

# Adaptive Tasks, Coping and Quality of Life of Chronically Ill Patients

*The Cases of Parkinson's Disease  
and Chronic Fatigue Syndrome*

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## Abstract

This article is a report of a larger study on the relationship between adaptive tasks, coping and quality of life, taking Parkinson's disease and chronic fatigue syndrome (CFS) as examples. The concept of adaptive tasks or disease-related stressors testing the adaptive capacities of chronically ill patients ( $N=134$ ) was explored by applying the method of concept mapping. Results show that patients both with Parkinson's disease and with CFS generally refer to the same themes when asked for the adaptive tasks their disease brings about. However, the actual contents of these adaptive tasks differ as well as their impact on coping and quality of life. In the case of patients with Parkinson's disease, objective disease characteristics appear to be more important in predicting quality of life than in the case of patients with CFS, whose evaluation of adaptive tasks is predictive of quality of life.

## Keywords

*adaptive tasks, chronic disease, chronic fatigue syndrome, coping, Parkinson's disease, quality of life*

LIVING WITH CHRONIC DISEASE makes great demands on the capacity to adapt: preserving a reasonable emotional balance, sustaining relationships with family and friends, dealing with pain and other symptoms, and developing and maintaining adequate relationships with health care professionals all take their toll. In particular, chronic disorders with an unpredictable course, such as rheumatoid arthritis, multiple sclerosis, Parkinson's disease or chronic fatigue syndrome (CFS), can test adaptive capacities to the full: work, relationships, and future plans have to be seen from a totally different perspective. These and other consequences of suffering from a chronic disease can be studied from the perspective of stressful situations. That is, chronic disease may be viewed as a major stressful life event which is the starting point of a chronic stressful condition characterized by a large number of 'minor' events (Cohen & Lazarus, 1979; Moos & Schaefer, 1984; Morse & Johnson, 1991). The stress perspective on chronic disease predicts that the way stressors are dealt with affects health and well-being, expressed in terms of quality of life or other indicators. Generally speaking, many chronic patients appear to make more use of emotion-focused and avoidant coping strategies, which are often associated with increased psychological distress, and thereby may be a risk factor for adverse responses to illness (De Ridder & Schreurs, 1996; Felton & Revenson, 1984; Maes, Leventhal, & De Ridder, 1996; Mishel & Sorenson, 1991; cf. Suls & Fletcher, 1985).

Although a number of studies corroborate these findings, other studies show that, depending on their personal characteristics and the stage and type of disease, many chronic patients do not limit their coping attempts to avoidant and/or emotion-focused strategies, but in fact use multiple strategies (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Heim, Augustiny, Blaser, Bürki, Kühne, Rothenbühler, Schaffner & Valach, 1987; Manuel, Roth, Keefe, & Brantley, 1987; Newman, Fitzpatrick, Lamb, & Shipley, 1990). There is also some evidence to suggest that those who employ multiple coping strategies may cope better with chronic disease than those who engage in a predominant coping style (Manuel et al., 1987). One rationale for this finding is

that coping strategies may be most effective when they are matched to the particular problem for which they are most useful (Lazarus & Folkman, 1984; Vitaliano, DeWolfe, Maiuro, Russo, & Katon, 1990). If people have multiple coping strategies available to them, they may be more able to engage in this matching process than those who have a predominant coping style (Collins, Taylor, & Skokan, 1990). An answer to the question as to which coping strategies work best for managing chronic illness, then, is complex, depending on which aspects of the disease an individual is coping with at a particular point in time in the adjustment process.

Viewed from this perspective, avoidant or emotion-focused coping strategies may also have a beneficial effect, depending on the kind of stressors confronting patients. For example, it has been argued that in case of uncontrollable diseases, engaging in emotion-focused strategies like positive reappraisal or suppression may be more adaptive than persisting with unfruitful attempts to control the situation (Stephoe, Sutcliffe, Allen, & Coombes, 1991; cf. Miller, 1992). However, few studies have taken into consideration the extent to which particular disease characteristics influence the employment and effect of coping responses. This is surprising, since in the general literature on coping, several researchers have acknowledged its situation-specific nature (Carver & Scheier, 1994; De Ridder & Te Vaarwerk, 1995; Perrez & Reicherts, 1992). This study was designed to provide a preliminary answer to the question as to whether different diseases create different types of stressors and, as a result, make different demands on ways of coping. To explore the issue of disease-specific coping patterns and their impact on well-being and quality of life, it is first necessary to categorize relevant disease characteristics.

This study, then, highlights patients' subjective evaluations of *adaptive tasks* associated with particular diseases (cf. Cohen & Lazarus, 1979; Moos & Schaefer, 1984). Several attempts have been made to make such an inventory of adaptive tasks. Moos and Schaefer (1984), for example, divide the psychological tasks generated by being ill into direct illness-related tasks and more general tasks. Tasks directly related to being ill are dealing

with pain, incapacitation and other symptoms, dealing with a hospital environment and special treatment procedures, and developing and maintaining adequate relationships with health care staff; more general tasks are preserving a reasonable emotional balance, preserving a satisfactory self-image and maintaining a sense of competence and mastery, sustaining relationships with family and friends, and preparing for an uncertain future (Moos & Schaefer, 1984). Although these tasks proposed by Moos and Schaefer appear to be an adequate listing of potential stressors facing chronic patients, due to the lack of empirical evaluation it remains unclear whether they are equally relevant for different types of chronic diseases. Yet, adaptive tasks may vary according to disease characteristics such as the availability of adequate treatment or the social reactions evoked by the disease, as is demonstrated in studies on the stressors related to particular diseases, like cancer (Dunkel-Schetter et al., 1992; Schag, Heinrich, Aadland, & Ganz, 1990), rheumatoid arthritis (Van Lankveld, Näring, Van der Staak, Van 't Pad Bosch, & Van de Putte, 1993) and HIV infection (Siegel & Krauss, 1991).

The results of the rare studies on adaptive tasks demonstrate that a systematic comparison of disease-specific stressors may be a promising way to explore the associations between disease-specific coping patterns and quality of life, as is also suggested in Somerfield's (1997) plea for a problem-specific systems approach of coping and adaptation. This article is a preliminary report of a larger study on these issues and focuses on the conceptualization of adaptive tasks, taking Parkinson's disease and CFS as examples. Both Parkinson's disease and CFS are characterized by a highly unpredictable course but differ with respect to medical knowledge of the cause and, as a result, they also differ in medical acknowledgement and the reactions of medical staff and other support providers. The primary focus of this article, then, is to report on adaptive tasks as experienced by patients suffering from Parkinson's disease or CFS by means of *concept mapping* (see next section). We think this approach may offer an important contribution to our knowledge since it allows both for bottom-up conceptual analysis and 'traditional'

statistical procedures. In addition, we present some preliminary figures about the associations between adaptive tasks, coping and quality of life, as well as a first analysis of the impact of adaptive tasks related to specific diseases on coping and quality of life within each patient group.

## Method

### Sample

The sample consisted of 89 patients with Parkinson's disease and 45 patients with CFS. Both Parkinson's disease patients and CFS patients were recruited via patient organizations. Although we have no information on motives for participation, we suspect that particularly active members reacted positively. In this sense, the results of the study may not be representative of the views held by other patients suffering from these diseases. Patients with Parkinson's disease (43 percent women) were aged 44 to 80 years (mean age 61.6 years, SD 9.6). Most patients (76 percent) were married; the others were divorced (14 percent) or widowed (10 percent). Due to their age and the disease, only 10 percent were in paid employment. About 48 percent had finished vocational training, 44 percent had finished high school, and only 8 percent had finished college or university. In contrast, the CFS sample (83 percent women) was much younger (mean age 41.3 years, SD 7.9). Many of them (57 percent) were married, 15 percent were divorced and 28 percent had never been married. Although many patients were well educated (34 percent had finished vocational training, 35 percent had finished high school and 31 percent had finished college or university), and were willing to work, most of them were unable to do so due to their illness (only 24 percent were in paid employment).

### Procedure

Both patients with Parkinson's disease and those with CFS were asked to participate in the study by an invitation in their patient organization's newsletter. Those who responded positively received a questionnaire on disease characteristics, coping and quality of life, as well as an open-ended format questionnaire on 'both positive and negative aspects of life they felt as a direct consequence of being ill', designed to

collect items for a more systematic exploration of adaptive tasks by means of the method of concept mapping.

### *Concept mapping*

The concept mapping method was used to gather information on the subjective beliefs that patients hold on adaptive tasks facing them. Concept mapping (Trochim, 1989) provides a procedure that helps subjects express their views: they first use free association on the topic under study, and then, after these associations have been printed on cards, subsequently sort these associations into content and priority dimensions. Using statistical analysis consisting of both multidimensional scaling and cluster analysis, the individual arrangements are then calculated into a group map in which the relative importance and the associations of the clusters are presented by means of a graphic presentation of a chi-square dissimilarity coefficient matrix. Once associations have been structured in this manner, subjects are invited to discuss and interpret the results. Concept mapping is a particularly suitable method for an exploratory study on a topic for which the subject's views are important to get a valid picture of the issues involved. Concept mapping helps to reveal those aspects which really matter to the people involved. The sorting part of concept mapping is similar to the better-known Q-sort method, which has been used to identify patterns in, for example, ideas on health and illness (De Ridder, Depla, Severens, & Malsch, 1997; Stainton Rogers, 1991).

In this study, both members of the Parkinson's disease organization and those of the CFS organization who had agreed to complete the questionnaire were asked to make a maximum of five statements on adaptive tasks specific to their personal situation. This resulted in two sets of about 200 statements; one for each patient group. After eliminating identical and ambiguous statements, sets of 60 items for each patient group remained. At two meetings (one for each patient group), the participants arranged these statements. Only 39 patients with Parkinson's disease and 24 patients with CFS attended these meetings, due to a number of reasons, varying from vacations or family obligations to not feeling able to travel. A comparison of disease characteristics in patients who did and

those who did not attend the meetings showed that there were no significant differences in number of symptoms or illness duration.

Following the concept mapping procedure, each participant sorted the 60 statements individually in order of priority and content. Sorting in order of priority means that they had to sort all statements into five groups of equal size, each with a certain priority (ranging from 1 = not important at all to 5 = very important). Sorting in order of content means they had to compile those statements which had something in common (into a minimum of three and a maximum of 12 categories). Subsequently, the individual arrangements were calculated in a concept map referring to a number of clusters or adaptive tasks which were discussed in the patient groups. The results will be described in the next section.

### *Other measures*

*Disease characteristics* of patients with Parkinson's disease were measured by asking for illness duration ( $M = 7.82$  years,  $SD = 6.58$ ) and the number of symptoms experienced, such as stiffness, slowness, trembling and speech impediments ( $M = 4.43$  symptoms,  $SD = 1.74$ ). All patients used medication to control their disease (especially levodopa preparations, dopamine-agonists and selegiline), but only 46 percent received treatment other than medical (especially physical therapy). A minority of patients (8 percent) had undergone (stereotactic) surgery.

With respect to the disease characteristics of CFS, patients reported that they had been suffering from fatigue complaints for a significant number of years ( $M = 9.65$  years,  $SD = 7.14$ ), but due to the medical status of the syndrome only a minority (24 percent) had been medically acknowledged as ill, most of them very recently (in the past 5 years). All CFS patients reported the persistent or relapsing presence of the following symptoms during the previous 6 months: fatigue that is not substantially alleviated by rest and which has resulted in substantial reduction in previous levels of occupational, social and personal activities; impairment in short-term memory or concentration; sore throat; muscle pain; multijoint pain; headache; and unrefreshing sleep—all symptoms which

have recently been proposed as the major criteria for defining CFS (Fukuda et al., 1994).

*Coping* was assessed by the shortened version of the Utrecht Coping Questionnaire (Schreurs, Van de Willige, Brosschot, Tellegen, & Graus, 1993), measuring three strategies: problem-focused coping (six items, Cronbach's alpha .79); emotion-focused coping (five items, Cronbach's alpha .72); and palliative coping (four items, Cronbach's alpha .66). Parkinson's patients reported using primarily palliative coping ( $M = 2.53$  on a scale ranging from 1 = rarely to 4 = very often,  $SD = .51$ ) and problem-focused coping ( $M = 2.49$ ,  $SD = .59$ ), followed by emotion-focused coping strategies ( $M = 1.77$ ,  $SD = .44$ ). CFS patients, on the other hand, indicated using primarily problem-focused coping ( $M = 2.70$ ,  $SD = .59$ ) and emotion-focused coping ( $M = 2.24$ ,  $SD = .54$ ), followed by palliative coping ( $M = 1.69$ ,  $SD = .39$ ). Two coping strategies of the patient groups differed significantly: patients with Parkinson's disease use more palliative coping strategies ( $t = -4.79$ ,  $d.f. = 91$ ,  $p < .001$ ) while CFS patients use more emotion-focused coping ( $t = 2.99$ ,  $d.f. = 93$ ,  $p < .01$ ).

*Quality of life* was chosen as the most proximal health outcome measure available to assess the impact of adaptive tasks and coping on well-being. The Sickness Impact Profile (SIP; Bergner, Bobbitt, Carter, & Gilson, 1981), a measure of several aspects of daily functioning, provides a particularly reliable picture of behavioural changes as a consequence of health status and has also proven a useful tool to discriminate between patient groups. In this study, the overall judgement of quality of life was used measured by the shortened 68-item version of the SIP (De Bruin, Diederiks, De Witte, & Stevens, 1994) with a sufficient reliability (Cronbach's alpha .92). CFS patients ( $M = 1.55$ ,  $SD = .09$ ) reported a significantly lower quality of life than did patients with Parkinson's disease ( $M = 1.66$ ,  $SD = .17$ ,  $t = 2.04$ ,  $d.f. = 73$ ,  $p < .05$ ).

## Results

### *Adaptive tasks*

What do people suffering from Parkinson's disease and CFS believe to be important tasks that call for adaptive efforts? Table 1 provides an overview of the adaptive tasks identified by

39 patients with Parkinson's disease and Table 3 does the same for 24 CFS patients. The sorting of the 60 statements on adaptive tasks by the patients with Parkinson's disease revealed eight clusters: adapting to the social identity of an ill person; being creative in defining new challenges; acceptance of being ill; learning to be dependent on others; finding a new way of maintaining social relationships; having to give up ordinary activities; dealing with physical impediments; and being able to recognize own needs (Table 1). These tasks were computed by clustering those associations which are most proximate to each other and may be interpreted as a representation of what the individual clusterings of expressions have in common (see Figure 1). For example, the cluster *having to give up ordinary activities* contains items such as 'not being able to drive a car', 'not being able to concentrate' and 'having to give up my hobby', while the cluster *dealing with physical impediments* is a representation of items like 'dealing with fatigue', 'dealing with pain' and 'mobilizing energy'. It has already been noted that the statistics provided by the programme do not allow for standard psychometric evaluation (e.g. Cronbach's alpha), since the clusters are computed by a chi-square dissimilarity coefficient matrix. However, an alternative measure for the goodness-of-fit of these clusters is provided by the eigenvalue, computed by principal components analysis for categorical data (Principals). These eigenvalues (all  $> .36$ , which roughly corresponds to a Cronbach's alpha of .60) prove satisfactory (see Table 1). In addition, Table 2 shows that the correlations between tasks are moderate, which may be interpreted as a sign that the eight adaptive tasks are related but do not overlap. Of course, the identification of adaptive tasks needs further corroboration but suffices for an exploratory study of their associations with coping and quality of life.

Differences in priorities of the eight tasks are rather small (ranging from 2.28 to 3.24 on a scale from 1 to 5) and show that patients with Parkinson's disease clearly find it difficult to attribute more importance to one task than to another. Still, it is remarkable that it is not so much the disease itself, best represented in the task *dealing with physical impediments*, but its social and psychological consequences that are considered the most important.

Table 1. Adaptive tasks identified by patients with Parkinson's disease ( $n=39$ ), in order of the ranking of priorities

Adaptive tasks (exemplary items)	<i>N</i> items	Priority <i>M</i> / <i>SD</i>	Eigenvalue*
5. Being creative in defining new challenges Finding new hobbies Finding alternatives for things you can not do anymore Enjoying things healthy people cannot	20	<i>M</i> 3.24 <i>SD</i> .36	.65
7. Acceptance of being ill Being satisfied with what you have Admitting to yourself that you are ill Accepting you are not able to do everything you want	6	<i>M</i> 3.12 <i>SD</i> .54	.36
2. Learning to be dependent on others Loss of autonomy Fear of being dependent Learning to be dependent on others persons	5	<i>M</i> 3.11 <i>SD</i> .86	.46
6. Adapting to the social identify of an ill person Being acknowledged by doctors Being treated as a competent person Fighting for respect	6	<i>M</i> 2.94 <i>SD</i> .62	.41
1. Having to give up ordinary activities Not being able to drive a car Not being able to concentrate Having to give up your hobby	9	<i>M</i> 2.94 <i>SD</i> .46	.36
4. Dealing with physical impediments Dealing with fatigue Dealing with pain Mobilizing energy	5	<i>M</i> 2.71 <i>SD</i> .74	.45
3. Finding a new way of maintaining social relationships Changing relationship with family Negative reactions of friends Feeling isolated	6	<i>M</i> 2.69 <i>SD</i> .63	.41
8. Being able to recognize own needs Worrying about not going out Not hesitating about getting information on Parkinson's disease you want	2	<i>M</i> 2.28 <i>SD</i> .71	.73

\*The eigenvalue was computed with Princals and can be interpreted as a psychometric evaluation (comparable to a squared Cronbach's alpha: in that sense an eigenvalue above .36 is satisfactory)

Table 2. Pearson correlations between adaptive tasks identified by patients with Parkinson's disease ( $n=39$ )

	Task 1	Task 2	Task 3	Task 4	Task 5	Task 6	Task 7
1. Having to give up ordinary activities							
2. Learning to be dependent on others	.11						
3. Finding a way of maintaining relationships	.12	.01					
4. Dealing with physical impediments	-.28	-.14	-.16				
5. Being creative in defining challenges	-.50**	-.51**	-.32	.15			
6. Adapting to the social identity	-.04	-.01	-.36	-.16	-.19		
7. Acceptance of being ill	-.23	-.23	.01	-.26	-.07	-.12	
8. Being able to recognize your needs	.09	-.24	-.12	-.16	-.19	.26	.31

\*\*  $p < .001$

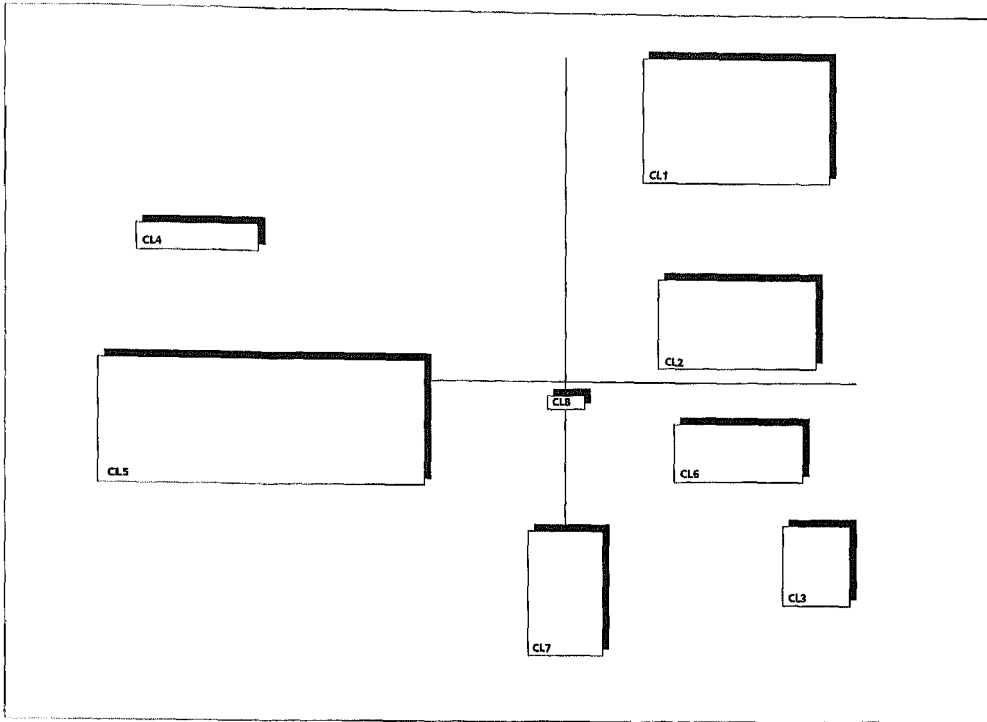


Figure 1. Concept Map: graphic representation of the chi-square dissimilarity coefficient matrix of sortings of patients with Parkinson's disease ( $n=39$ ). The height of the clusters refers to their mean priorities.

Table 3 provides an overview of adaptive tasks identified by CFS patients, as well as their priorities and eigenvalues, while Figure 2 contains a graphic representation of the chi-square dissimilarity coefficient matrix of the clustered items relating to adaptive tasks. Since the statements (items) are different, no psychometric measure is available to compare systematically the contents of the clusters identified by CFS patients with those of the patients with Parkinson's disease. Still, it appears that at face value the clustered statements can be interpreted likewise; that is, they refer to similar themes which, according to the patients of both groups, require adaptive efforts. Nevertheless, at a more concrete level, concerning the actual contents of the adaptive tasks, major differences appear between the two patient groups, as can be inferred from the exemplary items given in Tables 1 and 3. These exemplary items make clear that CFS patients stress different aspects from those accentuated by patients with Parkinson's disease, even if these items generally refer

to the same adaptive tasks. The cluster *adapting to the new social identity of an ill person*, for example, reveals different accents: CFS patients highlight their struggle to be acknowledged as 'a real patient' by doctors, friends and family, while in contrast, patients with Parkinson's disease fight to be treated like a healthy person. A second example concerns the task *having to give up ordinary activities* and probably points not so much to direct differences in both diseases but rather to the fact that both patient groups differ in age and, consequently, pursue other goals. CFS patients, for example, define working as an ordinary activity while patients with Parkinson's disease experience the fact that they are no longer able to practise their hobby as a loss.

Apart from the actual content of adaptive tasks, CFS patients also differ from patients with Parkinson's disease in their ranking of priorities of adaptive tasks. For example, in contrast to the patients with Parkinson's disease, CFS patients consider *acceptance of being ill* as the most important task imposed by their illness, although

Table 3. Adaptive tasks identified by CFS patients ( $n=24$ ), in order of the ranking of priorities

<i>Adaptive tasks (exemplary items)</i>	<i>N items</i>	<i>Priority M/SD</i>	<i>Eigenvalue*</i>
3. Acceptance of being ill Learning not to fight the disease at all moments Admitting that you are an ill person Accepting you cannot do the things you used to	7	<i>M</i> 3.97 <i>SD</i> .89	.55
2. Being creative in defining new challenges Learning to live by the moment Setting priorities in what you want to do Only doing things that really matter	14	<i>M</i> 3.51 <i>SD</i> .48	.39
7. Being able to recognize own needs Learning to ask for help without feeling inferior Knowing your limitations Recognizing variable levels of performance	5	<i>M</i> 3.13 <i>SD</i> .51	.54
1. Adapting to the social identity of an ill person Fighting to be taken seriously by friends and family Being acknowledged by your employer Fighting for respect from medical staff	14	<i>M</i> 2.98 <i>SD</i> .72	.40
4. Learning to be dependent on others Reorientation on being autonomous Accepting to be dependent on others Learning to say no when you want no help	5	<i>M</i> 2.71 <i>SD</i> 1.20	.53
8. Dealing with physical impediments Fear that it will never get better Feeling powerless Anger that your body will not do what you want it to do	4	<i>M</i> 2.69 <i>SD</i> 1.03	.61
6. Having to give up ordinary activities Noting being able to work Not being able to have a holiday Not being able to practise your favourite sport	5	<i>M</i> 2.46 <i>SD</i> .80	.51
5. Finding a new way of maintaining social relationships Finding new friends who will accept you Keep in contact with fellow-sufferers Accepting that friends do not always understand you	6	<i>M</i> 2.29 <i>SD</i> .99	.52

\* The eigenvalue was computed with Princals and can be interpreted as a psychometric evaluation (comparable to a squared Cronbach's alpha: in that sense an eigenvalue above .36 is satisfactory)

generally speaking, differences in priorities of the clusters identified by CFS patients are small (ranging from 2.29 to 3.97). Also, CFS patients appear to distinguish more incompatibilities in the tasks they have identified, as can be inferred from Table 4, providing an overview of the correlations between the eight adaptive tasks. For example, considering important the task of *dealing with physical impediments* does not agree with considering important tasks like *being creative in defining new challenges* and *being able to recognize own needs*.

To summarize, then, although adaptive tasks identified by CFS patients and Parkinson's disease patients generally concern the same themes, there is a divergence in the actual contents of these tasks that require adaptive efforts. In addition, appreciation of the importance of these tasks is different in both patient groups. The next question concerns the issue of whether adaptive tasks are associated with coping and quality of life in a similar manner in both patient groups.



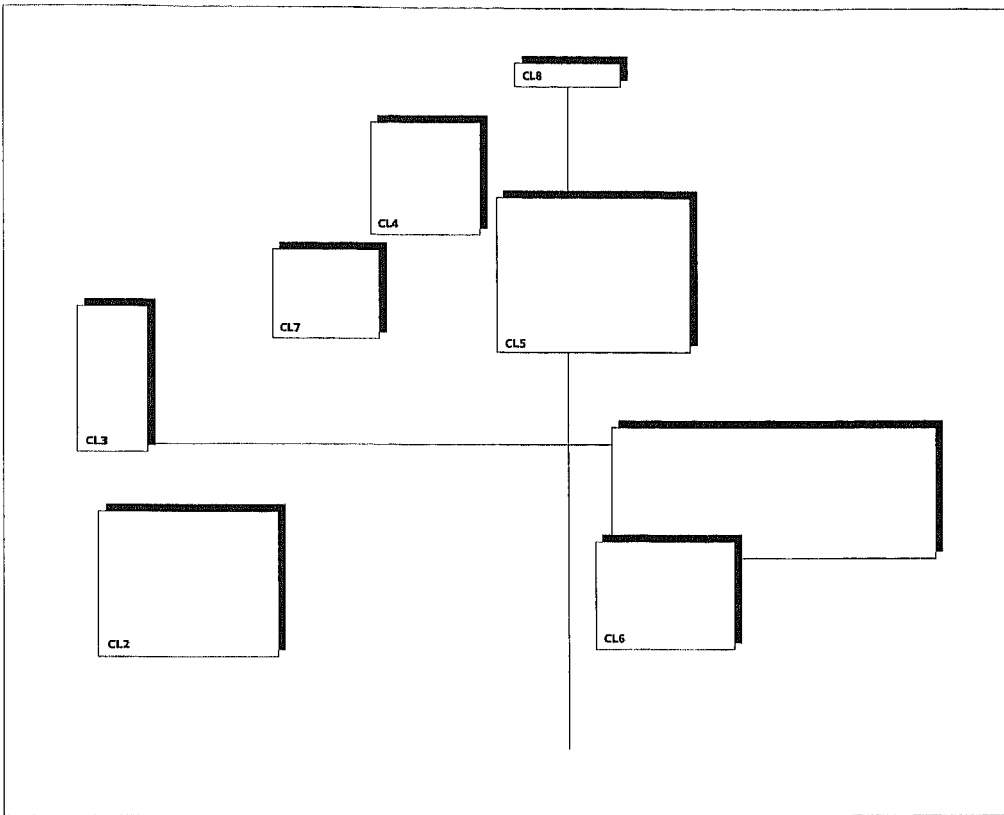


Figure 2. Concept Map: graphic representation of the chi-square dissimilarity coefficient matrix of sortings of CFS patients ( $n=24$ ). The height of the clusters refers to their mean priorities.

Table 4. Pearson correlations between adaptive tasks identified by CFS patients ( $n=24$ )

	Task 1	Task 2	Task 3	Task 4	Task 5	Task 6	Task 7
1. Adapting to the social identity							
2. Being creative in defining challenges	-.43*						
3. Acceptance of being ill	-.07	-.13					
4. Learning to be dependent on others	-.10	-.14	-.06				
5. Finding a way of maintaining relationships	-.09	-.05	.05	.01			
6. Having to give up ordinary activities	-.27	.06	-.63*	.37	-.17		
7. Being able to recognize your needs	-.28	.23	.57*	.09	.30	-.48*	
8. Dealing with physical impediments	.16	-.66**	.08	.11	-.32	.07	-.60*

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

### Adaptive tasks, coping and quality of life

Table 5 provides an overview of the correlations between adaptive tasks, disease characteristics, coping and quality of life for patients with Parkinson's disease. Generally, with the excep-

tion of some significant correlations between adaptive tasks and illness duration, adaptive tasks are unrelated to disease characteristics, coping and quality of life. Only a few tasks seem relevant when it comes to living with Parkinson's disease, and they are not necessarily

Table 5. Pearson correlations adaptive tasks with disease characteristics, coping and quality of life of patients with Parkinson's disease ( $n=39$ )

	Task 1	Task 2	Task 3	Task 4	Task 5	Task 6	Task 7	Task 8
Illness duration	-.08	-.28	-.38*	.06	.41*	.15	.04	.18
Number of symptoms	.24	.28	-.03	-.17	.02	-.11	-.15	-.08
Problem-focused coping	.11	.16	-.06	.05	-.13	-.02	.01	-.05
Palliative coping	-.01	.26	.04	-.10	-.26	-.19	.24	.11
Emotion-focused coping	-.26	.12	-.24	.32	.13	-.09	-.13	-.31
SIP/total score	.10	.21	.18	-.16	-.21	-.07	-.14	-.19

Task 1: having to give up ordinary activities

Task 2: learning to be dependent on others

Task 3: finding a new way of maintaining social relationships

Task 4: dealing with physical impediments

Task 5: being creative in defining new challenges

Task 6: adapting to the social identity of an ill person

Task 7: acceptance of being ill

Task 8: being able to recognize your needs

\*  $p < .01$

the tasks that are considered the most important. In fact, a task like *finding a new way of maintaining social relationships*, considered relatively less important, is as strongly associated with illness duration as the tasks considered the most important (*being creative in defining new challenges*).

The pattern of correlations between adaptive tasks, disease characteristics, coping and quality of life of CFS patients is unlike that of patients

with Parkinson's disease since the associations are generally much stronger, as is shown in Table 6. Also, the associations appear strongest when it comes to the relation of adaptive tasks with coping and quality of life. For example, when *being able to recognize own needs* is considered important, all coping strategies appear to be encouraged strongly. Also, the pattern of correlations suggests that some adaptive tasks, such as *being creative in defining new*

Table 6. Pearson correlations adaptive tasks with disease characteristics, coping and quality of life of CFS patients ( $n=24$ )

	Task 1	Task 2	Task 3	Task 4	Task 5	Task 6	Task 7	Task 8
Illness duration	-.23	.40*	-.08	-.35	-.18	.18	.09	-.34
Number of symptoms	-.11	.16	-.36	.28	.09	.29	-.31	-.20
Problem-focused coping	.05	.35	-.56*	-.37	-.30	-.13	.63*	-.60*
Palliative coping	-.26	.23	.20	.09	-.18	-.52*	.64*	.21
Emotion-focused coping	.61*	.39	.14	.19	-.37	-.24	.45*	-.48*
SIP/total score	-.01	.59*	-.05	-.40*	-.77**	.43*	.42*	-.44*

Task 1: adapting to the social identity of an ill person

Task 2: being creative in defining new challenges

Task 3: acceptance of being ill

Task 4: learning to be dependent on others

Task 5: finding a new way of maintaining social relationships

Task 6: having to give up ordinary activities

Task 7: being able to recognize your needs

Task 8: dealing with physical impediments

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

challenges or being able to recognize own needs, favour any coping strategy, while others, like dealing with physical impediments, appear to minimalize any coping effort.

In sum, then, our data show some very modest associations between adaptive tasks, coping and quality of life in patients with Parkinson's disease. Our data also reveal an interesting pattern of correlations between adaptive tasks, coping and quality of life in CFS patients—and these correlations are much stronger. Let us now turn to the third issue of this paper: whether adaptive tasks have a predictive value for coping and quality of life in both patient groups.

### *Prediction of coping and quality of life*

In order to provide an answer to this question, we performed a number of hierarchical regression analyses. The hierarchy of steps parallels a hypothetical model in which quality of life can be explained by coping, which in turn is affected by adaptive tasks. More particularly, we expect that adaptive tasks influence quality of life via their effect on coping. Because of the limited number of observations, only the three adaptive tasks considered the most important by patients were selected as predictors. For the same reason, the present model does not allow for other potential determinants of coping and quality of life, nor does it take into account the potential effect of patient characteristics like sex, age and educational level. Neither will we test explicitly

whether the impact of adaptive tasks on adaptation is different for both diseases. The concept mapping procedure which was chosen as the data sampling method is aimed at bottom-up clustering of participants' associations. The result is that we have conceptually similar variables which contain, however, different items (the procedure was performed separately for each patient group). Therefore, the variables referring to these items are also different for both groups and cannot be taken into one analysis. Therefore, we will suffice with an illustration of the role of adaptive tasks in both patient groups separately. For the sake of brevity, the variables in each hierarchical step will not be discussed in detail. Instead, the discussion will be limited to a step-by-step explanation of quality of life.

The first part of the question concerns the explanation of variance in coping strategies by adaptive tasks. Table 7 shows that the amount of variance in coping explained by disease characteristics and adaptive tasks is rather small. This is not particularly surprising, as this is generally the case (De Ridder & Schreurs, 1996). It points to the somewhat awkward fact that still little is known about the determinants of coping. Secondly, these data show that disease characteristics contribute only minimally to the variance in coping strategies, although in the case of CFS patients, the illness duration appears to call strongly for emotion-focused coping. These results urge further exploration of objective disease characteristics and the subjective percep-

Table 7. Hierarchical regression analysis of disease characteristics, adaptive tasks and coping of patients with Parkinson's disease ( $n=39$ ) and CFS ( $n=24$ )

	Dependent					
	Problem-focused coping		Emotion-focused coping		Palliative coping	
	Parkinson's AR <sup>2</sup>	CFS AR <sup>2</sup>	Parkinson's AR <sup>2</sup>	CFS AR <sup>2</sup>	Parkinson's AR <sup>2</sup>	CFS AR <sup>2</sup>
Step 1 disease characteristics <sup>a</sup>	NS	NS	NS	27% ( $p < .05$ )	NS	NS
Step 2 adaptive tasks <sup>b</sup>	NS	21% ( $p < .05$ )	NS	38% ( $p < .01$ )	NS	23% ( $p < .05$ )

<sup>a</sup> Illness duration and number of symptoms

<sup>b</sup> In case of Parkinson's disease: being creative in defining new challenges, acceptance of being ill, learning to be dependent on others. In case of CFS patients: acceptance of being ill, being creative in defining new challenges, being able to recognize own needs

Table 8. Hierarchical regression analysis disease characteristics, adaptive tasks, coping and quality of life of patients with Parkinson's disease ( $n=39$ ) and CFS ( $n=24$ )

	Dependent	
	SIP/total score	
	Parkinson's AR <sup>2</sup>	CFS AR <sup>2</sup>
Step 1 disease characteristics <sup>a</sup>	14% ( $p < .05$ )	NS
Step 2 adaptive tasks <sup>b</sup>	23% ( $p < .05$ )	24% ( $p < .05$ )
Step 3 coping <sup>c</sup>	NS	NS

<sup>a</sup> Illness duration and number of symptoms

<sup>b</sup> In case of Parkinson's disease: being creative in defining new challenges, acceptance of being ill, learning to be dependent on others. In case of CFS patients: acceptance of being ill, being creative in defining new challenges, being able to recognize own needs

<sup>c</sup> Problem-focused coping, emotion-focused coping and palliative coping

tion of problems attached to being ill, in order to find out to what extent the disease itself imposes its stressors. A third observation, ensuing from the second, is that coping is best predicted by adaptive tasks, but only in the case of CFS patients (as might be expected from the correlational patterns). Our data suggest, then, that the adaptive tasks identified by CFS patients are helpful in predicting their ways of coping, but that those identified by patients with Parkinson's disease are not.

Table 8 shows that quality of life can best be predicted from the adaptive tasks identified by CFS patients and Parkinson's disease patients. Quality of life can be accounted for, at least in part, by the adaptive tasks considered important by patients in both groups. Interestingly, disease characteristics are more powerful in the case of patients with Parkinson's disease, while adaptive tasks are more important in the case of patients with CFS. Furthermore, it appears that, in line with the explanation of coping patterns, adaptive tasks of CFS patients are more powerful in predicting the variance of quality of life. Both observations may be explained by the hypothesis that the quality of life of CFS patients is determined more strongly by their cognitions on the disease and the way they act as a result of those cognitions (cf. Surawy, Hackmann, Hawton, & Sharpe, 1995), while in the case of patients with Parkinson's disease,

actual physical limitations have more impact on quality of life—a hypothesis which we will discuss further in the discussion section.

In sum, these results strongly suggest that adaptive tasks may be a helpful concept in explaining both coping patterns of chronically ill patients and the quality of life they experience. Their ways of coping, partly resulting from the adaptive tasks they consider important, do not seem to contribute to quality of life, which indicates a strong need for studying more explicitly the role of coping as a mediating mechanism between disease characteristics, disease-related stressors and well-being.

## Discussion

Before discussing in some detail the results of this study, its limitations have to be considered. Firstly, as the study was exploratory, a rigorous psychometric evaluation of the measures of adaptive tasks is lacking. Therefore, it must be stressed that the results of this study are only preliminary and need replication, which will allow for a more elaborate test of validity and reliability of the measure as well as a more systematic comparison of adaptive tasks between patient groups (Bensing, De Ridder, & Schreurs, submitted). Secondly, as the number of subjects participating in the concept mapping procedure was small, especially in the CFS

patient group, the results may be not representative for all patients and therefore have to be interpreted with care. Thirdly, due to the correlational nature of the data, the actual value of adaptive tasks as a predictor of coping and quality of life needs corroboration from a prospective study.

In spite of the shortcomings of the present study, we think that the results show that adaptive tasks are a promising candidate for getting a better grip on the situational determinants of coping with chronic disease. As was clearly stated in the article by Somerfield (1997) on a problem-specific coping model that allows for the detailed analysis of individual meaning of threatening situations, published in this journal, focusing on the level of the target stressor may prove necessary to enlarge our understanding of adaptive processes and to begin exploiting the potential clinical relevance of stress and coping research. In addition to the issues brought up by Somerfield, we would like to stress that situations in chronic illness that are relevant for adaptation need not to be disease-specific or even relate directly to the objectively defined problem categories posed by disease as a medical entity (cf. Lazarus, 1997). The results of our study strongly suggest that, when asked for the consequences of their disease that affect them either positively or negatively, CFS patients and Parkinson's disease patients refer to common themes. However, although the themes they refer to may be very similar, both the actual content of these themes and the importance attributed to each varies by disease. The results become even more divergent when associations of adaptive tasks with coping and quality of life are considered. For patients with Parkinson's disease, adaptive tasks, even when considered important, appear to play only a minor role in their strategies of adaptation to disease and to well-being. Instead, disease characteristics like duration of illness and number of symptoms (which are very limited in describing the actual constraints of the disease) appear to be more strongly associated with quality of life, which suggests a strong need for a thorough exploration of the relationship between objective disease characteristics and the subjective evaluations of problems caused by the disease. For CFS patients, on the other hand, the associations between adaptive tasks, coping and quality of

life are much stronger, although the mediating role of adaptive tasks in predicting quality of life indirectly via coping remains an issue yet to be clarified.

An important issue is what role adaptive tasks have in the adaptation processes and whether this role is different across diseases. Of course, as stated earlier, the particular approach we have chosen to analyse the concept of adaptive tasks does not allow a single regression analysis and therefore it is open for debate whether our results suggest a different role of adaptive tasks in both patient groups. In a similar way, one may wonder whether assumed differences in the role of adaptive tasks across patient groups may not be attributed to different social characteristics of both patient groups. As most patients with CFS were female and young, and most patients with Parkinson's disease were male and old, this may have affected their perceptions of illness-related stressful situations. Although we did not control for demographic characteristics, the non-significant associations between demographic variables and adaptive tasks make it unlikely that this is the case. A final question, then, is why the role of adaptive tasks appears to be illness-dependent to some extent. A first possible explanation is that quality of life in patients with Parkinson's disease appears to be better; methodological flaws resulting from restriction of range in the case of patients suffering from Parkinson's disease may have contributed to the low predictive power of adaptive tasks for quality of life. A second possible explanation is that the differences between CFS patients and Parkinson's disease patients may be interpreted in terms of the actual constraints their disease imposes on coping and well-being. The lack of association between adaptive tasks, coping and quality of life reported by patients with Parkinson's disease may be the result of the stronger demands imposed by the disease itself, while the situational power of a disease like CFS allows for more subjective evaluations of what is actually at stake. Many researchers have argued that the impact of stressful events on the well-being of chronically ill patients depends upon how these events are appraised. Yet, with few exceptions, the actual stressors that affect coping and well-being have been left unspecified. Our study strongly suggests that adaptive tasks may play an important role in unravelling the impact of disease on well-being.

## References

- Bensing, J. M., De Ridder, D. T. D., & Schreurs, K. M. G. (submitted). Adaptive tasks of chronically ill patients: the development of a generic measure of disease-related stressors.
- Bergner, M., Bobbitt, R. A., Carter, W. B., Gilson, B. S. (1981). The Sickness Impact Profile: Development and final revision of a health status measure. *Medical Care*, *19*, 787-805.
- Carver, C. S., & Scheier, M. F. (1994). Situational coping and coping dispositions in a stressful transaction. *Journal of Personality and Social Psychology*, *66*, 184-195.
- Cohen, F., & Lazarus, R. S. (1979). Coping with the stresses of illness. In G. Stone, F. Cohen, & N. Adler (Eds.), *Health psychology*. San Francisco: Jossey-Bass.
- Collins, R. L., Taylor, S. E., & Skokan, L. A. (1990). A better world or a shattered vision. Changes in perspectives following victimization. *Social Cognition*, *8*, 263-285.
- De Bruin, A. F., Diederiks, J. P. M., De Witte, L. P., & Stevens, F. C. J. (1994). The development of a short generic version of the Sickness Impact Profile. *Journal of Clinical Epidemiology*, *47*, 407-418.
- De Ridder, D., Depla, M., Severens, P., & Malsch, M. (1997). Beliefs on coping with illness: A consumer's perspective. *Social Science and Medicine*, *44*, 553-559.
- De Ridder, D., & Schreurs, K. (1996). Coping, social support and chronic disease: a research agenda. *Psychology, Health and Medicine*, *1*, 71-82.
- De Ridder, D., & Te Vaarwerk, M. (1995). Situational determinants of the coping process [in Dutch]. In R. Sanderman, W. J. A. van den Heuvel & B. Krol (Eds.), *Interventiëren in de determinanten van gezondheid: resultaten van een onderzoekprogramma* (pp. 27-47). Assen: Van Gorcum.
- Dunkel-Schetter, C., Feinstein, L. G., Taylor, S. E., & Falke, L. R. (1992). Patterns of coping with cancer. *Health Psychology*, *11*, 79-87.
- Felton, B. J., & Revenson, T. A. (1984). Coping with chronic illness: A study of illness controllability and the influence of coping strategies on psychological adjustment. *Journal of Consulting and Clinical Psychology*, *52*, 343-353.
- Fukuda, K., Straus, S. E., Hickie, L., Sharpe, M. C., Dobbins, J. G., Komaroff, A., & The International CFS Study Group (1994). The chronic fatigue syndrome: A comprehensive approach to its definition and its study. *Annals of Internal Medicine*, *121*, 953-959.
- Heim, E., Augustiny, K., Blaser, A., Bürki, C., Kühne, D., Rothenbühler, M., Schaffner, L., & Valach, L. (1987). Coping with breast cancer: A longitudinal prospective study. *Psychotherapy and Psychosomatics*, *48*, 44-59.
- Lazarus, R. S. (1997). Hurrah for a systems approach. Commentary on Somerfield. *Journal of Health Psychology*, *2*, 158-160.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Maes, S., Leventhal, H., & De Ridder, D. (1996). Coping with chronic diseases. In M. Zeidner & N. S. Endler (Eds.), *Handbook of coping: Theory, research, applications* (pp. 221-251). New York: Wiley.
- Manuel, G. M., Roth, S., Keefe, F. J., & Brantley, B. (1987). Coping with cancer. *Journal of Human Stress*, *13*, 149-158.
- Miller, S. M. (1992). Monitoring and blunting in the face of threat: Implications for adaptation and health. In L. Montada, S.-H. Filipp & M. J. Lerner (Eds.), *Life crises and experiences of loss in adulthood* (pp. 255-273). Hillsdale, NJ: Erlbaum.
- Mishel, M. H., & Sorenson, D. S. (1991). Uncertainty in gynecological cancer: A test of the mediating functions of mastery and coping. *Nursing Research*, *40*, 167-171.
- Moos, R. H., & Schaefer, J. A. (1984). The crisis of physical illness. In R. H. Moos (Ed.), *Coping with physical illness. Vol. 2. New perspectives* (pp. 3-25). New York: Plenum.
- Morse, J. M., & Johnson, J. L. (1991). Towards a theory of illness: The illness constellation model. In J. M. Morse & J. L. Johnson (Eds.), *The illness experience* (pp. 315-342). London: Sage.
- Newman, S. P., Fitzpatrick, R., Lamb, R., & Shipley, M. (1990). Patterns of coping in rheumatoid arthritis. *Psychology and Health*, *4*, 187-200.
- Perrez, M., & Reicherts, M. (1992). *Stress, coping and health*. Seattle: Hogrefe & Huber.
- Schag, C. A. C., Heinrich, R. L., Aadland, R. L., & Ganz, P. A. (1990). Assessing problems of cancer patients: Psychometric properties of the Cancer Inventory of Problem Situations. *Health Psychology*, *9*, 83-102.
- Schreurs, P. J. G., Van de Willige, G., Brosschot, J. F., Tellegen, B., & Graus, G. M. H. (1993). *Manual of the Utrecht Coping Questionnaire* [in Dutch]. Lisse: Swets & Zeitlinger.
- Siegel, K., & Krauss, B. J. (1991). Living with HIV infection: adaptive tasks of seropositive gay men. *Journal of Health and Social Behavior*, *32*, 17-32.
- Somerfield, M. R. (1997). The utility of systems models of stress and coping for applied research. *Journal of Health Psychology*, *2*, 133-151.
- Stainton Rogers, W. (1991). *Explaining health and illness. An exploration of diversity*. New York: Harvester/Wheatstheaf.

- Stephoe, A., Sutcliffe, I., Allen, B., & Coombes, C. (1991). Satisfaction with communication, medical knowledge, and coping style in patients with metastatic cancer. *Social Science and Medicine*, 32, 627–632.
- Suls, J., & Fletcher, B. (1985). The relative efficacy of avoidant and nonavoidant coping strategies: A meta-analysis. *Health Psychology*, 4, 249–288.
- Surawy, C., Hackmann, A., Hawton, K., & Sharpe, M. (1995). Chronic fatigue syndrome: A cognitive approach. *Behavioral Research and Therapy*, 33, 535–544.
- Trochim, W. M. K. (1989). An introduction to concept mapping for planning and evaluation. *Evaluation and Program Planning*, 12, 1–16.
- Van Lankveld, W., Näring, G., Van der Staak, C., Van 't Pad Bosch, P., Van de Putte, L. (1993). Stress caused by rheumatoid arthritis: The relation between subjective stressors of the disease, disease status and well-being. *Journal of Behavioral Medicine*, 16, 309–321.
- Vitaliano, P. P., DeWolfe, D. D., Maiuro, R. D., Russo, J., & Katon, W. (1990). Appraised changeability of a stressor as modifier of the relationship between coping and depression. A test of the hypothesis of fit. *Journal of Personality and Social Psychology*, 59, 582–592.