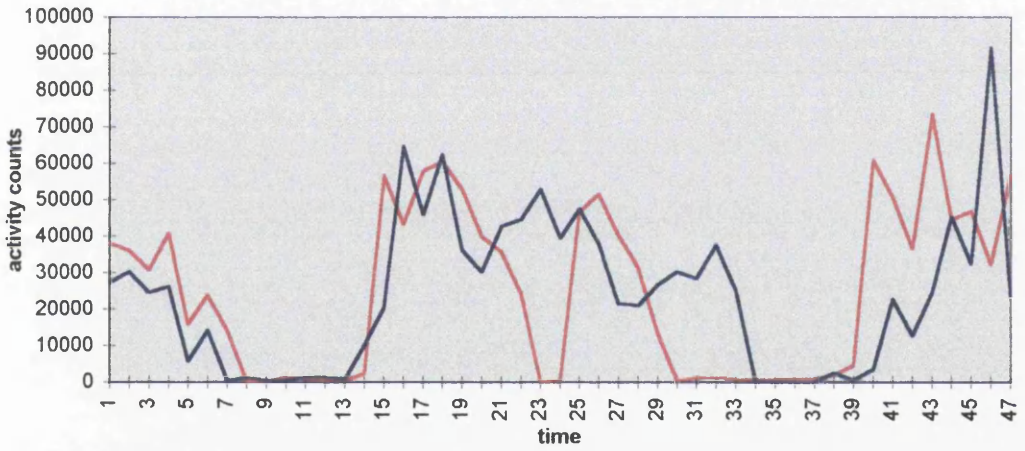
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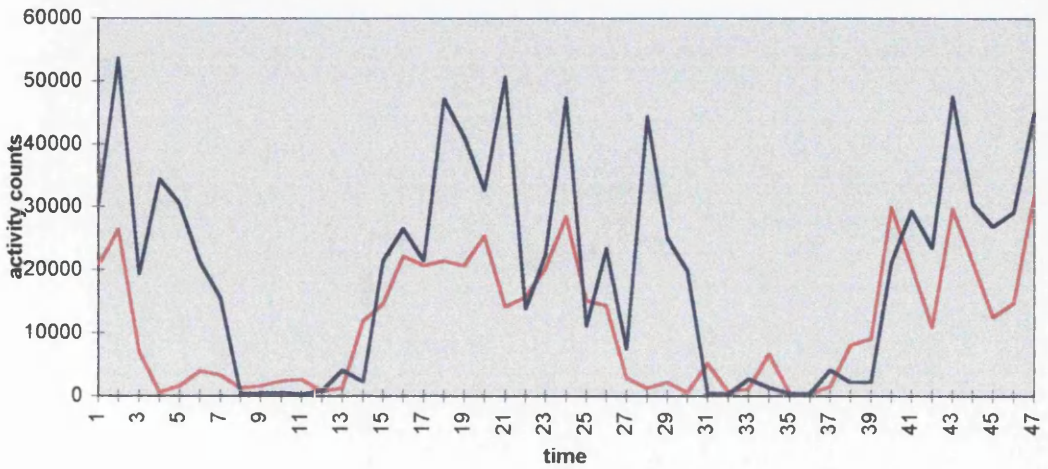
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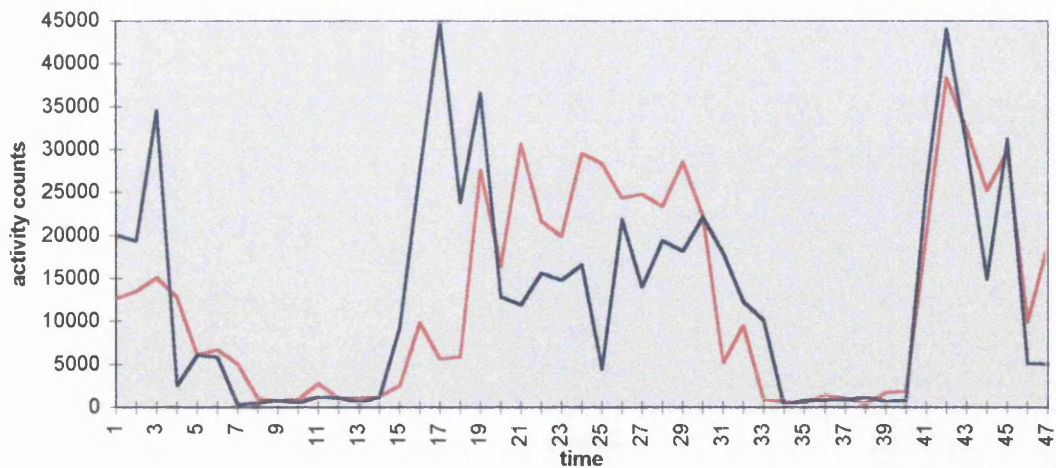
PAIR 8



PAIR 9



PAIR 10



## **APPENDIX 4.7**

### **FURTHER USE OF STUDY DATA**

The preceding Major Research Project Paper reported the analysis of data pertaining to a specific set of questions. These research questions should be viewed as the first level of an exploratory procedure. The nature of data collection and the experimental design used have yielded supplementary data on sleep patterns as well as reported levels of sleepiness and perceived levels of effort in CFS subjects. Furthermore, because of the momentary assessment method used in conjunction with objective activity measures, the data can be considered as ideal for formal time series analysis, such as ITSACOR. Such analyses are planned for completion at a later date and, like the previous paper, the results are expected to make an important contribution to this relatively under-researched area.

