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Coping and adaptive outcome in chronic fatigue syndrome: Importance of illness cognitions

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Abstract

In this study, the relations between illness representations, coping behavior, and adaptive outcomes in chronic fatigue syndrome (CFS) patients ($N=98$) were examined. Following Leventhal's self-regulation model, it was hypothesized that illness representations would be directly related to coping and, via coping, to adaptive outcome. The results showed patients who considered their illness to be a serious condition, who believed that they had no control over their illness, who saw little possibility for cure, and who believed their illness to have serious consequences to cope with their illness in a passive way, report higher levels of impairment in physical and social functioning and report greater problems in mental health and vitality. A series of regression analyses showed illness representations to be stronger predictors of adaptive outcome than coping scores. The implications of these findings for the treatment of CFS patients are discussed.

Introduction

Patients with chronic fatigue syndrome (CFS) experience persistent and debilitating fatigue that brings about severe limitations in their previously vital and productive lifestyles. The fatigue is often accompanied by other symptoms such as muscle weakness, myalgia, cognitive difficulties, and mood changes 1, 2. The etiology of CFS along with its symptomatology and management continue to be a source of controversy 3, 4. The course of the illness varies from patient to patient: most patients remain ill or worsen over time, and only a minority improve 5, 6, 7, 8. Because of the serious consequences of CFS for both the personal and social life of patients, the factors responsible for adaptive outcome and level of illness burden are now being studied. Two factors considered to play a crucial role are the illness cognitions and the coping responses of the patient 7, 9, 10, 11, 12. The present study is aimed at gaining greater insight into the nature of these illness cognitions and coping behaviors and how these factors influence adaptive outcome. For this purpose, we adopted the self-regulation model of illness cognition and behavior developed by Leventhal and colleagues [13]. Central to this model are the representations that patients hold about their illness, whereby illness representations are defined as "patients' own implicit, common-sense beliefs about their illness" [13,

p. 10]. The self-regulation model predicts that illness representations are directly related to coping and, via coping, to adaptive outcomes such as disability and quality of life. Research into a number of illnesses has shown illness representations to be generally organized along five major dimensions [13](#), [14](#): *identity* or the label assigned to the illness and knowledge of the symptoms associated with it; *time-line* or the course that the illness takes; *cause* or beliefs about the factors that are responsible for illness onset; beliefs about the possibilities for *cure*; and beliefs about the *consequences* of the illness for a person's life.

Clinical studies have mainly provided information about the beliefs that CFS patients hold with regard to the identity and cause of their illness. The coping strategies of CFS patients have also received attention, and CFS patients 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 [9](#), [15](#), [16](#). The latter may actually be maladaptive and in fact cause greater burden as the illness becomes chronic [6](#), [7](#), [8](#), [16](#), [17](#), [18](#), [19](#).

In light of these findings, it seems useful to further explore the illness cognitions of CFS patients. A major question is whether physical attribution and avoidance of physical activity are, indeed, most important for adaptive outcome or if other cognitions also play an important role. In an empirical study of the cognitive and behavioral factors involved in CFS, for example, Moss-Morris et al. [\[20\]](#) found CFS patients to have a particularly negative view of not only the cause of their illness but also its symptoms, expected course, consequences, and possibilities for cure.

Another point in need of greater attention is the relation between illness representations and coping. Self-regulation theory predicts that illness representations will be directly related to coping and, via coping, to adaptive outcome. Coping is assumed to mediate in self-regulation theory between illness representations and adaptive outcome [21](#), [22](#). The results of the study of Moss-Morris et al. [\[20\]](#), however, suggest that illness representations may also directly affect adjustment.

The main aim of the present study was to examine the implications of patients' illness representations for adaptive outcome in greater detail. Three specific research questions were formulated for this purpose: (1) In what ways do the illness representations of CFS patients resemble each other? Given the level of uncertainty with regard to the cause, course and treatment possibilities for CFS, we wondered whether this uncertainty would also be reflected in the illness representations of patients with CFS. (2) Are the beliefs held by CFS patients with regard to the identity, course, treatment possibilities, cause, and consequences of their illness clearly related to their coping strategies, adaptive outcome, or both? (3) What is the relative impact of the patients' illness representations on adaptive outcome when compared to the impact of the coping strategies they use?

Method

Sample

Subjects were 150 CFS patients randomly selected from the database of the Dutch association of CFS patients. These subjects were sent a letter inviting them to participate in a study dealing with the perception of and coping with CFS, accompanied by a written questionnaire intended to assess a number of dimensions of CFS. A total of 135 CFS patients returned the questionnaire (90%). Of these patients, 98 were subsequently interviewed to gain greater insight into their illness representations. Those interviewed had all been diagnosed by a GP or a specialist as having CFS and were between 18 and 65 years of age. The results presented in this article pertain to the 98 persons interviewed. The sample consisted of 84 women and 14 men, with a mean age of 41.9 years ($sd=10.6$). The majority of the subjects were married (65%), and 43% of the subjects had one or more children. Only 22% of the subjects had paid employment, and 28.6% were highly educated. The time since first complaint ranged from 0.5 to 32 years ($m=7.44, sd=7.28$). Diagnosis was made anywhere from 0.5 to 14 years prior ($m=2.46, sd=2.43$).

Measures

The illness representations, coping, and functioning of the patients were assessed in the interview by a number of structured questions and allowing the patients to explain their answers. Sociodemographic information was obtained with a written questionnaire.

The illness representations were measured using the five cognitive dimensions found in previous research to characterize people's representations of illness: identity, time-line, control/cure, cause, and consequences^{13, 14, 21}. Illness identity was measured as the number and frequency in which symptoms are endorsed as part of the illness. We used a 20-item list including 12 common symptoms taken from other questionnaires (e.g., the Illness Perception Questionnaire [22]), and 8 symptoms central to the recently formulated case definition of the illness [1]. The participants rated these symptoms on a four-point scale ranging from "never" to "constantly." The illness identity score was computed by averaging the scores for the 20 symptoms, with higher scores indicating stronger illness identity. Cronbach's α for this scale was 0.82. The cause dimension was measured with 15 items referring to the possible causes of CFS. The list includes the causes most frequently mentioned in response to an open-ended question at initial assessment: "In your opinion, what caused your illness?" Factor analysis showed three dimensions underlying the responses of the patients: a biological one (two items, $\alpha=0.63$); a psychological one (five items, $\alpha=0.72$); and an environmental one (five items, $\alpha=0.70$). A belief in a biological cause could pertain to a virus or a defect immune system. A belief in a psychological cause could pertain to stress, personality, or depression. A belief in an environmental cause could pertain to chemicals, pollution, or sprayed food (for example). The remainder of the interview items were designed to address the other three dimensions of illness representation: time-line, control/cure, and consequences. We computed a one-dimensional solution for each of these three dimensions of illness representation using Princals.1 Time-line (three items, $\alpha=0.66$) contained questions on the expected course of the illness: whether the illness is likely to improve in time; stay the same; or get worse. A high score on this dimension is indicative of a more chronic time-line perception. The control/cure dimension (two items, $\alpha=0.72$) addressed patients' beliefs about control of the disease. A higher score on this dimension is indicative of a greater belief in effective control/cure. The consequences dimension of illness representation (five items, $\alpha=0.67$) referred to the impact of the disease on the patient's lifestyle and family, the extent to which the disease has changed the patient's life, and how difficult it has been to adapt to the illness. A higher score on this dimension is indicative of more serious consequences.

The α values for the five different dimensions of illness representation were found to be satisfactory even when small numbers of items were taken into consideration. These reliability scores are comparable to those found in other studies, even though the measurement techniques and operationalization of the dimensions of illness representation differed 20, 22, 23, 24.

Coping was assessed with the shortened version of the Utrecht Coping Questionnaire [25], a Dutch measure consisting of seven conceptually different subscales and satisfactory psychometric properties [26]. The UCL is a generic measure of coping, applicable for the assessment of stressors in general or in specific situations; the subjects are asked to respond on the basis of their own illness. Five of the scales most relevant to coping with chronic illness were used in the context of the present study: problem-focused coping (six items, $\alpha=0.80$); behavioral-avoidant coping (three items, $\alpha=0.63$); cognitive-avoidant coping (four items, $\alpha=0.77$); venting emotions (two items, $\alpha=0.61$); and seeking social support (five items, $\alpha=0.85$). The CFS patients primarily reported use of problem-focused coping ($m=2.94$ on a scale ranging from 1="rarely" to 4="very often," $sd=0.55$). Cognitive-avoidant coping ($m=2.03, sd=0.69$) and behavioral-avoidant coping ($m=2.02, sd=0.62$) were least reported.

Adaptive outcome

Four scales from the 36-item Short-Form Health Survey [27] were used to measure adaptive outcome: a ten-item Physical Functioning Scale ($\alpha=0.87$); a two-item Social Functioning scale ($\alpha=0.79$); a five-item Mental Health Scale ($\alpha=0.85$), and a four-item Vitality Scale ($\alpha=0.75$). The scales measure physical functioning, social functioning, psychological adjustment, and subjective well-being, respectively. Higher scores on these scales indicate more positive functioning, adjustment, or well-being. CFS patients were found to score low on all of the scales with the exception of mental health.

Results

Illness representations

The mean number of symptoms from the 20-item symptom list considered as part of their illness by CFS patients (expressed by a score "sometimes" to "continuously") was found to be 17.03 ($sd=2.51$). Patients considered psychological symptoms such as melancholia or sleeping difficulties just as much a part of their illness as such physical symptoms as muscle weakness, nausea, or fever. A mean score of 2.64 on the identity dimension (Table I) indicates that patients experienced the aforementioned symptoms very regularly. This mean score was taken for further analysis. Although patients saw psychological symptoms as part of their illness, they did not generally believe that their illness was caused by psychological factors. In response to an open-ended question during initial assessment, 57% of the subjects mentioned a physical cause for their illness (predominantly viral infection); 24% mentioned psychological factors such as stress and lifestyle; 11% mentioned environmental factors such as pollution or chemicals; 4% mentioned heredity or fate; and another 4% had no idea about etiological factors. As can be seen from Table I, the same picture emerged in the interview. Although the mean number of causes considered by the subjects to be part of their illness was 9.3 ($sd=3.0$; range 1–15), they predominantly believed in a biological cause, followed by psychological and environmental causes. Mean scores on these three dimensions were taken in further analyses. It is of interest to note that this preference for a biological cause is also reflected in the label patients give to their illness: 96% of the patients labeled their illness as myalgic encephalomyelitis (ME), which emphasizes the physical aspects of the illness; only four patients preferred the label chronic fatigue syndrome, which carries no etiological implications [9].

[table 1]

The mean scores on the time-line, control/cure, and consequences dimensions of illness representation show CFS patients generally to consider their illness as serious and having major impact on their daily life and health in general. At the same time, however, many of the patients report being rather optimistic about the future course of their illness and treatment possibilities.

Correlations among dimensions of illness representation

To avoid type 1 errors, a significance level of $p<0.01$ was adopted for these and later calculations. As can be seen in Table II, some strongly significant relations exist between the different dimensions of illness representation. Respondents reporting larger numbers of symptoms characteristic of CFS were also found to experience their illness as less controllable, more chronic, and believe CFS to have more serious consequences. Similarly, assumption of a chronic time-line was associated with a belief in less control and more serious consequences. Those believing in a psychological or environmental cause experienced more control over their illness than those believing in a biological cause, which itself correlated with a belief in serious consequences.

[table 2]

Illness representations, coping and adaptive outcome

The correlations between the dimensions of illness representation, coping strategies, and aspects of adaptive outcome are presented in Table III. In general, the dimensions of illness representation were more strongly related to adaptive outcome than to coping.

[table 3]

With regard to the dimensions of illness representation and coping, strong illness identity was positively related to the use of behavioral- and cognitive-avoidant coping strategies and negatively related to social support seeking. Whereas an assumption of a more chronic time-line correlated negatively with problem-focused coping, seeking social support, and venting emotions, such an assumption correlated positively with cognitive-avoidant coping. A belief in illness controllability or cure was associated with less cognitive-avoidant coping and more problem-focused coping. A belief in serious consequences appeared to encourage behavioral-avoidant coping and discourage the venting of emotions. The causal beliefs with regard to the illness correlated only minimally with the use of particular coping strategies: belief in a biological cause appeared to encourage support seeking, whereas belief in an environmental cause appeared to encourage problem-focused coping.

Examination of the correlations between the dimensions of illness representation and adaptive outcome showed strong illness identity, perception of the time-line as chronic, and assumption of serious consequences to be related to greater impairment in all areas of functioning. A clear belief in control over the illness was associated with less impairment in physical functioning, mental health, and vitality. A belief in a biological cause was associated with fewer mental health problems but more problems with vitality. Finally, a belief in a psychological cause correlated with more mental health problems.

The correlations between coping strategies and aspects of adaptive functioning (not presented) were generally weak, with the exception of cognitive-avoidant coping which negatively related to social functioning ($r=-0.26$, $p<0.01$), mental health ($r=-0.63$, $p<0.001$), and vitality ($r=-0.30$, $p<0.001$). Both problem-focused coping and the seeking of social support were positively related to mental health ($r=0.25$, $p<0.01$ and $r=0.32$, $p<0.001$ respectively). No coping strategy was found to be significantly related to physical functioning.

Explanation of coping strategies and adaptive outcome using regression analysis

To determine whether the beliefs of CFS patients with regard to the identity, course, controllability, cause, and consequences of their illness contribute to the adaptation of particular coping strategies and the occurrence of a particular adaptive outcome, a number of regression analyses were undertaken. In the model used to explain coping, the variables age, gender, and illness duration were first controlled for (step 1). The scores for the dimensions of illness representation were entered at step 2. The results (not presented) show the dimensions of illness representation to only add significantly to the explanation of the variability in the scores for cognitive-avoidant coping and social support seeking. Particularly, a strong illness identity appeared to foster cognitive-avoidant coping. A belief in a biological cause fostered social support seeking. And strong illness identity negatively influenced social support-seeking. In general, the amount of variance explained by the preceding patient characteristics and the dimensions of illness representation was rather small.

In Table IV, the results of a series of regression analyses predicting physical functioning, social functioning, mental health, and vitality are presented. The steps reflect a model in which adaptive outcome is assumed to depend on coping, which is in turn assumed to depend on illness representation. The control variables of age, gender, and illness duration were once again entered at step one. As might be expected on the basis of the correlation matrix itself, the information on coping strategies contributes only minimally to explanation of the variance in adaptive outcome, although passive coping appears to produce mental health problems. In general, cognitive-avoidant coping seems to be most important for explaining impairment of social functioning, mental health, and vitality. Venting emotions significantly contributed to the explanation of problems in physical functioning. Two dimensions of illness representation appear to be particularly important for explanation of the aspects of adaptive outcome other than mental health. Identity and consequences were significantly related to impairment in physical functioning. Together with a belief in a biological cause, these dimensions of illness representation were also found to be important for the explanation of vitality. Finally, a strong illness identity, perception of the illness time-line as chronic, and belief in a psychological cause were most important for explaining the variability in mental health problems.

[table 4]

Discussion

On the basis of Leventhal's self-regulatory model, we expected illness representations to shape the manner in which patients cope with their illness and thereby influence the adaptive outcome for the patients. In fact, we found both illness representations and coping strategies to play a role in the adaptive functioning of CFS patients. All the dimensions of illness representation and passive coping in particular consistently related to different aspects of adaptive outcome. Our data also showed the illness representations of CFS patients to relate to their coping in the following manner: a stronger illness identity, more pessimistic view of the course of the illness, and limited beliefs in the possibilities for cure were positively related to the use of avoidant coping strategies, and negatively related to the venting of emotions, seeking of social support, and occurrence of problem-focused coping. Examination of the regression equation nevertheless shows the power of the different dimensions of illness representation to predict coping to be rather small. A possible explanation for this limited power may be our choice of a generic coping list to measure patients' coping with CFS. The coping scales from the UCL are designed for use in a variety of situations and may therefore miss some specific aspects of coping with CFS. In contrast, the items pertaining to illness representation in the present study are very specific to CFS. It has also been suggested by other researchers that a coping list tailored to the specific tasks of CFS patients may be more appropriate [19].

One of the most important findings in the present study is that illness representations appear to be a stronger predictor of vitality, physical functioning, and social functioning than coping strategies. The identity dimension of illness representation showed the most significant associations to physical functioning and vitality. In this respect, our results are the same as the results of Moss-Morris et al. [20] in her study of CFS patients, and Hampson et al. [24] in a study of osteoarthritis patients. It might be argued that illness identity may simply be a manifestation of disease pathology and that the severity of the illness and not the individual's perception of the symptoms is responsible for such poor adaptation [20]. However, there are at least two reasons to doubt this explanation, which have also been suggested by Moss-Morris et al. [20]. First, illness identity was operationalized in the present study with only 8 of the 20 items specifically pertaining to CFS [1]. Second, there are no known indicators of disease severity for CFS. Studies that have attempted to assess the relationship between symptom reports and disease abnormalities in CFS have found no relationship between these variables

over time [28]. In this study, then, it seems unlikely that the number of symptoms confounds illness identity with severity of biological disturbance. However, the operationalization of illness identity certainly needs greater attention and corroboration from more objective disease parameters might be necessary.

The intercorrelations observed among the dimensions of illness representation suggest that illness representations should be conceptualized as groups of beliefs or schemata instead of single cognitions. The strong correlation between the identity and the time-line dimensions suggests that patients take more severe or frequent symptoms to be an indicator of a worsening disease state. In her observations of medical patients, Surawy et al. [29] has indeed found CFS patients to often believe that every aggravation of symptoms is harmful and increases the risk of "relapse." As a consequence, activities that may aggravate the symptoms of CFS are avoided.

The illness representations of the CFS patients interviewed in our study confirm the findings of other research showing an external attribution of cause and increased symptom monitoring among CFS patients. The high scores on the identity dimension support the notion that CFS patients are predisposed to attribute symptoms of illness to CFS. Recall that the list of symptoms consisted of both specific symptoms of CFS and also everyday complaints. No differences were observed in the frequency with which the patients attributed the different symptoms to CFS, however. The CFS patients were also found to be convinced of the serious consequences of their illness for daily life. Moss-Morris and colleagues [30] compared CFS patients' illness representations with those of patients suffering from rheumatoid arthritis, diabetes, chronic back pain, or depression, and found CFS patients to consistently have more negative representations of their illness. They were also more likely to attribute their illness to a virus or pollution than to their own behavior. We also found our CFS patients to attribute their illness to predominantly biological causes. Another characteristic of the subjects assessed in the present study was the relative absence of mental health problems despite high levels of reported physical and social impairment along with low vitality. Surawy et al. [29] found the report of an anxious or depressed mood in response to direct questioning to be construed as a consequence of fatigue and not as the primary problem by the patients themselves. Put differently, Surawy often observed marked resistance to any suggestion of psychological or social factors being the cause of illness, which might also explain the report of only minor mental health problems by the subjects in our own study.

The tendency of CFS patients to favor physical disease as the basis for their symptoms and to reject psychological explanations has been noted in many studies 15, 31. It has been suggested that attribution to a physical cause may relieve the person of responsibility for the illness and thereby promote helplessness and discourage active behavior aimed at recovery [9]. In the present study, however, attribution to a physical cause was not found to be related to avoidant coping or a poor adaptive outcome, with the exception of vitality. It is possible that categorization of the causal beliefs of CFS patients as biological, psychological, or environmental is an oversimplification of their reality. Ray et al. [32] pointed out that the causal explanations provided by CFS patients tend to be very complex. The fact that the respondents in the present study considered a mean of 9.3 factors responsible for their illness also points in this direction.

We found cognitive-avoidant coping to be the most important of the coping strategies for predicting adaptive outcome. The UCL scale "cognitive-avoidant coping" involves giving up and withdrawal of any effort to deal with the illness, which negatively relates to social functioning, mental health, and vitality. Cognitive-avoidant coping occurs when a person has negative expectations of coping outcomes. Cognitive-avoidant coping correlated strongly in the present study with a more chronic perception of the time-line for the illness and the belief that CFS is an uncontrollable illness. These results suggest

that interventions designed at encouraging some sense of control over the illness and altering the negative expectations and beliefs about its course, treatment possibilities, and consequences could be important for improving the functioning of CFS patients. Avoiding activity should be discouraged, with social support-seeking and the venting of emotions offered as a possible alternative.

A final critical point pertains to the potential limitations of using a cross-sectional design for the study of chronic disease. In this light, however, Moss-Morris [33] found the illness representations of CFS patients to be remarkably stable over time: the 6-month test–retest correlations for illness identity, consequences, and control/cure were all greater than 0.70. The test–retest correlation for time-line was 0.54 and significantly above change. CFS is an ongoing stressor for most patients. This means that the process of appraisal is actually a continual process of reappraisal [13]. The initial appraisal may influence the adaptive outcome, and the adaptive outcome will influence future illness appraisal. In testing theoretical models, only a part of this ongoing process has been examined. Replication with a prospective design and repeated measures at different phases in the illness process would therefore be valuable.

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Tables

Table 1. Measures of illness representation, coping and adaptive outcome

	M	SD
Dimensions of illness representation (range 1–4)		
Identity (20 items)	1.91	.61
Time line (3 items)	1.94	.80
Control (2 items)	2.21	.87
Consequences	2.19	.82
Coping strategies (range 1–4)		
Problem-focused coping	2.61	.67
Behavioural avoidant coping	1.99	.62
Social support seeking	2.10	.57
Emotion venting	1.94	.62
Cognitive avoidant coping	1.75	.60
Adaptive functioning (range 1–100%)		
Physical functioning	77%	22%
Social functioning	73%	21%
Mental health	71%	17%
Vitality	54%	20%

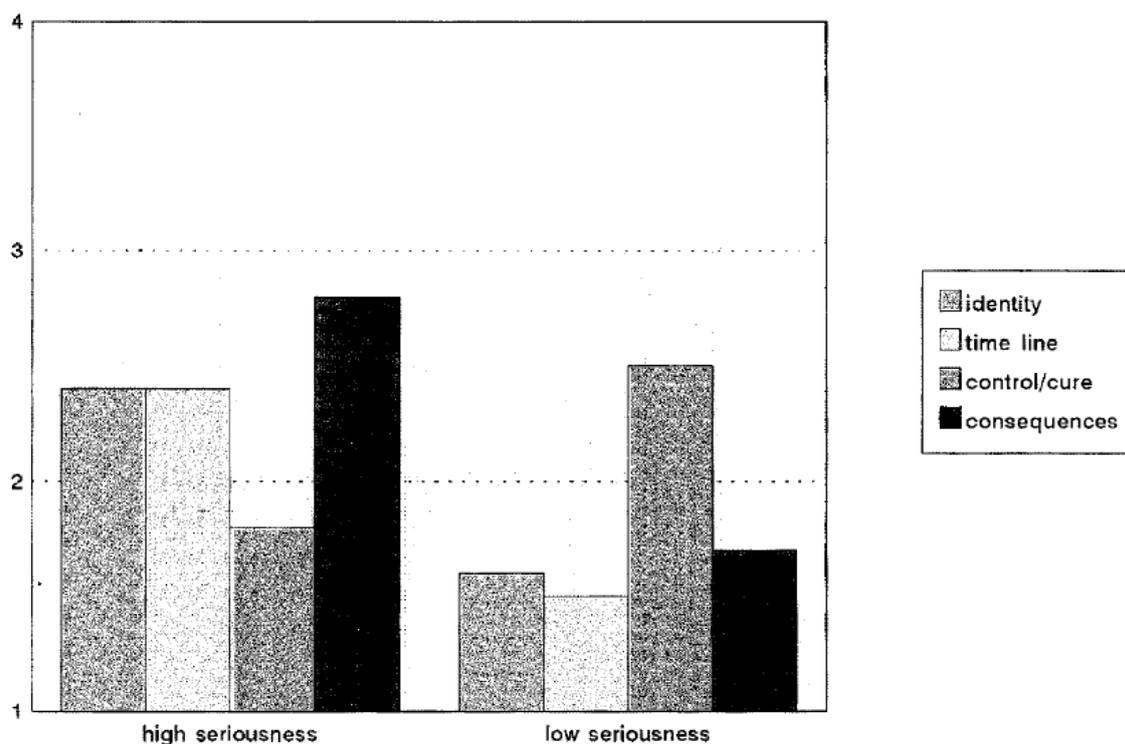


Figure 1. Illness representation clusters.

Table 2. Pearson correlations between different dimensions of illness representation, coping, and adaptive outcome

	Identity	Time line	Control/cure	Consequences
Coping				
Problem-focused	-.04	-.18	.15	-.15
Behavioural avoidant	.18	.40**	-.15	.20
Social support seeking	.24	-.03	-.09	.05
Cognitive avoidant	.66**	.29*	-.25*	.47**
Emotion venting	.28*	.07	-.16	.21
Adaptive outcome				
Physical functioning	-.58**	-.41**	.29*	-.53**
Social functioning	-.63**	-.37**	.31**	-.65**
Mental health	-.51**	-.26*	.37**	-.39**
Vitality	-.68**	-.38**	.47**	-.59**

* $p < .01$; ** $p < .001$.

Table 3. Results of regression analyses to predict different aspects of adaptive outcome from the illness representation clusters

Independent variable	Dependent variables							
	Physical functioning		Social functioning		Mental health		Vitality	
	β	AdjR ²	β	AdjR ²	β	AdjR ²	β	AdjR ²
Low seriousness ^a	.57***	.31***	.70***	.48***	.40***	.15***	.62***	.37***

* $p < .05$; ** $p < .01$; *** $p < .001$.

^aDichotomous variable (0 = no/1 = yes).

Table 4. Results of regression analyses to predict different aspects of adaptive outcome from coping strategies and the illness representation clusters

Independent variables	Dependent variables											
	Physical functioning			Social functioning			Mental health			Vitality		
	β	AdjR ²	Δ	β	AdjR ²	Δ	β	AdjR ²	Δ	β	AdjR ²	Δ
Step 1		.10*	*		.34***	***		.47***	***		.26**	**
Problem-focused coping	-.13			.05			.16			.02		
Behavioural avoidant coping	.05			-.15			-.03			.18		
Seeking social support	.07			.08			.02			-.10		
Venting emotions	.01			-.13			-.04			-.14		
Cognitive avoidant coping	-.19		***	-.34**		***	-.66***		n.s.	-.21		***
Step 2		.28***			.54***			.46***			.48***	
Low seriousness ^a	.51***			.52***			.02			.56***		

* $p < .05$; ** $p < .01$; *** $p < .001$.

^aDichotomous variable (0 = no/1 = yes).