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Running Head: Symptoms of Chronic Fatigue Syndrome

Comparing Symptoms of Chronic Fatigue Syndrome in a
Community-Based versus Tertiary Care Sample

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Abstract

Chronic Fatigue Syndrome (CFS) is a debilitating condition characterized by six or more months of prolonged or relapsing, unexplained fatigue of new or definite onset and at least four of eight associated somatic and cognitive symptoms. Almost all studies of samples with patients with CFS have relied on referrals from physicians or health facilities. Underserved minorities, who not only tend to manifest higher levels of chronic illness, but are also less likely to seek and receive adequate medical care, have not been adequately represented in these studies. The present study compared two groups of individuals with CFS, one from a community-based sample and another from a tertiary-based sample). Findings indicate that patients with CFS from tertiary care settings have a higher frequency of symptoms than those in the general population who have CFS.

Comparing Symptoms of Chronic Fatigue Syndrome in a Community-Based versus Tertiary Care Center

The first study of CFS epidemiology was initiated in the late 1980s by the CDC (Gunn, Connell, & Randall, 1993). As the definition had of CFS had only recently been developed, this was the first study of CFS that was conducted in the world. Physicians in four US cities were asked to identify patients who possessed a group of specified, fatigue-related symptoms. The prevalence rates of CFS in these patients ranged from 4.0 to 8.7 individuals per 100,000 cases (Reyes et al., 1997). This CFS epidemiological study, as well as others, were based on physician referrals from hospital and community-based clinics. Medical sociological studies have indicated that many low-income individuals do not have access to the health care system (Mechanic, 1983).

Disadvantaged minorities manifest higher levels of chronic illness, and they are less likely to receive adequate care and be counted in epidemiologic studies from treatment sources (Dutton, 1986). Therefore, it is inappropriate to estimate prevalence estimates solely from treatment facilities. The referral rate may also be affected by physicians who are skeptical of the disorder's existence, as they may be less likely to make referrals in epidemiological studies (Denz-Penhey & Murdoch, 1993; Richman, Flaherty, & Rospenda, 1994).

In 1993, Jason and colleagues interviewed a random community-based sample (Jason et al., 1995). Those individuals who self-reported having CFS, or many of the symptoms of CFS, were examined by a physician and interviewed by a psychiatrist in order to determine whether they met case criteria for CFS. The research team diagnosed 0.2% of the sample with current CFS, a number higher than one would have expected

given rates from past epidemiological studies. This rate of 200 per 100,000 was considerably higher than the rate originally reported by the CDC. Not only are CFS rates higher than expected, but there is also evidence to suggest that certain populations, such as nurses, may be even more susceptible to CFS than the general population (Jason et al., 1998). Another CFS epidemiology study by Buchwald, Umali, Umali, Kith, Pearlman, and Komaroff (1995) also found rates higher than the CDC's estimates based on a sample of individuals enrolled in a Health Maintenance Organization (i.e., from 75-267 per 100,000). Reyes, Nisenbaum, Stewart, and Reeves (1998) reported on the first phase of another CDC population-based prevalence study of fatigue-related disorders. Nearly 25% of the population of Sedgewick County (Wichita), Kansas were surveyed. The rate of CFS was estimated to be 217 per 100,000 (344 females per 100,000 and 78 males per 100,000)(Reeves, Personal Communication, May 21, 2001).

There is a need to compare individuals from community based samples to those from either primary or tertiary care settings. In Great Britain, Wessely, Chalder, Hirsch, Wallace, and Wright (1997) determined that 2,600 per 100,000 patients in a primary health care setting had CFS, using the Fukuda et al. (1994) case definition (this research case definition selects patients with six or more months of fatigue, and at least 4 out of 8 specified symptoms such as sore throat, postexertional malaise, etc.). Wessely et al. indicated that of the 2.6% with CFS, only 0.5% had no psychological disorder. Among the 36 individuals diagnosed with CFS, only 64% had sleep disturbances and 63% had postexertional malaise (Wessely, Chalder, Hirsch, Wallace, & Wright, 1996). Individuals diagnosed with CFS in this epidemiological study were subsequently compared to a sample of people with CFS who had been diagnosed from a hospital unit

(Euba, Chalder, Deale & Wessely, 1996). While 74% of the primary health sample had a previous psychiatric diagnosis before the onset of their fatigue, only 21% of the hospital sample had a previous diagnosis. The primary health sample had significantly worse mental health scores, and 59% felt their illness might be due to psychological or psychosocial causes (compared to 7% for the hospital sample). This is the only study, thus far, to have compared characteristics of individuals diagnosed with CFS from a primary versus a tertiary care setting.

Jason et al. (1999) conducted a CFS community-based epidemiologic study in a multi-ethnic, economically diverse urban area. Findings suggest an overall prevalence rate of 0.4% (Jason et al., 1999). The present study compares individuals diagnosed with CFS in that community-based sample to patients with CFS who were recruited from a tertiary-care setting. It is hypothesized that the patients from the tertiary care setting will have more symptoms, indicating a more severe form of the illness than the individuals recruited from a community-based sample.

Method

Participants

The data were derived from a larger community-based study of CFS that was carried out in three stages (Jason et al., 1999). Stage 1 entailed a cross-sectional screening telephone survey of a random sample of 28,673 households, with 18,675 adults completing the screening interview (65.1% completion rate). Of these participants, 780 (4.2%) of the respondents had six or more months of fatigue. Stage 2 involved a structured psychiatric interview for those respondents from Stage 1 who screened positive for a CFS-like syndrome based on the Fukuda et al. (1994) criteria.

In Stage 3, a physician (A.V. Plioplys) conducted a detailed medical examination to rule out exclusionary medical conditions. A team of four physicians and a psychiatrist were responsible for making a final diagnosis with two physicians independently rating each file using the current U.S. case definition of CFS. Where physicians disagreed, a third physician rater was used (see Jason, Richman et al., 1999). For the purpose of the present study, we focus on those 32 individuals who were diagnosed with CFS using the 1994 Fukuda case definition.¹ These patients represent the CFS-Community group.

The second author, A.V. Plioplys, was the Director the Chronic Fatigue Syndrome Center at Mercy Hospital and Medical Center Chicago. He diagnosed 123 patients with CFS. These patients represent the CFS tertiary group, as these patients all sought out help for their CFS from a clinic that specialized in the treatment of this condition.

Procedure

All patients underwent detailed reviews of their medical history and a thorough physical and neurological examination (A.V. Plioplys also examined all the patients within the community and tertiary based sample). All had routine blood tests performed including complete blood count, chemistry screen (including glucose, electrolytes, calcium, magnesium, liver function tests and renal function tests), sedimentation rate, rheumatoid factor, ANA, T3, T4, TSH, CPK, HIV, hepatitis screen, RPR, B12, red blood cell folate and serum carnitine determinations. All patients had a urinalysis performed. All patients underwent chest x-rays and intradermal intermediate-strength PPD testing. When clinically indicated, selected patients underwent Lyme disease screening, head MRI scanning and polysomnography.

Physicians utilized the current US case definition in their diagnoses of CFS after a thorough medical examination (Fukuda et al., 1994). To be diagnosed with CFS, participants were required to experience persistent or relapsing fatigue for a period of six or more months as well as the concurrent occurrence of 4 or more minor symptoms that did not predate the illness and had persisted for six or more months since onset. Minor symptoms of the current US case definition for CFS included: sore throat, lymph node pain, muscle pain, joint pain, postexertional malaise, headaches of a new or different type, memory and concentration difficulties, and unrefreshing sleep. Furthermore, the participant had to experience substantial reductions in occupational, educational, social, or personal activities as a result of their illness. Exclusionary illnesses as defined by Fukuda et al. (1994) were used identify ineligible people.

Measures

As part of a medical questionnaire, participants were asked if they were experiencing or had experienced each of the eight Fukuda et al. (1994) symptoms of CFS in the past six months. An additional checklist that was filled out by Dr. Plioplys indicated physical examination findings (including weight, height, body mass index, temperature, pulse, blood pressure, respiration rate, number of tender points), laboratory results (calcium, glucose, BUN, creatine, cholesterol, protein, SGOT, SPGT, sodium, potassium, chloride, T4, TSH, RF, ANA, positive PPD, Hgb, Hct, Plt., Sed rate, CPK), whether the patients had ever experienced certain medical illnesses (including allergies, arthritis, asthma, congestive heart failure, COPD, diabetes, hypertension, low back pain, migraine headache, peptic ulcer disease, sinusitis, stroke, thyroid disorder, Fibromyalgia), and medications being taken regularly (including nonsteroidal

antiinflammatories, antihypertensives, glucose reducing, insulin, antidepressants, antianxiety, hypnotics, antiacids, antireflux, antiallergy, antibiotics, L-carnitine)

Statistical Analyses

First, the demographic variables of gender, age, and ethnicity were examined using chi-square tests across the two groups. Binomial logistic regression was conducted for the dichotomous outcome variables, and any demographic variables that were found to be significant between the groups were first entered as predictors in the logistic regression model to control for the effects of these variables on the occurrence of symptoms. Multiple regression analyses were conducted for the continuous outcome measures and any demographic variables that were found to be significant between the groups were first entered as predictors.

Results

There were no age or sex differences between the samples (the overall sample was an average age of 40, and 29% were male and 71% were female). There were significant differences for the ethnic variable, with there being significantly more minorities in the CFS-Community sample than in the CFS-Tertiary sample ($\chi^2(3, N=153) = 47.63, p < .01$). Within the CFS-Community sample, 45% were white, 16% were Black, 29% were Latino, and 10% were other; whereas in the CFS-Tertiary sample 93% were white, 5% were Black, 1% were Latino and 1% were other. Ethnicity was controlled for in the subsequent analyses.

Using binomial logistic regressions, four out of the 8 Fukuda et al. (1994) symptom criteria were significantly higher among the CFS-Tertiary sample as compared with the CFS-Community sample (memory and concentration problems, 96% vs 74%;

sore throat, 76% vs 45%; tender lymph nodes, 65% vs 45%, post-exertional malaise, 94% vs 55%). In addition, the CFS-Tertiary sample, in comparison to the CFS-Community sample, was significantly less likely to have arthritis (2% vs 13%), but there were no significant differences on other medical conditions. In terms of physical examination findings, using multiple regression analysis, the CFS-Tertiary sample had a higher temperature (98.5 vs 98.1) and Albumin (4.5 vs 4.3), and significantly lower SGOT (21.9 vs 28.5) than the CFS-Community sample, but there were no other significant differences on physical examination or medication intake variables.

Discussion

Several studies from other primary and tertiary care settings have highlighted commonalities among individuals with CFS, including a greater likelihood of being female and Caucasian (Reyes et al., 1997; Gunn, Connell, & Randall, 1993). Both samples in the present study confirm the finding that CFS is more prevalent among women. However, community-based studies involving representative samples of ethnically and socioeconomically diverse populations indicate that the prevalence of CFS is actually higher for minority groups of Latinos and African-Americans than for Caucasians (Jason, Richman et al., 1999), and higher for individuals of lower socioeconomic status than for those of high socioeconomic status (Wessely et al., 1997). The findings from the present study indicate that samples from tertiary care settings will be ethnically different from more community-based samples, as these latter settings will have a higher proportion of minorities.

It is unclear as to why the community-based samples had higher rates of ethnic minorities. It is possible that those individuals with the resources and motivation to seek

help from tertiary care settings tend to be individuals who are more likely to be Caucasian and have a higher SES. Psychosocial and environmental risk factors may play important roles in the etiology of CFS as well as which patients are able to secure services at tertiary care settings. Individuals of varying ethnic and socioeconomic backgrounds have been found to differ with respect to a number of issues, including: health care practices (e.g., nutrition, regular exercise, routine medical examinations); behavioral risk factors (e.g., condom use, use of alcohol, drugs, and tobacco); access to adequate health care (e.g., health insurance benefits and adequacy of care provided); level of psychosocial stress (e.g., racism, discrimination, community violence, and unemployment); amount of negative environmental exposures (e.g., air pollution, lead, and other toxins); and level of hazard with respect to occupation (Davis, 1995). Some of these factors have been cited to explain observations of other medical conditions affecting low-income and some minority groups at differentially higher rates, such as hypertension (Richardson & Piepho, 2000). Perhaps these factors also play a role in the higher prevalence of CFS found in ethnic minorities and people with a low SES.

In another population based study, Wesseley et al. (1996) found 64% of individuals with CFS had sleep disturbances and 63% had postexertional malaise. These rates tend to be lower than those found in similar hospital based studies. Similarly, in the present study, rates of four classic Fukuda et al. (1994) symptoms (i.e., post-exertional malaise, memory and concentration problems, sore throats, tender lymph nodes) were significantly higher among the patients in the tertiary care setting. This finding indicates that the sample from the tertiary-care setting had more Fukuda et al. (1994) symptoms of CFS, and suggests that this sample was more impaired than the community-

based sample. It is possible that individuals seek tertiary care treatment when their symptoms become debilitating. It is also important to note that the majority of the individuals recruited in the community-based sample had never been diagnosed with CFS, whereas those in the tertiary care setting specifically sought care from a setting that specialized in the diagnosis and treatment of CFS. There are important differences between individuals who have all the critical symptoms of CFS but have not been diagnosed or seeking treatment of this disorder, and those that have been diagnosed and are seeking treatment. As shown here, ethnic and socioeconomic issues can influence whether or not individuals with CFS get appropriately diagnosed and recruited into treatment settings.

Among the physical findings, rates of arthritis were significantly higher in the community-based sample, suggesting that this sample might have more health related problems. In addition, temperature levels were significantly lower for the community-based sample, but the temperatures of both groups were within the normal range. The groups were also found to be statistically different in their levels of Albumin and SGOT. However, levels in the two CFS samples were within this normal range (3.5 to 5 grams per deciliter) for Albumin. While abnormal values of SGOT can be associated with hepatitis, nausea and vomiting, abdominal cramping, and fatigue (if severe liver damage is present), however, both samples were within the normal range (10 - 50 U/ML). Therefore it is unclear how to interpret the significance of the differences on these physical indices.

In summary, most of what we know about the characteristics and pathophysiology of CFS is derived from samples generated from referrals from physicians or health

facilities. The present study, which compared two samples, one from a community-based sample and another from a tertiary-care setting, indicated that underserved minorities were under-represented in the tertiary care setting. This finding suggests that minorities have not been adequately represented in most CFS studies, which have recruited patients from physician referrals or tertiary care settings. This study also found that patients with CFS from tertiary care settings had a higher frequency of Fukuda et al. (1994) symptoms than those with CFS in the general population who have not sought care at tertiary care settings. Methodological limitations in the present study include the small sample sizes, particularly in the community based sample, as well as the large number of comparisons, which probably increased the chances of committing a Type I error. There is a clear need to study CFS in larger cohorts that include representative samples, in ethnically and socioeconomically diverse sample unbiased by illness, help-seeking behaviors, and by differential access to the health care system.

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Footnote

¹Physical data on one of the 32 participants within the CFS-Community sample was not available for analysis, so the sample size of this group was 31. The drop from 780 individuals with chronic fatigue to 32 with CFS is due to several factors, including the fact that many individuals with chronic fatigue do not either have 4 or more Fukuda et al. symptoms or they have exclusionary medical or psychiatric reasons for their fatigue. In addition, some individuals who were interviewed by telephone refused to have a medical and psychiatric evaluation.

Author Notes

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