Disability in Chronic Fatigue Syndrome and Idiopathic Chronic Fatigue

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Abstract: The current investigation classified 31 people with chronic fatigue syndrome (CFS) and 44 people with idiopathic chronic fatigue (ICF) into mild, moderate, and severe/very severe categories of self reported functional impairment. Differences in sociodemographic characteristics, symptom frequency, symptom severity, and functional impairment were examined between individuals with CFS and ICF, and were examined among the three categories of functional impairment. Results indicated that there were no differences between the CFS and ICF groups in their functional impairment classification. People who were classified into the more disabled categories reported more severe symptoms, and were more likely to have scores indicating higher disability on other measures of functional status. Implications of these findings are discussed.

Key Words: chronic fatigue syndrome, idiopathic chronic fatigue, disability classification, functional impairment

Introduction

Chronic fatigue syndrome (CFS) is a highly heterogeneous condition, affecting people in various ways and fluctuating in terms of symptoms and severity (Anderson & Ferrans, 1997). Although the pathophysiology of CFS involves severe, prolonged fatigue, as well as neurological, immunological, and endocrinological abnormalities (Friedberg & Jason, 1998), it remains a poorly understood and controversial illness (Jason *et al.*, 1995). Like many other chronic illnesses, CFS has been difficult to define because exact causal agents are unknown, physical signs and symptoms are variant, and diagnostic laboratory tests have poor sensitivity and specificity (Holmes, 1991).

One major challenge facing CFS research is patient heterogeneity. Across studies, individuals with CFS have been found to differ across characteristics such as gender, ethnicity, socioeconomic status, symptom severity, functional disability, psychiatric status, and coping styles (Friedberg & Jason, 1998). Failure to address this heterogeneity has likely resulted in study conclusions that are inconsistent. These discrepant findings have caused the field to become highly polarized regarding issues of etiology, diagnosis, epidemiology, and treatment. When unique patient groups are unwittingly combined, important distinctions between specific subtypes of CFS may become blurred. Addressing this issue may improve the validity of future research findings by uncovering symptom variations in subgroups of people with CFS.

Persons with CFS appear to be heterogeneous with respect to the level of disability they exhibit. Compared to other chronically ill populations, persons with CFS experience a markedly higher degree of impaired functioning (Anderson & Ferrans, 1997; Buchwald et al., 1996). When using the Medical Outcomes Survey (MOS), Buchwald et al. (1996) determined that persons with CFS appear to be severely disabled on measures of role functioning, social functioning, and vitality. Scores on these MOS

subscales were markedly lower than previous work with other chronically ill populations. Anderson and Ferrans (1997) obtained similar results when examining Quality of Life Index (QLI) scores in persons with CFS. They concluded that QLI scores in the CFS group were lower than other chronic illness groups and healthy controls for all four domains (Health and Functioning, Social-Economic, Psychological/Spiritual, and Family).

One study addressed the issue of heterogeneity by creating four categories describing levels of functioning. Cox and Findley (2000) examined the varying levels of disability that people with CFS manifest and proposed a system of classification based on functional status. Persons classified in the mild category were mobile, providing self-care, and still working. However, in order to maintain work responsibilities they had stopped all leisure and social activities. Persons in the moderate category experienced reduced mobility, restrictions in activities of daily living, and were usually not working. They required many periods of rest, and sleep quality was generally poor and disturbed. Cox and Findley indicated that the moderate group has been most frequently studied in research. Persons in the severe category were able to carry out only minimal daily tasks, were wheelchair dependent, experienced severe postexertional malaise, and substantial cognitive and memory difficulties. Finally, persons in the very severe category were mainly bedridden and were unable to perform substantive daily tasks.

It would be expected that persons meeting the US case definition of chronic fatigue syndrome (Fukuda *et al.*, 1994) experience a greater amount of disability than those who do not meet the current US case definition. The current US case definition was derived by clinical consensus and was not empirically based. Several studies have attempted to empirically validate the diagnostic accuracy of this definition (Hartz *et al.*, 1998; Jason, King, *et al.*, 1999; Komaroff, *et al.*, 1996; Nisenbaum, *et al.*, 1998). The appropriateness of the case definition in accurately classifying persons with CFS continues to be studied. The implicit assumption that individuals diagnosed with CFS using the current CFS case definition have a more severe illness and are more disabled than those partially meeting the current CFS criteria has yet to be empirically examined.

The present investigation examined a group of persons with Chronic Fatigue Syndrome, who fully met the US case definition for CFS (Fukuda *et al.*, 1994), and a group of persons with Idiopathic Chronic Fatigue (ICF), who met partial but not full criteria for chronic fatigue syndrome. This larger sample of persons with chronic fatigue syndrome and with idiopathic chronic fatigue was then classified into the functional impairment categories proposed by Cox and Findley (2000) using self-reported disability. It was expected that persons with CFS who fully met the criteria for CFS would be more severely disabled than those only partially meeting CFS criteria. In addition, the occurrence of symptoms, the severity of symptoms, and scores on other disability measures were examined across the disability groups. It was expected that persons with greater disability according to self-report would exhibit increased symptom occurrence, more severe symptoms, and greater disability on other measures of functional status.

Method

Procedure

The data are derived from a larger community-based study of the prevalence of Chronic Fatigue Syndrome (for more details of this study see Jason, Richman, *et al.*, 1999). This larger study was carried out in three stages. Stage 1 involved administering an initial telephone-screening questionnaire in order to identify the symptoms of Chronic Fatigue Syndrome. Stage 2 consisted of the administration of a semi-structured psychiatric interview. In Stage 3, participants underwent a complete physical examination. Upon completion of the study, a team of four physicians and a psychiatrist made the final diagnoses of CFS, ICF, or fatigue explained by medical or psychiatric condition. These physicians were familiar with the CFS diagnostic criteria and did not know the experimental status of the participant. Two physicians independently rated each case to determine whether the participant met the CFS case definition (Fukuda *et al.*, 1994). If a disagreement occurred, a third physician rater was used to arrive at a diagnostic consensus. Following this final stage, four physicians and a psychiatrist made a final diagnosis.

Sample

Procedures developed by Kish (1965) were used to select one adult from each household. The birth dates of the adults residing in each household were gathered. The person with the most recent birthday was selected for the interview. A stratified random sample of several neighborhoods in Chicago was utilized. In the first stage, 28,673 residential/working telephone numbers were contacted with 18,675 adults actually completing the initial screening interview (a completion rate of 65.1%).

The Stage 1 screen revealed that of the 18,765 participants who were interviewed, 780 (4.2%) had chronic fatigue. Of these, 408 had chronic fatigue and the concurrent occurrence of four or more symptoms. These participants were defined as CFS-like. The suffix "like" was used to clarify that individuals in this group only met the Fukuda et al. (1994) criteria by self-report and did not necessarily qualify as having a final diagnosis of CFS rendered by a physician.

One hundred sixty-six of the 408 CFS-like participants agreed to complete a structured psychiatric interview (Stage 2) and a comprehensive physical examination (Stage 3). There were no significant differences on sociodemographic (i.e., gender, ethnic identification, age, occupation, education, and marital status) or fatigue scores between these 166 screened positive (CFS-like) participants and the 242 screened positive (CFS-like) non-participants. The control group was composed of 199 individuals selected randomly from the remaining 18,260 screened negatives (seven cases were excluded due to missing data). Of these 199 individuals, 47 completed medical evaluations. There were no significant sociodemographic differences (i.e., gender, ethnic identification, age, occupation, education, and marital status) or fatigue scores between the 152 screened negative non-participants and 47 screened negative participants.

Participants were then classified by independent physician consensus. For participants who reported chronic fatigue, physicians diagnosed 32 people with CFS, 45 people with idiopathic chronic fatigue, and 89 people with fatigue explained by a medical or psychiatric illness.

Participants

The present investigation examined the occurrence of symptoms in two groups of participants. The first group consisted of 32 persons from the larger group of 166 persons with CFS-like symptoms who were diagnosed with CFS by the independent physician review panel (CFS group). The functional impairment status was missing for one person in the CFS group so this person was excluded from all analyses. The second group consisted of 45 persons diagnosed with idiopathic chronic fatigue (ICF) who had unexplained fatigue, but did not meet the current case definition for CFS. One person in the ICF group did not report any functional impairment and was excluded from all analyses. Thus, in the present investigation, the CFS group consisted of 31 participants and the ICF group consisted of 44 participants.

Measures

Screening Questionnaire
The Stage 1 screening questionnaire assessed interviewee's sociodemographic characteristics and preliminary classification into screened positive (CFS-like) versus screened negative groups. This screening instrument has been found to have adequate reliability (Jason et al., 1997). Basic sociodemographic data included age, ethnicity, marital status, and gender. The revised scoring rules for Hollingshead's (1995) scale, developed and validated by Wasser (1991) were used to classify socioeconomic status.

Structured Clinical Interview for the DSM-IV (SCID) (Spitzer et al., 1995)
The SCID is a semi-structured interview designed to yield DSM-IV psychiatric diagnoses. It is a valid and reliable measure that approximates a traditional psychiatric interview (Rubinson & Asnis, 1989). This measure has been shown to offer the most accurate means of diagnosing psychiatric disorder in individuals with CFS (Taylor & Jason, 1998). Master's level psychology clinicians who were trained extensively in SCID administration and supervised by a licensed clinical psychologist administered the SCID. The SCID was administered in Spanish to Spanish-speaking participants by bilingual master's level psychology clinicians.

Levels of Disability
As part of the Screening Questionnaire, participants were asked to describe the impact of their fatigue during the last month on a seven point scale, with 1 being bedridden and 7 being able to do all work or family responsibilities without any problems. Responses to this question were then used to classify participants into the groups proposed by Cox and Findley (2000). The mild group consisted of participants who reported being able to work full time and on some family responsibilities, but who had no energy left for anything else. The moderate category consisted of participants who reported being able to do light housework or work part time or work on some family responsibilities. The severe group comprised participants that reported being ambulatory, but unable to do light housework. Finally, the very severe group reported being bedridden and unable to work or do other activities. Only two persons were classified into the very severe group. Therefore, the severe and very severe groups were combined and treated as one group (severe/very severe) in the subsequent analyses.

Symptoms

Participants were also asked to complete a detailed medical questionnaire assessing the occurrence and severity of Fukuda *et al.* (1994) symptoms (Jason *et al.*, 1997). The occurrence of symptoms that had occurred in the 6 months since the onset of fatigue was assessed. Severity of symptoms was rated on a 100 point scale with 0 = no pain or problem and 100 = severe pain or problem.

Fatigue

The Fatigue Scale was originally used in a hospital-based case control study (Wessely & Powell, 1989) and was further refined by Chalder *et al.* (1993). This scale was found to be reliable and valid with reasonable face validity and discriminant validity. The 11 items are rated on a four-option continuum with subscales assessing both mental and physical fatigue. Total score range from 0-33 (with higher scores being indicative of greater fatigue). This scale was used in the community-based study of fatigue (Pawlikowska *et al.*, 1994).

Medical Outcomes Study

Participants completed the Medical Outcomes Study 36-item Short-Form Survey (MOS) (Ware & Sherbourne, 1992), a reliable and valid measure that discriminates between gradations of disability. This instrument encompasses multi-item scales that assess physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality (energy/fatigue), social functioning, and mental health. Higher scores indicated better health, lower disability, and less impact of health on functioning. Reliability and validity studies for the 36-item version of the MOS have shown adequate internal consistency, discriminant validity among subscales, and substantial differences between patient and nonpatient populations in the pattern of scores (McHorney *et al.*, 1993; McHorney *et al.*, 1992; McHorney, *et al.*, 1994). The MOS Physical Composite Score (PCS) and Mental Composite Scores (MCS) were also utilized in the present investigation as combined measures of the eight MOS subscales to rate global impairment of physical and mental functioning. These PCS and MCS have appropriate validity and reliability as well as greater sensitivity and specificity in discriminating the gradations of health status among groups (Brazier *et al.*, 1992).

Degree of Impairment

Participants were asked to rate the degree to which their fatigue has impaired their functioning in daily activities on a 100-point scale, with 0 = no difficulties and 100 = total and complete disability.

Statistical Analyses

First, the sociodemographic variables of gender, age, ethnicity, marital status, parental status, work status, socioeconomic status, current psychiatric diagnosis, and lifetime psychiatric diagnosis were compared between the CFS and ICF groups using chi-square analyses. Next, these sociodemographic variables were compared between the mild, moderate, and severe/very severe groups using chi-square analyses. When

differences were found in the sociodemographic characteristics between the CFS and ICF groups, and between the mild, moderate, and severe/very severe categories, these variables were entered into the subsequent analyses in order to control for the effects of these variables on the outcome measures.

A chi-square analysis was performed to determine whether the CFS and ICF group significantly differed in the number of participants classified in each category of functional disability. Binomial logistic regressions, controlling for sociodemographic differences, were utilized to examine the occurrence of Fukuda et al. symptoms in the mild, moderate, and severe/very severe groups. ANCOVAs, which controlled for the sociodemographic differences between the mild, moderate, and severe/very severe group, were utilized to compare the severity of Fukuda *et al.* (1994) symptoms and to compare scores on other measures of functional impairment.

Results

Preliminary Sociodemographics Analyses

Using chi-square analyses, participants in the CFS and ICF groups did not significantly differ on sociodemographic variables. When examining differences between the mild, moderate, and severe/very severe categories, significant differences between these groups were found in age ($X2$ (1, N = 75) = 16.58, p < .05) and work status ($X2$ (1, N = 75) = 51.46, p < .01). Therefore, analyses of symptom occurrence, symptom severity, and functional impairment included age as a covariate to control for the effect of this variable. Work status was not entered as a covariate because it was expected that work status would be highly correlated with self-reported functional disability level.
CFS vs. ICF group

Chi-square analyses indicated that the CFS and ICF groups did not differ significantly in the number of persons classified into the mild, moderate and severe/very severe categories ($X2$ (2, N = 75) = 3.97, p>.05) (see Table 1). Because there were no difference between the CFS and ICF groups in whether they were classified as mild, moderate, or severe/very severe, in subsequent analyses, CFS/ICF status was not used a covariate in the analyses examining differences among these three groups.

Symptom Occurrence

Binomial logistic regression analyses were performed to compare the occurrence of the case definition symptoms (Fukuda *et al.*, 1994) across the three disability level groups, controlling for the effect of age. The mild and moderate groups were separately compared to the severe/very severe group (see Table 2). The mild group reported significantly lower rates of postexertional malaise than the severe/very severe group ($X2$ (1, N = 75) = 5.33, p < .05). Furthermore, the moderate group reported significantly lower rates of memory and concentration difficulties than the severe/very severe group ($X2$ (1, N = 75) = 4.13, p < .05).

Symptom Severity

ANCOVAs were conducted to examine the severity of the eight Fukuda *et al.* (1994) symptoms across the three disability level groups, controlling for the effects of age. The ANCOVA analyses indicated that the occurrence of sore throat ($F (2, 75) = 10.85$, $p < .001$), lymph node pain ($F (2, 75) = 4.35$, $p < .05$), muscle pain ($F (2, 75) = 4.35$, $p = < .05$), joint pain ($F (2, 75) = 3.40$, $p < .05$), post-exertional malaise ($F (2, 75) = 4.11$, $p < . 05$), memory and concentration ($F (2, 75) = 4.42$, $p < .05$), and unrefreshing sleep ($F (2, 75) = 5.38$, $p <. 01$) were significantly different across the mild, moderate, and severe/very severe categories (see Table 2). Bonferroni post hoc analyses indicated that participants in the mild group reported significantly less severe sore throat pain ($p < .001$), lymph node pain ($p < .05$), muscle pain ($p < .05$), unrefreshing sleep ($p < .05$), and memory and concentration difficulties ($p < .05$) than the severe/very severe group. The moderate group reported significantly less severe sore throat pain ($p < .05$), lymph node pain ($p < .05$), muscle pain ($p < .05$), joint pain ($p < .05$), post-exertional malaise ($p < .05$), and unrefreshing sleep ($p < .01$) when compared to the severe/very severe group. There were no significant differences between the mild and moderate groups in the occurrence of these symptoms.

Functional Impairment

ANCOVAs were conducted to examine differences on the MOS Physical Composite Score, MOS Mental Composite Score, self rated degree of impairment of functioning in daily activities, and fatigue severity scores between the mild, moderate, and severe/very severe groups with age as a covariate. The MOS Physical Composite Score (PCS) ($F (2,57) = 11.55$, $p < .01$) and participant self-ratings of impairment of functioning in daily activities ($F (2,59) = 9.88$, $p < .01$) were significantly different among the three disability level groups (see Table 2). Bonferroni post hoc analyses indicated that participants in the mild group had significantly higher physical functioning as measured by the PCS when compared to the moderate ($p < .05$) and severe/very severe ($p < .01$) groups. Further, the mild group reported significantly less impairment of physical functioning in daily activities on a 100-point scale than the severe/very severe group ($p < .001$).

Discussion

This study examined differences in sociodemographic characteristics, symptom frequency, symptom severity, and functional impairment in individuals with CFS and ICF, and classified persons with CFS and with CFS into mild, moderate, and severe/very severe categories of self reported functional impairment. It is interesting to note that the CFS and ICF groups did not significantly differ in self-reported functional impairment. In fact, fourteen persons with ICF reported functional impairment that could be classified as moderately, severely, or very severely disabled. This finding indicates that while persons with ICF do not fully meet the current US case definition for CFS (Fukuda *et al.*, 1994), many experience disruptions in occupational, educational, social, or personal activities that are similar to those reported by persons with CFS.

Important differences emerged between the mild, moderate, and severe/very severe groups with respect to symptom occurrence and symptom severity. When

examining symptom occurrence, differences among the disability groups were found only for postexertional malaise and memory/concentration difficulties. In contrast, differences were found between the disability groups on the severity ratings of all the symptoms except new headaches. This highlights the importance of considering severity of symptoms, not just symptom frequency, in differentiating people of varying disability levels.

People in the severe/very severe category were more likely to have lower scores in the MOS, indicating more disability on this measure, and higher scores on the self-reported 100-point scale of disability. These findings provided evidence for external validity of this disability classification. Further, there were relatively few differences between the mild and moderate categories. This suggests that there may be little distinction between the mild and moderate category. When examining disability, therefore, it may be useful to contrast those in the mild or moderate category with those in the severe or very severe category. However, in the present investigation, very few people fell into the very severe category, so that the severe and very severe people were considered together in the analyses. Future research should focus on comparing the severe and very severe categories to determine whether important distinctions would emerge between these two groups.

Finally, the current investigation found that very few people fell into the very severe category. It is possible that persons who were very severely disabled people were less likely to participate in the present investigation. Because of their very low functioning, they may have been less likely to answer the telephone in order to complete the initial CFS screening questionnaire, and, likewise, they may have been less likely to agree to complete the interviews and medical examination given to the study participants.

In summary, the present investigation found that people with CFS and ICF did not differ in the level of self-reported functional impairment. Further, when looking at the occurrence of symptoms, only post exertional malaise and memory/concentration difficulties differentiated the disability level groups, whereas the severity of all symptoms in the CFS case definition, with the exception of new headaches, significantly differentiated the disability level groups. The disability classification as proposed by Cox and Findley (2000) appeared to be associated with other disability measures. Future research on this classification system may provide further evidence for its validity. Finally, future research that classifies people according to their level of functional impairment will likely help delineate important differences among these subgroups of people with CFS.

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Table 1

Self-Reported Level of Ability
for the CFS and ICF Groups

CFS (N=31)   ICF (N=44)

Level of Ability	N	N
Mild	14	30
Moderate	12	10
Severe/Very Severe	5	4

Table 2

Comparison of Symptom Frequency, Symptom Severity,
and Functional Impairment for the
Mild, Moderate, and Severe/Very Severe Groups1

Mild (N=44)
Moderate (N=22)
Severe/Very Severe (N=9)

Symptom Frequency	%	%	%
Sore Throat	18.2	22.7	11.1
Lymph Node Pain	13.6	22.7	11.1
Muscle Pain	50.0	40.9	55.6
Joint Pain	34.1	36.4	44.4
Postexertional Malaise	25.0a	31.8	66.7a*
New Headaches	43.2	27.3	55.6
Memory and Concentration	56.8	40.9b	77.8b*
Unrefreshing Sleep	54.5	54.5	44.4

Symptom Severity	M	M	M
Sore Throat	23.7a	30.7b	78.0a,b**
Lymph Node Pain	22.1a	29.5b	100a,b*
Muscle Pain	51.7a	45.5b	87.5a,b*
Joint Pain	55.8	46.6b	86.4b*
Postexertional Malaise	55.6	47.6b	89.2b*
New Headaches	56.0	53.2	80.0
Memory and Concentration	49.2a	55.0	81.4a*
Unrefreshing Sleep	62.1a	54.4b	90.0a,b**

PCS3	42.8a,c	34.4c	27.9a**
MCS3	38.9	40.5	35.7
Chalder	18.8	20.5	20.7
Degree of Impairment	46.0a	59.0	77.2a**

a,b Similar letters next to two columns indicate that they are significantly different at the
p < .05 level using Bonferroni post hoc analyses.
* = P < .05, ** = P < .01
Higher scores on the MCS and PCS indicate less disability.