Financial, Occupational, and Personal Consequences of Disability in Patients with Chronic Fatigue Syndrome and Fibromyalgia Compared to Other Fatiguing Conditions

NASSIM P. ASSEFI, TIMOTHY V. COY, DONALD USLAN, WAYNE R. SMITH, and DEDRA BUCHWALD

ABSTRACT. ***Objective.*** To examine the nature and degree of self-reported disability in patients with chronic fatigue syndrome (CFS) and its associated conditions, fibromyalgia (FM) and subsyndromal fatigue (CF), compared with a chronically fatiguing but unrelated medical condition (MED).

Methods. Six hundred and thirty patients evaluated at the University of Washington Chronic Fatigue Clinic were sent questionnaires asking them to identify the financial, occupational, and personal consequences of their fatiguing illness. Thorough medical evaluations had previously applied accepted criteria for defining CFS, FM, and CF.

Results. The FM groups (those with and without CFS) were among the least employed. Likewise, the FM and CFS groups, more frequently than the other groups, endorsed loss of material possessions (such as car), loss of job, and loss of support by friends and family, as well as recreational activities as a result of their fatiguing illness. There were no reliable differences between groups in use of disability benefits.

Conclusion. There is substantial illness-related disability among those evaluated at a specialized chronic fatigue clinic. Those reporting the most pervasive disability met criteria for FM either alone or in conjunction with CFS. Employers and personal relations of patients with chronic fatigue should make a greater effort to accommodate the illness-related limitations of these conditions, especially for those with FM and CFS. (J Rheumatol 2003;30:804–8)

Key Indexing Terms:
FIBROMYALGIA CHRONIC FATIGUE SYNDROME CHRONIC FATIGUE
DISABILITY FINANCIAL LOSSES PERSONAL LOSSES

The World Health Organization and Social Security Administration define disability as the inability to sustain normal financial (including material), occupational, and personal (including social and recreational) standards due to a physical or mental impairment. Chronic fatigue syndrome (CFS) is a perplexing disorder marked by at least 6 months of disabling fatigue accompanied by other physical and psychological symptoms (i.e., myalgias, fever, sleep, and mood disturbances)[1] that is diagnosed more often among women[2]. Although health care providers may frequently hear reports regarding the negative impact of CFS on their patients' quality of life, little research substantiates these claims. Recent cross-sectional and longitudinal studies of disability in CFS indicate that impairments can be devastating and unremitting[3,4]. For example, the physical and emotional sequelae of CFS may prevent full or part time employment[5], which may bring about further financial hardship and emotional suffering. Yet, despite their poor functional level, patients often report difficulties obtaining disability benefits, in part because insurers are troubled by the subjective nature of the illness and the lack of objective markers for CFS[6]. At present, there are no universally accepted guidelines for determining disability in patients with CFS.

Other conditions characterized by fatigue are also associated with considerable impairment. For example, up to 70% of patients with CFS meet criteria for fibromyalgia (FM)[7], a condition marked by diffuse musculoskeletal pain and multiple tender points[8], which itself may lead to substantial physical[9], social[10,11], and financial[12] impairments. This may

From the Department of Medicine, University of Washington; Creekside Behavioral Health, Bellevue; the Chronic Fatigue Clinic, Harborview Medical Center; and Northwest Counseling Associates, Seattle, Washington, USA.

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N.P. Assefi, MD, Acting Instructor of Medicine and OB/GYN, University of Washington; T. Coy, PhD, Psychologist, Creekside Behavioral Health, Bellevue; D. Uslan, MA, MBA, Rehabilitation and Mental Health Counselor, Northwest Counseling Associates; W.R. Smith, PhD, Clinical Assistant Professor of Psychiatry; D. Buchwald, MD, Professor of Medicine, University of Washington.

Address reprint requests to Dr. N. Assefi, Harborview Medical Center, 325 9th Avenue, Box 359780, Seattle, Washington 98104, USA. E-mail: nassefi@u.washington.edu

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be particularly apparent among patients in whom FM is precipitated by trauma[13,14] and among those with a dual diagnosis of FM and CFS[5,15]. Finally, subsyndromal chronic fatigue (CF), a condition similar to CFS but with an insufficient number of the accompanying symptoms to meet strict criteria, may have similar negative consequences. Although patients with CF typically report less fatigue and fewer somatic and cognitive complaints[15], recent studies demonstrate that CF is also associated with considerable disability[5].

Our objective was to document the financial, occupational, and personal consequences of disability among chronically fatigued patients seen at a tertiary care, university-based specialty clinic. We therefore compared the impact of illness and receipt of disability benefits in patients with CFS, FM, concurrent CFS and FM (CFS+FM), CF, and a medical condition associated with fatigue (MED).

MATERIALS AND METHODS

Participants were patients previously seen at the University of Washington Chronic Fatigue Clinic in Seattle, Washington between 1988 and 1996. This clinic provides evaluation and treatment for fatigued adults, many of whom are not diagnosed with CFS. All patients underwent a protocol-based medical and psychological evaluation, including a physical examination with palpation of tender points, blood tests, and a structured psychiatric interview to determine current and lifetime diagnoses. In addition, all patients completed a 180-item self-report questionnaire detailing the occurrence, frequency, intensity, and time-course of symptoms relevant to making a CFS and FM diagnosis. Patients were diagnosed with CFS based on the 1994 CDC criteria[1] and with FM according to the American College of Rheumatology guidelines[8]. Patients not fully meeting the CDC criteria for CFS (such as an inadequate number of accompanying symptoms) who also had no evidence of a medical condition that could explain their fatigue were classified as unexplained or subsyndromal chronic fatigue (CF). Lastly, patients with a medical condition that was associated with persistent fatigue, who also did not meet criteria for FM, were categorized in the medical conditions group (MED). This group included patients with conditions such as thyroid disease, cancer not in remission, and multiple sclerosis; these diagnoses were almost always established prior to the patient's visit to the Chronic Fatigue Clinic.

In 1992, 630 patients were mailed a 22-item questionnaire inquiring about their financial, occupational, and social status. They were told that the goal of the research was to collect accurate information on how chronically fatiguing illnesses can affect patients' lives. Patients who did not return the questionnaire were contacted by telephone.

For the analyses, patients were placed into one of 5 mutually exclusive patient groups: CFS, FM, CFS+FM, CF, and MED. Group differences on dichotomous variables were examined with Pearson's chi-squared analyses. Continuous variables were compared with one-way analysis of variance and Tukey post-hoc tests. Given that multiple tests were done, only those with p values of 0.01 or less were considered significant.

RESULTS

Completed questionnaires were obtained from 555 (88%) of the sample; the remainder refused or did not reply (8.0%), were lost to followup (3.5%) or had died (0.5%). Overall, 37% of the study patients met criteria for CFS alone, 14% for FM alone, and 16% for CFS+FM. The CF and MED groups comprised 5% and 28% of the patients, respectively. As shown in Table 1, the groups did not differ in age, years of education, and length of fatigue. However, there was a greater proportion of women with CFS than CF ($p < 0.001$) and more women in the FM group than in MED ($p < 0.01$) and CF ($p < 0.001$) groups. In addition, there were more women in the CFS+FM group compared to the CFS, CF, and MED groups (all $p < 0.001$).

Overall, 54% of patients reported current employment, defined as paid work inside or outside the home, and the mean hours per week worked was greater than 40 for all employed groups. Among individuals with CFS, 61% were employed compared to 36% of the FM group ($p < 0.001$); almost three-quarters of CF patients were employed, which was greater than the employment rate reported by individuals with CFS+FM ($p < 0.01$) and FM alone ($p < 0.001$). In addition, those with FM had the highest rate of job loss, which was greater than those in the MED ($p < 0.01$) and CFS ($p < 0.001$) groups. A greater proportion of the CFS+FM than the CFS patients lost their jobs ($p < 0.01$).

The financial, occupational, and social impact of the fatiguing conditions is illustrated in Table 2. Since becoming ill, 21% of FM patients lost their car, a figure greater than the 8% and 5% reported by the MED ($p < 0.01$) and CFS ($p < 0.001$) groups, respectively. The groups did not differ in the percentage that had lost their homes or businesses. FM patients more often experienced a decreased standard of living than those in the MED, CFS, and CF groups ($p < 0.01$–0.001). Likewise, patients with CFS+FM reported a decrease in their standard of living more often than those with CF and CFS (both $p < 0.01$). There were no significant differences between groups in the proportion who changed jobs or accepted a pay decrease.

Adding to material and occupational losses, many patients suffered personal consequences of their illness, including disconnection from their intimate partners, family, friends, and hobbies. Eighty-seven percent of all patients reported a significant decrease in their social lives. This was reported more frequently among individuals with CFS+FM and FM than those with CF (both $p < 0.01$). Overall, 23% of patients reported losing a significant other, and 46% had lost friends as a result of their condition. Individuals with FM had lost friends more frequently than the CFS, MED, and CF patient groups (all $p < 0.001$). Losing friends since becoming ill occurred more often in the CFS+FM than CFS and CF groups (both $p < 0.01$). Among all patients, 28% noted that their family had become distant, unsupportive, or uninterested since the onset of their illness. Again, persons with FM endorsed this item more frequently than those in the MED ($p < 0.01$) and CF ($p< 0.001$) groups; these family difficulties also were more common in CFS+FM than CF ($p < 0.01$). Approximately 90% of all patients decreased recreational activities with CFS+FM and FM patients endorsing this item more frequently than those with CF (both $p < 0.01$).

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Table 1. Demographic and employment characteristics among patients with chronic fatigue syndrome (CFS), fibromyalgia (FM), chronic fatigue syndrome and fibromyalgia (CFS + FM), subsyndromal chronic fatigue (CF), and fatigued individuals with a medical condition (MED).

	CFS n = 207	FM n = 76	CFS + FM n = 87	CF n = 31	MED n = 154
Demographics					
Female, n (%)*	157 (76)	66 (87)	82 (94)	13 (42)	103 (67)
Age, mean yrs (SD)	38.2 (10.3)	41.9 (10.7)	42.5 (10.3)	37.4 (13.9)	40.4 (12.0)
Education, mean yrs (SD)	13.5 (4.8)	13.1 (5.0)	13.9 (4.4)	15.0 (3.0)	13.6 (4.5)
Fatigue duration, mean yrs (SD)	4.4 (5.4)	5.7 (7.4)	5.6 (6.6)	4.2 (5.9)	5.7 (6.9)
Employment					
Currently employed, n (%)**	126 (61)	27 (36)	38 (44)	23 (74)	83 (54)
Hours/week worked in year before illness, mean (SD)	42 (13)	45 (18)	41 (13)	42 (10)	42 (15)
Hours/week currently working, mean (SD)	33 (11)	31 (12)	32 (15)	36 (11)	34 (12)
Job did not allow changes to accommodate health, n (%)	92 (49)	49 (66)	48 (62)	15 (50)	76 (55)
Decreased hours at previous job, n (%)	91 (44)	40 (53)	44 (51)	12 (39)	63 (41)
Lost job due to illness, n (%)***	60 (29)	41 (54)	42 (49)	8 (26)	51 (34)

* CFS + FM > CFS; CF, MED; FM > CF; FM > MED; CFS > CF ($p < 0.01$); ** CF > FM; CF > CFS + FM; CFS > FM ($p < 0.01$); *** FM > CFS; FM > MED; CFS + FM > CFS ($p < 0.01$).

Table 2. Impact of illness among patients with chronic fatigue syndrome (CFS), fibromyalgia (FM), chronic fatigue syndrome and fibromyalgia (CFS + FM), subsyndromal chronic fatigue (CF), and fatigued individuals with a medical condition (MED)[a]. Numbers of subjects with each fatiguing condition differ slightly from Table 1 due to incomplete responses.

	CFS n = 207	FM n = 76	CFS + FM n = 86	CF n = 31	MED n = 152
Financial losses					
Lost car, n (%) [a]	10 (5)	16 (21)	11 (13)	3 (10)	12 (8)
Lost home, n (%)	18 (9)	15 (20)	13 (15)	0 (0)	14 (9)
Lost business. n (%)	18 (9)	9 (12)	8 (9)	3 (10)	11 (7)
↓ Standard of living, n (%)[b]	92 (44)	58 (76)	55 (64)	9 (29)	79 (52)
Occupational changes[c]					
Changed jobs, learned new job, n (%)	27 (23)	8 (31)	11 (31)	3 (15)	22 (28)
Took job requiring fewer skills than pre-illness job, n (%)	30 (25)	10 (38)	9 (25)	4 (18)	18 (23)
Took significant pay cut, n (%)	35 (30)	8 (32)	16 (44)	7 (33)	36 (45)
Personal (social/recreational) impact					
Significantly ↓ social life, n (%)[d]	174 (84)	71 (93)	81 (94)	21 (68)	132 (87)
Lost significant other, n (%)	40 (19)	25 (53)	21 (24)	8 (26)	35 (23)
Lost friends, n (%)	79 (38)	52 (68)	51 (59)	8 (26)	63 (41)
Family unsupportive, uninterested, n (%)[f]	53 (26)	32 (42)	33 (38)	1 (3)	36 (24)
Significant ↓ recreational activities, n (%)[g]	186 (90)	73 (96)	81 (94)	23 (74)	132 (87)
Social/recreational impact					
Times/week contact with friends in person, mean (SD)	2.8 (2.8)	3.8 (11.7)	2.2 (2.4)	6.8 (10.3)	3.5 (5.4)
Times/week contact with friends by phone, mean (SD)	4.2 (4.4)	4.2 (4.4)	4.0 (4.7)	5.6 (9.8)	4.4 (4.3)

Significant differences ($p < 0.01$) are demarcated by a letter. [a] FM > CFS; FM > MED; [b] FM > CFS, CF; FM > MED; CFS + FM > CFS, CF; [c] Employed patients only: CFS = 119, FM = 26, CFS + FM = 36, CF = 22, Med = 81; [d] FM > CF; CFS + FM > CF; [e] FM > CFS, CF, MED; CFS + FM > CFS, CF; [f] FM > CF; FM > MED; CFS + FM > CF; [g] FM > CF; CFS + FM > CF; iCF > CFS, CFS + FM.

Table 3 summarizes the array of disability benefits and financial assistance received by unemployed patients. With the exception of individuals with CFS+FM receiving more help from their significant others than MED patients ($p < 0.01$), the groups did not differ. Likewise, use of an attorney (34% by unemployed patients) and type of health insurance did not reveal reliable group differences (data not shown). A family member's health insurance plan (25%) and personal funds (23%) were the most common methods of payment for health care among all patients. Overall, 31% of unemployed patients were on Medicare and 25% had coverage through medical coupons or Medicaid.

After controlling for gender in all of the above analyses, there were no significant differences between the 4 subgroups, except that males in the MED group had experienced a longer duration of fatigue compared to females (8.04 vs 4.6 years, $p < 0.01$).

DISCUSSION

Our study suggests substantial financial, occupational, and personal disability among patients seen at a university-based specialty clinic for fatigue-related complaints. Overall, almost half of the patients were unemployed, and about half of these received some form of disability benefits. Many

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Table 3. Disability benefits and financial assistance among unemployed subjects with chronic fatigue syndrome (CFS), fibromyalgia (FM), chronic fatigue syndrome and fibromyalgia (CFS + FM), subsyndromal chronic fatigue (CF), and fatigued individuals with a medical condition (MED). Numbers of unemployed subjects are slightly less than reported in Table 1 due to incomplete responses. Categories of financial assistance are not mutually exclusive.

	CFS, n = 79	FM, n = 49	CFS + FM, n = 48	CF, n = 8	MED, n = 70
Unemployment benefits, n (%)	1 (1)	2 (4)	1 (2)	0 (0)	5 (7)
Supplemental security income, n (%)	8 (10)	11 (22)	12 (25)	1 (13)	18 (23)
Social security disability insurance, n (%)	24 (30)	22 (45)	16 (33)	1 (13)	15 (21)
Short term employer or private disability insurance, n (%)	6 (8)	3 (6)	1 (2)	0 (0)	3 (4)
Long term employer or private disability insurance, n (%)	10 (13)	9 (18)	10 (21)	1 (13)	7 (10)
GAU/Public assistance, n (%)	7 (9)	9 (18)	5 (10)	0 (0)	10 (14)
Financial assistance from extended family, n (%)	13 (16)	7 (14)	5 (10)	0 (0)	8 (11)
Financial assistance from significant other, n (%)*	18 (23)	11 (22)	17(35)	1 (13)	6 (9)
No assistance from any of the above, n (%)	16 (20)	3 (6)	7 (15)	1 (12)	12 (17)

*CFS + FM > MED, $p < 0.01$.

who remained employed had to change jobs, work fewer hours, and/or receive less pay for their work since becoming ill. Likewise, patients suffered substantial losses as a result of their condition, including loss of personal possessions, recreational activities, and support from family and friends. Those with FM, either alone or with concurrent CFS, were more frequently disabled across several dimensions in comparison to the CFS, CF, and MED groups. Overall, the degree of disability in this sample of patients with CFS and FM was greater than that reported in comparable studies of patients with other rheumatologic conditions such as rheumatoid arthritis and osteoarthritis[16, 17].

Our results support previously published findings regarding work-related disability. Similar to figures reported elsewhere[5,18], 39% of our CFS patients were unemployed. Many individuals with CFS find employment difficult to sustain and are unable to meet work deadlines[3], which may be secondary to cognitive deficits, fatigue, pain, and psychological factors associated with CFS. Certain work environments also appear to exacerbate symptoms, and work accommodations may not be readily made[6]. The striking rate of current unemployment in FM (64%) was higher than previously reported[11,19,20] and post-job losses were considerable. This finding is especially troubling given that unemployment is associated with a poor outcome among chronic pain patients[21]. In addition, FM patients experienced the highest rate of job loss secondary to their illness, again surpassing that observed in CFS. Repetitive motor tasks, prolonged sitting and/or standing, and stressful work environments in particular may exacerbate FM symptoms such that employment is no longer possible[22].

Among our unemployed patients, the nature and extent of disability compensation varied. Overall, 30–45% of patients with CFS, FM, or CFS+FM received social security disability income, a figure higher than estimates recently reported for FM[19]. Interestingly, receipt of disability compensation has been found to vary by geographical region, and male gender, functional disability, and pain levels independently predicted social security disability income benefits[19]. Another report has suggested a positive association between receipt of disability benefits and FM precipitated by physical trauma[23]. Of note, the unemployment rate and the likelihood of receiving unemployment benefits from governmental or private sources was similar among patients with well-recognized medical conditions (MED) and CFS, FM, and CFS+FM. This finding challenges the general perception that CFS and FM patients receive an unfavorable reception when applying for disability benefits compared to those with other fatiguing and painful conditions where biological markers lend greater objectivity to diagnostic classifications.

The 4 chronically fatiguing conditions in this study were associated with other financial consequences. For example, over a third of currently working patients had taken a significant decrease in income since becoming ill, nearly 10% had lost their home or car, and decreases in the standard of living were common. In addition to individual losses, societal costs occur when diminished work productivity secondary to these fatiguing conditions is considered. Not only do individuals with CFS and FM have decreased personal income, but there is a loss in state and federal tax revenue as well[24]. In 1992, it was estimated that CFS alone cost the Australian national government and local communities approximately 60 million dollars per year based on direct and indirect costs of the illness[24].

Perhaps the most striking finding was the degree of personal disability among our sample, manifested as a decrement in social and recreational activities. Over 90% of patients with FM and CFS+FM experienced a significant decrease in their social life and in time spent in recreational activities or hobbies. In this regard, a recent study of CFS patients found that 20% were unable to undertake any social activities whatsoever[4]. As previously reported, fatigued patients often lost friends and the support of family members since becoming ill[3]. Decreased social and recreational functioning may be associated with high rates of mood disturbances among those with CFS and FM[25]. Lack of social support has been linked to depression in the

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general population and among those with chronic conditions[26,27]. Of note, despite gender differences in the prevalence of affective disorders and the potential for gender-biased social constructions to influence material, occupational, and personal activities in men and women, we found very little evidence for gender differences in reported disability in all subgroups.

Our study has several limitations. First, data were collected at a university-based specialty clinic for fatigue-related symptoms, where symptoms of chronic fatigue tend to be more severe and long-lasting than those in the community[28,29]. Thus, our results may not be generalizable to primary care or other settings, or to individuals not seeking medical attention. Second, our financial, occupational, and personal data were obtained from the patients using questions of unknown reliability, and thus may be influenced by the usual self-report biases. No attempts were made to verify information with written documentation or verbal reports from others. Finally, data were collected at only one time point. Despite the generally poor prognosis of patients with CFS and FM, symptoms vary considerably over time; therefore, cross-sectional studies may not adequately reflect the fluctuating nature of some impairments.

Despite these limitations, our study underscores the substantial impact across many domains of fatiguing conditions. This appears particularly true for individuals with FM and CFS+FM, supporting the view that FM is one of the most troubling and disabling chronic conditions[16,17]. Of importance to insurers, employers, and patients alike is the finding that unemployment was associated with a failure to make accommodations in the workplace. Making such changes to insure that persons with chronically fatiguing conditions can continue to be productive members of the work force would likely benefit patients and minimize the costs of these disorders to society. Similarly, educating intimate partners, family, and friends about the debilitating effects of these conditions could help combat the personal and social deteriorations in the lives of CFS and FM patients.

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