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COGNITIVE IDIOSYNCRASIES AMONG CHILDREN WITH THE CHRONIC FATIGUE SYNDROME: ANOMALIES IN SELF-REPORTED ACTIVITY LEVELS

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Abstract—The possibility that children with the chronic fatigue syndrome (CFS) and their parents tend to display idiosyncratic cognitive processing concerning levels of activity was examined by means of subjective and objective measures of current activity, together with subjective and objective measures of desired and expected future activity. The degree to which subjective reports of current activity level reflect objectively measured activity level was examined in a group of children with CFS and a healthy control group. All subjects were assessed over a 3-day period by means of ambulatory activity monitoring, and self-reports and parent-reports of current activity level were collected by means of visual analog scales. Analysis of variance revealed a significant interaction between the method of measurement (objective versus subjective) and the participant group (CFS versus Healthy) with the CFS children and their parents underestimating actual level of activity relative to the healthy group. Desired and expected levels of future activity were also assessed by means of subjective report. Child and parent expected levels of future activity were compared with their desired levels. Although expected levels of future activity were similar in the two groups, the divergence between expected levels and corresponding desired levels was significantly greater in the CFS group. These results are discussed in terms of idiosyncratic cognitive processes, which are hypothesized to be associated with CFS and which may play a role in the maintenance of the disorder.

Keywords: Chronic Fatigue Syndrome; Children; Activity levels; Cognitive processes.

INTRODUCTION

The onset of chronic fatigue syndrome (CFS) during childhood or adolescence can have very serious implications for education and social development, disabling the patient for months and sometimes for years. It is characterized by persistent feelings of physical and mental fatigue that are out of proportion to exertion and severe enough to seriously interfere with normal activities.

While much of the literature concentrates on the etiology of chronic fatigue syndrome, its maintaining factors must be of equal importance in finding an efficacious treatment program. The influence of psychological factors on the way in which a patient interprets and reacts to symptoms of any illness, whether of organic or emotional origin, may have implications for suitable treatment strategies and eventual outcome. The possibility is explored here that CFS is associated with idiosyncrasies

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in the cognitive processes of both patients and their parents concerning levels of activity. Cognitive biases of this type have been hypothesized to play an important role in a number of other disorders, such as those of depression and anxiety, among both adults [1, 2] and children [3, 4].

Do patients with CFS have idiosyncratic cognitive processes?

The limitation of activity due to muscle fatigue in CFS occurs in the absence of evidence for peripheral abnormalities in muscle physiology [5–7]. Studies of cardiac function are less consistent, but the overall picture is again of a normal cardiac profile, where it is possible that observed group differences may be explained by confounding factors in experimental design or deconditioning rather than impaired heart rate response [8–10]. Consistent with the clinical picture, and in spite of the evidence for a normal physiological response to exercise, CFS patients show an altered perception of their degree of physical exertion. Riley and colleagues' [10] CFS patients perceived workload at peak exercise to be significantly greater than either healthy controls or patients with the irritable bowel syndrome. Gibson and colleagues [9] similarly showed that CFS patients have a lower threshold for sensation during exercise compared with normal subjects, showing higher perception of effort in relation to heart rate. These data have been taken by some authors as evidence that patients with the chronic fatigue syndrome have some cerebral dysfunction affecting perceptual threshold [5, 6].

The supposition has been that subjective fatigability in CFS is due to a physiological source and that central factors (in particular a reduced sensory threshold) are contributing to the increase in perceived exertion and exercise limitation of these patients. However, this is not fully consistent with experimental observation. First, the enhanced sensation of aerobic exertion in CFS was not replicated for muscle exertion [11]. If the subjective complaint of fatigue during aerobic exercise [9, 10] is due to a reduction in sensory threshold, we would expect anaerobic exercise such as muscle exertion to be similarly affected.

In addition, subjective symptoms of CFS other than those related to "sensory" factors are not reliably consistent with objective findings. A common complaint of this patient group is cognitive deficit, including problems with memory, attention, and decision making. A number of studies have examined the cognitive profile of adult CFS patients, but have often failed to find objective evidence to corroborate patient report. Where objective deficits have been found, findings from different studies tend to vary considerably and include reduced digit span [12], discrete impairment in short-term recall [13], and poor retrieval from semantic memory [14]. Other studies have found no evidence for cognitive impairment on tests of memory, concentration, and abstract reasoning, with CFS subjects performing significantly better than would be expected from normative data [15] or at least within normal limits [16]. McDonald and colleagues [17] found deficits in attention and concentration, but objective impairment bore little relation to subjective impairment. These results point to an association between CFS and distorted cognitive processes, but leave open the question of how, if at all, the distortions in cognitive processing might influence the course of CFS.

Could the relation between desired and expected levels of activity differ in CFS?

Models of CFS that include some cognitive component in the maintenance of the disorder have developed over recent years. Surawy and colleagues [18] put forward a

theory that life stresses and viral infection may cause CFS in psychologically vulnerable individuals, but that its perpetuation depends on the interaction between behavioral, physiological, social, and notably cognitive factors. Clinical observation indicates a hard-driving, achievement oriented personality style to be associated with CFS [18, 19], which may lead to raised expectations of performance and of what is an acceptable standard of functioning. Indeed, the most common theme encountered by Surawy and colleagues [18] during treatment of a CFS group was concerned with high standards and the notion that failure to meet such standards would indicate failure as a person. The patients' self-imposed standards tended to have an "all or nothing" quality, consistent with the observed bursts of activity and relapse. Thus, a desired level of functioning that is elevated relative to the normal population and expectations of immediate return to a premorbid level of functioning may be helping to maintain the illness in two ways. First, patients' perceptions of their illness states are distorted such that they overestimate the extent of their functional impairment and, second, attempts at recovery are frustrated by an unwillingness to adopt the recommended graduated approach. This is not to suggest that CFS has no organic basis, but rather that individual characteristics of this patient group may help to maintain illness behavior.

The present study examines a cognitive model of CFS in which the maintenance of illness behavior might, at least partially, be explained from a cognitive perspective of distorted perception and unrealistic expectation. First, it was predicted that differences found between subjective complaint and objective observation could be replicated in another domain, outside of sensory perception, which would be sensitive to levels of expectation and cognitive distortion. Activity levels were chosen because they are not a symptom of the syndrome per se, but are reported to be reduced as a consequence of illness and can be measured objectively. Anomalies have already been observed in self-reported premorbid levels of activity in an adult group of patients with CFS. Compared to patients with the irritable bowel syndrome, CFS patients indicated that they had a greater capacity for activity before their illness, and aspired to return to this high level of activity on recovery [10]. For the current study, activity levels of a group of children with CFS and a healthy control group were measured over a 3-day period using an ambulatory activity monitor and compared to subjective reports of current activity level from both the subjects and their parents. Between-group comparisons were made to assess overall differences in objective and subjective activity levels, and within subject comparisons examined the extent to which subject (and parent) report reflected the objective measure. Secondly, it was predicted that the desired level of activity in the CFS group would be greater than that in the control group, and that expectations of future postmorbid activity level would be correspondingly higher in the patient group. Self-report and parent-report of expected and desired activity level on recovery (or in the future) were collected, with analyses of both between-group (CFS/control) and within subject (expectation/aspiration) differences.

METHOD

Subjects

Patients were recruited from a number of pediatricians and child psychiatrists in the Oxfordshire area. Although labeling of the disorder varied between clinics, uniform criteria for chronic fatigue syndrome were applied. These criteria were adapted from the adult literature [20] only in terms of duration of fatigue. To be recruited into the study, a child must have been suffering from fatigue for at least 2 months (adult criteria require 6 months). The fatigue must have been severe enough to seriously disrupt normal activities and have been present for more than 50% of the time (according to the referring clinician's judgment). Neither physical disease nor psychiatric disorder should have been present at onset to which symptoms

could be ascribed. (It was anticipated that secondary diagnoses of depression or anxiety would be common, and hence the confounding effects of mood were considered during the analyses). Children were to be of school age and resident in the Oxford region.

A group of 19 patients who were part of a larger study of sleep disorders in children with CFS were recruited. They ranged in age from 11.8 to 16.4 years (mean age 14.3 years). There were 10 males and 9 females. Duration of their fatigue ranged from 5 months to 9.5 years. Consistent with a reported disruption of normal activities, the majority had missed long periods of schooling.

A group of 19 healthy control subjects were recruited with the help of patients and their teachers. A control subject was typically a friend of the patient who was of the same sex and age (mean age 14.7 years). There were 10 males and 9 females.

The reliance on the clinical judgment of a number of different referring clinicians is an issue that will be referred to in the discussion.

Materials

A Gaehwiler Electronic Activity Monitor (and accompanying software) was used. It was set to an epoch of 1 minute and programmed to begin recording at 7:30 A.M. on the first study day. The monitor consists of a black box measuring 51 by 36.5 by 21 mm and weighing 68 g. It is worn with a strap similar to that of a wristwatch, in this case on the ankle. It has a sampling time of 125 ms (equivalent to 8 Hz) and a sensitivity of 0.1 g, and it integrates the occurrences of suprathreshold motor activity over each epoch. The numerical output is therefore an indication of the intensity of the monitor's movements throughout the measuring period. In the present study, the reported measure is the percentage of epochs in which movements of the leg had occurred that were above the 0.1 g threshold, which has previously been validated against energy expenditure [21, 22] and observation [23].

Subjective measures of activity level were made on 100 mm visual analog scales, to be comparable to the percentage measure of the activity monitor. A sheet giving general information about the activity monitor was given to subjects and their parents to remind them of the basic instructions for its use. Levels of fatigue were measured using Chalder and colleagues' Fatigue Scale [24]. Mood was assessed using the Children's Depression Inventory (CDI) [25] and the Revised Children's Manifest Anxiety Scale (RCMAS) [26].

Procedure

All subjects' parents were initially contacted by a letter explaining the study of sleep, of which a part was to monitor activity levels for 3 days. This was followed with a telephone call to discuss the study further and answer any questions that subjects or their parents might have. If both the child and the parents agreed to take part, they were visited in their home. The activity monitor was tried on by the child, and full instructions for its use were given. It was to be worn on the nondominant leg for 3 consecutive days (in all but one case a Tuesday, Wednesday, and Thursday), from the time the subject got up in the morning until bedtime. It was to be removed for bathing, showering, or any other activity for which water damage was likely. The child was given a log-sheet on which to record any time at which the monitor was put on or removed. This was to ensure that periods in which it was not being worn could be edited from the data. Subjects were told that the monitor would count their movements, and it was stressed that they should try to forget its presence and act as they would usually do.

In addition to the objective activity measure, both the subject and a parent (usually the mother) were given a booklet containing questions on their perception of the child's activity levels. All answers were indicated as responses on a 100-point visual analog scale (VAS) for which careful instructions and practice were given. Four questions were answered during the researcher's visit, with the VAS ranging from 0 "Not at all active" to 100 "Extremely active":

1. Before *your (their)* illness, how active were *you (was your child)* compared to other healthy children of the same age and sex?
2. How active *are you (is your child)* now, compared to other healthy children of the same age and sex?
3. When *you get (your child gets)* better, how active do you expect *(them)* to be, compared to other healthy children of the same age and sex?
4. When *you get (your child gets)* better, how active would you like *(them)* to be, compared to other healthy children of the same age and sex?

Questions for the healthy subjects and their parents were adapted by asking about levels of activity 6 months ago (rather than before illness) and 6 months in the future (rather than on recovery). The period of 6 months was chosen as it was anticipated that this would be the minimum length of time for which the patient group had been ill, controlling for retrospective report.

In addition, subjects and parents were left with 3 identical sets of questions to be answered at the end of each day on which the monitor was worn:

1. How active *were you (was your child)* today, compared to a typical day in the last month? (VAS ranged from *Not at all active* to *Extremely active*.)

2. Compared to other healthy children of the same age and sex, how active *were you (was your child)* today? (VAS ranged from *Not at all active* to *Extremely active.*)

3. For how much of the time *were you (was your child)* active today? (VAS ranged from *Active none of the time* to *Active all of the time.*)

4. For how much of the time *did you (did your child)* rest (or do nothing) today? (VAS ranged from *None of the time* to *Rested all of the time.*)

The fatigue and mood questionnaires were completed with the help of the researcher. The monitor and questionnaire booklets were collected after the 3 days, and the data were downloaded to a PC. Using the Gaehwiler software, periods for which the subject had not been wearing the monitor (as recorded on the log sheet) were removed from the data. An "active" epoch was defined as any epoch for which movement count was greater than zero, and the percentage of active epochs (from the total valid epochs) was computed for each day and for the 3 days overall. All but one of the subjects wore the activity monitor for the full 3 days. One of the control subjects was unhappy about wearing the monitor to school and, instead, agreed to wear it over the weekend, giving a 2-day recording. Results from one of the CFS patients were not included in the final analyses because activity was at floor level.

RESULTS

Summary

(1) There were discrepancies between the objective measure and subjective reports of activity level in both the CFS group and the healthy group, for both children and parents. However, the discrepancy was significantly larger for the CFS group, with CFS children and their parents effectively underestimating the patient's objective level of activity.

(2) Both CFS and healthy children aspire to be more active in the future than they are at present. While the desired and expected levels of activity are similar for healthy children and their parents, the CFS children show a significant difference between expected postmorbid activity level and desired activity level. In other words, CFS children aspire to higher levels of activity than they expect to attain, and this is reflected in parental aspirations as well.

Statistical methods

To reduce the probability of a Type I error, activity data were initially examined with analyses of variance (using SPSS 4.1 for VAX/VMS [27]). These were then supplemented with a priori pairwise comparisons of means. Dunn's multiple comparison procedure [28] was chosen, as it allows comparisons between means that are not orthogonal. The possible effects of fatigue and mood on activity variables were assessed using analysis of covariance.

A general potential problem with analyzing subjective measures is that they may be nonlinearly related to underlying factors of primary interest. In the present case, however, regression analysis of the control children's data confirmed that there was a strong linear relation between the subjective and the objective measures of activity ($F[1, 12] = 9.28$, $p<0.01$).

Levels of fatigue and mood

The Fatigue Scale discriminated between the CFS and healthy groups, with mean Fatigue levels of 26.7 and 13.3, respectively, ($F[1, 17] = 53.98$, $p<0.001$). The CFS group showed elevated levels of Depression, with a mean CDI score of 11.5 compared to the control group's 6.6, ($F[1, 16] = 7.44$, $p = 0.015$). Levels of Anxiety in the CFS group (mean 10.8) were also significantly higher than in the control group (mean 6.7), ($F[1, 16] = 5.68$, $p = 0.030$).

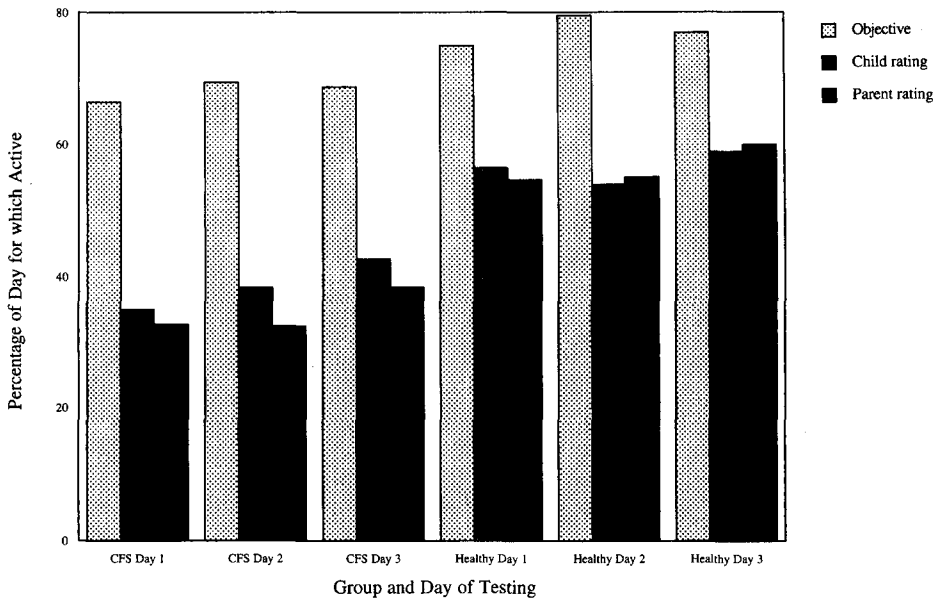

Fig. 1. Objective activity and subjective ratings of activity by children and their parents in the CFS and healthy groups.

Do children with CFS (and their parents) overestimate their level of functional impairment?

Analysis of variance was used to examine the relation between the between-subjects factor of Group (CFS and Healthy), the within-subjects factor of Activity Measure (Objective, Child Rating, Parent Rating), and the within-subjects factor of Day of Testing (First, Second, Third). Two cases were rejected due to missing data—subjects had failed to complete all subjective measures, giving a sample size of 16 in each group. There was a significant effect of Group ($F[1, 15] = 17.96$, $p = 0.001$) and of Activity Measure ($F[2, 30] = 69.93$, $p < 0.001$). In addition, there was a significant interaction between Group and Activity Measure ($F[2, 30] = 3.53$, $p = 0.042$), (see Figure 1). There were no significant effects involving Day of Testing (all $F < 1.6$).

Dunn's multiple comparison procedure was used to evaluate pairwise comparisons among the 6 means of the Group by Activity Measure interaction (shown in Table I). Overall, the procedure demonstrated that both Child Ratings and Parent Ratings of activity were significantly higher for the Healthy than for the CFS group (both $p < 0.01$), but that objective activity did not differ significantly between the two Groups.

Table I.—Mean (SD) measures of activity (percentage of active epochs), averaged over three days

	Type of Measure		
Group	Objective	Child rating	Parent rating
CFS	68.2 (8.0)	38.6 (16.6)	34.4 (16.1)
Healthy	77.1 (9.7)	56.4 (17.6)	56.5 (10.1)

Table II. – Mean (SD) ratings of past activity by child and parent

Group	Child	Parent
CFS	73.2 (19.8)	75.3 (19.6)
Healthy	62.9 (15.8)	67.4 (18.0)

In addition, there was no significant difference between Child and Parent Ratings for either of the two Groups. Further, the Objective level was higher than both the Child and Parent Ratings for both Groups (all $p<0.01$).

It is possible, in principle, that the overall main effect of Group on level of activity could be attributed to a difference in mood or fatigue levels between the CFS and Healthy groups. Three analyses of covariance were performed with level of Depression, Anxiety, and Fatigue as covariates using the same design as in the 3-way ANOVA. As expected, the ANCOVA regression for fatigue was significant, $F[1, 14] = 8.52$, $p = 0.01$, and when Fatigue was covaried out, the main effect of Group was no longer significant, $F[1, 14] = 2.04$. In contrast, the ANCOVA regressions were not significant for either Depression ($F[1, 14] = 0.66$) or Anxiety ($F[1, 14] = 0.38$), demonstrating that the difference between the CFS Group and the Healthy Group cannot be attributed to differences in mood between them.

A further analysis of variance was carried out on the ratings of past activity (see Table II). A 2-way analysis showed that the effects of neither Group (CFS, Healthy) nor Activity Rater (Child, Parent) was significant either as main effect or as interaction ($F[1, 17] = 3.31$, 0.75 and 0.11, respectively).

Do children with CFS (and their parents) have distorted expectations and aspirations of future activity level?

Analysis of variance was also used to examine the relations between the between-subjects factor of Group (CFS and Healthy), the within-subjects factor of Activity Rater (Child, Parent), and the within-subjects factor of Activity Type (Expected, Desired) (see Table III).

Desired levels of activity were higher than expected levels ($F[1, 17] = 36.57$, $p<0.001$). The effect of Activity Rater ($F[1, 17] = 4.04$) and of Group ($F[1, 17] = 0.02$) did not reach significance. The only interaction that reached significance was that between Activity Type and Group ($F[1, 17] = 7.36$, $p = 0.015$). A Dunn's multiple comparison procedure showed that desired levels of activity were significantly higher than expected levels of activity for the CFS group ($p<0.01$), but were not significantly different for the Healthy group, (see Figure 2).

Table III. – Mean (SD) ratings of desired and expected future activity by child and parent

	Desired		Expected	
Group	Child	Parent	Child	Parent
CFS	87.3 (14.0)	77.4 (13.8)	71.7 (16.9)	61.7 (16.5)
Healthy	80.9 (15.9)	75.9 (15.0)	71.2 (19.6)	72.4 (16.7)

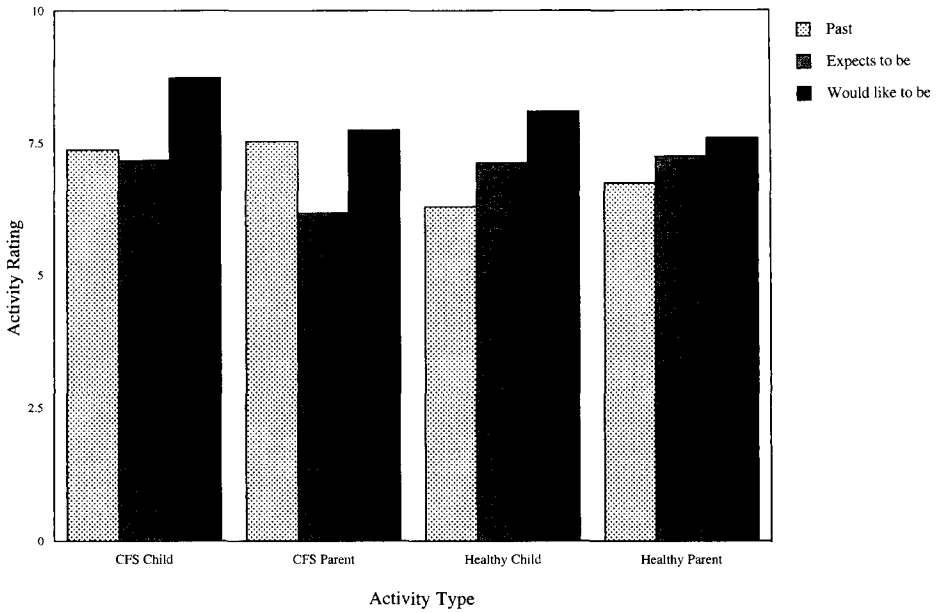

Fig. 2. Self-reported and parent-reported desired and expected levels of activity.

DISCUSSION

Despite the diagnostic criteria that children with CFS should have fatigue that is severe enough to seriously interfere with normal activities, there was surprisingly no significant difference between the monitor measures of activity levels in the two groups. This is of interest in itself, as it suggests that the effect of fatigue on activity that is reported to the clinician is perhaps more severe than actual activity level would suggest. Indeed from the results of this study, children with CFS and their parents do appear to report greatly reduced patient activity, to a degree in excess of that indicated by objective measure. The result of this distorted perception might be to convince patients (and their parents) that their illness is more severe than objectively observed behavior would actually suggest. In other words, the perception that activity levels are much lower than they really are could magnify the feeling of ill health, possibly having a maintaining role in the course of the disorder. What could be causing such an underestimation of activity level, since clearly the concept of a "reduced sensory threshold" [5, 6] is not applicable in the case of patients' parents?

In view of the hard-driving personality characteristic that has been attributed to this patient group [18, 19], one suggestion might be that their evaluation of a normal level of activity is elevated. However, premorbid levels of activity reported in this study do not support such an explanation. If a change in baseline for "normal" activity is not the reason for the distorted perception of morbid activity level, there must be some other explanation, possibly an elevated idea of what is a desirable level of activity. From the analyses of covariance, it is level of fatigue, and not mood, that is responsible for this distortion.

The significant interaction between subject group and projected measure of activity

(whether expected or desired) provides clearer insight into the processes involved in activity judgments. Children with CFS aspire to an activity level that is higher than either they or their parents expect them to attain. Expectations of postmorbid activity by the CFS group and their parents are comparable to expectations of future activity by healthy controls, but it is the discrepancy between expectation and desirability that is increased in both patients and their parents and that is potentially playing a role in maintaining illness behavior. Personality characteristics may be involved. If a desired goal is expected to be unattainable, a coping strategy might be to avoid the challenge and hence inevitable disappointment. Lewis and colleagues [19] report that CFS patients do indeed use more "escape avoidance" coping strategies post-illness. In this case, analysis of covariance suggests that mood rather than fatigue is responsible for the different patterns of responses between groups. The role of depression and anxiety may be to increase the gap between what is desirable and what is perceived to be attainable.

At this point, it should be noted that there are difficulties in trying to measure activity objectively [29, 30]. There is no published validity study of the Gaehwiler activity monitor. However, validity studies of accelerometers have yielded encouraging results relating to energy expenditure [21, 22] and observation [23] (particularly when the device is attached to the ankle). In addition, our patient group was referred from a number of different sources, and the influence of clinician variability on the homogeneity of our sample should not be ignored. However, this should have been reduced by the application of uniform recruitment criteria. Finally, it should be noted that, in principle, it is possible that results similar to those reported here may be observed for patients with other disorders associated with inactivity and fatigue, and such comparisons would be a valuable line for future research to take.

How do the present findings enhance our understanding of CFS and relate to a cognitive model of the disorder? If children with CFS and their parents underestimate morbid levels of activity, perhaps they also have a distorted perception of other symptoms and signs of the illness. Rather than explaining exercise intolerance in terms of a reduced physiological sensory threshold, the enhanced perception of bodily sensations may be related to an elevated conception of desirable levels of performance. Further research is required to examine how far our results generalize to other symptoms. For example, objective performance on a cognitive task could be compared to subjective performance and a desired level of performance. Patients with CFS in Surawy and colleagues' study [18] thought of symptoms as *not only being unpleasant but also of being an indicator of worsening of the disease process.* Such a cognition in a patient group who may be oversensitized to bodily symptoms would result in a viscious circle of (1) symptoms associated with initial virus and deconditioning, (2) overestimation of symptom severity, (3) confirmation of worsening of the disease process, and hence (4) continued illness behavior.

The discrepancy between our patient group's desired and expected level of activity is consistent with the personality, cognitions, and clinically observed behavior described in Surawy and colleagues' study [18]. Premorbid personality, characterized by achievement orientation and perfectionism in all areas of life, leads to an *all or nothing* criterion for performance. In addition, the anticipated consequence of not meeting standards is failure and rejection. If the patient's goal for an acceptable level of activity is out of proportion to what he or she realistically feels able to achieve (or

has failed to achieve during brief bursts of activity), the result may be avoidance of further attempts.

Implications of this study for clinical practice are twofold. First, use of activity as an outcome measure for treatment of CFS may be problematic if relying only on patient report. Second, the finding that children with CFS have large discrepancies between desired activity level and expectations of what they can achieve on recovery requires consideration. If patients and their parents believe that they must strive for unrealistic levels of activity, efficacy of a treatment program (for example, graded activity) may be hindered. It may be that such beliefs should be addressed systematically at the cognitive level, as has been proposed in the case of disorders such as panic attack [31].

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