



Being homebound with chronic fatigue syndrome: A multidimensional comparison with outpatients

Jan F. Wiborg^{a,*}, Sieberen van der Werf^b, Judith B. Prins^b, Gijs Bleijenbergh^a

^a Expert Centre Chronic Fatigue, Radboud University Nijmegen, Medical Centre, PO Box 9101, 6500 HB Nijmegen, The Netherlands

^b Department of Medical Psychology, Radboud University Nijmegen, Medical Centre, PO Box 9101, 6500 HB Nijmegen, The Netherlands

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ABSTRACT

Many patients with chronic fatigue syndrome (CFS) seem to experience periods in which they are homebound due to their symptomatology. Despite a growing body of research about CFS, little is known about patients who no longer feel able to leave their homes. The purpose of the present study was to examine whether homebound patients differ from other CFS patients on illness-specific characteristics. Besides experiencing more impairment in daily functioning than participants of an outpatient intervention study, homebound patients were characterised by extremely high levels of daily fatigue, predominant somatic attributions, and pervasively passive activity patterns. The course of symptomatology was similarly stable in both groups. Our findings suggest that homebound patients form a distinct subgroup of CFS patients who might profit from a treatment approach that is tailored to their specific needs. The exploratory nature of this first systematic investigation of homebound CFS patients is stressed, and suggestions for future research are made.

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1. Introduction

Chronic fatigue syndrome (CFS) is characterised by a severe and disabling fatigue that persists for at least 6 months and is not the result of a medical condition (Fukuda et al., 1994). CFS can dominate patients' lives to such a degree that they feel no longer able to leave their homes. According to surveys conducted by patient organisations, many patients with CFS seem to have experienced a period in which they were bound to their homes due to symptomatology (e.g. Action for M.E., 2001). Unfortunately, virtually all scientific effort has been concentrated on CFS patients who were able to visit outpatient treatment settings. Thus, little is known about the illness-specific characteristics of homebound CFS patients. More insight into these characteristics will enhance the understanding of the complex nature of CFS and may also contribute to the development of specifically tailored treatment approaches.

The purpose of the present study was to determine whether homebound patients differ from other CFS patients on illness-specific characteristics. For this purpose, we compared a group of homebound patients with the natural course condition of an outpatient intervention study, previously conducted to test the effect of cognitive behaviour therapy for CFS (Prins et al., 2001). The two groups were compared on multiple illness-specific dimensions, validated for the clinical evaluation of patients with medically unexplained fatigue

(Vercoulen et al., 1994). Besides the assessment of fatigue, impairment and additional complaints such as concentration problems, unrefreshing sleep and deterioration in psychological well-being, those factors were assessed that have been shown to inflate and prolong symptomatology in CFS (Vercoulen et al., 1994, 1998). These perpetuating factors have received much attention, both in research and cognitive behaviour therapy for CFS (Prins et al., 2006). Prominent factors are physical inactivity, caused by the idea that the complaints are due to a somatic cause, and an experienced lack of control over the symptoms. We hypothesised that the scores on these factors are more problematic in homebound patients than in outpatients, leading to more severe fatigue and impairment.

Earlier research has shown that spontaneous recovery in CFS is rare (for a systematic review, see Cairns and Hotopf, 2005). No specific findings exist about the course of CFS in homebound patients. We therefore reassessed the severity of fatigue and impairment at 1-year follow-up and tested whether the course of symptomatology in homebound patients differs from that of outpatients.

2. Methods

2.1. Design

A Dutch patient organisation was asked to recruit CFS patients among its members who felt bound to their homes. In order to participate, these members had to be between 18 and 60 years of age, had to meet the CDC criteria for CFS (Fukuda et al., 1994), and should not have participated in research on CFS before. Eighteen members fulfilled these criteria and were visited twice at home during a period of 2 weeks to complete baseline assessment. To prevent attrition among homebound patients, a

* Corresponding author. Tel.: +31 24 3610030; fax: +31 24 3610041.

E-mail address: j.wiborg@nkv.umcn.nl (J.F. Wiborg).

limited test battery was used at follow-up assessment 12 months later. Fifteen homebound patients were able to complete follow-up assessment.

As reference group, we chose the natural course condition of a multicenter randomized controlled trial, previously conducted by Prins et al. (2001) to test the effect of cognitive behaviour therapy on CFS. These 88 participants differed from the group of homebound patients in that they were able to participate in an outpatient treatment study despite their symptomatology. In this trial, follow-up assessment took place 14 months after baseline assessment. Of the 88 patients, 79 completed follow-up assessment.

2.2. Assessment

2.2.1. Checklist Individual Strength

We used subscales of the Checklist Individual Strength (CIS) to assess fatigue severity and concentration problems. Higher scores indicate more severe fatigue and problems with concentration. The CIS is a reliable and valid instrument for multidimensional assessment of fatigue in CFS (Vercoulen et al., 1994; Dittner et al., 2004).

2.2.2. Daily observed fatigue

Patients were asked to rate the intensity of fatigue four times a day from 0 (no fatigue) to 4 (intense fatigue). The daily sum score was averaged across a period of 2 weeks (Vercoulen et al., 1996a). This score was used to compare fatigue levels at baseline because daily assessment of fatigue is less prone to a ceiling effect than one-time assessment and therefore helps to differentiate between groups of severely fatigued patients.

2.2.3. Sickness Impact Profile

Several subscales of the Sickness Impact Profile (SIP; Bergner et al., 1981) were used to measure impairment in different areas of functioning due to health problems. We were interested in the following subscales: home management, ambulation, mobility, alertness behaviour, social interactions, and sleep. Higher weighted scores indicate more impairment on these scales.

2.2.4. Karnofsky scale

The Karnofsky performance status scale (O'Dell et al., 1995) is a descriptive, ordinal scale. An independent clinical psychologist rates patient's level of daily functioning at 10-point intervals from 0 to 100. Lower ratings indicate more impairment in daily functioning.

2.2.5. Symptom Checklist

The Dutch version of the Symptom Checklist 90 (SCL; Arindell and Ettema, 1986) was used to assess psychological well-being. We were interested in the subscales anxiety, agoraphobia, depression, interpersonal sensitivity, somatisation, and sleep. Higher scores indicate more problems in these areas.

2.2.6. Actometer

Actigraphy was used to assess the level of physical activity. The Actometer is a motion-sensing device that is worn around the ankle during a period of 2 consecutive weeks. A mean score was computed to indicate the average daily level of physical activity, with higher scores indicating more physical activity. The Actometer has been shown to be a reliable and valid instrument for the assessment of physical activity in CFS (van der Werf et al., 2000).

2.2.7. Causal Attribution List

Attribution of CFS-related symptoms was assessed with the Causal Attribution List (CAL). Somatic as well as non-somatic attributions were assessed on a 4-point Likert scale with five items per subscale. The mean norm score for CFS patients on somatic attributions is 14.0 (S.D. = 2.6) and 9.1 (S.D. = 2.4) on non-somatic attributions (de Vree et al., 2002), with higher scores indicating a stronger tendency to attribute symptoms to a certain cause. The internal consistency of the CAL ranges between 0.71 and 0.77 (Vercoulen et al., 1996b; Prins et al., 2001; de Vree et al., 2002).

2.2.8. Self-efficacy scale

Sense of control over fatigue was measured with the Self-Efficacy Scale (SES). This scale consists of five items. Four of these items were scored on a 5-point, and one item was scored on a 4-point Likert scale. Higher scores on the SES reflect a greater sense of control over symptoms. The mean norm score for CFS patients is 15.6 (S.D. = 3.4) and the internal consistency ranges between 0.68 and 0.77 (Prins et al., 2001; de Vree et al., 2002).

2.3. Statistical analysis

To avoid bias due to considerable differences in group size (i.e. 18 vs. 88), we selected the 28 patients of the natural course condition who scored within the same range as the homebound patients on age, gender and illness duration (i.e. between 27 and 56 years of age, female, with an illness duration between 4 and 32 years). Twenty-five of these 28 patients completed follow-up assessment.

Not all variables were normally distributed. Therefore, Mann-Whitney's non-parametric test was used to analyse differences between the groups. At first, we tested

the differences in age and illness duration to assure that differences on the main outcome measures were not simply due to differences on these variables. Then, we tested the median differences on the main outcome measures at baseline assessment. Finally, we examined the median differences in change scores (follow-up vs. baseline) on fatigue and impairment. The *P*-value for statistical significance was set at *P* < 0.05. Due to the exploratory nature of the study, no formal correction for a type I error was applied.

3. Results

Table 1 presents the baseline differences between homebound patients and outpatients. While the group of homebound patients did not differ significantly from the selection of outpatients in age, illness duration, and education, none of the homebound patients held a paid job, which was a significantly lower level of employment than was found in the selection of outpatients.

Table 1

Testing differences in median baseline scores (range) between homebound patients and the selection of outpatients using Mann-Whitney's test.

	Homebound (<i>n</i> = 18)	Selection outpatients (<i>n</i> = 28)	<i>z</i>	<i>P</i>
<i>Patient characteristics</i>				
Age in years	41.5 (27–56)	45 (27–56)	−0.79	0.430
Female	18 (100%)	28 (100%)	n.a.	n.a.
Illness duration in years	10.0 (4–32)	7.5 (5–25)	−0.39	0.700
Paid occupation	0 (0%)	8 (28%)	n.a.	0.015 ^a
Education ^b	4 (2–7)	4.5 (1–7)	−0.20	0.845
<i>Psychological well-being</i>				
SCL anxiety	15 (3–30)	14 (9–30)	−0.20	0.839
SCL agoraphobia	7 (7–21)	8 (7–18)	−1.22	0.222
SCL depression	26.5 (20–51)	28 (16–59)	−0.78	0.436
SCL sensitivity	20 (18–41)	24 (19–43)	−2.04	0.041
SCL somatisation	33 (23–52)	29 (14–45)	−2.03	0.042
<i>Fatigue</i>				
Daily observed fatigue	14.1 (8.6–15.6) ^c	7.3 (0.4–13.2) ^d	−4.77	0.000
<i>Daily functioning</i>				
SIP home management	309 (54–498)	216 (54–421)	−2.29	0.022
SIP ambulation	231.5 (0–678)	137 (0–315)	−2.85	0.004
SIP mobility	336.5 (86–457)	127.5 (0–585)	−4.35	0.000
Karnofsky scale	50 (40–70) ^c	70 (60–90) ^c	−5.28	0.000
<i>Concentration</i>				
SIP alertness behaviour	309.5 (0–687)	403.5 (0–777)	−1.35	0.176
CIS concentration	24 (5–35)	29 (5–35)	−2.01	0.044
<i>Social functioning</i>				
SIP social interactions	235.5 (44–683)	325.5 (123–696)	−0.98	0.327
<i>Sleep</i>				
SCL sleep	7.5 (3–15)	7 (3–13)	−0.82	0.414
SIP sleep	144 (83–499)	173.5 (49–395)	−0.66	0.512
Hours sleep at night	7 (3–13)	8.5 (5–12)	−1.16	0.248
Hours sleep at daytime	1 (0–6)	1 (0–4)	−0.35	0.972
<i>Physical activity</i>				
Actigraphy	28.5 (5–46)	60 (30–97)	−5.11	0.000
<i>Causal attributions</i>				
CAL somatic	16.5 (9–20)	14.5 (10–18)	−2.62	0.009
CAL non-somatic	10.5 (4–14)	9 (5–14)	−0.35	0.725
<i>Sense of control</i>				
SES	14 (6–21)	13.5 (10–20)	−0.21	0.837

Note. ^aFisher's exact test. ^bHigher scores indicate a higher level of education. ^cOne patient missing. ^dThree patients missing.

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