

Descriptors of Fatigue in Chronic Fatigue Syndrome

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ABSTRACT. Objective: To explore how individuals with chronic fatigue syndrome (CFS) describe their fatigue experience and examine how this differs from descriptions of fatigue in healthy controls.

Methods: Fifty-two individuals with CFS and 27 controls listed words that described their fatigue. These words were grouped into 18 categories.

Results: Individuals with CFS used more categories to describe their fatigue and more descriptors within each category. The most popular category used by both groups was energy depletion/physical weakness. CFS participants also experienced their fatigue as limiting their ability to

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function, frustrating, permanent/persistent, out of their control, depressing, and pervading all aspects of their lives. Controls reported that when they experienced fatigue, it was temporary, and they felt unmotivated, sleepy, and comfortable.

Conclusion: The multidimensional descriptive pattern characterizing the fatigue of individuals with CFS differs dramatically from the experienced fatigue of healthy individuals, suggesting their "language of fatigue" has a distinctive quality. doi:10.1300/J092v14n03_04 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2007 by The Haworth Press. All rights reserved.]

KEYWORDS. Fatigue, chronic fatigue syndrome, measure

INTRODUCTION

The complaint of fatigue is commonly presented by patients, frequently ignored by their physicians (1), and at times misdiagnosed as depression. Researchers have long recognized fatigue as a psychobiosocial construct. In the few psychometric instruments that exist, however, there is little common language to describe the subjective experience of fatigue and its objective manifestations. Existing conceptualizations of fatigue and its measurement have typically been constructed using descriptors derived from available measures and from dictionary and thesaurus entries (2-4). In the present study, rather than trying to impose a common language in this manner, we listened to how individuals described their fatigue in their own words. To do this we recruited a sample of individuals diagnosed with chronic fatigue syndrome (CFS), an illness in which fatigue is the hallmark feature.

CFS has a chronic course (5,6,7). There is no specific etiology or pathophysiology (cf. 8), no single diagnostic test (6,9), and no consistently effective treatment (see 10 for a review). The current procedure for diagnosing CFS is one of elimination when no medical, psychiatric or drug related conditions can be found to explain the prolonged fatigue. The impairment to functioning is pervasive, adversely affecting both social (11) and working (12) lives. Despite growing evidence that abnormal, objective biologic processes are present (cf. 13), even some researchers have postulated that CFS is primarily a psychiatric disorder because no physiological marker has been identified (14). Patients with

CFS are often presented with the medical opinion that “it’s all in your head,” that their problem is “only depression” or perhaps a somatoform disorder (15,16).

In the present investigation descriptors of fatigue provided by individuals with CFS were compared with those provided by healthy individuals. The aim was to identify a descriptive pattern that might provide a meaningful assessment component in CFS. We asked the following questions: “Is there an identifiable pattern of descriptors related to the fatigue experience that characterizes individuals with CFS?” and “How do their fatigue descriptors differ from those of healthy individuals, who also experience fatigue from time to time?”

It has previously been suggested that the unique reported biography of the patient should be part of each diagnostic evaluation (17). The present study explores how language is used to describe the lived fatigue experience of people with CFS.

METHOD

The 52 participants with CFS (5 males, 47 females) were part of a larger study evaluating and treating sleep disorder in this population (18,19). They were recruited from physicians specializing in the disorder as well as from a large CFS support group in the Montreal area. Our neurologist team member verified the diagnosis using current criteria (e.g., medically unexplained fatigue of at least 6-months’ duration, sudden onset, complaints of nonrestorative sleep, disproportionate fatigue after exertion, sore throat, tender lymph nodes (20,21). Individuals who had both fibromyalgia as well as CFS were included in the sample. Individuals with CFS were excluded if they indicated during the screening interview with one of the team psychologists that they had a current diagnosis of depression or another psychiatric disorder. A convenience sample of 27 healthy controls (7 males, 20 females) was recruited from the staff of a large Montreal hospital. Chi square and t-tests show that the two groups were not significantly different on gender composition or years of education ($M = 15$ years for both samples). The Control sample, however, was significantly younger than the CFS sample ($M = 38$, $SD = 3.88$; $M = 45$, $SD = 3.05$, respectively), $t(77) = 2.55$, $p = .013$.

All participants responded in writing to the question, “When you feel fatigued, what words would you use to describe your fatigue?” They were provided with 15 lines (2" in length) for their response.

Fatigue-related words and phrases from all participants were combined into a list in alphabetical order. A team of five psychologists familiar with the concepts of this research grouped these into 18 mutually exclusive intuitively meaningful content categories (see Figure 1) and compiled a coding manual. "One-of-a-kind" items which did not fit into any of the coded categories were excluded from analyses. Two coders, blind to participant status and trained to a minimum of 70% code-by-code inter-rater agreement evaluated all protocols with a mean spot-check reliability of 83% (range = 78-92%).

RESULTS

As can be seen in Table 1, the two significant t-tests comparing the numbers of descriptive words and phrases generated by participants with CFS were significantly more numerous and were represented in more categories than were those of Control participants. Figure 1 shows that the pattern of responses within categories differed dramatically between the two groups, with significant findings on 10 of the comparisons.

Responses of individuals with CFS predominated in six categories with negative overtones; Chi square tests show that words in the following categories were reported significantly more often by CFS participants: Limitation of Functioning, $\chi^2(1, N = 79) = 13.61, p < .001$, Frustration/Anger/Irritability/Annoyance, $\chi^2(1, N = 79) = 6.84, p < .01$, Permanent/Persistent, $\chi^2(1, N = 79) = 4.38, p < .05$, Out of One's Control, $\chi^2(1, N = 79) = 6.64, p < .05$, Depressed/Sad/Discouraged, $\chi^2(1, N = 79) = 4.20, p < .05$, and Pervasiveness/Touches All Aspects Of One's Life, $\chi^2(1, N = 79) = 4.62, p < .05$. The percentage of individuals with CFS who reported words in each of these categories ranged from 15% to 54%, compared with 0% to 15% for controls.

Control participants were significantly more likely to have responses in the following four categories: Temporary/Transient/Restoring/Variable, $\chi^2(1, N = 79) = 13.52, p < .001$, Comfortable, $\chi^2(1, N = 79) = 10.48, p = .001$, Sleepy, $\chi^2(1, N = 79) = 6.86, p < .01$, and Amotivational, $\chi^2(1, N = 79) = 4.77, p < .05$. The percentage of individuals in the control group reporting words in these categories ranged from 22% to 33% compared with only 2% to 10% for individuals with CFS.

The most popular category, used by the majority of individuals in both groups, was Energy Depletion/Physical Weakness (56% to 60%).

FIGURE 1. Percentage of CFS and Control participants providing responses in each descriptive category. * indicates a significant ($p < .05$ or better) difference using Chi Square between the groups.

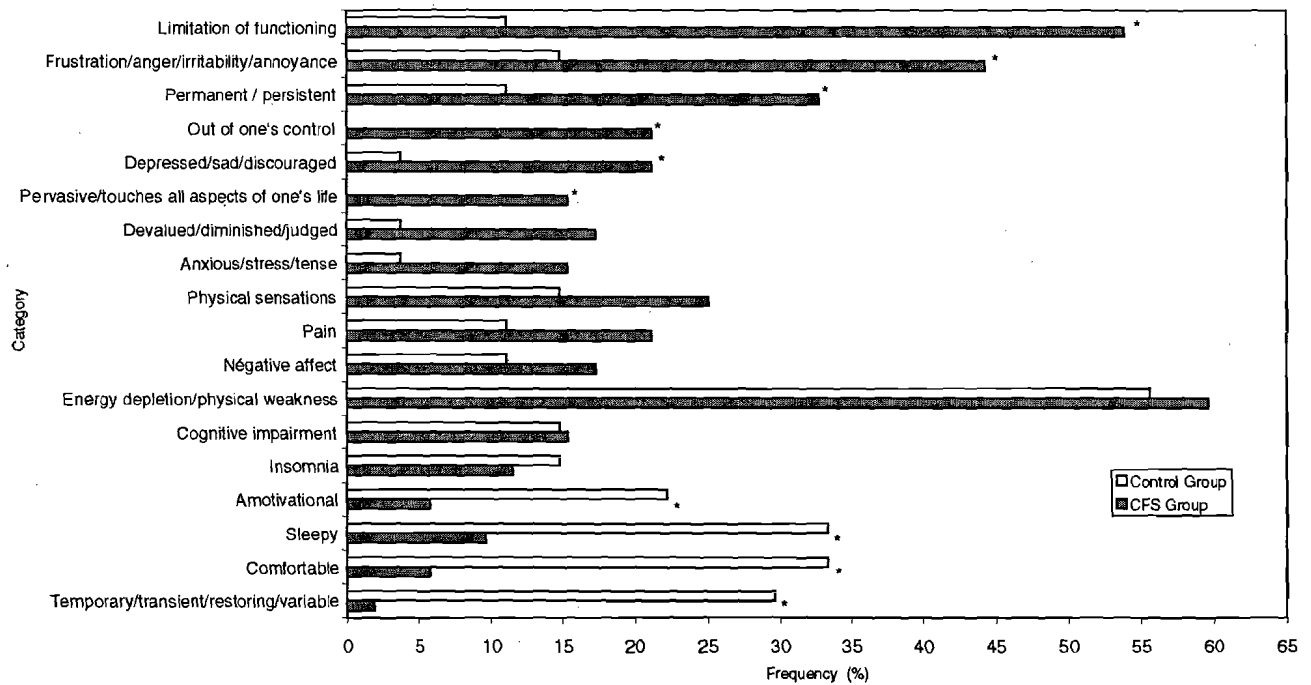


TABLE 1. Descriptors and Categories: Means and Test Results

	N	Mean	SD	t-test		
				df	t	p=
Number of Descriptors						
CFS	50	6.34	4.25	75.00	3.107	0.003
Controls	27	4.07	2.15			
Number of Categories						
CFS	50	4.32	2.27	75	2.76	0.007
Controls	27	2.96	1.58			

The popularity of all other categories depended on group membership, with words in the Limitation of Functioning category being reported by 54% of the CFS participants, but only 11% of controls, and words in the Frustration/Anger/Irritability/Annoyance category used by 44% of participants with CFS but only 14% of healthy Controls.

DISCUSSION

As noted by others (22,23), the experience of fatigue can vary in different medical conditions. Terms used most frequently by all our participants, regardless of whether they did or did not have CFS, come from the energy depletion/physical weakness category and include: exhausted, insufficient energy, tired, lack of vitality, and fatigued. This suggests that fatigue has a common core experienced by all individuals.

On the other hand, there were also major differences in the way fatigue was perceived by our two groups. Individuals with CFS used more descriptive categories to describe their fatigue and more descriptors overall. This, perhaps, is not surprising since fatigue, not contingent on any particular activity, was experienced daily by our participants with CFS, and this had a widespread impact on their day-to-day functioning. The healthy controls, on the other hand, experienced fatigue only episodically and under conditions that could readily explain it.

The more dramatic difference was in the affective quality of participants' fatigue-related descriptive words and categories: responses of individuals with CFS were characterized by terms which dealt with limitation of functioning (e.g., disruptive, disabling), frustration (e.g., irritable, annoying), out of one's control (overwhelming, powerlessness), permanence (e.g., constant, continuous), depression (e.g., discouraging, demoralizing), and pervasiveness (e.g., immense, touching all aspects

of one's life). Healthy controls described their fatigue as temporary (e.g., transient, occasional), comfortable (e.g., neutral, normal), and amotivational (e.g., not motivated, lack of motivation), with a sleepiness component.

Our participants told us that it took many years to have their CFS diagnosed. Their lack of energy and physical weakness had often been misdiagnosed as depression, even though our data show that this sample of individuals with CFS did not differ significantly from narcolepsy patients on depression scores (18). In addition, unlike people who have depression, they reported being motivated to participate in various activities and frustration at not being able to function. Their descriptors of fatigue corroborate this statement.

The multidimensional descriptive pattern related to the fatigue experience of individuals with CFS differs dramatically from that of healthy individuals, suggesting that their "language of fatigue" has a distinctive quality. This raises the possibility that there may be a characteristic descriptive profile in other disorders, too, where fatigue is a central or important aspect (e.g., multiple sclerosis, cancer, depression, sleep apnea). Such a descriptive profile may have predictive implications even for currently healthy individuals (e.g., pregnant women at risk for postpartum depression). Our group is currently investigating descriptive profiles in a range of disorders. To date, the profile that has emerged for individuals who were later diagnosed with sleep apnea is sufficiently compelling to be diagnostically predictive. Since CFS is a syndrome that is, at present, diagnosed by exclusion, listening to the language of patients may emerge as an important diagnostic component for this disorder as well.

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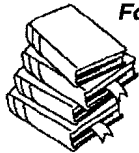
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