

# Social Support and the Persistence of Complaints in Chronic Fatigue Syndrome

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## Key Words

Social support · Chronic fatigue syndrome · Cognitive behaviour therapy · Support groups

## Abstract

**Background:** Several studies suggested that the surroundings of chronic fatigue syndrome (CFS) patients are of importance in the persistence of complaints. Contrary to what was expected, participation in support groups has not led to clinical improvement. The purpose of the present study was to describe social support in CFS patients as compared with other fatigued and non-fatigued groups. Further, changes in social support and the influence of social support on the course of CFS over a period of more than 1 year were studied in patients with and without treatment. **Methods:** Baseline data were assessed in 270 CFS patients, 150 disease-free breast cancer patients, 151 fatigued employees on sick-leave and 108 healthy subjects using the Social Support List and Significant Others Scale. CFS patients were followed in cognitive behaviour therapy (CBT), guided support groups and natural course at 8 and 14 months. **Results:** CFS patients and fatigued employees reported

more negative interactions and insufficiency of supporting interactions than cancer patients and healthy controls. No differences in frequency of supporting interactions were found. Negative interactions decreased significantly after treatment with CBT, but did not change in support groups or natural course. In the natural course, higher fatigue severity at 8 months was predicted by more negative interactions at baseline. **Conclusions:** In CFS patients and fatigued employees, social support is worse than in disease-free cancer patients and healthy controls. Lack of social support was identified as a new factor in the model of perpetuating factors of fatigue severity and functional impairment in CFS.

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## Introduction

Chronic fatigue syndrome (CFS) is characterised by persistent or relapsing unexplained chronic fatigue of new or definite onset and lasting for at least 6 months. Fatigue is not the result of an organic disease or ongoing exertion, rest does not alleviate it, and it results in substantial reduction in previous levels of occupational, educational,

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social and personal activities [1]. Causes for CFS have not been found and most patients do not recover. No somatic or pharmacological treatments have proved to be effective. So far, cognitive behaviour therapy (CBT) and graded exercise therapy (GET) are the only interventions for CFS patients, which consistently have shown positive results [2, 3]. In our study, in which the effectiveness of CBT was shown, CBT was compared with guided support groups and the natural course [4]. Guided support groups were intended to control for the absence of specific cognitive-behavioural interventions and the presence of therapist's attention and treatment expectations. We assumed that support groups, as in other chronic diseases, might contribute to a feeling of mutual understanding, acceptance and support, and thereby would have a healing effect [5, 6]. An unexpected finding was that support groups were no more effective than the natural course. However, 80% or more of the patients experienced mutual understanding in the support group, and rated the contact with the therapist and the atmosphere in the group as good [4]. This discrepancy between the absence of clinical improvement and patients' satisfaction raised questions about the role of social support in CFS.

Social support is a very broad concept referring to the help and protection of others. Social support is not a unitary concept, but rather a metaconstruct of conceptually different components, ranging from the quantity of social interactions or the size of the social network to the perceived availability or quality of supporting interactions [7]. Different types of social support are distinguished, like emotional support, instrumental support, esteem support or informational support. Cobb [8] was the first to describe the positive influence of social support on health, like accelerated recovery and enhanced compliance. He saw social support as a buffer against stress. Several theories were offered to explain the mechanisms, by which social support directly or indirectly affects health.

Several studies found a relation between social support and CFS. Prior to illness, CFS patients perceived less social support compared with patients with irritable bowel syndrome and healthy controls in a retrospective study [9]. We have hypothesised that after onset of CFS, perceived social support may also be less, since medical professionals consider CFS to be a controversial condition [10]. The quantity of social support also seems affected. CFS patients were found to report a substantial reduction of social relationships due to functional impairment in work and pastimes [11]. As a result of changes in social networks, family members and partners have become

increasingly important resources of social support. CFS patients, whose partners were more optimistic about the course of the illness, reported less functional impairment [12]. A solicitous attitude of the partner was associated with worse patient functioning [13]. As to illness course and outcome of CFS, cross-sectional studies have shown that perceived social support was associated with improvement [14] and with less aggravation of CFS complaints after a natural disaster [15]. In our study of CFS patients with a relatively short illness length, we found that persistence of complaints after 1-year follow-up was associated with higher levels of insufficiency of social support at baseline [16]. Although the results of all these studies suggest that the surroundings of CFS patients are of importance in the persistence of complaints, many questions concerning the exact relation between social support and CFS remain. For example, are demographic characteristics, like age, gender or civil status of importance for social support of CFS patients? Does social support of CFS patients differ from social support of other patients with fatigue complaints, patients with a chronic disease or healthy controls? Does social support of CFS patients change as a result of treatment with CBT or after participation in support groups?

The objectives of the present study were to assess the relation between social support and several demographic characteristics and to describe quantitative and qualitative aspects of social support in CFS patients. Further, we were interested in comparing social support of CFS patients with other patients with fatigue complaints, with other patients with a chronic disease and with healthy subjects. In addition, we intended to study changes in social support of CFS patients over a period of more than 1 year and the relation between social support and the course of CFS in patients with and without treatment.

## Patients and Methods

### *Patients, Design and Procedure*

The sample consisted of 270 CFS patients, who entered a multi-centre randomised controlled trial of CBT [4]. All patients had a major complaint of fatigue and were referred to the out-patient clinic of the departments of internal medicine of 2 university medical centres in the Netherlands. Patients aged between 18 and 60 years were assessed by means of a detailed history, physical examination and computer assessment of questionnaires and had to fulfil criteria for CFS [1], with the exception of the criterion of 4 out of 8 additional symptoms [17]. Severe fatigue was assessed with a score of 40 or more on the subscale fatigue severity of the Checklist Individual Strength (CIS) and severe impairment with a score of 800 or more on the Sickness Impact Profile (SIP).

### Comparison Groups

The sample of disease-free cancer patients consisted of 150 patients who participated in a cross-sectional study on determinants of chronic fatigue [18]. The 151 fatigued employees on sick-leave had severe fatigue for more than 4 months without a somatic explanation and complete absenteeism from work for 6–26 weeks [19]. Healthy control subjects were family members, friends or colleagues of the patients participating in one of the above-mentioned studies on CFS or breast cancer [4, 18].

### Assessments

Fatigue severity, functional impairment and social support were assessed at baseline, 8 and 14 months. Relations with significant others were assessed at baseline.

**Fatigue Severity.** A subscale of the CIS assessed fatigue severity. In this questionnaire, the patient is asked about fatigue in the 2 weeks preceding the assessment. The subscale consists of 8 items, each scored on a 7-point Likert scale (range 8–56). The CIS has good reliability and discriminative validity [4, 20–22].

**Functional Impairment.** The SIP measured functional impairment. A total score was calculated by addition of the weights of items in 8 subscales: home management, mobility, alertness behaviour, sleep/rest, ambulation, social interactions, work, and recreation and pastimes. This measure has good reliability and content validity [4, 23].

**Social Support.** Social support was measured by the Social Support List (SSL) [24], consisting of two 34-item questionnaires, interactions (SSL-I) and discrepancies (SSL-D), and a 7-item questionnaire of negative interactions (SSL-N). Both SSL-I and SSL-D assess 6 types of social support: emotional interactions (range 4–16), problem-focused emotional support (range 8–32), esteem support (range 6–24), instrumental interactions (range 7–28), social companionship (range 5–20) and informational support (range 4–16). In the SSL-I, the frequency of supporting interactions is assessed. The SSL-D measures the perceived discrepancy in actual support and wanted support, further called insufficiency of supporting interactions. Total scores of SSL-I and SSL-D range from 34 to 136, total score of SSL-N from 7 to 28. The SSL has good reliability [Cronbach's alpha 0.93 (SSL-I) and 0.95 (SSL-D)] and content validity [25].

**Significant Others.** Twelve questions concerning the relationship with spouse/partner, relatives, friends, chief, colleagues and general practitioner were administered and subjected to an exploratory principal component analysis with a subsequent orthogonal rotation. One item concerning the spouse/partner was too skewed and was therefore excluded. With an eigenvalue over 1, factor analysis resulted in 3 factors explaining 66% of the variance. Items that loaded at least 0.45 on one factor and a difference in loading on another factor of >0.30 were retained. All items had a sufficient factor loading. The first factor consisting of 4 items explained 24% of the variance and was described as 'relationship with general practitioner'. The score ranged from 4 to 16, with a higher score reflecting a better relationship (Cronbach's alpha 0.91). 17% of the variance was explained by the second factor, which consisted of 4 items and reflected the 'relationship with family and friends'. The score ranged from 5 to 21, with a higher score reflecting a better relationship (Cronbach's alpha 0.63). The third factor consisting of 2 items explained 15% of the variance and was described as 'empathy from colleagues and chief'. The score ranged from 4 to 8, with a higher score reflecting more empathy (Cronbach's alpha 0.75). If a patient did not work, no score was obtained for this factor.

### Statistical Analyses

The relation between baseline data of social support and several demographic characteristics, like age, gender, education, civil status, job status and illness length was analysed by comparing categories of the demographic variables using t tests.

Baseline social support data of CFS patients were compared with data of disease-free breast cancer patients, fatigued employees on sick-leave and healthy controls. Since these samples were not similar in age and gender, pairwise group comparisons were made with estimated marginal means standardised for age and gender using ANCOVA with Bonferroni corrections.

Changes in social support during the 14 months of the study were analysed with a multivariate analysis of variance (general linear method repeated measures within-subjects design).

Predictors of treatment outcome were selected by computing correlations between the variables concerning social support and significant others, and the primary outcome variables fatigue severity and functional impairment at 8 months for each of the 3 conditions. The baseline value of the dependent variable and significantly correlating variables were entered as independent variables in two blocks in separate multiple regression analyses for each of the dependent variables using the method entered. Variables not adding substantially to the variance in the dependent variable were removed. Factors were entered in the multiple regression which related to the outcome measures at  $p < 0.05$  or added substantially to the variance in the dependent variable.

## Results

### Relation between Social Support and Demographic Characteristics

In table 1, the baseline characteristics of the CFS sample concerning social support and significant others are shown. Female patients reported significantly more supporting interactions and a better relationship with family and friends than male patients. Patients older than 35 years had significantly less supporting interactions, reported significantly more insufficiency of social support, but had a significantly better relation with the general practitioner than younger patients. Lower educated patients had a significantly better relation with the general practitioner than higher educated patients. No differences were found between patients with and without a partner, with and without a job, or with a shorter or longer illness length.

### Comparisons between CFS Patients, Disease-Free Breast Cancer Patients, Fatigued Employees on Sick-Leave and Healthy Controls

In table 2, the means and standard deviations of supporting interactions and negative interactions of CFS patients, disease-free breast cancer patients, fatigued employees on sick-leave and healthy controls are shown. In

**Table 1.** Baseline scores of social support and relation with significant others

	Percent of sample	Social support (mean ± SD)			Significant others (mean ± SD)		
		SSL-I (n = 270)	SSL-D (n = 270)	SSL-N (n = 270)	REL-GP (n = 268)	REL-FF (n = 269)	EMP-CC (n = 149)
<i>Condition</i>							
Cognitive behaviour therapy	34	79.6 ± 11.3	46.9 ± 10.5	11.1 ± 3.5	12.6 ± 3.1	14.9 ± 2.6	6.2 ± 1.6
Guided support groups	33	78.9 ± 12.9	47.9 ± 12.1	11.8 ± 3.0	12.7 ± 2.7	14.7 ± 2.9	6.4 ± 1.5
Natural course	33	81.3 ± 12.4	46.4 ± 10.8	11.0 ± 2.8	12.8 ± 2.9	14.9 ± 2.5	6.4 ± 1.5
p		0.410	0.626	0.209	0.912	0.844	0.734
<i>Sex</i>							
Male	21.5	73.4 ± 9.9	46.9 ± 11.2	11.3 ± 2.9	12.6	14.2	6.3
Female	78.5	81.7 ± 12.2	47.1 ± 11.1	11.3 ± 3.2	12.7	15.0	6.4
p		0.000***	0.904	0.920	0.742	0.042*	0.799
<i>Age</i>							
<35 years	44.8	82.7 ± 11.1	45.5 ± 9.3	11.4 ± 3.0	12.3	15.1	6.4
≥35 years	55.2	77.7 ± 12.6	48.3 ± 12.3	11.3 ± 3.2	13.1	14.6	6.3
p		0.001**	0.036*	0.842	0.019*	0.093	0.540
<i>Civil status</i>							
Spouse/partner	69.9	79.7 ± 12.4	46.4 ± 10.6	11.2 ± 3.2	12.9	14.9	6.3
No spouse/partner	30.1	80.5 ± 11.9	48.7 ± 12.3	11.5 ± 3.0	12.3	14.8	6.4
p		0.629	0.126	0.520	0.114	0.768	0.916
<i>Education</i>							
Lower	33.5	78.6 ± 11.5	45.3 ± 10.2	11.1 ± 3.2	13.3	15.1	6.2
Higher	66.5	80.6 ± 12.5	48.0 ± 11.5	11.4 ± 3.1	12.4	14.7	6.4
p		0.207	0.061	0.471	0.017*	0.308	0.337
<i>Job</i>							
No	48.3	80.3 ± 13.3	47.2 ± 11.5	11.6 ± 3.3	12.8	14.7	6.0
Yes	51.7	79.5 ± 11.3	47.1 ± 11.0	11.2 ± 3.1	12.6	14.9	6.5
p		0.618	0.923	0.341	0.477	0.728	0.083
<i>Illness length</i>							
≤2 years	35.6	81.8 ± 12.1	46.2 ± 10.5	10.9 ± 3.1	12.7	15.2	6.2
>2 years	64.4	78.9 ± 12.2	47.5 ± 11.5	11.5 ± 3.2	12.7	14.5	6.5
p		0.061	0.356	0.109	0.967	0.054	0.252

\* p < 0.05; \*\* p < 0.01; \*\*\* p < 0.001.

REL-GP = Relation with general practitioner; REL-FF = relation with family/friends; EMP-CC = empathy from chief/colleagues.

the three mixed samples, gender differences were found in the total score of supporting interactions, in social companionship, problem-focused emotional support and emotional interactions. Females reported significantly more supporting interactions than males. In the two samples of patients selected on fatigue severity, equal gender differences were also observed in instrumental interactions. Esteem support was significantly higher for female than for male fatigued employees on sick-leave. No gender differences occurred for informational support and negative interactions.

Table 2 also depicts group differences while controlling for age and gender. No significant differences between the groups were found in the total score of supporting interactions and in esteem support and informational support. However, significant differences were found in some other types of supporting interactions. CFS patients had significantly more instrumental interactions than disease-free breast cancer patients and healthy controls. Fatigued employees on sick-leave had significantly less emotional interactions compared with the other three groups. The three patient groups had significantly more problem-

**Table 2.** Means and standard deviations of supporting interactions (SSL-I) and negative interactions (SSL-N) for patients with CFS, disease-free breast cancer patients (DFBC), fatigued employees on sick leave and healthy controls, and pairwise group comparisons of estimated marginal means standardised for age and gender

Supporting interactions	CFS (37 years; group 1)		DFBC (46 years; group 2)	Fatigued employees (43 years; group 3)		Healthy controls (45 years; group 4)		Significant pairwise comparisons	
	female (n = 210)	male (n = 58)	female (n = 149)	female (n = 83)	male (n = 68)	female (n = 99)	male (n = 9)	groups	p
Emotional interactions	11.2±2.4	10.0±2.3***	11.1±2.5	10.1±2.2	9.2±2.2*	11.1±1.9	9.4±1.7*	1 vs. 3 2 vs. 3 3 vs. 4	<0.001 <0.01 <0.05
Esteem support	15.9±2.8	15.1±2.5	15.7±2.9	16.5±3.2	14.6±3.3**	15.7±2.7	14.5±2.1		
Emotional support problems	19.1±3.7	16.2±3.2***	18.2±4.1	18.8±4.3	16.7±4.0**	16.9±3.4	13.1±3.6**	1 vs. 4, 3 vs. 4 2 vs. 4	<0.001 <0.05
Informational support	8.4±1.7	8.0±1.7	8.1±2.1	8.4±2.1	8.0±2.3	8.4±1.8	7.3±2.0		
Instrumental interactions	14.4±3.3	12.6±2.8***	12.8±2.9	13.6±3.6	12.1±2.9**	12.9±3.1	10.9±2.6	1 vs. 2, 1 vs. 4	<0.05
Social companionship	12.7±2.7	11.6±2.3**	13.9±2.5	13.4±2.9	11.6±2.9***	14.2±2.5	11.3±2.1***	1 vs. 2, 1 vs. 4 3 vs. 4	<0.001 <0.05
Total (SSL-I)	81.7±12.2	73.4±9.9***	79.8±12.5	80.7±13.8	72.2±13.3***	79.2±11.6	66.7±9.7**		
Negative interactions	11.3±3.2	11.3±2.9	9.8±2.5	11.5±3.5	11.6±3.4	9.5±2.0	9.0±1.8	1 vs. 2, 1 vs. 4 2 vs. 3, 3 vs. 4	<0.001 <0.001

Gender differences: \* p < 0.05; \*\* p < 0.01; \*\*\* p < 0.001.

**Table 3.** Means and standard deviations of insufficiency of supporting interactions (SSL-D) for patients with CFS, disease-free breast cancer patients (DFBC), fatigued employees on sick leave and healthy controls, and pairwise group comparisons of estimated marginal means standardised for age and gender

Insufficiency of supporting interactions	CFS (37 years; group 1)		DFBC (46 years; group 2)	Fatigued employees (43 years; group 3)		Healthy controls (45 years; group 4)		Significant pairwise comparisons	
	female (n = 211)	male (n = 58)	female (n = 149)	female (n = 83)	male (n = 68)	female (n = 99)	male (n = 9)	groups	p
Emotional interactions	5.8±2.3	5.9±2.3	5.7±2.3	6.1±2.3	6.5±2.1	5.4±2.0	5.8±1.6	3 vs. 4	<0.05
Esteem support	7.7±2.0	7.6±1.9	7.6±2.1	7.4±1.7	8.6±2.6*	7.2±1.6	7.1±1.2		
Emotional support problems	11.9±3.9	11.9±4.1	10.7±3.3	11.9±3.9	13.0±3.9	10.6±3.0	9.7±2.7	1 vs. 2 1 vs. 4, 2 vs. 3 3 vs. 4	<0.05 <0.01 <0.01
Informational support	5.5±1.7	5.2±1.4	5.6±1.8	5.7±2.0	6.0±2.0	5.4±1.5	5.4±1.9		
Instrumental interactions	9.1±2.4	9.3±2.4	8.7±2.2	9.4±2.9	9.7±2.5	8.5±1.8	7.7±1.3	1 vs. 4, 2 vs. 3 3 vs. 4	<0.05 <0.01
Social companionship	7.1±2.6	7.0±2.1	6.2±2.1	6.5±2.2	7.0±2.1	5.8±1.6	6.7±1.7	1 vs. 2 1 vs. 4 3 vs. 4	<0.01 <0.001 <0.05
Total (SSL-D)	47.1±11.1	46.9±11.2	44.5±11.0	47.1±11.1	50.7±12.2	42.9±8.5	42.3±9.1	1 vs. 4 2 vs. 3 3 vs. 4	<0.01 <0.05 <0.001

Gender differences: \* p < 0.01.

**Table 4.** Course of supporting interactions (SSL-I), insufficiency of supporting interactions (SSL-D), and negative interactions (SSL-N) over 14 months for each of the three treatment arms

	Baseline mean $\pm$ SD	8 months mean $\pm$ SD	14 months mean $\pm$ SD	Repeated measures	
				F	p
Cognitive behaviour therapy (n = 57)					
SSL-I	82.3 $\pm$ 10.0	80.6 $\pm$ 12.0	79.7 $\pm$ 11.7	4.661	0.013*
SSL-D	45.5 $\pm$ 8.8	43.3 $\pm$ 8.4	43.0 $\pm$ 8.9	2.830	0.068
SSL-N	10.9 $\pm$ 3.1	9.9 $\pm$ 2.0	9.6 $\pm$ 2.4	4.705	0.013*
Guided support groups (n = 62)					
SSL-I	78.9 $\pm$ 12.2	78.3 $\pm$ 11.4	78.1 $\pm$ 11.9	0.326	0.723
SSL-D	48.2 $\pm$ 12.5	47.3 $\pm$ 11.8	45.7 $\pm$ 10.7	1.820	0.171
SSL-N	11.6 $\pm$ 3.1	11.2 $\pm$ 3.4	11.2 $\pm$ 3.0	0.707	0.497
Natural course (n = 75)					
SSL-I	81.9 $\pm$ 12.0	79.9 $\pm$ 10.2	78.7 $\pm$ 11.6	3.244	0.045*
SSL-D	46.2 $\pm$ 10.9	46.7 $\pm$ 10.2	45.0 $\pm$ 10.6	1.741	0.183
SSL-N	10.8 $\pm$ 2.7	10.5 $\pm$ 2.8	10.4 $\pm$ 3.1	1.46	0.239

\* p < 0.05.

focused emotional support than healthy controls. CFS patients had significantly less social companionship than disease-free breast cancer patients and healthy controls, and fatigued employees on sick-leave less than healthy controls. CFS patients and fatigued employees on sick-leave reported significantly more negative interactions than disease-free breast cancer patients and healthy controls.

Data pertaining to insufficiency of supporting interactions are shown in table 3. CFS patients had a significantly higher total score of insufficiency of supporting interactions than healthy controls, and employees with work-related fatigue had a higher total score than disease-free breast cancer patients and healthy controls. As to the different types of insufficiency of supporting interactions, CFS patients experienced significantly more insufficiency of social companionship and problem-focused emotional support than both disease-free breast cancer patients and healthy controls. The same pattern was found in fatigued employees on sick-leave, although the comparison of social companionship with disease-free breast cancer patients did not reach significance. CFS patients experienced significantly more insufficiency of instrumental interactions than healthy controls and fatigued employees on sick-leave significantly more than disease-free breast cancer patients and healthy controls. Fatigued employees on sick-leave reported more insufficiency of emotional interactions than healthy controls. No group differences in esteem support and informational support were found. No gender differences occurred for the total score of insufficiency of supporting interactions.

#### *Course of Social Support over 14 Months in CFS Patients*

Table 4 shows the mean scores of supporting interactions, negative interactions and insufficiency of supporting interactions of CFS patients at baseline, 8 and 14 months in each of the treatment groups, as well as differences within groups reflecting changes over time. In patients treated with CBT, supporting interactions and negative interactions decreased significantly after 14 months. In this group, a decrease in insufficiency of supporting interactions was also found, although this change did not reach significance. Patients in guided support groups showed no significant changes during 14 months. Patients in the natural course group reported significantly less supporting interactions after 14 months. Insufficiency of supporting interactions and negative interactions did not change significantly in this group.

Significant differences between groups after 14 months were only found in negative interactions ( $F = 4.555$ , d.f. = 2,  $p = 0.012$ ), and not in supporting interactions ( $F = 0.107$ , d.f. = 2,  $p = 0.898$ ) or insufficiency of supporting interactions ( $F = 1.193$ , d.f. = 2,  $p = 0.305$ ). Post hoc analyses showed a significant difference in negative interactions between patients treated with CBT and patients in guided support groups ( $p = 0.009$ ).

#### *Predictors of Fatigue Severity and Functional Impairment*

Higher fatigue severity after CBT was predicted by higher fatigue severity (7%) and more insufficiency of problem-focused emotional support (5%) at baseline (ta-

**Table 5.** Predictors of fatigue severity and functional impairment after 8 months

	Adjusted R <sup>2</sup>	beta
<i>Fatigue severity</i>		
Cognitive behaviour therapy		
Model 1: baseline fatigue severity	0.073**	0.290**
Model 2: baseline fatigue severity insufficiency emotional support problems	0.126**	0.285* 0.252*
Natural course		
Model 1: baseline fatigue severity	0.046*	0.243*
Model 2: baseline fatigue severity negative interactions	0.106**	0.260* 0.257*
<i>Functional impairment</i>		
Cognitive behaviour therapy		
Model 1: baseline functional impairment	0.250***	0.509***
Model 2: baseline functional impairment relationship with family and friends insufficiency emotional interactions	0.325***	0.460*** -0.172 0.190
Guided support groups		
Model 1: baseline functional impairment	0.288***	0.556***
Model 2: baseline functional impairment social companionship empathy from colleagues and chief	0.355***	0.491*** -0.190 -0.196
Natural course		
Model 1: baseline functional impairment	0.193***	0.451***
Model 2: baseline functional impairment relationship with general practitioner	0.271***	0.454*** 0.294**
* p < 0.05; ** p < 0.01; *** p < 0.001.		

ble 5). No predictors were found for fatigue severity after guided support groups. In the natural course group, higher fatigue severity (5%) and more negative interactions at baseline (6%) predicted fatigue severity at 8 months. Higher functional impairment after CBT was predicted by higher functional impairment (25%) and by a worse relationship with family and friends and more insufficiency of emotional interactions at baseline. Although the latter variables just did not reach significance, together they added 7.5% to the variance in fatigue severity. After guided support groups, higher functional impairment was predicted by higher functional impairment (29%) and by less social companionship and less empathy from colleagues and friends at baseline. Together these variables added 6.5% to the explained variance in fatigue severity, although they did not reach significance. In the natural course group, baseline functional impairment (19%) and a better relationship with the general practitioner (8%) predicted functional impairment.

## Discussion

Our study of social support in CFS patients revealed several new findings.

### *Relation between Social Support and Demographic Characteristics*

Demographic variables, like age, gender and education, appeared to represent relevant factors in the quantitative and qualitative aspects of social support of CFS patients. Female CFS patients reported more supporting interactions than males. In this respect, CFS patients did not differ from other samples in our study in which similar gender differences were found. Insufficiency of supporting interactions and negative interactions were similar for both genders, in CFS patients and in both other mixed samples. Marriage and work are both sources for social support, and were therefore expected to coincide with higher levels of social support. However, the presence of a partner or a job did not seem to be related to the quantity or quality of social support of CFS patients, nor did illness length, while we supposed that changes in

social networks due to increasing illness length would result in a decrease in social support.

#### *Comparisons between CFS Patients, Disease-Free Breast Cancer Patients, Fatigued Employees on Sick-Leave and Healthy Controls*

Based on the group comparisons, we concluded that CFS patients and fatigued employees differed in qualitative aspects of social support from disease-free breast cancer patients and healthy controls and not in quantitative aspects. CFS patients and fatigued employees on sick-leave reported more negative interactions and more insufficiency of supporting interactions than disease-free breast cancer patients and healthy controls. In the sample of disease-free breast cancer patients, 38% were severely fatigued. These patients also had significantly more negative interactions and insufficiency of supporting interactions than those patients who were not fatigued [18]. Severe fatigue seems to be related to a worse quality of social support.

No significant differences between the four samples in the frequency of supporting interactions were found, although some differences in types of supporting interactions were identified. Roughly, fatigued persons, CFS patients as well as fatigued employees on sick-leave, had more instrumental and problem-focused interactions and less social or emotional interactions than one or both of the other groups, which were not selected on fatigue severity. CFS patients reported more instrumental support, but at the same time also experienced more insufficiency of instrumental support than healthy subjects. Evidently, they were not fulfilled in their need for instrumental support.

As to the quality of social support, fatigued patients had more negative interactions and more insufficiency of support than healthy controls. This finding is of interest because negative aspects of social relationships are supposed to reduce the helpful effect of social support.

There is one methodological point which should be considered. The way of recruiting healthy control subjects, who were family members, friends or colleagues of the patients participating in our studies, might have introduced some selection bias. Since these subjects were willing to join the patient in the study and thereby were showing support, they possibly had a more positive network interaction than other people in the normal population.

#### *Course of Social Support over 14 Months in CFS Patients*

Perceived support rather than quantity of social relationships is considered to affect health-related behaviours

[7]. Therefore, we were especially interested in the effect of CBT and guided support groups on negative interactions and insufficiency of supporting interactions. We found that negative interactions and to a lesser extent insufficiency of supporting interactions decreased after CBT. The statistically significant decrease in negative interactions was also clinically significant, since the mean score at 14 months was similar to the mean score of healthy subjects. Insufficiency of supporting interactions and negative interactions did not change significantly during natural course and guided support groups. Supporting interactions decreased after CBT, as was the case in the natural course group. Clinically, this finding was of little importance, since after 14 months, the frequency of supporting interactions was still at a level considered as normal for healthy subjects. The new contacts in the guided support groups may explain the finding that the supporting interactions of the patients in the guided support groups did not decrease significantly. In addition to our former conclusion that guided support groups were not effective in decreasing fatigue and functional impairment in CFS patients, we concluded that support groups did not contribute to a decrease in negative interactions or insufficiency of supporting interactions either.

Higher levels of functional impairment, less social companionship and less empathy from colleagues and chief at baseline were found to predict higher levels of functional impairment in the support groups. Apparently, participation in support groups did not satisfy the need for companionship and empathy. There might be another explanation for the ineffectiveness of support groups for CFS patients. Despite the fact that only in the first two meetings attention was paid to symptoms and functional impairment, in all of the subsequent meetings CFS patients remained focused on each other's symptoms and frequently exchanged information about aids to facilitate daily life. A strong focus on bodily symptoms was found to predict a worse outcome in our trial [4].

#### *Predictors of Fatigue Severity and Functional Impairment*

In the patients with CBT, insufficiency of supporting interactions and a worse relationship with family and friends predicted higher fatigue severity or functional impairment. Therefore, in the treatment protocol of CBT for CFS patients, more attention for insufficiency of social support is needed. In the patients without treatment, more negative interactions predicted higher fatigue severity.

Our conclusion was that insufficiency of social support and negative interactions are important factors in the persistence of CFS. Social support should be added as a new factor to the model of perpetuating factors of fatigue and functional impairment in CFS [26]. Until now, the model has been limited to complaint-related cognitions and behaviours, like somatic attributions, sense of control over complaints, physical activity and a strong focus on bodily symptoms. From the results of this study, it is

obvious that cognitions and behaviours concerning the individual's support system need equal attention. Further studies should pay special attention to different ways in which social support might be of influence for CFS patients, helping them to accept and tolerate symptoms and disability or reinforcing illness behaviour. The mediating role of psychological distress should also be considered. In general, patients with low levels of perceived social support report more psychological distress.

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