Functional Capacity Evaluations of Persons With Chronic Fatigue Immune Dysfunction Syndrome

Diane M. Barrows

Key Words: activities of daily living evaluation

Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) is estimated to affect 2 to 5 million people in the United States. Despite its high incidence, persons with CFIDS have been neglected by the medical community mainly because there is no singular confirming diagnostic test or proven effective treatment. The CFIDS population is incorrectly stereotyped as upper-middle-class, white, female hypochondriacs: consequently, symptoms often are belittled or ignored. In reality, CFIDS is a severe medical condition that affects women, men, and children of any race and often causes long-term or total disability.

The results of a modified functional capacity evaluation developed by the author and completed on 86 persons with CFIDS between 1988 and 1990 confirm that this population has severe physical and cognitive disabilities that affect their professional, familial, and social lives. The results of these evaluations are used to present a profile of persons with CFIDS that can serve as a basis for understanding this population and for guiding intervention.

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The etiology of Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) remains unresolved, even though many studies have indicated that the cause is most likely organic (Goldstein, Mena, & Yunis, 1993; Lapp, 1992; Patterson, 1993). Persons with CFIDS are largely misunderstood by the medical community and often are treated as hypochondriacs. This tendency is probably due to the absence of a specific diagnostic test for CFIDS. The lack of such a test, coupled with the media’s use of derogatory terms like "yuppie flu," has led to widespread antipathy and misunderstanding of persons with this syndrome.

Because there is no singular diagnostic test or proven treatment regime, persons who have been diagnosed with CFIDS create serious dilemmas for primary caregivers, rehabilitation specialists, and disability administrators.

For occupational therapists, evaluating clients’ functional ability takes on added importance when these clients have conditions that require them to prove that they are sick and that their ability to perform activities of daily living (ADL) is altered in order to be approved for medical leave, modified work duty, or disability compensation. In 1988, because there were no existing procedures or grouping of tests documented as useful in demonstrating altered function in persons with this disease, I developed a modified functional capacity evaluation (FCE) that, in addition to assessing physical and cognitive status, also appraises cognitive status. Since then I have used this evaluation with more than 140 clients with CFIDS.

FCEs are traditionally used in industrial rehabilitation to provide objective functional ability baseline data for occupational and physical therapists, clients, physicians, insurance carriers, employers, and disability administrators. The goal of the FCE, as modified to assess persons with CFIDS, is to demonstrate a client’s current capacity for functional activities and compare that capacity to the client’s reported premorbid ADL status and to the critical cognitive and physical job demands required for the client to complete his or her job successfully.

The objective of this article is to present a profile of persons with CFIDS based on the results of the modified FCE. The profile may serve as a basis for rehabilitation professionals to begin to understand this underserved population.

Description of CFIDS

CFIDS is a chronic illness that mimics many other dis-
The disease has many names, depending, in some cases, on the geographical location or institution where the onset occurred (Briggs & Levine, 1994). In Great Britain and Canada it is known as myalgic encephalomyelitis and, in Japan, as low natural kill cell syndrome (Cowley, Hager, & Joseph, 1990). Other terms include Iceland disease, Royal Free disease (Briggs & Levine, 1994), epidemic neuro-myasthenia, atypical poliomyelitis (Levine, 1994); since then more than 60 outbreaks have been reported in medical literature for more than 120 years (Dechene, 1993), and outbreaks have been reported under many names and in many countries during the last 45 years (Briggs & Levine, 1994; Holmes et al., 1987). The first well-described outbreak in the United States was reported in 1938 by Gilliam (cited in Briggs & Levine, 1994); since then more than 60 outbreaks have been reported (Levine, 1994). Until the 1980s, when epidemics occurred in Northern Nevada and California (1984-1986) and New York (1985), CFIDS was considered to be a rare condition (Cowley, Hager, & Joseph, 1990).

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The onset of CFIDS is often linked to the onset of a flu-like or viral illness followed by unremitting severe fatigue, systemic complaints, and nervous system involvement including parasesthesias and tremoring. Clients present with such a large list of symptoms (see Appendix) that they often are perceived as hypochondriacal.

In 1988, the CDC developed a working case definition to be used as diagnostic criteria for CFIDS. According to Holmes et al. (1988), to meet the CDC case definition for diagnosis, a patient must fulfill (a) the two major criteria and (b) either 8 of 11 symptom criteria or 6 or more of the 11 symptom criteria and 2 or more of the 3 physical criteria. The major criteria are:

- New onset of persistent or relapsing, debilitating fatigue that does not resolve with bed rest and that reduces activity level by 50% for at least 6 months.
- Other plausible disorders of fatigue are ruled out by evaluation based on history, examination, and laboratory findings.

The minor criteria are broken down into two groups: symptom criteria and physical criteria. The symptom criteria are:

- Low-grade fever
- Sore throat
- Painful nodes
- Unexplained generalized muscle weakness
- Myalgia
- Prolonged fatigue after levels of exercise that would have been easily tolerated before onset
- Headaches
- Migratory arthralgia
- Neuropsychologic complaints
- Sleep disturbance
- Main symptom complex developing over a few hours to a few days.

The physical criteria are:

- Low-grade fever between 37.6-38.6 C
- Non-exudative pharyngitis
- Palpable anterior or posterior cervical or axillary lymph nodes.

Bell (1989) proposed the following diagnostic criteria for children:

"I. Symptoms present on a constant or intermittent basis for at least 6 months.
II. Presence of at least 6 of 8 “major” symptoms:

1. Fatigue
2. Neurologic Complaints
3. Headache
4. Sore Throat
5. Arthralgia (Joint Pain)
6. Myalgia (Muscle Pain)
7. Abdominal Pain
8. Lymphatic Pain

or 5 of 8 major symptoms and at least 2 of 3 minor symptoms:

1. Rash
2. Fever, Chills, and/or Night Sweats
3. Eye Pain and/or Photophobia (Light Sensitivity)” (Bell, p. 7)

However, because there is no definitive diagnostic laboratory test, the CDC definition of CFIDS is based on signs and symptoms only. It is intentionally restrictive in order to eliminate clients who complain of fatigue but do not have a systemic illness and to provide baseline criteria for research (Holmes et al., 1988).

Researchers do not agree on a singular possible cause for CFIDS. Viruses, retroviruses, exposure to toxic chemicals in the environment, stress on the limbic system, unknown infectious agents, genetic susceptibility to immune activation, and metabolic disorders are a few of the potential causes being examined (Carpman, 1993). At least nine different RNA and DNA viruses have been thought to be associated with the disease (Levy, 1994). Additionally, immunological studies have demonstrated...
reduced function of natural killer cells in persons with CFIDS (Klimas, Salzano, Morgan, & Fletcher, 1990; Levy, 1994). However, many researchers agree that most of the symptoms reported by persons with CFIDS are caused by an up-regulation (hyperactive state) of the immune system (Carpman, 1993). Therefore, CFIDS, in its hyper-responsiveness, can resemble an autoimmune disease (Levy, 1994).

On the basis of this hypothesis, a virus could enter the host, cause immune abnormalities leading to CFS, and then be eliminated. The immune system, however, might not recover sufficiently to return to normal balance. It appears that the reduction in the function of NK [natural killer] cells and/or the activity of suppressor CD8+ T cells is involved. Thus a hyperactive immune state resulting from the viral infection continues in the host (Levy, 1994, pp. S18-S19).

Although neither cause nor treatment has been discovered, promising research is ongoing. One research group (Goldstein, Mena, Jouanne, & Lesser, 1993) is using single photon emission computerized tomography (SPECT) scans, which examine brain function by measuring cerebral blood flow, to evaluate persons with CFIDS. They have found the blood flow pattern of distribution for persons with CFIDS to be different from the uniform pattern of distribution found in persons without CFIDS. For persons with CFIDS, flow is diminished primarily in the right hemisphere and is also decreased in the frontal and temporal lobes. The pattern also projects into the limbic system, which could explain many CFIDS symptoms, such as muscle pain, sleep disorders, and cognitive disturbances (Goldstein, Mena, Jouanne, et al., 1993).

In another study, correlations in the degree of reduced blood flow with cognitive dysfunction have been demonstrated, and memory loss in persons with CFIDS has been found to be greater than that assumed by initial CDC criteria (Sandman, 1991). In addition, potentially novel retroviruses have been isolated from persons with CFIDS, and a potential genetic predisposing marker for CFIDS has been identified (Patterson, 1993).

CFIDS or Depression?
Depression is often associated with CFIDS and is frequently referred to as the cause of the disease. Because affective disorder is often a response to chronic illness, this depression may be at least partly a reaction to disability and fatigue (Friedberg & Krupp, 1994). However, depression cannot explain the physical symptoms and signs associated with CFIDS, such as fevers, pharyngitis, and swollen and painful lymph nodes. In addition, persons with CFIDS express strong desires to return to their previous life-styles. This desire is not expressed by persons with clinical depression, whose desire to live is diminished or lost (Lapp, 1992). Psychometric testing also has demonstrated that the profiles for clients with CFIDS and clients with depression are different. Daugherty (1991) found that the mean Minnesota Multiphasic Personality Inventory (MMPI) profile of clients with CFIDS resembled that of persons with chronic illnesses and did not resemble the profile of persons whose MMPI scores indicated the presence of malingering, conversion, or thought disorders. In addition, magnetic resonance imaging (MRI) scans demonstrated two general patterns of abnormality in the brains of persons with CFIDS. The most common pattern was the presence of small multiple foci of increased signal intensity in the centrum semiovale and in the parasagittal convolutional white-matter tracts (Daugherty, 1991). The abnormal patterns are not seen in Alzheimer's disease, focal head injuries, multiple sclerosis, systemic lupus erythematosus, personality disorders, depression, psychosis, anxiety, or situational stress” (Daugherty, 1991, p. S42).

Studies that have found organic bases for CFIDS symptoms—the identification of a retrovirus in the blood (Lapp, 1992), the different cerebral blood flow pattern (Goldstein, Mena, & Yunis, 1993), and the low intracellular ATP (adenosine triphosphate) during peak exercise (Kuratsune et al., 1994) —validate the idea that CFIDS does not have a solely psychological etiology.

Functional Capacity Evaluations for CFIDS
The FCE that I administer to CFIDS clients takes 6 to 8 hr to complete and includes tests of both physical and cognitive functioning. A range of physical abilities is assessed, including, but not limited to (a) joint range of motion, (b) muscle strength, (c) grasp strength, (d) endurance, (e) fitness status, (f) coordination, (g) material handling activities, (h) nonmaterial handling activities, and (i) dexterity. In addition, observations are made of the ease and pattern of movement, the presence of tremors, trigger points associated with fibromyalgia, muscular atrophy, and signs of the presence of syndromes that may accompany the illness, such as carpal tunnel syndrome (CTS) (Goldstein, 1988).

The cognitive abilities assessed in the FCE for CFIDS clients include, but are not limited to (a) attention, (b) memory, (c) numerical processing, (d) reasoning, (e) abstract thinking, (f) judgment, and (g) general intellectual skill.

Aptitude tests that simulate the essential cognitive job tasks required for clients' previously successful employment situations are administered. The scores of the client with CFIDS are then compared to the scores of well populations in the same or similar occupation. In this way, the client's previously demonstrated abilities can be compared to his or her present abilities. Deficits in perceptual and cognitive areas can be identified, and the client's potential for a successful return to work can be determined. The CFIDS FCE includes, but is not limited to, physical tests and pain scales, cognitive and aptitude tests, and subjective and physical demand level tests. The physical tests and pain scales are...
The cognitive and aptitude tests are

- Neurobehavioral Cognitive Status Examination (Mueller, 1988)
- Employee Aptitude Survey
- Raven Standard Progressive Matrices
- Rivermead Behavioral Memory Test (Wilson, Cockburn, & Baddeley, 1985)
- Wide Range Achievement Test

The subjective and physical demand level tests are

- Functional Capacity Checklist (Burke & Dillman, 1984)
- Assessment of physical demand level (Dictionary of Occupational Titles, 1991)
- Maximum voluntary effort and validity (Blankenship, 1989)

During the physical and cognitive testing, the client is observed for general fatigue while sitting and standing and while performing nonmaterial and material handling activities, such as reaching, bending, stair climbing, lifting, and carrying. The client is also observed for signs of inappropriate illness behaviors that are disproportionate to observed physical signs, such as extraneous facial grimacing and subjective pain statements.

In addition to physical and cognitive tests, clients are asked to bring to the evaluation a detailed written description of their jobs from their employers. They also complete a computerized subjective functional capacity checklist and a thorough interview with the occupational therapist regarding their premorbid abilities for self-care, work, and recreational activities.

Analysis of FCE Findings

On completion of the FCE, the therapist determines the client's capacity to perform physical and cognitive activities on the basis of the results of evaluations, clinical observation, accepted normative data from the National Institute of Occupational Safety and Health (NIOSH) (U.S. Department of Health and Human Services, 1983), and a subjective client-family report. With the information collected, the therapist assigns the client a physical demand level as defined in the Dictionary of Occupational Titles (1991) and, when applicable, compares the client's demonstrated physical and cognitive abilities to the characteristics (as defined by the Dictionary of Occupational Titles) of workers in the same or similar occupations.

The therapist also evaluates the client's perceptions of the effects of the disease and its associated disabilities in relationship to objective findings. In this way, the FCE verifies or clarifies the client's subjective evaluations of his or her own abilities.

The therapist assesses whether the client's abilities match the essential job tasks of a previous occupation and whether the client is able to safely and successfully return to work. The FCE results assist physicians in deciding whether clients require vocational rehabilitation, referral to work conditioning programs, or continued medical leaves of absence.

FCE Profile of Persons With CFIDS

Functional capacity evaluations were completed on 86 persons with CFIDS during a 24-month period between 1988 and 1990: 70 were women who ranged in age from 20 years to 60 years, and 16 were men who ranged in age from 30 years to 60 years (see Table 1). Seventy percent of the women and 82% of the men held baccalaureate or master's degrees or had completed some years of college. Sixty percent of the women and 63% of the men had previously been successfully employed in professional

Table 1

<table>
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<tr>
<th>Age Group (Years)</th>
<th>Women (n = 70)</th>
<th>Men (n = 16)</th>
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<tr>
<td></td>
<td>Number %</td>
<td>Number %</td>
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<tr>
<td>20-30</td>
<td>7 (10)</td>
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<td>30 (43)</td>
<td>4 (25)</td>
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<td>40-50</td>
<td>22 (31)</td>
<td>5 (31)</td>
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<tr>
<td>50-60</td>
<td>11 (16)</td>
<td>7 (44)</td>
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Note: CFIDS = Chronic Fatigue Immune Dysfunction Syndrome.
occupations.

Thirty of the clients had worked in business, administrative, or sales occupations; 13 were medical professionals; 9 were in the computer industry; 6 were in education; 5 were employed by the airlines; 4 were engineers; 4 were attorneys; and 15 were employed in various other fields.

At the time of evaluation, 53 (76%) of the women and 13 (81%) of the men were not working. They were either unemployed, on medical leave, or on disability as a result of CFIDS symptoms. Twelve (17%) of the women and two (13%) of the men continued to work full time, and five (7%) of the women continued to work on a part time or modified basis. One man was retired.

One hundred percent of the men and 99% of the women stated that before the onset of their illnesses, they had been independent in all ADL and considered themselves very active. The majority of clients had worked full time and had consistently participated in recreational and social activities, including competing in triathlons, diving, snorkeling, jet skiing, square dancing, sailing, and aerobics. One client was a pilot, one had been taking airplane flying lessons, and another enjoyed master's rowing competitions. In summary, these persons were educated, highly active persons who were successfully employed before the onset of CFIDS.

All of the clients reported a debilitating fatigue akin to paralysis. The clients described the fatigue as being so deeply incapacitating that they occasionally were unable to dress themselves, eat, or crawl to the bathroom. Clients also reported experiencing considerable memory loss, decreased ability to attend, calculation deficits, reading difficulty, and word finding problems that were severe enough to disrupt any social aspect of their lives as well as limit or prevent them from performing job tasks.

Interview data indicated that the number and variety of reported symptoms inevitably led to decreased ability or inability to perform ADL in all aspects of the clients' lives. Many of the clients reported having quit their jobs or having been asked to leave when it became apparent that they could no longer successfully fulfill their job responsibilities. A history of social isolation followed in cases when clients found it too difficult to follow conversations, communicate, or participate in sports or recreational activities that they previously enjoyed. Some clients reported that their marriages ended as a result of ignorance regarding the inconsistent course of the disease and of financial strain that occurred because they could no longer work. These symptoms that clients reported to have most affected their functional ability (not listed in order of severity or occurrence) are

- Debilitating chronic fatigue
- Decreased memory for recent events-time sequence
- Decreased ability to attend to tasks, (i.e., work tasks, reading, following conversations or television shows)
- Decreased ability to complete numerical calculations
- Poor word finding ability (Clients know what they are trying to say but cannot retrieve the word; often describe the object, place, or person they cannot name)
- Muscular pain, especially upper back or neck
- Joint pain (without edema or signs of inflammation)
- Decreased muscular endurance or strength
- Panic or anxiety attacks
- Increase in symptoms following exercise
- Depression.

The ADL that the clients listed most often as being seriously affected or too difficult to perform are:

- Working at previously performed job because of decreased memory, cognitive ability, fatigue, pain, and decreased endurance
- Completing self-care in a timely manner (under 2 hr)
- Reading books and remembering what was read
- Participating in exercise, recreational, or social activities
- Watching television or movies and following story line
- Participating in exercise, recreational, or social activities
- Walking more than short distances
- Climbing stairs
- Performing housework
- Shopping
- Performing activities requiring sustained overhead reach such as washing, drying, setting, or combing hair
- Driving.

Almost all of the clients reported that they got lost while driving. Some had to have family members come and lead them home. One client stated that after driving short distances she would often stop her car in parking lots where she slept for 2 hr before attempting to drive home. Clients stated that driving was limited to physicians' appointments or infrequent but necessary trips to the market.

Many clients stated that it took nearly twice as long as long as it did before the onset of CFIDS to shower and dress in the mornings, and that this self-care activity had to be divided into multiple short tasks with rest periods in between. Often the act of dressing and showering precluded all other activities for that day.

As a result of severe fatigue, many of the clients' lives revolved solely around their work. Often clients stated that they had only enough energy to drag through the work day; they then spent each evening and weekend in bed in preparation for the next work day or work week.
Chronic pain was consistently listed as affecting function. When asked to rate their pain from 0 (no pain) to 10 (excruciating pain or pain that would require emergency room procedures), 69% of the women rated their pain at or below level 5; 11% rated their pain at level 6; 16% rated their pain at level 7 or 8; and none of the women rated their pain at level 9 or 10. Seventy-seven percent of the men rated their pain at or below level 4, and only one man (6%) rated his pain at level 7. The mean pain rating was 4.3 for the women and 3.5 for the men.

Clients who rate their pain at levels 4 or 5 are usually not magnifying symptoms or expressing inappropriate illness behavior. Clients who rate their pain at levels 7 through 10 either have severe impairment or are magnifying their symptoms. Clients with this degree of pain do not engage in many ADL, and they may spend most of the day sitting or lying down. Their facial expressions demonstrate constant strain, and their movement patterns may be altered or nonfluid. In contrast, the affect and movement patterns of clients who are demonstrating inappropriate illness behavior do not correlate with their high verbal pain ratings (Blankenship, 1989).

The observed affect and physical characteristic of the 86 CFIDS clients whom I evaluated were consistent with their subjective pain ratings (see Figure 1).

Nearly all of the clients reported decreased memory. Sixty-three of the 86 clients completed the Neurobehavioral Cognitive Status Evaluation (NCSE) (Mueller, 1988). This examination screens clients' status for orientation, attention, language, constructions, memory, calculations, and reasoning. Each subtest is scored on a point system spanning from 0 to 12. The results of NCSE scores place clients in average, mildly impaired, moderately impaired, or severely impaired ranges for each subtest.

For the purpose of this discussion and to present a valid profile of the CFIDS population, a low average range was added to account for the considerable number of clients whose scores fell between the average and mildly impaired ranges for constructions and calculations.

Each range was assigned a numerical value as follows: The average range was assigned a value of 0; low average—1; mild impairment—2; moderate impairment—3; and severe impairment—4. From the clients' cumulative range scores for each subtest, a cognitive status profile emerged (see Figure 2).

Consistent with their subjective reports, 48 (76%) of the clients who were tested on the NCSE scored in the lower average to severely impaired ranges for memory; 22 (35%) scored below average for constructions; 16 (25%) scored below average for calculation ability; and 9 (14%) scored below average for attention.

The NCSE scores corroborated individual clients' perceptions of their own cognitive impairments in almost every case. The cumulative profile in Figure 2 is representative of the cognitive impairments most often noted by persons with the disease and reported in the literature. The close grouping of scores in the memory category is especially noteworthy (see Figure 3).

Portions of the Employee Attitude Survey (EAS) (Ruch & Ruch, 1980) were used to evaluate clients' aptitudes for skills required for successful performance in their previous jobs. The scores of persons with CFIDS were compared to EAS normative data of persons without disabilities in similar occupations.

The EAS battery consists of the following tests: verbal comprehension, numerical ability, visual pursuit, visual speed and accuracy, space visualization, numerical reasoning, verbal reasoning, word fluency, manual speed and accuracy, and symbolic reasoning.

When compared to well persons in similar occupations, the majority of clients scored below the 50th percentile in all tests but verbal comprehension. More than 50% of the clients scored below the 10th percentile for numerical ability, visual pursuit, space visualization, nu-
**NAME:** C E I D O  P r o s i c e  
**OCCUPATIONAL STATUS:** 
**AGE AND DATE OF BIRTH:** 
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**NATIVE LANGUAGE:** 
**TIME:** 
**HANDEDNESS (circle):**  L  R 
**LEVEL OF EDUCATION:** 
**EXAMINATION LOCATION:**

### COGNITIVE STATUS PROFILE

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<th>LANGUAGE</th>
<th>CONST</th>
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<td>-5</td>
<td>-2</td>
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Write in lower scores

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<th>ATT</th>
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<th>COMP</th>
<th>CONST</th>
<th>MEM</th>
<th>NAM</th>
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<td>Calculations</td>
<td>Comprehension</td>
<td>Constructions</td>
<td>Memory</td>
<td>Naming</td>
<td>Impaired</td>
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**ABBREVIATIONS**

- ATT - Attention
- CALC - Calculations
- COMP - Comprehension
- CONST - Constructions
- MEM - Memory
- NAM - Naming
- IMP - Impaired

- JUD - Judgment
- ORI - Orientation
- REP - Repetition
- LOC - Level of Consciousness
- S - Screen
- SIM - Similarities

*The validity of this examination depends on administration in strict accordance with the NCSE Manual.
†For patients over age 65 the average range extends to the “mild impairment level” for Constructions, Memory and Similarities.

Note: Not all brain lesions produce cognitive deficits that will be detected by the NCSE. Normal scores, therefore, cannot be taken as evidence that brain pathology does not exist. Similarly, scores falling in the mild, moderate, or severe range of impairment do not necessarily reflect brain dysfunction (see the section of the NCSE Manual entitled “Cautions in Interpretation”).

**Figure 2.** Neurobehavioral Cognitive Status Examination (NCSE); Cumulative group profile. Reprinted with permission from Mueller, J., and Kiernan, R. J. (1983). The Neurobehavioral Cognitive Status Examination. Fairfax, CA: Northern California Neurobehavioral Group.
merical reasoning, word fluency, and manual speed and accuracy.

Regardless of their occupations, most clients were given EAS No. 8, a test of word fluency, because word finding was cited as a major difficulty by all of the clients. In this evaluation, clients were asked to write as many words beginning with a specific letter of the alphabet as they could think of in 5 min. Fifty-three percent of the clients scored below the 10th percentile, and 42% scored below the 5th percentile. These findings corroborated their symptomatic complaints.

Because the majority of the clients evaluated with the EAS had been successfully employed before developing CFIDS, it was assumed that their scores on job-related aptitude tests should fall, at least, in the average range. The significantly low scores of the clients indicated that their aptitudes and performance levels for previously performed skills were affected and, for the most part, seriously diminished. These findings suggest that for these clients, returning to work in the same occupations or occupations requiring similar skills was questionable.

The majority of clients reported muscle weakness along with generalized fatigue. It was often difficult for the clients to indicate or pinpoint specific muscular weakness. However, when questioned about weakness in regard to function, many clients complained of difficulty performing activities that required sustained overhead reach, prolonged standing or walking, and stair climbing.

On manual muscle testing of gross muscle groups of both the upper and lower extremities, a numerical scale was used as follows: 0 - zero, 1 - trace, 2 - poor, 3 - fair, 4 - good, 5 - normal (Kendall et al., 1971). A majority of the clients tested in the good to normal range for short, singular contractions. However, muscular fatigue was quickly noted when clients were asked to repeat the contractions several times. Poor muscular endurance, along with occasional manual muscle test scores that did fall below the good to normal range, were most often observed in the shoulder and pelvic girdles. This observation was consistent with clients' perceived difficulties...
with activities like washing or drying their hair and walking up stairs.

Isometric strength testing, with either a Chatillon digital force gauge or BTE Dynamic Lift equipment, was used during the FCEs. Strength scores were compared to NIOSH accepted normative data (U.S. Department of Health and Human Services, 1983) to ascertain each client's strength at the time of his or her evaluation. With the Dictionary of Occupational Titles (1991) definitions for sedentary, light, medium, heavy, and very heavy work categories, each client was assigned a physical demand level. Although isometric testing could not be used to judge a client's ability to perform the essential demands of a specific job in postoffer screenings or return-to-work evaluations, the strength scores provided insight into the clients' current strength versus probable strength as ascertained from subjective premorbid work and ADL capabilities.

Forty-six women (66%) and 9 men (56%) completed isometric testing scored in the sedentary physical demand level. Fewer than 1% of the women and fewer than 2% of the men scored above the light physical demand level. (Note that the standard NIOSH accepted norms [U.S. Department of Health and Human Services, 1983] for this type of strength testing are based on the scores of men and women in manual labor occupations, who, because of their occupations, may be stronger than the tested population. However, on the basis of this group of clients' previous work and recreational histories, higher ratings were expected.)

In 1990, an ADL screening—the Functional Capacity Checklist (FCC; Elliot & Fitzpatrick, Inc., content developed by L. Burke & E. Dillmann, 1984) — became available. The FCC is a computerized screening of a client's perception of his or her current ability to perform 165 activities in 22 basic categories versus self-ratings of his or her ability before the onset of an illness or disability, including walking, standing, lifting, carrying, pushing, and pulling. The client rates himself or herself on a 0-5-point scale for each category as follows: 0 = I don't know; 1 = no change; 2 = a little more difficult; 3 = only with some pain; 4 = very difficult to do, and 5 = impossible to do. The scores then are averaged into four performance areas: overall strength, gross motor ability, fine motor ability, and psychosocial ability.

The FCC was given to 14 of the clients. Their average scores were as follows: overall strength = 3.07; gross motor = 2.95; fine motor = 3.40; and psychosocial = 2.56. These scores indicated that the clients perceived their ability to perform functionally as more difficult or involving more pain than their premorbid ability levels.

The clients' observed abilities to perform material handling activities; lifting, carrying, handling, and nonmaterial handling activities; and sitting, standing, walking, stair climbing, bending, squatting, and reaching, affirmed their perceived ability levels when compared to their FCC scores. In many cases, the clients reported that they had higher ability levels than they were able to demonstrate.

Discussion

Profile of the CFIDS client

The results of objective testing and subjective observations from FCEs of persons with CFIDS provide a working profile of this population. These results demonstrated that the 86 clients had multiple physical and cognitive impairments that in most of the cases severely affected their ability to perform functional activities, including the ability to return to occupations in which they were previously successful.

Although other cognitive abilities were affected, as a group, the CFIDS clients' most frequent disorders were poor ability to attend, poor ability to retain newly learned material (memory), difficulty with word recall (word finding), and decreased ability to perform numerical calculations. The inability to attend or focus on any one task, which many clients reported, may interfere with creating new memories or performing basic mathematical functions. Other activities that the clients reported as being difficult or impossible to perform, such as reading, watching a movie, following a recipe, and driving, could also be related to attention and memory deficits. Unfortunately, the many skills affected by the syndrome were skills that the clients needed in order to remain successful in their occupations.

The results of the FCEs also indicated that the 86 clients had poor endurance for activity, as compared to their previously reported life-styles. Decreased physical fitness as a result of decreased physical activity could be considered at least a partial reason for limited endurance. However, consistent reports of unremitting pain, reported and observed muscle tremors, observed trigger points with pain which referred distally and proximally, and observed decreased strength and muscular endurance of the shoulder and pelvic girdles may also have contributed to their lowered physical functional levels.

Limitations

Overwhelming fatigue, usually the primary symptom affecting CFIDS clients, could not be objectively measured with the FCEs. (The effects of fatigue, such as increased word finding problems, decreased ability to attend, decreased ability to follow directions and physical signs, difficulty supporting one's head, tendency to slump in a chair, or increased requests for breaks, could be observed. Clients' subjective reports had to be relied on to
determine their previous life-styles and ADL abilities and to assess the effects that the 6 to 8 hr of testing had on the clients' functional abilities in the days after the evaluations. Another limitation was that the clients were seen for evaluation for only 1 day, most often because they lived out of the area or out of state.

Implications

Functional capacity evaluations, modified for clients with CFIDS to include cognitive evaluations and performed by occupational therapists knowledgeable about the syndrome, provide physicians, disability administrators, and vocational and rehabilitation specialists with information helpful in managing their care. The information ascertained from the evaluation assists decision making regarding clients' potential treatments, disability qualifications, and employability. The FCE also helps clients and their families understand, and put into perspective, the effects that the disease has upon function.

The functional capacity evaluation discussed in this article is the result of several years of evaluating persons with CFIDS; it remains an evolving tool. Formal evaluation tools and treatment protocols need to be developed in order to assist this underserved population in living with a chronic illness.

Appendix

CFIDS Symptoms

According to the Centers for Disease Control case definition and the CFIDS Association of America, CFIDS symptoms may include the following...

- Profound fatigue
- Low-grade fever
- Sore throat
- Painful lymph nodes
- Muscle weakness
- Myalgia
- Sleep disturbances
- Headaches of a new type
- Migratory arthritis
- Photobia
- Transient visual scotomata (spots)
- Memory disturbances
- Irritability
- Confusion and difficulty thinking
- Inability to concentrate
- Depression
- Spatial disorientation
- Dyslogia (word finding impairment)
- Visual disturbances (blurring, eye pain)
- Chills and night sweats
- Shortness of breath
- Dizziness and balance problems
- Irregular heart beat
- Irritable bowel
- Low body temperature
- Numbness of or burning of hands or feet
- Sicca syndrome (dry eyes, mouth)
- Rashes

Allergies to odors, chemicals, or medications
- Weight changes (usually gain)
- Hair loss
- Muscle twitching
- Seizures


References


Add These AOTA Publications to Your Hand Therapy Library

Scleroderma: Caring for Your Hands and Face is a new consumer guide for clients with systemic sclerosis and scleroderma to help them maintain, monitor and improve their mobility. Suggestions on how to use heat to decrease swelling and stiffness and exercises to improve hand and finger dexterity are included. Exercises are illustrated with ample room for the OT to make specific suggestions for the client.

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This new consumer guide demonstrates therapeutic strategies and exercises for managing carpal tunnel syndrome. Includes testing and diagnosis, exercises to help prevent carpal tunnel syndrome, and therapeutic management. 32 pages, 1994. Order #1118
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