

The role of the partner and relationship satisfaction on treatment outcome in patients with chronic fatigue syndrome

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Background. Cognitive behaviour therapy (CBT) for chronic fatigue syndrome (CFS) leads to a significant decrease in CFS-related symptoms and disability. The primary objective of this study was to explore whether partners' solicitous responses and patients' and partners' perceived relationship satisfaction had an effect on treatment outcome.

Method. The treatment outcome of a cohort of 204 consecutively referred patients treated with CBT was analysed. At baseline, CFS patients completed the Maudsley Marital Questionnaire. The Checklist Individual Strength subscale Fatigue and the Sickness Impact Profile total scores completed by CFS patients post-treatment were used as measures of clinically significant improvement. Partners completed the Family Response Questionnaire, the Maudsley Marital Questionnaire, the Brief Illness Perception Questionnaire, and the Causal Attribution List. Logistic regression analyses were performed with clinically significant improvement in fatigue and disability as dependent variables and scores on questionnaires at baseline as predictors.

Results. Solicitous responses of the partner were associated with less clinically significant improvement in fatigue and disability. Partners more often reported solicitous responses when they perceived CFS as a severe condition. Patients' relationship dissatisfaction was negatively associated with clinically significant improvement in fatigue.

Conclusions. Partners' solicitous responses and illness perceptions at the start of the therapy can negatively affect the outcome of CBT for CFS. We emphasize the importance of addressing this in therapy.

Received 15 July 2014; Revised 24 January 2015; Accepted 27 January 2015; First published online 3 March 2015

Key words: Chronic fatigue syndrome, cognitive behavioural model, cognitive behavioural therapy, illness perceptions, partner relationship, partners' responses, relationship satisfaction, social support.

Introduction

Chronic fatigue syndrome (CFS) is a condition characterized by severe and disabling fatigue that is not alleviated by rest. According to the US Centers for Disease Control and Prevention criteria of CFS (Fukuda *et al.* 1994), the fatigue has to be present for at least 6 months, be unexplained by a medical condition, and must be accompanied by ≥ 4 of the following symptoms: substantial impairment in short term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain; new headaches; non-refreshing sleep; and post-exertion malaise. Although the aetiology of CFS remains unclear, cognitive-behavioural factors that

perpetuate CFS have been identified (Knoop *et al.* 2010). Cognitive behaviour therapy (CBT) aimed at changing fatigue-related cognitions and a gradual increase of activity levels leads to a significant reduction of fatigue and functional impairments (Castell *et al.* 2011). Different models have been developed to explain how behavioural, psychological, and social factors interact to perpetuate CFS (Moss-Morris, 2005; Knoop *et al.* 2010; Wiborg *et al.* 2010; Chalder & Hill, 2012; Jason *et al.* 2012). Fatigue-related cognitions and behaviours of the patient are relevant, but the social environment and social support as perceived by the patient also play a role in the maintenance of CFS symptoms. Obtaining adequate social support may be difficult for people with CFS. CFS is a controversial condition and individuals with CFS consistently report negative experiences with health-care providers, family, friends, and colleagues (Taylor, 2005; Jason *et al.* 2010; Sperry, 2012). Prins *et al.* (2004) found that CFS patients' perceived lack of social support

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perpetuated fatigue. Further, negative social interactions seem to encourage illness behaviour in the sense that CFS patients often try to prove that they are indeed ill (van Houdenhove & Luyten, 2008).

Some studies suggest that CFS patients become more reliant on close family members and partners for support due to a decreased social network (Anderson & Ferrans, 1997; Kelly *et al.* 1999). Of all the people in the CFS patients' social network, it is likely that spouses or partners are the most influential. Partners adapt to the illness by forming their own illness perceptions and developing ways of coping. Adaptive mechanisms of patient and partner interact, becoming manifest in behavioural and communication patterns. Recent research findings suggest that the quality of this dyadic adjustment is associated with patients' daily functioning and symptoms (Blazquez *et al.* 2012). Not all of the partners' adaptive behaviours may be beneficial for the patient – in fact, they may perpetuate patients' fatigue and impairments. A cross-sectional study showed that solicitous behaviour of the partner was related to more symptoms, illness behaviour, and worse functioning of CFS patients (Romano *et al.* 2009). Solicitous behaviour was defined as exhibiting concern for the other's physical condition, comforting the patient, and discouraging the patient from activity. Such responses may have a negative impact on the patient's treatment outcome. Further, the solicitous behaviour of the partner is likely influenced by his/her perception of the illness. If a partner perceives CFS as a severe illness, they might be more inclined to be solicitous. The attribution of symptoms by the partner can also influence their response to the patient. White *et al.* (2006) found that close others who attributed the illness of their partner to internal psychological causes were inclined to offer less support. Partners who attribute CFS to physical causes might be inclined to be more supportive towards their ill partner.

When considering the role of the partner, it is relevant to take into consideration that the relationship may be challenged by the CFS, and relationship dissatisfaction may become a stressor on its own and therefore a perpetuating factor of fatigue and functional impairments. Studies have shown that women with CFS presented more symptoms when they had conflicts with their partners (Goodwin, 2000). Research in other chronic illnesses showed that positive relationship interactions predicted reduction of pain and fatigue (DiMatteo, 2004; Cano *et al.* 2010; Stadler *et al.* 2012).

The aforementioned findings, mainly from cross-sectional studies, suggest that there is an association between solicitous behaviour of the partner, relationship dissatisfaction, and CFS-related symptoms and impairments. Little is known to what extent the former two influence treatment outcome of CBT for CFS. The main

objective of this study was to determine if partners' solicitous responses and CFS patients' and partners' perceived relationship dissatisfaction impact treatment outcome. We hypothesized that solicitous responses by the partner and relationship dissatisfaction hinder the reduction of fatigue and functional impairments. We also hypothesized that the more partners perceive CFS as a serious condition and attribute CFS to physical causes the more they will show solicitous responses.

Method

Participants

Consecutively referred patients visiting the Expert Centre for Chronic Fatigue of the Radboud University Nijmegen Centre between December 2009 and February 2012 were eligible for this study if they met the following inclusion criteria: aged ≥ 18 years, able to speak and read Dutch, meeting US Centers for Disease Control and Prevention criteria for CFS (Fukuda *et al.* 1994; Reeves *et al.* 2003), being severely fatigued as reflected by a score of ≥ 35 on the Fatigue subscale of the Checklist for Individual Strength (CIS; Vercoulen *et al.* 1999), being severely disabled, operationalized as scoring ≥ 700 on the Sickness Impact Profile-8 (SIP-8; Steward *et al.* 1998; Vercoulen *et al.* 1999), having started with CBT for CFS, and having a partner. Partners were defined as those who were called 'partner' by the patient. Partners had to be willing to complete the questionnaires and verbally consent to answer the extra questions for this study. No extra criteria for partners or the partner relationship had to be met.

Procedure

Both partners and patients completed a baseline assessment consisting of questionnaires. Post-treatment, CFS patients completed questionnaires with regard to the severity of both fatigue and level of disability. Baseline questionnaires were completed during two test sessions separated by a period of 2 weeks. The assessment was discussed by the therapist with the patient and, if possible, partner before start of the treatment. Directly following treatment, about 6 months after the first treatment session, the follow-up assessment took place. The Family Response Questionnaire (FRQ; Cordingley *et al.* 2001) and the Maudsley Marital Questionnaire (MMQ; Arrindell *et al.* 1983) were already part of the routine clinical assessment at the Expert Centre for Chronic Fatigue. The Brief Illness Perception Questionnaire (Brief IPQ; Broadbent *et al.* 2006) and Causal Attribution List (CAL) – adapted for partner use – were added for this prospective study. These two lists, together consisting of 15 items, were

considered not burdensome to complete. The medical ethical committee ruled that no formal ethical approval was needed for this study. All partners were informed about the study and the two additional questionnaires, and verbal informed consent was obtained.

Intervention

Patients were treated according to a CBT for CFS treatment protocol (see Knoop & Bleijenberg, 2010). It prescribes 12–14 sessions over a period of 6–8 months. First, the model of fatigue-sustaining factors is explained to the patient. Next, personal goals are formulated. The goal of treatment is that a patient is no longer severely fatigued and no longer disabled. Patients start by normalizing their sleep/wake pattern. Following this, fatigue-related cognitions are challenged to improve the sense of control over symptoms and facilitate behavioural change. Next a graded physical activity programme starts. The protocol differentiates between low active patients and relatively active patients on the basis of their level of physical activity. Low active patients immediately start with graded activity; relatively active patients first learn to divide their activities more evenly. After having increased their level of physical activity, patients work towards meeting their personal goals. The final sessions deal with relapse prevention.

Instruments

Patients completed the following questionnaires

Fatigue severity was assessed with the subscale Fatigue Severity of the CIS-20. It consists of eight items scored on a 7-point Likert scale (range 8–56). A score of ≥ 35 , being 2 standard deviations above the mean of a healthy control group, indicates severe fatigue. The psychometric properties of the CIS are good (Vercoulen *et al.* 1999). In our study, Cronbach's α was 0.78.

Functional impairment was assessed with the SIP-8 (Prins *et al.* 2001). The SIP-8 assesses daily functioning in relation to health on eight domains, and scores on the domains are combined to form a total score. The eight subscales are: Ambulation, Home management, Mobility, Alertness behaviour, Sleep/rest, Work limitations, Social interactions, Recreations and pastimes. The SIP-8 has demonstrated good psychometric properties (Vercoulen *et al.* 1996; Prins *et al.* 2001). In our study Cronbach's $\alpha = 0.84$.

Partners completed the following instruments

Partners' solicitous responses were assessed by the FRQ (Cordingley *et al.* 2001). The FRQ contains 25 questions divided into four subscales: Active Engagement (seven items), Sympathic/Empathic Responses (six items),

Rejecting/Hostile (seven items), and Concern with Self (six items). Principal component analysis indicated the presence of two clusters, one including the items from the subscales Active Engagement and Sympathic/Empathic Responses, and the other containing the items of the subscales Rejecting/Hostile and Concern with Self. The FRQ has shown high test–retest reliability and internal reliability (Cordingley *et al.* 2001). We applied the cluster of items from the subscales Active Engagement and Sympathic/Empathic Responses as indicators of partners' solicitous responses. In our study Cronbach's α was 0.71.

Partners' illness perceptions were measured by the Brief IPQ (Kaptein *et al.* 2004; Broadbent *et al.* 2006), an eight-item version of the revised multifactorial IPQ questionnaire (Moss-Morris *et al.* 2002). The Brief IPQ shows good test–retest reliability and validity (Kaptein *et al.* 2004; Broadbent *et al.* 2006). We adapted the Brief IPQ for partners' use by referring to the illness of their partner. Because of this new context, a principal component analysis was conducted on the Brief IPQ for partners. The scores on the positively worded items were reversed in order to assess the reliability of the IPQ (Broadbent *et al.* 2006). The Illness Coherence item, Treatment Control item, and Personal Control item of the Brief IPQ correlated weakly with all other items and were dropped from the scale (Pearson's $r < 0.40$). As a result of this analysis we selected the following five out of the original eight items: Consequences, Timeline, Illness identity, Concern, and Emotional representation, which loaded on the same construct that can be defined as Seriousness of illness. In the original Brief IPQ the final item asks participants about causal attributions, but we omitted this item because a causal attribution list was already administered. In our study Cronbach's α was 0.62.

Partners' psychological and somatic causal attributions of CFS were assessed with the CAL (Vercoulen *et al.* 1996). Both the Psychological attribution subscale and the Physical attribution subscale consist of five items (score range 5–20). All items are scored on a 4-point scale ranging from 'yes, that is very true' to 'no, that is not true at all'. High scores indicate respectively high levels of psychological and somatic attributions of symptoms. The CAL has good psychometric properties (Vercoulen *et al.* 1996). For the use in this study, the introduction in the CAL was adjusted for use for partners. In our study Cronbach's α was 0.79 for the Physical attribution subscale, and 0.72 for the Psychological attribution scale.

Patients and partners completed the following questionnaires

Relationship dissatisfaction was measured by the MMQ. The questionnaire consists of 10 items. Higher scores

indicate greater relationship dissatisfaction. The MMQ scale has good psychometric properties (Arrindell *et al.* 1983; Orathinkal *et al.* 2007). In our study Cronbach's α was 0.90 for the MMQ patient and 0.89 for the MMQ partner.

Data analysis

All analyses were performed using SPSS v. 20.0 for Windows (IBM, USA). In case of ≤ 2 missing values on a scale, the participant's average score on the remaining items replaced the missing values. Within-group effect sizes for both fatigue and disability were calculated and compared to the 95% CI of the mean effect size of CBT of several randomized controlled trials, calculated in the benchmark study of Scheeres *et al.* (2008). In this way we wanted to determine if the efficacy of the intervention was comparable to that of previously published RCTs. Means (or medians) and standard deviations of fatigue severity, functional impairments, solicitous responses, and relationship satisfaction for respondents and dropouts were calculated. Group comparisons were conducted to detect significant differences on these variables between the group of dropouts and the patients included in the study, using *t* tests for independent groups. We performed logistic regression analyses (method enter) with clinically significant improvement in fatigue as dependent variable, and in a next analysis clinically significant improvement in functional impairments as dependent variable. Clinically significant improvement of fatigue was defined as having a change index >1.96 between baseline and post-treatment and scoring <35 on the subscale Fatigue severity, this being a score lower than the mean plus 2 standard deviations of a healthy control group (Knoop *et al.* 2007; Tummers *et al.* 2012). Clinically significant improvement in functional impairments was defined as a change index of >1.96 and scoring <700 on the SIP-8 total score (Jacobson & Truax, 1991; Knoop *et al.* 2007; Scheeres *et al.* 2008). Predictors in the first two logistic regression analyses were relationship dissatisfaction of the patient and partner, partners' solicitous responses, patients' fatigue severity at baseline, and severity of functional impairments at baseline. Fatigue severity at baseline and severity of functional impairments at baseline served as control variables in these analyses. To test our last hypothesis, we conducted a linear regression analysis with partners' solicitous responses as dependent variable and with partners' perception of the seriousness of the illness, partners' psychological and physical attributions, and severity of functional impairments of the patient at baseline as predictors. Severity of functional impairments at baseline served as control variable in this analysis. A *p* level of 0.05 two-tailed was applied in all analyses.

Results

Baseline characteristics

Of the 243 CFS patients who completed baseline measurements, 39 (16%) did not complete the second assessment. Fifteen (6%) dropped out during treatment. The final sample consisted of 204 respondents who completed both pre- and post-treatment assessment. Means (or medians) and standard deviations for the measures for the 204 included patients and partners and 39 dropouts are shown in Table 1. Dropouts were significantly less functionally impaired at baseline ($t = 2.13, p = 0.04$). No significant differences existed on other characteristics or variables.

Effect of the intervention on fatigue severity and functional impairments

Of the 204 patients who completed both assessments, 104 (51%) CFS patients showed a clinically significant improvement with regard to fatigue severity (Fatigue severity pre-treatment: $\bar{x} = 50.76, s.d. = 5.40$; post-treatment: $\bar{x} = 28.21, s.d. = 14.34$; change 22.55). In total 136 CFS patients (66.7%) showed a clinically significant improvement in functional impairments (Functional impairments pre-treatment: $\bar{x} = 1627.26, s.d. = 549.19$; post-treatment: $\bar{x} = 631.75, s.d. = 668.38$; change 995.51). The within-group effect size was 2.08 for fatigue severity and 1.63 for severity of functional impairments. Both effect sizes are larger and outside the 95% CI of the benchmark study of Scheeres *et al.* (2008).

Testing the hypothesis that partners' solicitous responses and relationship dissatisfaction of partner and patient has a negative effect on treatment outcome

Patients whose partners reported solicitous responses showed less often an improvement in fatigue. The more patients were dissatisfied with their relationship, the less likely they were to show an improvement in fatigue. This latter relationship was only marginally significant. Together, partners' solicitous responses and patients' relationship dissatisfaction explained 7% of the variance in treatment outcome with respect to fatigue (Table 2). Reporting more solicitous responses by the partner also predicted less clinically significant improvement of functional impairments. Partners' solicitous responses and patients' functional impairments at baseline explained 16% of the variance of post-treatment clinically significant improvement of functional impairments (Table 2). Relationship dissatisfaction was not related to improvement in functional impairment.

Table 1. Baseline characteristics of CFS patients and partners and clinical data of the final sample and dropouts

	Possible scores	Pre-treatment (<i>n</i> = 204) mean (s.d.)	Dropouts (<i>n</i> = 39) mean (s.d.)
Partner			
Age, years	18–64	39.94 (12.02)	41.13 (10.24)
Gender	0/1	55 female (26.9%)	11 female (28.3%)
Relationship duration, years	1–44	Median 9.5	Median 9.5
Solicitous responses	0–52	16.74 (3.13)	15.93 (3.25)
Relationship dissatisfaction	0–80	12.41 (9.95)	10.78 (7.69)
Perception seriousness of illness	0–10	6.83 (1.28)	7.15 (1.15)
Psychological attributions	5–20	10.02 (2.70)	10.56 (2.49)
Physical attributions	5–20	12.65 (2.88)	12.86 (2.34)
Patient			
Age	18–68	38.60 (11.78)	40.67 (9.88)
Gender	0/1	152 female (74.5%)	29 female (74.4%)
Duration fatigue prior to treatment, years	0.25–56	Median 4.0	Median 4.0
Relationship dissatisfaction	0–80	11.38 (9.82)	8.97 (8.98)
Severity of fatigue at baseline	35–56	50.76 (5.40)	50.05 (4.74)
Level of functional impairments at baseline*	700–5799	1627.26 (549.19)	1426.81 (514.25)

* Mean difference between participants and dropouts on variables. *t* test significant at $p < 0.05$ level.

Table 2. Unstandardized logistic regression parameters of post-treatment outcome fatigue severity and functional impairment

	Post-CBT clinically significant improvement of fatigue severity			Post-CBT clinically significant improvement of functional impairments		
	<i>B</i>	s.e.	OR	<i>B</i>	s.e.	OR
Partners' solicitous responses	−0.10*	0.05	4.25	−0.15**	0.06	7.16
Partners' relationship dissatisfaction	−0.10	0.19	0.48	−0.18	0.20	0.84
Patients' relationship dissatisfaction	−0.34†	0.20	3.13	−0.08	0.19	0.17
Patients' fatigue severity at baseline	−0.02	0.03	0.25	−0.02	0.03	0.38
Patients' level of functional impairments at baseline	0.01 ^{−2}	0.01 ^{−2}	0.01	0.01 ^{−2} **	0.01 ^{−2}	7.22
Nagelkerke's R^2	0.07			0.16		

OR, Odds ratio.

Significance level: † $p < 0.10$, * $p < 0.05$, ** $p < 0.01$.

Testing the hypothesis that the more partners perceive CFS as a serious condition and the more partners attribute CFS to physical causes, the more partners show solicitous responses

In a linear regression analysis with partners' solicitous responses as dependent variable, partners' perception of seriousness of illness was significantly related to their solicitous responses. The more partners viewed CFS as a severe condition, the more they showed solicitous responses. The perception of the partner of the seriousness of the illness explained 8% of the variance of partners' solicitous responses. Partners' psychological or physical attributions were not related to their solicitous responses (Table 3).

Discussion

To the best of our knowledge this is the first prospective study to explore the influence of partners' responses and relationship satisfaction on treatment outcome in CBT for CFS. We hypothesized that a higher level of partners' solicitous responses and more relationship dissatisfaction of partner and patient would lead to less reduction in fatigue and disabilities. The present study showed that partners' solicitous responses were indeed a predictor of clinically significant improvement of both fatigue and functional impairments. The more solicitous behaviour partners reported, the less improvement CFS patients showed. These findings may suggest that partners who are

Table 3. Standardized linear regression parameters of pre-treatment partners' illness perceptions and attributions on pre-treatment partners' solicitous responses

	Partners' solicitous responses, β
Partners' perception of seriousness of illness	0.21**
Partners' psychological attributions	-0.06
Partners' physical attributions	0.05
Patients' severity of fatigue at baseline	0.01
Patients' level of functional impairments at baseline	0.08
R^2	0.08

Significance level: * $p < 0.05$, ** $p < 0.01$.

solicitous may unintentionally stimulate unhealthy behaviour in the patient. Although it is important for CFS patients to feel supported, overly solicitous partner responses may make it difficult for the patient to actively engage in CBT and work towards recovery. Talking about the fatigue and functional impairments and emphasizing the need for rest likely interferes with the autonomous, active behaviour that the patient has to achieve during treatment to become less impaired and fatigued. Partners who focus less on symptoms and stimulate gradual build-up of activities in the patient in line with therapeutic interventions help the CFS patient to regain control over his or her life and let go of the sick role. With regard to perceived relationship dissatisfaction we found that relationship dissatisfaction as perceived by the patient, but not the partner, was weakly related to improvement in fatigue severity. Patients who reported being dissatisfied with their relationship less often showed a clinically significant improvement in fatigue following CBT. It is possible that the more CFS patients are troubled by their partner relationship, the less they can fully engage in CBT and benefit from it. Their limited energy may partly be spent on relationship issues, negative interactions, and difficult emotions, all of which are likely to maintain or even enhance the fatigue. Relationship satisfaction did not predict clinically significant improvement in the severity of functional impairments.

Partners who perceived CFS as a severe and serious condition were more solicitous. Whether partners attributed the illness to physical or psychological causes was, however, not found to influence partners' solicitous responses.

Limitations

One limitation of this study is that we adapted the Brief IPQ for partner use. Based on the results of a

principal components analyses we selected five items instead of the original eight items of the Brief IPQ. The construct validity may therefore be questionable. Furthermore, we used the cluster of items from the subscales Active Engagement and Sympathic/Empathic Responses from the FRQ as indicators for partners' solicitous responses. There might be other questionnaires or instruments available that measure the construct solicitous responses in a more direct way. Although we tried to ensure non-contamination of questionnaires between partners, the fact that not all baseline assessments were completed by the partner at the treatment centre is a limitation. At the treatment centre patients and partners were placed in separate test rooms. Partners who completed the questionnaires at home were instructed to complete the forms in a quiet place without discussing the questions with the patient. However, it is possible that partners did discuss the questions or answers with the patients and that contamination took place. A further limitation of our study is that we did not account for the presence of children at home or living arrangements of the couples (i.e. cohabitating or not) – which will influence how partners and patients interact. Moreover, we did not measure patients' and partners' sexual satisfaction. Data on this subject with regard to CFS are scarce, but the notion emerges that CFS interferes with sexual behaviour and this can have a negative impact on the relationship (Blazquez *et al.* 2009).

Implications

A severe and disabling illness like CFS is challenging for patients and their partners. Future studies are needed to gain more knowledge about what it is in the solicitous behaviour of the partner that reduces the chance of improvement of fatigue and functional impairments. Is it merely giving too much attention to the fatigue and impairments and spending time talking about it? Or, is it primarily about taking over activities and insisting that the patient rests? It would also be interesting to study the effect of (dis)agreements in partner and patient perceptions on CFS on treatment outcome. Further research is also needed to clarify which factors predict relationship dissatisfaction in the patient, and which other relationship aspects might be a predictor for treatment outcome. In this study, we focused on the partner and partner relationship. As stated earlier, the social network of CFS patients contains additional significant others: family members, colleagues, friends, and healthcare providers. The influence of these members on treatment outcome could be examined as well.

Our study provided information on how CBT for CFS could be further improved. It is helpful for

therapists to know that the responses and illness perceptions of the partner influence the outcome of CBT for CFS. Therapists may therefore assess these responses and perceptions before starting CBT and actively change perceptions and responses of the partner if these do not facilitate change in the patient. This, in turn, could improve the outcome of CBT.

Acknowledgements

We thank the patients and partners who participated in this study, Lianne Vermeeren for assistance in data collection, and the therapists of the Expert Centre for Chronic Fatigue of the Radboud University Medical Centre who treated the patients.

Declaration of Interest

None.

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