

Postprint Version	1.0
Journal website	http://www.informaworld.com/smpp/content~db=all~content=a788682333
Pubmed link	
DOI	

This is a NIVEL certified Post Print, more info at <http://www.nivel.eu>

DISSIMILITARY IN PATIENTS' AND SPOUSES' REPRESENTATIONS OF CHRONIC ILLNESS: EXPLORATION OF RELATIONS TO PATIENT ADAPTATION.

HEIJMANS, M. DE RIDDER, D. BENSING, J.

ABSTRACT

Focuses on a study which compared the illness representations of patients suffering from Chronic Fatigue Syndrome and Addison's Disease and those of their spouses. Themes and dimensions used in organizing illness representations; Methodology; Dissimilarity scores for the different dimensions of illness representations; Methodological limitations in relation to the measures and design of the study.

In this cross-sectional study, the illness representations of patients suffering from Chronic Fatigue Syndrome (n = 49) and Addison's Disease (n = 52) and those of their spouses were compared. Couples generally held similar views with regard to the dimensions of illness identity and cause but disagreed on time-line, control/cure, and consequences of the illness. The effects of such dissimilarity in a couple's illness representations on the patient's coping behaviour and adaptation were then examined. Dissimilarity was found to have a weak impact on coping and a rather strong impact on adaptive outcome. In general, minimization of the disorder's seriousness by the spouse was found to have a negative impact on adaptive outcome, although this effect differed with the dimension of illness representation and the type of illness. These results demonstrate the importance of the role of significant others and their beliefs for patient's coping and adaptation with chronic illness.

KEY WORDS: Illness representations, chronic illness, Chronic Fatigue Syndrome, Addison's Disease, coping, spouses, dissimilarity scores.

INTRODUCTION

Long-term disease often means a profound disruption of normal life: patients have to face changes in functioning and appearance, disappearance of social roles, disruption

of plans for the future, and major assaults on their self-image and self-esteem (Burish and Bradley, 1983; Taylor, Helgeson, Reed and Skokan, 1991; Turk, 1979). As many health events are social in nature, the patient's family and friends are also confronted with a number of adaptive tasks in the case of chronic illness (Ell, 1996; Helgeson, 1993; Patterson and Garwick, 1994; Revenson, 1994). Growing empirical literature suggests that the social network of a chronically-ill patient is indeed profoundly affected by the illness. In turn, the response of the social network may influence a patient's health-related behaviours, attempts to alter these behaviours, the symptomatic expression of the disease, and even the course of the disease itself (Kerns and Weiss, 1994; Reich and Zautra, 1995; Thompson and Pitts, 1992). The social network also appears to influence patients' beliefs about health and illness (Croyle and Hunt, 1991).

Surprisingly, health psychologists have largely ignored the social nature of the health beliefs of chronically-ill patients. The large amount of literature on social support reflects the degree of importance assigned by investigators to the role of social interactions in dealing with the stress caused by chronic illness, but very little is known about how social interactions affect patients' ideas and beliefs about chronic illness and their corresponding coping behaviours (Croyle, 1992; Heller, Schwindle and Dusenbury, 1986; Schreurs and de Ridder, 1997). Following the line of reasoning found in social-support research, it may be assumed that not only the supportive interactions themselves but also the beliefs held by people within a patient's social network (expressed in the form of advice or opinions) can affect the patient's illness representations and health-related behaviour. In fact, empirical support for this assumption has been provided by an experiment carried out by Croyle and Hunt (1991), who found individuals even rely on a relative stranger when attempting to evaluate the seriousness of an ambiguous health threat. That is, open minimization of the seriousness of a disorder by another person resulted in lower levels of perceived threat on the part of the patient.

Although the number of studies of illness representations and coping with chronic illness has rapidly increased in the past years, the systematic exploration of the role of significant others in shaping particular illness beliefs has mainly been limited to the experimental work of Croyle and colleagues. In the present study, we have therefore examined the illness beliefs of patients and their spouses in order to determine their joint influence on the coping behaviours and well-being of the patients. Although spouses generally appear to be the most important source of emotional and instrumental support for many patients suffering from chronic illness (Thompson and Pitts, 1992), it is obvious that patients' and spouses' ideas about an illness may diverge. For example, spouses may feel that the consequences of the illness are not as serious as the patient claims, which is expressed as problem minimization (Cohen Silver, Wortman and Crofton, 1990; Wortman and Lehman, 1985). The opposite may also occur: spouses may judge the consequences of an illness as far more serious than patients themselves do. This expresses itself as problem maximization or exaggeration and overprotective behaviour on the part of the spouse ('maximization') with passive coping on the part of the patient as a possible result (Coyne, Wortman and Lehman, 1988; Thompson and Pitts, 1992).

The main question addressed in this study is how a difference in illness representation - either expressed in minimization or in maximization by the spouse - affects the patient's coping behaviour and adaptive outcome. For this purpose, we adopted the model of illness appraisal and coping developed by Leventhal and colleagues (1980) with illness representation as a core concept. Illness representations are defined as "a person's own implicit, common-sense beliefs about illness" (Leventhal, Meyer and Nerenz, 1980, p. 10). They most directly reflect the individual experiences, beliefs, expectations and goals related to health and illness. The model predicts illness representations to be associated with coping and, via coping, with such outcome variables as disability and adaptive functioning. Leventhal's model is particularly useful in the context of the present study because, unlike most other models of illness cognition and coping, it acknowledges the role of social factors in the appraisal of illness and explicitly states that information from significant others may be especially salient during the appraisal stage (Leventhal et al., 1980; Leventhal, Nerenz and Steele, 1984).

Research on a number of illnesses has shown illness representations to be organized around five common themes or dimensions (Leventhal et al., 1980; Lau and Hartman, 1983): identity, time-line, cure, cause and consequences. Identity includes the illness label and knowledge of the symptoms associated with it. Time-line refers to the expectations that a person has about how long the disease is likely to last and the course that it will take. Cause refers to factors responsible for the onset of the illness. Cure refers to the controllability or curability of the illness. Finally, consequences refer to the effects and outcomes of the disease. These dimensions also constitute major points for the sharing of information and development of coping strategies (Leventhal, Leventhal and Van Nguyen, 1985).

In comparing patients' and spouses' illness representations, we will focus on possible differences in each of these five dimensions outlined above. As stated before, the differences between patients' and spouses' representations can go in two directions. Spouses can minimize the seriousness of their partner's disease, by playing down the complaints and consequences of the illness or by exaggerating the possibilities for cure. Spouses can also exaggerate the seriousness of the illness and thereby become overprotective. From the literature on chronic illness and the marital relationship, it is known that spouses try to establish a balance in both their marital relationship and patient's functioning. Minimization or maximization by the spouse serves as a function to establish this balance: when patients minimize their illness, spouses tend to maximize and become overprotective and vice versa (Thompson and Pitts, 1992). In general, expression of maximization or overprotective behaviour by the spouse has been found to negatively affect patients' well-being. It supports sick-role behaviour on the part of the patient and leads to negative consequences for the patient, such as increased dependency, lowered competence, and greater depression (Evans and Miller, 1984; Nerenz and Leventhal, 1983; Thompson and Pitts, 1992). However, it seems likely that the size of the effects of minimization or maximization by the spouse may be moderated by such factors as the characteristics of the disease itself (symptoms, course, treatability) and the quality of the marital relationship. For this reason, we selected two diseases that are similar in one vein but different in another. Addison's Disease (AD) is characterized by an adrenal insufficiency

resulting in symptoms of weakness, fatigue, weight loss and gastrointestinal complaints (Burke, 1992). Although not curable, AD can be managed quite adequately by medication. Given the right dosage, most AD patients function rather well and they have been found to generally minimize the seriousness of their illness (Knappen and Puts, 1993). Therefore, we hypothesize that spouses of AD patients may express their concern just because of patient's minimizing and warn the patient for the seriousness of their illness and the necessity of medication use. We further expect maximization by the spouse to be detrimental for the patient's health in the case of Addison's Disease.

Chronic Fatigue Syndrome (CFS) resembles AD in its most important symptom, which is a persistent and debilitating fatigue, but CFS is also characterized by a multiplicity of other symptoms including muscle and joint pain, concentration difficulties and mood disturbances (Fukuda, Straus, Hickie, Sharpe, Dobbins and Komaroff, 1994; Komaroff and Buchwald, 1991). In contrast to AD patients, CFS patients experience their illness as extremely disabling and as bringing about severe limitations in their previously vital lifestyles. CFS patients have to cope with an illness for which there is no diagnostic test so far and for which well-established treatment is lacking (Wilson, Hickie, Loyd and Wakefield, 1994), although the results of two controlled studies on the effects of cognitive behaviour therapy appear to be promising (Deale, Chalder, Marks and Wessely, 1997; Sharpe, Hawton and Simkin, 1996). Patients suffering from CFS have been found to exaggerate the seriousness of their illness (Fry and Martin, 1996). They can be characterized by an increased focus on bodily symptoms, a tendency to attribute their illness to a physical cause, and avoidance of physical activity as a coping strategy (Sharpe et al., 1996). The latter may actually be maladaptive and in fact cause greater burden as the illness becomes chronic (Petrie, Moss-Morris and Weinman, 1995). Therefore, we hypothesize that spouses will minimize the seriousness of CFS, partly because of the vague character of the illness, but mostly in an attempt to cheer the patients up and to motivate the patient to some activity. We further believe that minimization by the spouse will positively affect patients' well-being.

METHOD

Subjects

The sample consisted of 49 CFS patients, 52 AD patients, and their spouses. The couples were selected from the database of a larger study (N=315) on illness - perceptions and coping in chronic illness (Heijmans and de Ridder, in press). All patients were recruited via patient organizations and selected for this study according to the following criteria: being married, agreement to have their spouse involved in the study, age between 18 and 65 years, and a diagnosis of CFS or AD by a medical practitioner. The mean age of the CFS patients, most of them (92%) female, was 40.4 years (SD = 10.3) and the mean age of their spouses was 42.7 years (SD = 10.5). The couples had been married for an average of 18.1 years (SD = 11.1), the majority of them (86%) being married before the onset of CFS. The patients had suffered complaints for a mean of 7.6 years (SD = 7.4) but were only recently diagnosed as CFS patients (M = 2.5, SD = 2 years). The mean age of the AD patients, many of them (72%) female, was 45.3 years (SD = 12.4) and the mean age of their spouses

was about the same ($M = 45.9$, $SD = 14.3$ years). The couples had been married for an average of 23.4 years ($SD = 14.8$). Like the CFS patients, the majority of the AD couples (71%) were already married before the onset of the illness. The patients had a mean illness duration of 16.5 years ($SD = 13.3$) and had been diagnosed as AD patients for a mean of 11.6 years ($SD = 9.9$). When compared to the CFS patients, the AD patients were significantly older ($t(99) = -2.15$, $p < 0.05$), longer ill ($t(99) = -4.83$, $p < 0.001$), diagnosed earlier ($t(99) = -5.63$, $p < 0.001$), married for a longer period of time ($t(99) = -3.18$, $p < 0.05$), and more often male ($t(99) = 2.73$, $p < 0.01$).

Procedure

The patients were interviewed at home with their spouses not present during the interview. The interview was designed to gain detailed insight into the patients' illness representations and the consequences of illness for both themselves and their spouses. At the end of the interview, the patients were asked to give their partner a written questionnaire with questions pertaining to the spouse's representation of the partner's disease. The questionnaires were returned in a self-addressed stamped envelope.

Measures

For both patients and their spouses, the representations of the particular illness were assessed: For the patients only, their view of the marital relationship, their coping, and the adaptive outcome were also assessed.

The illness representations were measured by assessing the five cognitive dimensions found in previous research to characterize people's representations of illness: identity, time-line, control/cure, cause and consequences (Leventhal et al., 1980, 1984; Lau and Hartman, 1983). Illness identity was measured as the number of symptoms identified as being typical for the illness. A 20-item symptom list was used, including 12 common symptoms taken from the Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris and Home, 1996). An additional 8 symptoms central to the medical definitions of the respective illnesses were also included. Participants rated the symptoms on a 4-point scale, ranging from "never" to "all the time." An illness identity score was then computed by summing the scores for the 20 symptoms, with higher scores indicating a stronger, more concrete model of illness. Internal consistencies were computed for both diseases and for the patients and spouses separately; they were all found to be satisfactory ($\alpha > 0.75$).

The time-line dimension contained three items pertaining to the expected course of the illness: that is, whether the illness was likely to improve over time, stay the same, or get worse. A high score on this dimension was indicative of more pessimistic ideas about the course of the illness. Internal reliability was rather low ($\alpha = 0.59$ and 0.58) for CFS patients and their spouses but satisfactory ($\alpha > 0.70$) for the AD patients and their spouses.

The control/cure dimension was measured by 2 items pertaining to the extent to which the condition was thought to be controllable. A high score reflected a stronger

belief in controllability or cure. The internal consistency for this dimension was satisfactory for the CFS patients and their spouses ($\alpha > 0.70$), but rather low for AD patients and their spouses ($\alpha = 0.54$ and 0.63).

The cause dimension was measured by 15 items related to possible causes of the illness. Factor analysis with varimax rotation of the data from the CFS patients and their spouses revealed three scales referring to a belief in a biological cause (virus, flu, immune dysfunction), a psychological cause (stress, personality or depression, workaholic, lack of rest) and an environmental cause (chemicals, malnutrition, pollution, sprayed food, use of medication). Taken together, the three scales explained 52% of the variance; all had eigenvalues > 1.5 and proved reliable ($\alpha > 0.70$). The mean scores for each cause scale were then computed. As expected, little variation appeared in the answers of the AD patients and their spouses who almost unanimously believed in a biological cause. The cause dimension for AD patients was therefore dropped from the correlational analyses.

The consequences dimension consisted of five items pertaining to the impact of the disease on everyday life. A higher score on this dimension is indicative of more serious consequences. The reliability of the scale proved satisfactory ($\alpha > 0.70$). In sum, all of the dimensions of illness representation proved reliable with a few exceptions, which we will discuss at a later point. The reliabilities are also similar to what has been found in other studies of illness representations in chronic illness (Hampson, Glasgow and Toobert, 1990; Hampson, Glasgow and Zeiss, 1994; Moss-Morris, Petrie and Weinman, 1996).

The quality of the marital relationship from the perspective of the patient was measured using three variables. (1) Satisfaction with the relationship consisted of four items (e.g. "Since the onset of the illness, I feel my relationship has improved") ($\alpha > 0.70$). (2) Burden on spouse or the extent to which the patient felt his or her disease was a burden for the spouse consisted of four items (e.g. "My spouse finds it difficult to accept my illness") ($\alpha = 0.68$ for CFS patients and 0.69 for AD patients). (3) Social support or an indication of the extent to which the patients felt supported by their spouse consisted of five items (e.g. "My spouse is interested in the way I feel" or "My spouse comments upon the way I handle my illness") ($\alpha = 0.63$ for CFS patients and 0.72 for AD patients). Both the CFS patients and the AD patients were found to be rather satisfied with their marital relationship but to feel differently about the burden their illness caused for their spouses ($T = 3.72$, $df = 96$, $p < 0.01$). The CFS patients believed their spouses had more problems accepting their illness and, as a consequence, criticized their management of the illness with the provision of unrequested help or advice. They also differed in the extent to which they felt supported by their spouses ($T = -2.66$, $df = 96$, $p < 0.01$), with the CFS patients being less happy than the AD patients in this regard.

Coping was measured using a shortened version of the Utrecht Coping Questionnaire (Schreurs, Van de Willige, Tellegen and Brosschot, 1993), which is a Dutch coping measure with satisfactory psychometric properties (Schaufeli and Van Dierendonck, 1992). We used the three-dimensional solution of the UCL measuring three possible ways of coping: (1) problem-focused coping (six items) ($\alpha = 0.81$ for CFS and

0.89 for AD), (2) palliative coping (four items) ($\alpha = 0.62$ for CFS and 0.80 for AD) and (3) emotion-focused coping (five items) ($\alpha = 0.78$ for CFS and 0.75 for AD). CFS patients reported using more problem-focused coping strategies ($t(98) = 2.96, p < 0.01$), and emotion-focused coping strategies ($t(98) = 4.33, p < 0.001$) than AD patients did.

Adaptive outcome was measured using four scales of the Short Form Health Survey-36 (Ware and Sherbourne, 1992). These include the (1) Physical Functioning Scale, (2) Social Functioning Scale, (3) Mental Health Scale and (4) Vitality Scale. The internal consistency of the scales was found to be satisfactory ($\alpha > 0.75$). High scores on the scales are indicative of positive well-being. The CFS patients reported a significantly higher level of impairment than the AD patients on the physical functioning scale ($t(99) = -7.98, p < 0.001$), social functioning scale ($t(99) = -8.54, p < 0.001$), and vitality scale ($t(99) = -6.24, p < 0.001$).

RESULTS

Comparison of Illness Representations

In Table 1, the results for the five dimensions of illness representation for the CFS patients, AD patients and their spouses can be found. In general, the CFS patients scored high on illness identity and consequences, held rather negative ideas about the time-line of the illness and strongly believed in a biological explanation for the onset of their illness. The AD patients, in contrast, scored moderately on illness identity, low on consequences, and were rather positive with regard to the time-line of their illness. As mentioned earlier, they strongly agreed on a biological explanation for their illness.

Paired t-tests revealed no significant differences between the mean scores for the CFS patients and their spouses on the identity, control/cure, or cause dimensions. At a group level, the CFS patients and spouses appear to agree on the core symptoms of the illness and the possibilities for cure. They also have similar ideas about the causes of CFS: both the patients and their spouses predominantly believe in a biological cause. In fact, "immune system dysfunction" was the most favoured biological attribution. However, large differences exist between the CFS patients and their partners with regard to the time-line and consequence dimensions. When compared to their spouses, the patients had a stronger belief that their illness would improve or, at worst, stay the same. The CFS patients were also more convinced than their spouses of the serious consequences of the illness.

The spouses of AD patients rated the consequences of the illness more seriously than their sick partners. The remaining dimensions show results similar to those for the CFS patients and their spouses. That is, AD patients and their spouses appear to hold the same view on the core characteristics of AD and about the causing agents but divergent opinions with regard to the time-line and control/cure dimensions. The AD patients were more optimistic than their spouses about the course of their illness, and they were more convinced that they could control it either by treatment or by their own behaviour. In general, the spouses of both AD and CFS patients tended to exaggerate their partner's illness in the sense that they were more pessimistic about

the future course of the illness and about the possibilities for control/cure than their sick partners were. The spouses of AD patients were also more pessimistic in their assessment of the consequences of the illness than the spouses of CFS patients who tended to 'minimize' the consequences of their partners' illness.

Dissimilarity Scores

Dissimilarity scores for the different dimensions of illness representation were computed for each couple by subtracting the spouse's score from the sick partner's score.⁽ⁿ¹⁾ In such a manner, a continuous variable was created that describes the direction of difference from the spouses framework, i.e., as maximizing or minimizing relative to the patients ratings. The descriptive statistics for the dissimilarity scores are presented in Table 2. The percentages in the first column of Table 2 reflect the frequency with which spouses minimized or maximized as compared to their sick partner on a particular dimension. As can be seen from this column, spouses of AD patients generally maximized the seriousness of AD on all dimensions of illness representation: they reported more symptoms, worse consequences and were less optimistic about the time-line and possibilities for cure than their sick partner. In contrast, spouses of CFS patients generally minimized the seriousness of CFS: they reported less symptoms, less serious consequences and were more optimistic about the possibilities for cure. The correlations between the dissimilarity scores and the individual scores for both the patients and the spouses were all found to be above 0.50 and below 0.80. This shows the dissimilarity scores to reflect the beliefs of both sets of spouses, on the one hand, and to tell us more than the patient scores and spouse scores alone, on the other hand. An exception is the dissimilarity score for the AD group on the consequences dimension. This score correlates much more strongly with the spouse ratings than with the patient ratings, which shows this score to represent the ideas of the spouse in particular.

Dissimilarity Scores in Relation to Coping, Adaptive Outcome and Quality of the Marital Relationship

Correlations were computed to detect any associations between the dissimilarity scores for the different dimensions of illness representation, and coping, adaptive outcome, and the perceived quality of the marital relationship. As can be seen in Table 3, dissimilarity is only weakly associated with the coping strategies employed by the AD patients but strongly associated with several aspects of adaptive outcome. When dissimilarity is high because spouses maximize the number of symptoms (identity), the expected duration of the disorder (time-line) and its consequences, patients are better adjusted, that is, they have higher scores on the scales measuring physical and social functioning, psychological adjustment and vitality.

The association of dissimilarity in the illness representations of CFS patients and their spouses to the measures of coping and adaptive outcome for the CFS patients was found to be generally weak, as can be seen in Table 4. Nevertheless, palliative coping and emotion-focused coping appear to relate to a dissimilarity in the views of patients and their partners with regard to the course, cause of CFS, possibilities for cure, and consequences of their illness. Palliative coping is fostered by a more

pessimistic view of the course of the illness, less confidence in the possibilities for cure, greater doubt about the role of psychological and environmental factors on the part of the spouse. Maximization of the consequences of CFS together with minimization of the role of psychological and environmental factors by the spouse also encourage emotion-focused coping. A more positive perception of the time-line of the illness by the spouse is associated with less problems in functioning (i.e., a better adaptive outcome for CFS). A less strong belief in the role of biological factors on part of the spouse correlated positively with problems in vitality and social functioning. In sum, the pattern of association between the dissimilarity scores and the measures of coping and adaptive outcome for both groups shows the dissimilarity scores to be somewhat associated with the adaptive outcomes. In Addison's Disease particularly when couples disagree on the identity, time-line, and consequences of the illness, in CFS when couples disagree on the time-line and cause of illness.

Examination of the correlations between the dissimilarity scores and the perceived quality of the marital relationship for the two groups shows a consistent pattern of less satisfaction being associated with a higher degree of dissimilarity in the illness representations. This particularly appears to be the case when the spouse holds a more negative and pessimistic view of the possibilities for cure and time-line of illness. Of course, our data do not allow us to draw conclusions about the direction of these associations. Comparison of the AD couples with the CFS couples, however, shows patients to generally be happier with the relationship when their spouse recognizes and acknowledges their illness.

Explanation of Coping and Adaptive Outcome

To find out whether divergent views on the identity, time-line, cure, cause, and consequences of illness can actually help explain the coping and adaptive outcomes for CFS patients and AD patients, we performed a number of hierarchical regression analyses. The control variables age, gender and illness duration were omitted because they did not significantly relate to any of the outcome variables nor to any of the dimensions of illness representation. In the CFS group the marital status variables 'feelings of support' and 'relationship satisfaction', and in the Addison group 'feelings of support' were omitted for the same reason. In our final model, the marital status variables were entered first, and then the dissimilarity scores. The results show only palliative coping to be explained by the independent variables. For AD patients, minimization of the possibilities for cure by the spouse explained 26% of the variance in palliative coping. For CFS patients, minimization of the consequences and the role of environmental factors in the etiology of CFS on the part of the spouse together with a more pessimistic time-line perception accounted for 32% of the variance in palliative coping.

To predict adaptive outcome, the hierarchy of steps followed in the regression analysis parallels our hypothetical model in which adaptive outcome can be explained by the manner in which patients perceive the marital relationship, which presumably affects the way in which patients and spouses represent the illness. In Tables 5 and 6, the results of four series of multiple regression analyses with these two clusters of independent variables on physical functioning, social functioning,

psychological adjustment, and vitality are presented. As can be seen from Table 5, the physical functioning, social functioning, psychological adjustment, and vitality of patients with AD are explained rather well. Dissimilarity scores added most to the explanation of adaptive outcome. When dissimilarity is high because the spouse has more pessimistic ideas about the time-line of AD, patients are better adjusted, that is, they have higher scores on all scales of functioning. Minimization of the characteristic symptoms of AD explained some of the variance in physical and social functioning. A feeling of being a burden to the spouse contributed significantly to the prediction of problems in social functioning.

For the CFS patients, only psychological adjustment and social functioning were explained by the independent variables. Minimization of the symptoms of illness and the role of psychological factors together with a maximization of the role of environmental factors on the part of the spouse meant more problems in psychological adjustment. A feeling of being a burden to the spouse appeared to play a role in social functioning, although the increase in the amount of variance explained by the total set of independent variables was not significant.

DISCUSSION

The present study constitutes a small step towards gaining greater insight into the way in which dissimilar illness representations on the part of patients and their intimates may affect patients' adaptation to their condition. Our results clearly show that, when one partner has fallen ill, spouses can diverge in the way they think about illness, even when they are happy with their relationship. Both the spouses of CFS patients and AD patients hold more pessimistic views with regard to the time-line of the illness than patients themselves. They also think differently than the patients about the symptoms, consequences and possibilities for cure of the illness: the spouses of CFS patients are inclined to minimize the seriousness of the illness on these dimensions, while the spouses of AD patients are inclined to maximize or exaggerate the seriousness. These findings are in line with our hypotheses. At this point however, it should be stressed that minimization or maximization by the spouse is only in relation to the beliefs of the patient. This was most interesting to us as we hypothesized that minimization or maximization by the spouse serves as a function to establish a balance in both the marital relationship and patient's functioning. From a methodological point of view it could be argued that the spouse's minimizing or maximizing of the consequences dimension is due to already extreme scores on part of the patients in these groups. From the literature, for example, CFS patients are known for exaggerating the consequences of their illness (Fry and Martin, 1996) while, AD patients have been found to trivialize the consequences of their illness (Knapen and Puts, 1993). This makes maximization in the one case and minimization in the other case less likely to occur. In our opinion however, it is more likely that minimization or maximization reflects the spouse's concern or "worry" about the manner in which the patient is coping with the illness. The results from the spouse questionnaires clearly show the spouses of AD patients to feel a need to curb the enthusiasm of their sick partner for undertaking activities while the spouses of CFS patients try to motivate their partner to fight the illness to a greater degree and to become more active.

From the literature on chronic illness, it is known that diverging views on an illness can constitute a great source of stress (Leventhal et al., 1985). When satisfaction with the marital relationship was found to be low in our study, either as a cause or a consequence of the illness, patients tended to feel misunderstood by their spouse. We originally hypothesized that minimization would positively affect patient's well-being and that maximization would lead to negative consequences for the patient. Our data only partly confirm these hypothesis. Minimizing appears to be more detrimental for the patient's adjustment than maximization, although the actual impact depends on the nature of the disease and the particular dimension of illness representation. Spouses of AD patients who minimize the identity and consequences of the illness and are more optimistic about the time-line of illness appear to negatively influence the well-being of their sick partner as a higher level of impairment is found for all aspects of adaptive outcome, in this case. When the spouses of CFS patients are more optimistic about the time-line of the illness, in contrast, the CFS patients appear to benefit. This finding, then, confirms in part our hypotheses. However, minimization of the role of biological factors was also found to be associated with more problems in vitality and social functioning for CFS patients. The tendency of CFS patients to favour physical disease as the basis for their symptoms and to reject psychological explanations has been noted in many studies (Manu, Lane and Matthews, 1989).

Our finding that minimization generally correlates positively with higher levels of impairment contradicts the findings of Croyle and Hunt (1991) mentioned in the introduction. This discrepancy can possibly be explained by the fact that the expression of more optimistic views in the case of chronic illness is less adaptive than when expressed in the context of immediate health threat (as in the experiment of Croyle and Hunt). Minimizing the seriousness of being chronically ill may give the patient the impression of not being taken seriously. In the literature on social support and chronic illness, for example, problem minimization is commonly seen as unhelpful by the patient (Wortman and Lehman, 1985). And this may be particularly the case for AD patients. AD patients generally function rather well, and this is also expressed in their illness representations. The risk of looking healthy, however, is that outsiders do not fully realize that the AD patient is ill. This may also be an explanation for the strong correlation between minimization by the spouse and high levels of impairment on part of AD patients. Minimization also correlated negatively with feelings of marital satisfaction, support feelings and positively with the patients' feelings that their illness is a burden to their spouses. In other words, patients with spouses who minimize their illness find it more difficult to accept and handle the illness. A spouse who acknowledges the illness and is realistic about the future course of the illness seems to be most beneficial for AD Patients. CFS patients, in contrast, are constantly struggling for recognition of their complaints as constituting a real medical problem. Moreover, CFS is a very unpredictable disease for both patients and spouses. Being optimistic about the time-line of the illness thus provides support for the patient, as we found and it seems that CFS patients benefit most from a spouse who recognizes the seriousness of the illness but remains optimistic about recovery at the same time. Examination of the relation between the various outcome measures and marital satisfaction showed not marital satisfaction but the burden on

the spouse to be most important. If the feeling of being a burden to the spouse was high, both AD and CFS patients reported more problems in social functioning.

The fact that the correlations between the dissimilarity scores and the measures of adaptive outcome are far more robust for the AD patients than for the CFS patients is in need of greater consideration. It is possible that the beliefs of CFS patients and their spouses are more in agreement than the beliefs of AD patients and their spouses. The results in Tables 1 and 2 support this assumption. If only a small difference exists between the individual scores for the patients and the spouses, then the dissimilarity scores will vary less and weaker correlations are the results. Another possible explanation is that Addison patients do not fully realize the chronicity and potential uncontrollability of their illness because their symptoms react so well to medication. Maximization on part of the spouse is then more likely. A third possible explanation is based on the fact that CFS patients tend to feel substantially more ill than AD patients and CFS is more visible than AD. The possibility of the patients' and spouses' illness representations matching in the case of CFS is thus greater than in the case of AD.

Finally, methodological limitations in relation to the measures and design of the present study need to be noted. First, both of the illness groups have been drawn from self-help groups. This may limit the representativeness of the sample. Second, because this study involved a single assessment of the couple's ideas, it was not possible to study the process of mutual influence over time, which would certainly present a more accurate view of the way in which couples deal with chronic illness. In order to determine the actual value of using the illness representations of spouses and patients, corroboration from prospective study is needed. Such prospective study would also allow us to test the validity and reliability of the measures used here and to test our implicit assumption that patients and spouses actually express their own beliefs about the illness in question. Now, of course, we do not know the extent to which the patient has been influenced by the spouse's ideas or behaviour. Nor do we know to what extent the illness representations of the spouse are a reflection of patients adjustment or a tool to reach a balance in the relationship with their sick partner (as hypothesized). With regard to the reliability of the measures of illness representation, our present data reveal small reliability coefficients for the time-line dimension of CFS patients and the control/cure dimension for AD patients. The fluctuating course of CFS and the fact that control/cure have a different meaning in the case of chronic illness are likely to be one of the causes of these small coefficients. Despite these methodological limitations, the results of the present study suggest that the simultaneous study of the illness representations of patients and their spouses may be particularly fruitful for understanding the way in which illness beliefs develop and the role of significant others and their beliefs in patient adaptation.

[table 1]

[table 2]

[table 3]

[table 4]

[table 5]

[table 6]

ACKNOWLEDGEMENTS

We would like to thank the statisticians Dr. Gerard Maassen and Dr. Jos Dessens, Utrecht University, for their help and advice in preparing the dissimilarity scores for this study. We also thank two anonymous referees for their comments on earlier versions of this manuscript.

References

- Burish, T.G. and Bradley, L.A. (1983). Coping with chronic disease: Definitions and issues. In: T.G. Burish and L.A. Bradley (Eds.), *Coping with Chronic Disease* (pp. 3-12). New York: Academic Press.
- Burke, C.W. (1992). Primary adrenocortical failure. In: A. Grossman (Ed.), *Clinical Endocrinology* (pp. 393-404). Oxford: Blackwell.
- Cohen Silver, R., Wortman, C.B. and Crofton, C. (1990). The role of coping in social support provision: the self-presentational dilemma of victims of life crises. In: B.R. Sarason and I.G. Sarason (Eds.), *Social Support: An Interactional View* (pp. 397-427). New York: Wiley.
- Coyne, J.C., Wortman, C.B. and Lehman, D.R. (1988). The other side of support. Emotional involvement and miscarried helping. In: B.H. Gottlieb (Ed.), *Marshalling Social Support: Formats, Processes and Effects* (pp. 305-330). Newbury Park: Sage Publications.
- Croyle, R.T. (1992). Appraisal of health threats: cognition, motivation, and social comparison. *Cognitive Therapy and Research*, 16, 165-182.
- Croyle, R.T. and Hunt, J.R. (1991). Coping with health threat: social influence processes in reaction to medical test results. *Journal of Personality and Social Psychology*, 60, 382-389.
- Deale, A., Chalder, T., Marks, I. and Wessely, S. (1997). A randomized controlled trial of cognitive behavior therapy versus relaxation therapy for chronic fatigue syndrome. *American Journal of Psychiatry*, 154, 408-414.
- Evans, R.L. and Miller, R.M. (1984). Psychosocial implications of treatment of stroke. *Social Casework: The Journal of Contemporary Social Work*, 65, 242-257.
- Ell, K. (1996). Social networks, social support and coping with serious illness: the family connection. *Social Science and Medicine*, 42, 173-183.
- Fry, A.M. and Martin, M. (1996). Fatigue in the Chronic Fatigue Syndrome: a cognitive phenomenon? *Journal of Psychosomatic Research*, 41, 415-426.
- Fukuda, K., Straus, S., Hickie, I., Sharpe, M.C., Dobbins, J.G. and Komaroff, A. (1994). The Chronic Fatigue Syndrome: a comprehensive approach to its definition and study. *Annals of Internal Medicine*, 121, 953-959.
- Hampson, S.A., Glasgow, R.E. and Toobert, D.J. (1990). Personal models of diabetes and their relations to self-care activities. *Health Psychology*, 9, 632-646.
- Hampson, S.A., Glasgow, R.E. and Zeiss, A.M. (1994). Personal models of osteoarthritis and their relation to self-management activities and quality of life. *Journal of Behavioral Medicine*, 17, 143-158.
- Heijmans, M. and Ridder, D. de (in press). Structure and determinants of illness representations in chronic disease: A comparison of Addison's Disease and Chronic Fatigue Syndrome. *Journal of Health Psychology*.
- Helgeson, V.S. (1993). The onset of chronic illness: its effect on the patient-spouse relationship. *Journal of Social and Clinical Psychology*, 12, 406-428.
- Heller, K., Schwindle, R.W. and Dusenbury, L. (1986). Components of social support processes: Comments and integration. *Journal of Consulting and Clinical Psychology*, 54, 466-470.

- Kerns, R.D. and Weiss, L.H. (1994). Family influences on the course of chronic illness: a cognitive-behavioral transactional model. *Annals of Behavioral Medicine*, 16, 116-121.
- Knapen, M.H.J.M. and Puts, P.H.M. (1993). Addison patients in the Netherlands. Social aspects, final results. Dutch Addison Society, Den Haag.
- Komaroff, A. and Buchwald, D. (1991). Symptoms and signs of Chronic Fatigue Syndrome. *Review of Infectious Diseases*, 13(suppl 1): S8-S11.
- Lau, R.R. and Hartman, K.A. (1983). Common sense representations of common illnesses. *Health Psychology*, 2, 167-185.
- Leventhal, H., Leventhal, E.A. and Nguyen, T. van (1985). Reactions of families to illness: theoretical models and perspectives. In: D.C. Turk and R.D. Kerns (Eds.), *Health, Illness and Families - a Life-Span Perspective* (pp. 108-147). New York: John Wiley & Sons.
- Leventhal, H., Meyer, D. and Nerenz, D.R. (1980). The common-sense representation of illness danger. In: S. Rachman (Ed.), *Medical Psychology* (Vol. II) (pp. 7-30). New York: Pergamon Press.
- Leventhal, H., Nerenz, D.R. and Steele, D. (1984). Illness representations and coping with health threats. In: A. Baum and J. Singer (Eds.), *Handbook of Psychology and Health* (pp. 229-252). Hillsdale, NJ: Erlbaum.
- Manu, P., Lane, T. and Matthews, D. (1989). Somatization disorder in patients with chronic fatigue. *Psychosomatics*, 30, 388-395.
- Nerenz, D.R. and Leventhal, H. (1983). Self-regulation theory in chronic illness. In: T. Burish and L. Bradley (Eds.), *Coping with Chronic Disease: Research and Applications* (pp. 13-37). New York: Academic Press.
- Moss-Morris, R., Petrie, K.J. and Weinman, J. (1996). Functioning in chronic fatigue syndrome: Do illness perceptions play a regulatory role? *British Journal of Health Psychology*, 1, 15-25.
- Patterson, J.M. and Garwick, A.W. (1994). The impact of chronic illness on families: A family systems perspective. *Annals of Behavioral Medicine*, 16, 131-142.
- Petrie, K.J., Moss-Morris, R. and Weinman, J. (1995). Catastrophic beliefs and their implications in the chronic fatigue syndrome. *Journal of Psychosomatic Research*, 39, 31-37.
- Reich, J.W. and Zautra, A.J. (1995). Spouse encouragement of self-reliance and other-reliance in rheumatoid arthritis couples. *Journal of Behavioral Medicine*, 18, 249-260.
- Revenson, T.A. (1994). Social support and marital coping with chronic illness. *Annals of Behavioral Medicine*, 16, 122-130.
- Schaufeli, W. and Dierendonck, D. van (1992). The reliability and validity of the Utrecht Coping List. *Gedrag en Gezondheid*, 20, 38-45.
- Schreurs, K.M.G. and Ridder, D.T.D. de (1997). Towards an integration of coping and social support in chronic diseases. *Clinical Psychological Review*, 17, 89-112.
- Schreurs, P.J.G., Willige, G. van de, Tellegen, B. and Brosschot, J.F. (1993). *The Utrecht Coping List-Manual*. Lisse: Swets & Zeitlinger.
- Sharpe, M., Hawton, K. and Simkin, S. (1996). Cognitive behaviour therapy for chronic fatigue syndrome: a randomized controlled trial. *British Medical Journal*, 312, 22-26.
- Taylor, S.E., Helgeson, V.S., Reed, G.M. and Skokan, L.A. (1991). Self-generated feelings of control and adjustment to physical illness. *Journal of Social Issues*, 47, 91-109.
- Thompson, S.C. and Pitts, J.S. (1992). In sickness and in health: chronic illness, marriage, and spousal caregiving. In: S. Spacapan and S. Oskamp (Eds.), *Helping and Being Helped: Naturalistic Studies* (pp. 115-151). Newbury Park: Sage publications.
- Turk, D.C. (1979). Factors influencing the adaptive process with chronic illness: Implications for intervention. In: I.G. Sarason and C.D. Spielberger (Eds.), *Stress and Anxiety* (Vol. 6) (pp. 291-311). Washington: Hemisphere.
- Ware, J.E. and Sherbourne, C.D. (1992). The MOS 36-item short form health survey. *Medical Care*, 30, 473-483.
- Weinman, J., Petrie, K.J., Moss-Morris, R. and Home, R. (1996). The Illness Perception Questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health*, 11, 431-445.
- Wilson, A., Hickie, I., Loyd, A. and Wakefield, D. (1994). The treatment of chronic fatigue syndrome: science and speculation. *American Journal of Medicine*, 96, 544-560.

Willet, J.B. (1989). Some results on reliability for the longitudinal measure of change: Implications for the design of studies of individual growth. *Educational and Psychological Measurement*, 49, 587-602.

Wortman, C.B. and Lehman, D.R. (1985). Reactions to victims of life crises: support attempts that fail. In: I.G. Sarason and B.R. Sarason (Eds.), *Social Support: Theory, Research and Applications* (pp. 498-516). Dordrecht, The Netherlands: Martinus Nijhoff.

Tables

Table 1 Means and standard deviations of patients' and spouses' ratings on the different dimensions of illness representation

Legend for Chart:

- A - Dimension
- B - CFS Patient (n = 49)
- C - CFS Spouse (n = 49)
- D - CFS p
- E - AD Patient (n = 52)
- F - AD Spouse (n = 52)
- G - AD p

A	B	E	C	F	D	G
Identity (1-4)	2.59 (0.41)		2.55 (0.40)			ns
		1.90 (0.53)	1.96 (0.54)			ns
Time-line (1-4)	2.49 (0.84)		3.41 (0.75)			<0.001
		1.90 (0.85)	3.17 (0.76)			<0.001
Control/cure (1-3.9)	2.15 (0.92)		1.93 (0.73)			ns
		2.35 (0.84)	2.03 (0.82)			<0.05
Cause						
Biological (1-4)	3.45 (0.75)		3.53 (0.55)			ns
		3.89 (0.35)	3.91 (0.44)			ns
Psychological (1-4)	1.96 (0.66)		1.94 (0.63)			ns
		1.14 (0.21)	1.09 (0.27)			ns
Environment (1-4)	1.97 (0.70)		1.84 (0.58)			ns
		1.23 (0.35)	1.21 (0.40)			ns
Consequence (1-3.5)	2.67 (0.46)		1.91 (0.35)			<0.001
		1.60 (0.48)	2.59 (0.66)			<0.001

Note: CFS = Chronic Fatigue Syndrome; AD = Addison's Disease.

Table 2 Means, standard deviations, and correlations with the individual patient's and spouse's ratings on the illness representation dimensions for dissimilarity scores

Legend for Chart:

- A - Nature of spouse's dissimilarity in percentages
- B - (%)
- C - M(SD)
- D - Range
- E - Patient score r
- F - Spouse score r

A	B E	C F	D
Spouse Min CFS Identity	61 0.53[***]	0.04 (0.41) -0.51[***]	0.01-1.2
Spouse Max Ad Identity	52 0.68[***]	0.60 (0.42) -0.69[***]	0.05-1.8
Spouse Max CFS Time-line	63 0.70[***]	1.20 (0.87) -0.65[***]	0.05-3.0
Spouse Max Ad Time-line	75 0.66[***]	1.35 (0.95) -0.67[***]	0.02-3.0
Spouse Max CFS Cure	51 0.80[***]	1.14 (0.76) -0.77[***]	0.07-2.5
Spouse Min AD Cure	60 0.77[***]	1.05 (0.75) -0.76[***]	0.02-2.9
Spouse Max CFS Biol. cause	70 0.77[***]	0.59 (0.63) -0.51[**]	0.01-2.5
Spouse Max CFS Psych. cause	57 0.64[***]	0.56 (0.50) -0.55[***]	0.01-2.2
Spouse Min CFS Env. cause	53 0.70[***]	0.60 (0.50) -0.49[***]	0.01-2.0
Spouse Min CFS Consequences	88 0.82[***]	0.83 (0.51) -0.70[***]	0.05-2.3
Spouse Max AD Consequences	89 0.63[***]	1.13 (0.63) -0.82[***]	0.13-2.5

Note: CFS = Chronic Fatigue Syndrome; AD = Addison's Disease; Min = spouses score lower on this variable than patients; Max = spouses score higher on this variable than patients. [***] $p < 0.001$.

Table 3 Pearson's correlations between dissimilarity scores for different dimensions of illness representation and measures of coping, adaptive outcome, and quality of the marital relationship for Addison Disease patients (N = 52)

Legend for Chart:

- B - Identity
- C - Time-line
- D - Cure
- E - Consequences

A	B	C
	D	E
Coping		
Problem-focused coping	0.01	-0.17

Palliative coping	0.09	0.02
Emotion-focused coping	0.32[**]	0.26[*]

	-0.02	-0.08
	0.25[*]	-0.02
	-0.08	0.14

Adaptive outcome

Physical functioning	-0.32[**]	-0.38[***]
Social functioning	-0.39[***]	-0.57[***]
Psychological adjustment	-0.14	-0.37[***]
Vitality	-0.27[*]	-0.39[***]

	0.01	-0.30[**]
	0.07	-0.48[***]
	0.24[*]	-0.26[*]
	0.18	-0.36[***]

Quality of the marital relationship

Feelings of support	-0.33[**]	0.14
Burden on spouse	0.00	0.40[***]
Relationship satisfaction	0.18	0.02

	-0.09	-0.26[*]
	-0.02	0.14
	-0.35[**]	-0.09

Note: Omission of the cause dimension because AD patients and their spouses completely agreed on a biological cause.

[*] p < 0.05;

[**] p < 0.01;

[***] p < 0.001.

Table 4 Pearson's correlations between dissimilarity scores for different dimensions of illness representation and measures of coping, adaptive outcome, and quality of the marital relationship for Chronic Fatigue Syndrome patients (N = 49)

Legend for Chart:

- B - Identity
- C - Time-line
- D - Cure
- E - Consequences
- F - Biol. cause
- G - Psych. cause
- H - Envir. cause

	A	B	C	D
	E	F	G	H
Coping				
Problem-focused coping		-0.15	0.10	-0.14

	0.13	-0.08	0.07	0.19
Palliative coping		-0.17	-0.31[*]	0.25[*]
	-0.07	0.14	0.31[*]	0.41[***]
Emotion-focused coping		0.15	-0.22	0.19
	-0.24[*]	0.08	0.27[*]	0.31[*]
Adaptive outcome				
Physical functioning		0.20	0.42[**]	0.02
	0.09	0.04	-0.07	0.15
Social functioning		0.21	0.17	-0.08
	0.08	-0.30[**]	-0.09	-0.16
Psychological adjustment		-0.23	0.30[**]	0.06
	-0.19	0.14	-0.09	0.24
Vitality		-0.19	0.25[*]	-0.09
	0.19	-0.29[**]	-0.07	0.15
Quality of the marital relationship				
Feelings of support		-0.13	0.07	0.08
	-0.19	0.11	0.03	-0.20
Burden on spouse		0.28[*]	-0.19	0.25[*]
	0.04	0.18	0.29[*]	0.10
Relationship satisfaction		-0.01	0.11	-0.19
	0.22	0.46[***]	0.02	-0.17

[*] $p < 0.05$;

[**] $p < 0.01$;

[***] $p < 0.001$.

Table 5 Results of regression analyses to predict aspects of adaptive outcome for Addison Disease patients (N = 52)

Legend for Chart:

- B - Physical functioning beta
- C - Physical functioning AR^2
- D - Physical functioning change p
- E - Social functioning beta
- F - Social functioning AR^2
- G - Social functioning change p
- H - Psychological adjustment beta
- I - Psychological adjustment AR^2

J - Psychological adjustment change p
 K - Vitality beta
 L - Vitality AR²
 M - Vitality change p

	A	B	C	D	E
		F	G	H	I
		J	K	L	M
Step 1		0.19[***] [*]	0.02 [***]	ns 0.09[*]	0.07[*] [*]
Spouse's burden		0.10		-0.18	-0.30[**]
			-0.20[*]		
Relationship satisfaction		0.27[*] [*]	[***] 0.16	[**] 0.20	0.11
Step 2		0.43[***]	0.22[**]	0.28[**]	0.14[*] [**]
d-Identity		-0.24[*]		-0.06	-0.24[*]
			-0.04		
d-Time-line		-0.43[***]		-0.29[*]	-0.29[*]
			-0.28[**]		
d-Control/cure		0.01		0.26[*]	-0.05
			0.17		
d-Consequences		-0.08		-0.22	-0.20
			-0.27[**]		

Note: d-Identity means dissimilarity score on the illness representation dimension Identity.

[*] p<0.05;
 [**] p<0.01;
 [***] p<0.001.

Table 6 Results of regression analyses to predict aspects of adaptive outcome for Chronic Fatigue Syndrome patients (N = 49)

Legend for Chart:

B - Physical functioning beta
 C - Physical functioning AR²
 D - Physical functioning change p
 E - Social functioning beta
 F - Social functioning AR²
 G - Social functioning change p
 H - Psychological adjustment beta

I - Psychological adjustment AR²
 J - Psychological adjustment change p
 K - Vitality beta
 L - Vitality AR²
 M - Vitality change p

	A	B	C	D	E
		F	G	H	I
		J	K	L	M
Step 1		0.11[**] ns	0.01 [**]	ns 0.00	0.03 ns
Spouse's burden		-0.11	-0.05	-0.27	-0.40[**]
Step 2		0.15 [**]	0.08 ns	ns 0.05	0.25[**] ns
d-Identity		0.18	-0.15	-0.29[*]	0.30[*]
d-Time-line		0.41[*]	0.22	0.28[*]	0.06
d-Control/cure		0.14	-0.01	0.11	0.08
d-Consequences		0.03	0.21	-0.19	0.11
d-Biol. cause		0.01	-0.31[*]	0.25	-0.30[*]
d-Psych. cause		-0.17	-0.20	-0.34[*]	-0.04
d-Envir. cause		0.23	0.25	0.38[*]	0.02

Note: d-Identity means dissimilarity score on the illness representation dimension Identity.

[*] p<0.05;
 [**] p<0.01;
 [***] p<0.001.