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# Does graded activity increase activity? A case study of chronic fatigue syndrome

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## Abstract

The reliance on self-report outcome measures in clinical trials of graded activity-oriented cognitive-behavior therapy in chronic fatigue syndrome (CFS) makes it difficult to draw definitive conclusions about actual behavioral change. The participant in this case study was a 52-year-old married male with CFS who was working full-time. Outcome measures included a step counter to objectively measure physical activity as well as a daily diary measure of exercise activity and in vivo ratings of perceived energy, fatigue, and affect. The following psychometric instruments were also used: the CFS Symptom Inventory, the SF-36, the Beck Depression Inventory, and the Beck Anxiety Inventory. The 26-session graded activity intervention involved gradual increases in physical activity. From baseline to treatment termination, the patient's self-reported increase in walk time from 0 to 155 min a week contrasted with a surprising 10.6% decrease in mean weekly step counts. The final follow-up assessment revealed a "much improved" global rating, substantial increases in patient-recorded walk time and weight lifting intensity, yet a relatively modest increment in weekly step counts. It appeared that improvement was associated with mood-enhancing, stress-reducing activities that were substituted for stress-exacerbating activities.

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## 1. Introduction

### 1.1. Cognitive-behavioral treatment studies

Chronic fatigue syndrome (CFS), a perplexing illness of uncertain etiology, is defined by at least 6 months of medically unexplained debilitating fatigue plus a minimum of four out of eight secondary symptoms, such as neurocognitive difficulties, flu-like symptoms, and exercise intolerance (Fukuda et al., 1994). Although no effective medical therapy has been established for CFS, randomized clinical trials of cognitive-behavioral treatment (CBT) conducted in England (Deale, Chalder, Marks, & Wessely, 1997; Sharpe et al., 1996) and the Netherlands (Prins et al., 2001) have all reported substantial improvements in physical and role functioning as well as clinically impressive reductions in fatigue symptoms. By comparison, the control conditions in these studies, standard medical care (Sharpe et al., 1996), coping-oriented relaxation (Deale et al., 1997) and guided support or no treatment (Prins et al., 2001), did not show significant behavioral changes. These clinical investigations have used a combination of incremental activity scheduling, i.e., graded activity or operant behavior therapy, to reverse physical deconditioning, and cognitive therapy to overcome purportedly exaggerated fears of activity-related symptom flare-ups.

Three other randomized clinical trials (Fulcher & White, 1997; Powell, Bentall, Nye, & Edwards, 2001; Wearden et al., 1998) that used graded exercise, ostensibly without cognitive intervention, have also reported significant improvements in fatigue, functional capacity, and physical fitness in a majority of their CFS patients. The Powell et al. trial reported findings comparable to the CBT studies, while the remaining graded exercise studies found somewhat less improvement. The Powell et al. treatment regimen may have approximated a CBT protocol because all subjects received educational booklets that described the principles of graded activity with cognitive intervention. In general, both graded activity-oriented CBT and graded exercise studies reported a return to near pre-morbid functioning in many, if not all, of their largely low functioning participants.

### 1.2. Self-report vs. objective measures

Despite the apparent successes of these clinical trials, the reliance on self-report outcome measures makes it difficult to determine if patient reports (e.g., return to work) reflected illness improvements or simply improvements in coping with the illness (Whiting et al., 2001). One of these behavioral treatment studies (Prins et al., 2001) did attempt to document patient-rated improvements in physical and role functioning with an objective measure of activity. In that study, the patient sample treated with CBT evidenced no significant change in actigraph-measured activity from pre-treatment baseline to treatment termination and follow-up assessments (Gijs Bleijenberg, pers. comm., 1/29/01). Given this unexpected result, it should be useful to both clinicians and researchers to explore why patient-reported improvements may not correspond to objective measures of activity.

In preliminary studies, relatively modest correlations have been found between patient-rated activity or exertion and actigraph-measured objective activity in CFS (Jason et al., 1999; Vercoulen et al., 1997). Likewise, one cannot necessarily assume a strong association between physical improvement as perceived by the patient and as measured objectively by an ambulatory monitoring device. Such monitoring devices, specifically the actigraph, have been used to delineate sleep/wake cycles in the evaluation of both sleep disorders (Klosch, Gruber, Anderer, & Saletu, 2001) and diurnal blood pressure variation (e.g., Eissa, Poffenbarger, & Portman, 2001). These instruments offer an efficient method to distinguish rest and activity patterns over long periods that is superior to sleep logs and daily diaries. They may also be useful in assessing the effects of clinical interventions that are assumed to have a substantial impact on physical functioning.

### *1.3. High vs. low functioning in CFS*

Reported improvements in physical functioning may reflect several possibilities with respect to actual activity: (a) increased activity, especially in low function patients, if they resume pre-illness pursuits, e.g., employment; (b) no change in absolute activity level, indicating perhaps a redirection of activity into behaviors considered more functional by subjects or investigators; or (c) decreased activity, a more likely result for high function patients who may actually reduce symptom-producing over-activity (Friedberg, 1999).<sup>1</sup> Thus, high functioning patients may respond differently to a specific behavioral intervention in comparison to low function patients. For example, in a clinical study utilizing graded activity in high functioning, mostly employed chronic pain patients (Newton-John, Spence, & Schotte, 1995), graded activity was no more effective than a relaxation-oriented EMG biofeedback condition in reducing perceived level of disability.

Because previous graded activity-based CBT studies in CFS have not separately analyzed outcomes in relatively high functioning patients, it is not clear if the type and magnitude of behavioral change is different from that found for low functioning patients. In addition, cognitive-behavioral theories of CFS (Butler, Chalder, Ron, & Wessely, 1991; Prins, & Bleijenberg, 1999; Surawy, Hackmann, Hawton, & Sharpe, 1995) have postulated a generalized avoidance of activity in people with CFS—a premise which does not account for the behavior of high functioning patients who continue to perform the bulk of their responsibilities despite being ill. Given their high level of performance, a theory-driven graded activity program may be counterproductive if its prescriptions exceed the patient's capabilities.

In this case study, a regimen of graded activity was implemented on a high functioning patient with CFS. Clinical outcome variables included psychometric and

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<sup>1</sup> A review and synthesis of behavioral data in CFS studies (Friedberg, 1999) suggests that high and low function patients may be distinguished on behavioral, symptomatic, and psychiatric variables. However, in the absence of a precise definition of high and low function in CFS, I will consider people who are working full-time, such as the study participant, as falling into the high function category and those who are not working because of their illness, which applies to most of the subjects in the above cited CBT studies, to be low functioning.

in vivo self-report assessments, as well as objective measurement of physical activity. The goals of this study were to: (1) examine the specific behavioral outcomes that result from graded activity treatment in a high functioning patient in comparison to the predictions of cognitive-behavioral theories of CFS; (2) determine the correspondence between self-report and in vivo measures of improvement; (3) assess the clinical utility of objective activity measurement using a step counter.

## 2. Case description

The patient, A.L., was a 52-year-old male, married for 27 years with two adult children living independently. A.L. was high school educated and employed full-time as a maintenance worker. His CFS of 5 years duration was diagnosed by a physician and verified in this study with a CFS symptom checklist based on the case definition of the illness (Fukuda et al., 1994). Illness onset was characterized by a flu-like illness that caused the patient to be bedridden for 4 weeks. In the weeks prior to illness onset, A.L. had been working a physically exhausting 20 hours-a-week overtime. He reported no other significant lifestyle stress during the preceding year.

After the 4-week acute illness, the patient resumed working, yet remained moderately symptomatic. Over the 2 years prior to his initial visit to the therapist, he reported feeling 50% better, although intrusive residual symptoms remained. These included severe physical and mental fatigue, memory and concentration difficulties, muscle pain, multi-joint pain, and shortness of breath from minor exertion. Illness-related functional losses included the elimination of regular racquetball, daily walking, and weight lifting as well as reduced participation in social activities. Based on a semi-structured clinical interview (DSM-IV), the client fulfilled diagnostic criteria for current dysthymia that began during his initial flu-like illness. No pre-illness psychiatric diagnoses were found.

## 3. Measures

The client's baseline and outcome assessments were completed at pre-treatment (T1), treatment midpoint (T2), treatment termination (T3), and at 3- (T4), 6- (T5) and 12-month follow-up (T6) intervals.

### 3.1. Psychometric measures

#### 3.1.1. CFS symptom inventory

CFS symptoms were measured with a 16 item/five response choice format inventory (alpha reliability = 0.77;  $N = 23$ ; Friedberg, 2000) that was derived from a CFS symptom list administered to 565 patients (Hickie et al., 1995).

### 3.1.2. SF-36

The SF-36, a 36-item broadly based self-report measure of functional status, identifies six dimensions, including physical activities, mental health, social functioning, bodily pain, energy and fatigue, and perceptions of health (Ware & Sherbourne, 1992). Test construction studies for the SF-36 (McHorney, Ware, & Raczek, 1993; McHorney, Ware, Wu, & Sherbourne, 1994) have shown adequate internal consistency, discriminant validity among subscales, and substantial differences between patient and non-patient populations in the pattern of scores. The SF-36 has also shown adequate psychometric properties as a measure of functional status in a CFS population (Buchwald, Pearlman, Umali, Schmalings, & Katon, 1996).

### 3.1.3. Beck depression inventory (BDI)

Depressive symptomatology was measured with the BDI (Beck, 1967; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), a 21-item self-report instrument with well-established psychometric properties. The BDI is the only depression rating scale to be empirically tested and interpreted for both depressed and non-depressed patients with CFS (Johnson, DeLuca, & Natelson, 1996).

### 3.1.4. Beck anxiety inventory (BAI)

Anxiety symptoms were measured with the BAI, a 21-item self-report measure with established and replicated construct validity (Hewitt & Norton, 1993; Steer, Clark, Beck, & Ranieri, 1995).

### 3.1.5. Global rating of change

At the final follow-up assessment, global change in illness was measured on a seven point rating scale, ranging from “very much improved” to “very much worse” (Sharpe et al., 1996). This seven-point scale has shown sensitivity to treatment change in CFS (Sharpe et al., 1996).

## 3.2. In vivo measures

### 3.2.1. Daily diary

The patient kept a daily paper diary for 1 week during each of the six assessment periods. Diary entries were made six times a day at approximately 2-h intervals beginning in the morning after awakening. Each diary entry could be completed at any time within each consecutive 2-h period. Diary entries included ratings of on a 0–100 numerical rating scale of the following subjective states: perceived energy, fatigue, positive feelings, and negative feelings. Zero represented a complete absence of the subjective state and 100, the presence of the subjective state as strong as it could be. As explained to the patient, perceived energy referred to the level of energy one experiences at any particular moment. Fatigue referred to a sense of generalized tiredness. Positive feelings indicated the sum total of all positive feelings and negative feelings referred to the sum total of all negative feelings. The patient also recorded the duration and intensity of assigned walking and weight lifting, respectively.

### 3.2.2. Step counter

To measure physical activity during assessments T1–T6, the patient was instructed to wear, for 1 week during each assessment period, a battery-operated step counter (Radio Shack pedometer) on his beltline at all times except when sleeping or bathing. A.L. recorded his daily steps as displayed on the step counter during each 2 h assessment period and entered the type and duration of daily physical activity and exercise in the diary.

The step counter records the number of steps taken during ordinary locomotion. For one step counter tested on a single participant, the mean absolute deviation (an estimate of intradevice reliability) of the step counts for 100 steps walked on 10 occasions was 1.3. In addition, the step counter showed a high reliability coefficient ( $r = 0.90$ ) when tested over seven consecutive days of collected data against an actigraph accelerometer (mini-motionlogger actigraph; Ambulatory Monitoring, Inc.), a device with established reliability.

## 4. Treatment

The intervention given was graded activity which involved the prescription of gradual increases in physical activity over the course of treatment. The patient was told that treatment was designed to restore, as much as possible, his ability to do sustained physical exercise by assigning very gradual increments over several weeks in selected exercises, i.e., walking and possibly weight lifting. The first 13 sessions were scheduled once-a-week, followed by four biweekly sessions, then, three tri-weekly sessions, and finally six monthly sessions. Sessions were 15–30 min in duration.

After a 1-week baseline in vivo assessment, activity homework began at session two with daily 10-min walks and progressed, in 5-min increments as tolerance increased, to 40-min daily walks by session 14. In addition, a three times-a-week weight lifting regimen was begun at session 13 and included six repetitions of a 30 lb bench press and six repetitions of a 15 lb dumbbell press. By session 19, the weight training had progressively increased to 15 repetitions of a 35 lb bench press and 10 repetitions of a 20 lb dumbbell press. The completion of each activity assignment was verbally reinforced by the therapist. A clinical relapse at session 20 resulted in a recalibration of activity assignments (see Results section).

## 5. Results

From baseline to treatment termination, mean weekly step counts decreased 10.6% (Fig. 1), although the patient's self-report activity record indicated that walk time increased from 0 to 155 min a week (approximately 39 min every other day). Both weekly step counts (Fig. 1) and patient-recorded walk time (Table 1) increased from treatment termination to the 12-month follow-up assessment. At the 1 year

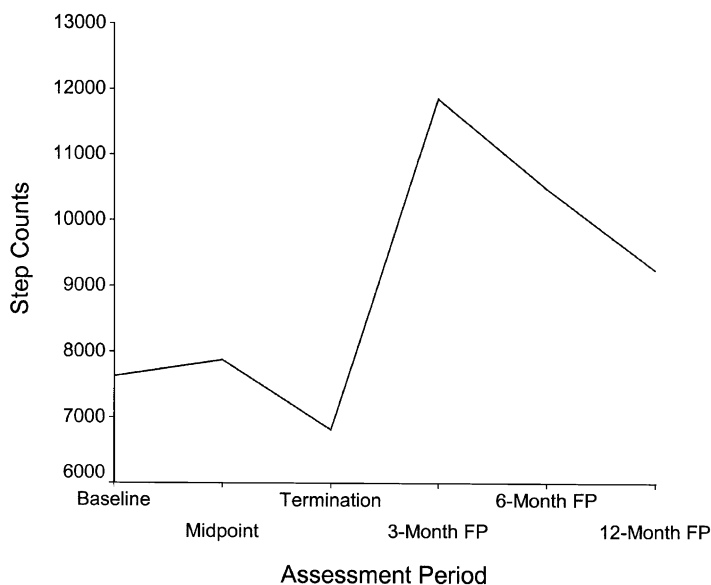


Fig. 1. Total weekly step counts for each assessment period.

Table 1

Mean values for in vivo and psychometric measures for each assessment period

	T1	T2	T3	T4	T5	T6
Steps <sup>a</sup>	7624.0	7875.0	6816.0	11,857.0	10,482.0	9245.0
Walk time <sup>b</sup>	0	23.6	22.1	29.2	31.4	30.0
Fatigue <sup>a</sup>	20.3	16.4	14.5	15.0	11.3	12.3
Perceived energy <sup>a</sup>	77.0	73.7	77.9	78.2	81.4	80.9
Negative feelings <sup>a</sup>	6.9	10.0	5.0	5.1	17.9	5.2
Positive feelings <sup>a</sup>	93.2	90.0	95.0	94.9	82.1	94.8
SF-36 PCS	52	62	58	71	73	64
BAI	11	8	10	9	6	7
BDI	22	14	20	18	13	15
CFS symptom inventory	46	43	36	38	39	45

<sup>a</sup> Mean weekly values.

<sup>b</sup> Mean daily values (min.).

follow-up, the patient's activity record showed that self-reported walk time had increased to 30 min a day, 6 days a week.

At treatment termination, all weight lifting had been suspended following a behavioral relapse that had occurred 6 months earlier. Between the 6- and 12-month follow-up assessments, the weight lifting was resumed and gradually increased to 18

repetitions of a 45 lb bench press and 16 repetitions of a 20 lb dumbbell press, three times a week.

### 5.1. Psychometric measures (*Table 1*)

The CFS Symptom Inventory showed a 21.7% reduction in scores at treatment termination, followed by a return to near baseline level at the 12-month follow-up. The SF-36 Physical Component summary score improved (52–64) from baseline to the 12-month follow-up assessment, although these scores are well below the mean of the general US population ( $X = 84.2$ ;  $SD = 23.3$ ; Ware, 2000). In addition, both the BAI and BDI scores decreased from the moderate to mild range (36.4% and 31.2% reductions, respectively) from baseline to the 12-month follow-up assessment. The patient's rating on the global assessment of illness change measure was "much improved", the second highest rating.

Patient-recorded walk time was significantly negatively associated with in vivo fatigue ratings ( $r = -0.93$ ;  $p < 0.009$ ) and BAI scores ( $r = -0.86$ ;  $p < 0.03$ ), and moderately, but non-significantly, correlated with step counts ( $r = 0.58$ ;  $p > 0.30$ ). On the other hand, step counts were significantly associated with the physical function score of the SF-36 ( $r = 0.86$ ;  $p < 0.03$ ).

### 5.2. Late treatment relapse

The systematic assignments of increasing activity proceeded without symptom exacerbation until a 4-week symptom flare-up was reported at session 20. Prior to the exacerbation, the patient had increased his employment workload to 20 hours-a-week overtime and subsequently contracted an 8-day illness with flu-like symptoms. After 2 days off from work, he reduced his overtime to 8–12 h a week and eliminated all exercise for 2 weeks. Although walking was sporadic during the cold winter months, A.L. gradually restored his prescribed exercise to a somewhat reduced schedule of 30 min daily walking and restored his weight lifting to pre-relapse levels.

## 6. Discussion

### 6.1. Graded activity outcomes and clinical significance

In this case study, a high functioning participant with CFS substantially increased self-reported weekly physical exercise on a graded activity schedule over a 26-session, 12-month behavioral intervention. However, self-reported improvements in assigned physical exercise were not significantly associated with objectively measured locomotion (step counts). Furthermore, step counts increased a relatively modest 21.2% from baseline to the 12-month follow-up. Improvements from moderate to mild severity levels were noted on standard self-report measures of depression and anxiety.

If clinically significant improvement is defined by achieving normal or functional population values (Jacobsen & Truax, 1991), then this patient's regular weekly exercises of walking and weight lifting at follow-up probably falls within the upper limits of the normative range. Yet, his (reduced) anxiety and depression scores at follow-up indicate the presence of at least mild clinical affect, while his SF-36 scores showed considerably more impairment than population values. In addition, the patient's symptom profile still met symptom criteria for CFS at treatment termination and the 1-year follow-up assessment. By contrast, his global rating of change at follow-up was much improved. Thus, the patient's response to treatment cannot be easily categorized and may reflect a combination of improved coping with ongoing symptoms, substantially increased exercise tolerance, and healthy lifestyle adjustments, i.e., reduced overtime hours.

These findings are consistent with the improved behavioral and affective outcomes, based on self-report data, found in previous studies of graded activity-oriented CBT for CFS (e.g., Sharpe et al., 1996). As in previous CBT studies, this patient largely overcame his initially reported fear of triggering symptom exacerbations. Yet his concern about exceeding the maximum prescribed weight lifting levels appeared to be realistic because scheduled attempts to exceed these levels consistently triggered symptom flare-ups. In addition, the work-related 4-week relapse revealed an apparent upper limit on his ability to work. This suggests that eradication of a fear-based activity avoidance will facilitate functional improvements up to a point, beyond which a more biologically based mechanism of symptom generation may be involved.

Although people with CFS are often intent on restoring full pre-morbid functioning, this may not be a realistic goal. Prospective naturalistic studies of CFS patients have revealed very low recovery rates (Joyce, Hotopf, & Wessely, 1997), while successful cognitive-behavior treatment studies have not produced outcomes that are equivalent to recovery or cure (e.g., Deale, Husain, Chalder, & Wessely, 2001).

## 6.2. Activity substitution as a possible mechanism of graded activity.

The results of this study raise questions about the presumption that the active ingredient in successful graded activity is cognitively mediated increases in activity (Butler et al., 1991; Prins et al., 1999; Surawy et al., 1995). Perhaps this mechanism is more likely to be operative in the predominantly low functioning subjects treated in previous CBT studies. High functioning CFS patients, in general, may have reached the upper limits of their functional abilities and thus increasing absolute activity levels beyond this limit may trigger increased illness severity. In order to facilitate improvements, high functioning patients may require a more flexible form of CBT that involves redirection of activities, such as substitution of stress-reducing activities for stress-exacerbating activities. A parallel may be found in successful chronic pain treatment programs wherein improved functioning and well-being are associated with

performing activities differently (e.g., via pacing of activity) rather than simply increasing physical activity (Morley, Eccleston, & Williams, 1999).

The possibility that the patient in this study substituted stress-reducing activities for stress-exacerbating activities may be one explanation for the relatively modest changes in step counts from baseline assessment to treatment termination and the 1-year follow-up. Specifically, the prescribed gradual increases in walking may have been accompanied by countervailing reductions in job-related overtime. Because daily hours worked was not recorded by the patient, this conclusion cannot be definitively confirmed. Such data may in part have explained the non-significant correlation between recorded walk time and step counts. In addition, the step counter did not fully capture non-walking activities that were reportedly improved, i.e., weight lifting. Perhaps a wrist-worn actigraph that measures both frequency and intensity of movement may have provided a more complete record of the participant's activity level (Tryon & Williams, 1996). Such a record may have revealed more substantial activity increments at treatment termination and follow-up assessments.

### 6.3. *The importance of multi-method assessment*

This study confirms the importance of using both self-report and non-verbal measures of outcome, which may show only modest correspondence (Hadjistavropoulos & Craig, 2002). Such multi-method assessments may better capture the multi-dimensional nature of CFS-related cognitions and behaviors. For example, multi-method assessments were used in a recent exercise and behavior therapy study of 59 low back patients (McCracken, Gross, & Eccleston, 2002). Pain-related anxiety was significantly correlated with all behavioral outcomes (e.g., pain severity, interference), while only one of three physical performance composite scores was associated with improvements in all outcome variables (except interference). These somewhat disparate findings suggest that behavioral outcomes in complex, disabling conditions require both self-report and non-verbal (or objective) measures to more fully understand the changes that occur.

Finally, in this uncontrolled case study, treatment gains may be attributable to non-specific effects such as therapist attention, rather than the targeted treatment. The argument for treatment-specific effects may be stronger in this case because of the relapse that occurred. This unscheduled relapse approximated the original precipitating conditions of the subject's CFS, including severe symptom exacerbation, work stoppage, and cessation of physical exercise. After the patient's initial illness, however, he avoided exercise for 5 years because he was apprehensive about triggering symptom flare-ups. On this second occasion, he resumed walking exercise within 1 month and weight lifting within 6 months. Because he was seeing the therapist only once a month at this point in his treatment, he received a minimum amount of support and attention. Thus, it is more plausible that the mostly patient-directed exercise program was responsible for his renewed progress. Daily records of his walk time confirmed his progress during this interval.

For the clinician, the actigraph is a rather costly and time-consuming method of activity measurement (Vercoulen et al., 1997). The step counter, on the other hand, is a reliable and inexpensive device for measuring locomotor activity in the behavioral treatment of CFS. It can inform both clinician and patient of objective levels of walking in comparison to subjective diary reports and assess if activity is in fact changing in the expected direction. If objective activity levels are not changing, despite clinical progress, the clinician can determine in collaboration with the client what behavioral changes *have* occurred by examining daily logs and determining how those changes are associated with clinical improvements. Then clinical attention can be refocused on reinforcing the identified successful elements of progress, such as redirecting behavior, substituting less stressful activities for more stressful ones, or performing activities in a less fatiguing manner.

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