Changes in Functional Status in Chronic Fatigue Syndrome Over a Decade: Do Age and Gender Matter?

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ABSTRACT. Objective: Patients with chronic fatigue syndrome (CFS) have substantial deficits in functional capacity, but the course of these deficits over time has not often been studied. This study measured functional capacity on three occasions over a decade, in patients with CFS.

Methods: The study was a longitudinal cohort study, and employed the Medical Outcomes Study Short Form-36 (SF-36) instrument to assess physical and mental/emotional functional status.

Results: Physical function, as reflected in several different scales, improved modestly but significantly over time, particularly for patients aged 18-60 years and for women. Mental/emotional function was not substantially impaired at the outset of the study, and did not change over time.

Conclusion: This study found that physical function tended to improve for many patients over time, despite the fact that they were aging. Physical function did not deteriorate with time. doi: 10.1300/J092v 14nOl_04 *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address:<docdeliverly@haworthpress.com> Website: <http://www.HaworthPress.com>*

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INTRODUCTION

Chronic fatigue syndrome (CFS) is a chronic debilitating illness of unknown origin characterized by unexplained severe fatigue lasting for at least 6 months-the fatigue is not resolved by rest-resulting in a significant decline in previous occupational, educational, and social activity levels (1). Approximately] 00-800 per 100,000 people in the United States suffer from CFS (2-5). Both adults and adolescents (6,7) can be affected. Although some people with CFS have reported complete remission, this occurs in only a small fraction of patients. Recovery is usually associated with younger age, shorter duration of illness, and is more common in those not fully meeting the criteria for CFS (8-10,7).

Research has shown that the effect of CFS on one's functional abilities is profound and can be at least as disabling as other chronic illnesses, including congestive heart failure, diabetes, and major depression (11-14). It has been estimated that the annual cost to the U.S. economy from lost productivity due to CFS is approximately $9.1 billion (15). As a result, rates of unemployment are high (over 50%) and functional capacity at home is limited in nearly 40% of sufferers (15).

There are few longitudinal studies assessing the change in functional abilities over time in people suffering from CFS. The few studies that have examined the long-term effects of CFS have concluded that functional deficits persist over the course of the illness (14,] 6).

The purpose of this study was to examine the change in both the mental and physical functional status of patients with CFS over a decade and whether or not this change occurred in specific age and gender subgroups.

METHODS

Participants

This was a longitudinal cohort study in which participants were recruited from among patients seen in the practice of one of us (ALK) at Brigham and Women's Hospital in Boston, MA. All participants met the 1994 CDC criteria for CFS at baseline, 1993 (1). Participation was voluntary and informed consent was given. Patients did not receive remuneration for their participation and they were treated in accordance with

experimental ethics specified in the policies of the Partners HealthCare, Inc., Human Research Committee. Periodically, each patient was asked to complete a well-validated and widely used instrument to assess functional capacity, the *Medical Outcomes Study Short Form-36* or *SF-36.*

Total Group. Overall, 234 patients had at least three SF-36 scores between 1991 and 2002. The largest group of patients had fully completed the SF-36 in 1993, 1995, and 2002 ($N = 99$): This group is the subject of this report. This group was no different from patients who did not have scores in all three years, with respect to gender, education, race, years since the onset of the illness, severity of fatigue upon entrance into the study, and employment status upon entrance into the study (data not shown). Those in the study group were somewhat older ($M = 53.2 \pm 10.8$) than those who did not have scores in all three years ($M = 50.5 \pm 11.8$), a significant difference ($p < 0.001$).

Age and Gender Subgroups. Data were analyzed separately for subgroups defined by age (as of July 23, 2002) and gender. The age subgroups were 18-44 years, 45-60 years, and 61 years and older. The number of subjects in each age subgroup is summarized in Table 1, by gender.

SF-36: The Functional Status Instrument

The SF-36 is a self-administered health status questionnaire composed of 36 questions. It is designed to assess one's perception of his or her mental and physical capacities (17). The SF-36 has been used to evaluate the functional status of healthy individuals and people with chronic illnesses that produce constant debility or symptoms that wax and wane, such as CFS, multiple sclerosis, or major depression (11,14,18,19,20).

The Eight Subscales. The SF- 36 generates scores for each of the following eight subscales: Physical Functioning Index (PH), Role-Physical Index (RPI), Bodily Pain Index (BPI), General Health Index (GHI), Vitality Index (VI), Social Functioning Index (SFI), Role-Emotion Index (REI), and Mental Health Index (MHI). In order for a subscale score to

TABLE 1. Patient subgroups.

Age Subgroup	Number of Females	Number of Males
18-44	13	7
45-60	38	7
61 and older	26	8
Total	77	22

be computed, respondents had to have answered at least half of its aggregate items or half plus one when there was an odd number of items (17,21).

The Two Major Scales. Scores from the SF-36 are aggregated into two major scales: the Physical Component Summary (PCS) and the Mental Health Component Summary (MCS). The PCS score was based on the scores of the following subscales: PFI, RPI, BPI, and GHI. The MCS score was calculated based on the scores ofthe following subscales: VI, SFI, REI, and MHI (17,21).

SF-36Administratioll. The SF-36 was sent to patients via mass mailing. In all years, except 2002, it was sent just once. In 2002, in order to increase the number of respondents, a second SF-36 was mailed approximately 3 months later to patients that had not returned the first mailing.

Statistical Analysis

The change over time in the PCS and MCS scores, and in each of the eight subscale scores was examined separately-first for the total group, and then for each of the age-specific and gender-specific subgroups. When a subscale score showed a significant change over time, we attempted to identify the changes in specific symptoms that had led to the changes in the subscale scores. This allowed us to see whether changes in some symptoms but not others explained the changes in the subscale's score.

A repeated-measures analysis of variance (ANOV A) was used to examine changes in scores for the total group, and for each of the subgroups, over three time periods-1993, 1995, and 2002-as well as for the interactions, such as the relationship between changes in scores and subgroup. A one-way ANOV A was also used to compare differences in scores between and within subgroups, in each of the three specific years. All analyses were conducted with SPSS statistical software (SPSS Version 11.0. SPSS Inc., Chicago, IL, USA).

RESULTS

The Eight Subscales

Physical Functioning Index (PFI)

Total Group. For the total group, there was a significant rise in PFI scores over time (Table 2), meaning that patients experienced less

TABLE 2. The eight subscale and two major scale scores (Mean ± SO) for the total group.

Subsea Ie	N	1993	1995	2002	P-Value
Physical Function Index (PFI)	99	55.5 ± 25.8	57.6 ± 26.6	60.8 ± 27.8	<0.05
Role-Physical Index (RPI)	99	19.4 ± 34.4	24.2 ± 38.0	31.1 ± 41.1	<0.02
Bodily Pain Index (BPI)	99	52.4 ± 27.3	53.0 ± 26.9	55.3 ± 25.5	>0.05
General Health Index (GHI)	99	37.9 ± 20.9	38.4 ± 21.5	44.6 ± 23.5	<.001
Vitality Index (VI)	99	26.3 ± 20.5	29.7 ± 23.6	34.6 ± 24.8	<0.01
Social Function Index (SFI)	99	51.5 ± 27.0	54.1 ± 30.3	55.1 ± 30.4	>0.05
Role-Emotion Index (REI)	99	74.4 ± 38.8	73.1 ± 39.9	74.4 ± 38.0	>0.05
Mental Health Index (MHI)	99	68.2 ± 15.2	67.9 ± 18.3	67.8 ± 17.0	>0.05
Summary Scale					
Physical Component Summary (PCS)	99	34.09 ± 12.40	35.24 ± 12.11	37.56 ± 12.53	< 0.01
Mental Health Component Summary (MCS)	99	45.73 ± 9.70	45.81 ± 10.89	45.65 ± 9.99	>0.05

difficulty when conducting typical daily physical activities. The rise in PFI scores were caused by improvement in the following specific symptom questions: vigorous activities; moderate activities; climbing several flights of stairs; bending, kneeling, and stooping; walking more than one mile; and walking several blocks.

Subgroups. The rising scores were found primarily in those 45-60 years old ($p < 0.05$) and in women ($p < 0.02$). There was no significant rise in the scores of the other subgroups.

Role-Physical Index (RPI)

Total Group. For the total group, there was a significant rise in RPI scores over time (Table 2), meaning patients found conducting daily or work related activities less difficult. The rise in RPI scores was caused by improvement in the following specific symptom questions: cut down time spent on work and activities; accomplishing less than you would like; and difficulty performing work or other activities.

Subgroups. The rising scores were found primarily in those 18-44 years old ($p < 0.05$), 45-60 years old ($p < 0.0\ 1$), and in women ($p < 0.00\ 1$). There was no significant rise in the scores of the other subgroups.

Bodily Pain Index (BPI)

Total Group. For the total group, BPI scores rose (meaning that patients were experiencing *less* pain) somewhat over time, but the difference was not statistically significant (Table 2).

Subgroups. The scores in all years tended to be higher for those 18-44 years old, and were significantly higher in this group versus those 45-60 ($p < 0.05$) in 2002 and those 61 years and older in 1993 and 2002 ($p < 0.05$ and $p < 0.01$, respectively). Although scores were generally higher for men, the difference between men and women was not statistically significant.

General Health Index (GHI)

Total Group. For the total group, there was a highly significant rise in GHI scores overtime (Table 2), meaning that patients experienced an improvement in their overall health. The rising GHI scores were caused by improvement in the following specific questions: in general, you would say your health is __ ; I am as healthy as anybody I know; and my health is excellent.

Subgroups. The rising scores were found primarily in those 18-44 years old ($p <0.05$) and those 45-60 years old ($p <0.01$). Scores for those 45-60 years old were significantly higher than those61 years and older, in 2002 ($p < 0.05$). In addition, there was a highly significant increase in scores over time for women ($p < 0.00\ 1$) but not for men. There was no significant rise in scores in the other subgroups.

Vitality Index (VI)

Total Group. For the total group, there was a significant rise in VI scores overtime (Table 2), meaning that patients experienced an increase in their energy level. The rising VI scores were caused by improvement in the following specific symptoms: do you feel full of pep; did you have a lot of energy; did you feel worn out; and did you feel tired.

Subgroups. The rising scores were found primarily for those 18-44 years old ($p <0.02$) and those 45-60 years old ($p <0.01$), and primarily in

women ($p < 0.0$ 1) but not in men. There was no significant rise in scores in the other subgroups.

Social Functioning Index (SFI)

Total Group. For the total group, SFI scores rose (meaning that patients *increased* their normal social activities) somewhat over time, but the difference was not statistically significant (Table 2).

Subgroups. In each of the three years examined, the SFI scores were somewhat lower for the men than for the women but the difference was not significant ($p > 0.05$). There was no significant rise in scores in the other subgroups.

Role-Emotion Index (REI)

Total Group. For the total group, there was no significant rise in REI scores over time (Table 2).

Subgroups. REI scores rose significantly over time in the age group 18-44 years old ($p < 0.01$), that is, this group experienced an improvement in its overall emotional health. There was no significant rise in scores in the other subgroups.

Mental Health Index (MHI)

Total Group. For the total group, there was no significant rise in MHI scores over time (Table 2).

Subgroups. MHI scores rose significantly over time in the 18-44 years old group ($p <0.01$), that is, this group experienced an improvement in its overall mental health symptoms such as anxiety and depression. There was no significant rise in scores in the other subgroups.

The Two Major Scales

Physical Component Summary (PCS)

Total Group. For the total group, there was a significant rise in pes scores rose over time (Figure 1, Table 2).

Subgroups. The rising scores were primarily found for those 18-44 years old($p <0.05$) and those 45-60 ($p<0.00$l). In 2002, there was a borderline significant difference in scores for those 18-44 years old versus those 61 years and older ($p = 0.050$). The rise in scores was primarily due to the most prevalent subgroup: females 45-60 years old ($p< 0.001$). There was no significant rise in scores in the other subgroups.

and mental resources to direct toward their recovery. Previous studies also have found that recovery and improvement in symptoms is seen more often in those of younger age and with a shorter duration of the illness (7-10).

Although the rise in scores was not always significant for the total group or each subgroup (e.g., men and those 61 years and older), there was an upward trend with respect the major scales and 6 of the 8 subscales (REI and **MHI** being the exceptions) for most of the patient groups. It is possible that the relatively small sample *(N* = 99) studied in all three years led to a Type II error. On the other hand, it is not clear that the relatively small improvements in function-even if statistically significant-were clinically significant.

It is encouraging that we saw an improvement in physical function over time, even as subjects aged, given that many patients with CFS are concerned that they will "go downhill" as the illness persists. We speculate that the slight improvement in physical function over time was due to both actual amelioration of illness related symptoms as well as the patients' adaptation to the limitations imposed by CFS. At the same time, as found in a recent systematic review (22), full recovery from untreated CFS is unusual.

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