

This article was downloaded by:[University Library Utrecht]
[University Library Utrecht]

On: 7 June 2007

Access Details: [subscription number 768375375]

Publisher: Routledge

Informa Ltd Registered in England and Wales Registered Number: 1072954

Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



Psychology & Health

Publication details, including instructions for authors and subscription information:

<http://www.informaworld.com/smpp/title~content=t713648133>

Adaptive Tasks in Multiple Sclerosis: Development of an Instrument to Identify the Focus of Patients' Coping Efforts

Jozien M. Bensing; Karlein M. G. Schreurs^a; Denise T. D. de Ridder^a; Robert L. Hulsman^b

^a Department of Health Psychology, Utrecht University, P.O. Box 80140, 3508 TC Utrecht, The Netherlands.

^b Nivel, Utrecht.

To cite this Article: Bensing, Jozien M., Schreurs, Karlein M. G., de Ridder, Denise T. D. and Hulsman, Robert L., 'Adaptive Tasks in Multiple Sclerosis: Development of an Instrument to Identify the Focus of Patients' Coping Efforts', *Psychology & Health*, 17:4, 475 - 488

To link to this article: DOI: 10.1080/0887044022000004957

URL: <http://dx.doi.org/10.1080/0887044022000004957>

PLEASE SCROLL DOWN FOR ARTICLE

Full terms and conditions of use: <http://www.informaworld.com/terms-and-conditions-of-access.pdf>

This article maybe used for research, teaching and private study purposes. Any substantial or systematic reproduction, re-distribution, re-selling, loan or sub-licensing, systematic supply or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The accuracy of any instructions, formulae and drug doses should be independently verified with primary sources. The publisher shall not be liable for any loss, actions, claims, proceedings, demand or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.

© Taylor and Francis 2007

ADAPTIVE TASKS IN MULTIPLE SCLEROSIS: DEVELOPMENT OF AN INSTRUMENT TO IDENTIFY THE FOCUS OF PATIENTS' COPING EFFORTS

JOZIEN M. BENSING^{a,b,*}, KARLEIN M.G. SCHREURS^a,
DENISE T.D. DE RIDDER^a and ROBERT L. HULSMAN^b

^aDepartment of Health Psychology, Utrecht University, P.O. Box 80140, 3508 TC Utrecht,
The Netherlands; ^bNivel, Utrecht

(Received 13 September 2000; In final form 24 September 2001)

Objective: Adaptive tasks, referring to the subjective evaluation of disease-related stressors in relation to personal concerns, have been neglected in the extensive literature on coping with chronic disease. In this study, the development of an instrument for measuring adaptive tasks is described: the Questionnaire Adaptive Tasks in Multiple Sclerosis (QuAT-MS).

Method: The QuAT-MS is based on a bottom-up categorization of patients' statements on the losses, threats, and challenges brought about by their disease, and employs 10 scales to measure the importance attached to particular disease-related stressors. Validity and reliability of this bottom-up categorization were established in a sample of MS patients ($N=259$) by examining their associations with related concepts relevant in adaptation to disease, such as coping (CISS), coping resources (LOT, self-efficacy), and quality of life (SIP). We also investigated whether patients' backgrounds and disease characteristics were related to adaptive tasks.

Results: Adaptive tasks are more closely related with concepts relevant for adaptation (coping and coping resources) than with physical functioning (SIP) and disease-related characteristics (illness duration). Adaptive tasks are also associated with gender and level of education.

Conclusion: It is concluded that adaptive tasks can be distinguished from related concepts like coping and quality of life. Furthermore, the QuAT-MS offers a reliable and patient-centred instrument for measuring the tasks which MS patients identify in their adaptation process.

Keywords: Adaptation; Adaptive tasks; Stress-coping; Chronic disease; Multiple sclerosis

INTRODUCTION

Like many other chronic diseases Multiple Sclerosis (MS) is a condition which threatens patients with considerable losses including those of physical independence, social activity, and role function (O'Brien, 1993). MS, a progressive disease which starts early in life (mostly between 20 and 40 years of age), is also a threatening condition because of its idiosyncratic nature, its unpredictable course, the difficulty of

*Corresponding author. Tel.: +31 30 2729666. Fax: +31 30 2729729. E-mail: J.Bensing@fss.uu.nl

diagnosis, and the limited effect of medical treatment. Although drug treatments may delay progression of MS, these are expensive and not effective for all (Eklund and MacDonald, 1991; Antonak and Livneh, 1995). Under such conditions, one can imagine that MS patients face serious problems in adjusting to their illness. However, patient reports show that contracting a serious disease like MS is not always a devastating experience and can have positive aspects as well – for example, redefining what is important in life (cf. Folkman, 1997). Moreover, it has been observed that patients' adjustment to illness bears surprisingly little relationship to the objectively threatening characteristics of the disease (Wineman, 1990; Warren *et al.*, 1991; Antonak and Livneh, 1995). The apparent discrepancy between biological disease parameters and psychological indicators of adjustment is also shown by the finding that there is no relationship, or possibly even an inverse one, between disease duration and adjustment to it (Pollock *et al.*, 1990; Antonak and Livneh, 1995).

These findings on the discrepancy between psychological adaptation and biological deterioration, together with the limits of biomedicine in MS, have elicited wide interest in the psychological aspects of MS and chronic diseases of a similar nature. While undoubtedly a somatic disorder (characterised by the demyelination of fibres of the central nervous system), it is clear that MS is a stressful condition as a result of its psychological, social, and physical consequences. Considering chronic disease a stressful event or even a series of stressful events implies that the way patients deal with these events affects adaptation, expressed in terms of quality of life or other indicators of well-being (Lazarus and Folkman, 1984; Morse and Johnson, 1991). In the past, numerous research efforts have been spent on articulating which ways of coping are beneficial in dealing with the stress of chronic disease (for a review, see Maes *et al.*, 1996). Much less research effort, however, has been spent on identifying the characteristics of the stressors which confront patients with chronic disease. As a result, very little is known about the nature of these events and the demands they make on patients' adaptive capacity.

This study highlights an approach in which patients' subjective evaluation of the demands imposed by their disease are crucial for understanding adaptive processes. The focus of the study lies in the concept of *adaptive tasks*, relating the notion of disease-related stressors to the personal concerns of the individual patient (Moos and Schaefer, 1984; De Ridder *et al.*, 1998). Adaptive tasks refer to disease-related stressors as they involve a subjective appraisal of the demands imposed by disease and, as such, have implications for ways of dealing with these stressors. In that sense, adaptive tasks fit into the transactional stress-coping perspective (Lazarus and Folkman, 1984), which states that a stressor is appraised as such because a particular situational demand involves a threat or challenge to personal concerns. It has been argued that the development of a problem-specific coping model that allows for the detailed analysis of the individual meaning of disease-related threatening situations is necessary to improve our understanding of adaptive processes and to begin exploiting the clinical relevance of stress and coping research (Somerfield, 1997). The concept of adaptive tasks implies an explicit consideration of the meaning of threat imposed by disease and its consequences for adaptation. Put differently: adaptive tasks become salient when disease disrupts valued goals in life and thus become the focus of patients' coping efforts. The proposed perspective implies that, in addition to threats and losses, disease-related stressors may also involve challenges and possibilities for growth – an important aspect of chronic disease which we mentioned earlier in this section.

The notion of personal concerns, inherent in the concept of adaptive tasks, implies a close relationship with personal goals, which are considered highly relevant in self-regulation theories of coping (Carver and Scheier, 1998). This means that, like personal goals, personal concerns relate to things that are considered worth striving for. As such, they represent a standard for evaluating current circumstances in comparison with future, desired ones.

This latter view implies that adaptive tasks have relevance for new, more dynamic approaches to quality of life in which the subjective evaluation of one's situation compared with an ideal state or personal goals is more salient than is the case in traditional medical approaches to quality of life which mostly relate to a particular level of personal (e.g., physical or psychological) functioning (cf. Cantril, 1965; Cela and Tulskey, 1990; Sprangers and Schwartz, 1999). Therefore, the study of adaptive tasks also bears the possibility to eventually develop more sophisticated measures of quality of life than the ones which are currently employed and which focus on rather general parameters of medically relevant functioning (cf. Aronson, 1997). In the present study, we will focus on the association between adaptive tasks and a traditional measure of quality of life.

The aim of the present study is to develop a multidimensional and psychometrically sound instrument for measuring adaptive tasks encountered by the patient in dealing with chronic illness in general and in dealing with MS in particular. The concept of adaptive tasks fits within the general framework of stress-coping theory but broadens this perspective with notions from self-regulation theory, linking disease-specific stressors with personal goals. In the recent past, several publications – both in the psychological (Moos and Schaefer, 1984) and in the nursing literature (Miller *et al.*, 1992) – have highlighted the importance of adaptive tasks for explaining adaptive processes in chronic disease. However, due to the lack of empirical evaluation, the status of the concept remains unclear. The development of an instrument to identify adaptive tasks is the first logical step in providing evidence for its usefulness in health psychological research. Our overall goal is to test the validity of the concept of adaptive tasks as an important variable in adjustment to chronic illness.

The following issues will be addressed: (1) the development of an Adaptive Task Questionnaire to identify important adaptive tasks in MS patients (in short: QuAT-MS); and (2) the conceptual validity of this questionnaire compared to other variables relevant for measuring adjustment.

METHOD

Sample

MS patients were recruited by an invitation in the newsletter of the MS patient-organization. Patients who responded positively ($n = 367$) received the first questionnaire, containing demographic and disease characteristics, as well as the focus question with regard to the identification of adaptive tasks. This sample provided the items for the development of the initial QuAT-MS (see Measures section). This questionnaire was returned by 341 respondents (93%). Six months after the first measurement, patients who had agreed to continue participation in the study ($n = 317$) received a second questionnaire measuring adaptive tasks, coping and quality of life and a

TABLE 1 Demographic characteristics ($n = 259$)

	<i>Total</i>	<i>Men</i>	<i>Women^a</i>
Demographic			
Age	44.2 (9.7)	46.8 (9.1)	43.1 (9.8)**
% partner	77	82	75
Level of educational attainment			
Low/Medium	44	29	41*
High	56	71	49
Employment			
Changes in work (% yes)	76	81	74
Paid employment (% yes)	22	36	17
Health status			
Number of complaints	7.7 (3.6)	7.0 (3.4)	7.9 (3.7)
Disease duration (years)	13.8 (8.2)	13.8 (7.8)	13.8 (8.4)

^agender differences. * $p < 0.05$; ** $p < 0.01$.

number of other scales (see Measures section); 272 patients (86%) returned the second questionnaire of which 259 were used in the analyses (after elimination of questionnaires with more than 5% missing values on the central variables). The latter sample was employed to develop and validate the definitive QuAT-MS questionnaire. Demographic characteristics of the 259 patients are displayed in Table I. The majority of patients is female (71%), mean age is 44 years (SD 9.7 years) ranging from 19 to 71 years, with male patients being significantly older than female patients ($t = 2.70$, $df = 256$, $p < 0.01$). A minority of patients reported paid employment, whereas the majority had experienced changes in their work such as becoming unable to work or reducing the number of working hours. Mean disease duration was 13.8 years. Most patients had the relapsing-remitting variant of MS (RR-MS); 60% reported they were in a stable period at the time of the interview.

The representative status of the study was assessed by comparing the sample characteristics with samples from three different study populations. These were: the PO-sample, consisting of members of the Dutch MS Patient Organisation (Van Buuren *et al.*, 1998), the PS-sample, consisting of MS-patients from a regional Population Survey (Zwanikken, 1997), and the GP-sample, based on the Dutch National Study of Morbidity and Intervention Study in General Practice (Donker *et al.*, 1996). The study's age-sex distribution is comparable with that of the other samples, with an overall slight under-representation of the older age groups, and a slight over-representation of women as compared to the GP-sample. Disease duration and age of onset are comparable with the figures reported in the other samples.

Measures

Adaptive Tasks Measurement of adaptive tasks was intended to reflect patients' views on disease to the extent that it interfered with valued goals as a theory-guided operationalization of disease-related stress. The present questionnaire was developed employing a systematic bottom-up method collecting and categorizing patients' statements on adaptive tasks. First, patients were invited to reflect on the following focus question: "Could you say which major tasks and challenges you experience in dealing with your disease?". With a maximum of five statements per patient, 1283 statements from 341 respondents were collected and clustered into twelve categories

with the computer program KWALITAN (Peters and Wester, 1990): keywords were attached to each statement which were then further condensed into a smaller number of categories. After coding the statements of the first twenty patients, all keywords were scrutinized in order to combine synonymous keywords and keywords with related meanings. The resulting keywords were then used to code the statements of the next twenty cases; new keywords were added if necessary. The procedure of coding, scrutinizing and combining keywords was repeated until all statements had been coded. Afterwards, keywords were condensed in a hierarchical tree of more encompassing categories. This procedure resulted in twelve categories: 'Facing an uncertain future', 'Learning to be a patient', 'Defining new challenges', 'Giving up ordinary activities', 'Acknowledging one's limits', 'Looking at the bright side', 'Learning to be dependent on others', 'Dealing with physical impediments', 'Maintaining self-esteem', 'Maintaining emotional balance', 'Acceptance of being ill', and 'Re-establishing social relationships'. Fifteen percent of the statements were categorized by two researchers; inter-rater reliability (Cohen's kappa) was 0.80. For the final version of the questionnaire, ten statements from each category were selected, based on variability and coverage of the entire range of the underlying concept, resulting in a 120-item questionnaire with a 5-point scale, ranging from 'not important at all' to 'very important'.

Construct validity of the Adaptive Task Questionnaire (QuAT-MS) could be established by comparing the results with the findings from another study, employing a different method. In a concept mapping study among patients with Parkinson's disease and Chronic Fatigue Syndrome (De Ridder *et al.*, 1998), eight categories of adaptive tasks were found of which seven were shown to be identical to those in the KWALITAN-analysis.

Physical, psychological and social functioning were measured by the 68-item version of the Sickness Impact Profile (SIP-68) (De Bruin *et al.*, 1994), which has sub-scales for somatic autonomy, mobility control, psychological autonomy, social behaviour, emotional stability and mobility range. Reliability coefficients (Cronbach's alpha) of the scales in the present sample ranged from 0.72 to 0.86. Additional disease information was gathered by questions about *disease duration* ($M = 13.8$; $SD = 8.2$), and *number of symptoms* on a 21-item Symptom Checklist which covered the entire range of MS-related symptoms, ($M = 7.7$; $SD = 3.6$). *Depressive feelings* were measured by the Beck Depression Inventory (BDI) (Beck *et al.*, 1961; Bouman *et al.*, 1985). Cronbach's alpha in the present sample was 0.82.

Coping was measured with the Coping Inventory for Stressful Situations (CISS; Endler and Parker, 1994), which has sub-scales for task-oriented coping ($\alpha = 0.89$), emotion-oriented coping ($\alpha = 0.90$) and avoidant coping ($\alpha = 0.67$). *Optimism* was measured with the Life Orientation Test (LOT; Cronbach's alpha in the present sample 0.78; Scheier and Carver, 1985). *Self-efficacy* was measured with a 1-item statement referring to the extent patients thought themselves able to control their complaints with answers ranging from (1) not at all to (5) perfectly capable of controlling complaints.

Analyses

Two types of analyses were performed. First, the categorical factor structure of the 120-item initial version of the Adaptive Tasks Questionnaire was analyzed by means

of Principal Components Analysis (PCA). This method was used to detect the factors which were represented most clearly in the instrument, as well as to eliminate less relevant items. Only those patients were accepted who had 5% or fewer missing values on the Adaptive Tasks Questionnaire. In the PCA, these missing values were substituted by the variable means. Criteria for the selection of relevant items were based on the factor loadings of items after varimax rotation. Items with factor loadings of less than 0.40 on their primary factor or more than 0.35 for any other factor were eliminated. A factor loading of 0.40 means that the item has 16% of its variation involved in the factor score. Second, correlational and regression analyses were performed with the resulting sub-scales to determine the discriminatory power of adaptive tasks in MS patients. The full correlation matrix is shown in Appendix 2. The resulting adaptive tasks subscales were regressed on demographic characteristics entered in the first step, disease-related characteristics in the second step, and coping and coping resources in the third step. Within the three blocks, variables were entered by a stepwise method.

RESULTS

Identification of Adaptive Tasks

The first step in our analyses was to replicate the assumed structure of the 10 factors. An *eigenvalue* of 2 was chosen as a criterion to determine the number of factors. Based on this criterion, the first PCA analysis resulted in 11 factors which explained 52.9% of variance. The 11th factor comprised only one item and was eliminated. In this factor solution, 32 items appeared to have either weak factor loadings on the primary factor (< 0.40), or too high loadings on any other factor (> 0.35). With the remaining 88 items a second PCA analysis was carried out with a forced ten-factor solution to verify whether the concepts from the first factor analysis could be replicated and also to check the robustness of the remaining items. In this ten-factor solution, 54.2% of variance was explained. The factor solution had the same structure as the solution of the first analysis. Another nine items appeared to have weak factor loadings. After elimination of these items, a ten-factor solution with a total of 79 items remained. These 79 items, representing 10 different categories of adaptive tasks were chosen for the final version of the QuAT-MS (see Table II). The internal consistency of the sub-scales was high with alpha's ranging from 0.82 to 0.92. The inter-relationships between the sub-scales varied between 0.09 and 0.59 (mean correlation 0.39). Means varied between 3.25 and 4.30, suggesting that all adaptive tasks were relatively important, with 'Preserving autonomy' as the most important adaptive task and 'Facing an uncertain future' as the least important.

Adaptive Tasks and Demographic Characteristics

Table III provides the results of the regression analyses. Gender shows a significant association with six out of ten adaptive tasks, with female MS-patients being more engaged in 'Defining new challenges', 'Acknowledging one's limits', 'Maintaining self-esteem', 'Preserving autonomy', 'Learning to be a patient' and 'Re-establishing social relationships'. Age was related to 'Preserving autonomy' and to 'Re-establishing

TABLE 2 Means and standard deviations of adaptive tasks ($n = 259$)

<i>Variables</i>	<i>N items</i>	<i>alpha</i>	<i>M</i>	<i>SD</i>	<i>Sample items</i>
Defining new challenges	9	0.92	3.58	0.88	Develop new spheres of interest.
Acknowledging one's limits	10	0.89	3.93	0.72	Learning to recognize the limits of my body.
Giving up ordinary activities	12	0.88	3.50	0.83	Being not able to practice my favorite sport.
Maintaining emotional balance	8	0.89	3.84	0.77	Keeping annoyance to myself when something is not going well.
Maintaining self-esteem	8	0.85	3.67	0.89	Not feeling inferior to others.
Facing an uncertain future	6	0.87	3.25	0.90	Fear of the future.
Preserving autonomy	7	0.82	4.30	0.62	Only accept the most necessary help.
Learning to be a patient	6	0.86	3.62	0.83	Learn to accept help.
Re-establishing social relationships	7	0.82	4.13	0.67	Staying in contact with friends and family as much as possible.
Looking at the bright side	7	0.84	4.03	0.69	Living more intense and enjoying the things that are still possible.

social relationships' while marital status was related to 'Acknowledging one's limits' and 'Looking at the bright side'. Patients who are (still) employed were more involved in 'Defining new challenges' while patients with a high education level attached less importance to 'Maintaining emotional balance', 'Preserving autonomy' and 'Looking at the bright side'. Taken together, demographic characteristics explained zero to 9 % of the variance in adaptive tasks.

Adaptive Tasks and Disease Characteristics

Table III also shows that adaptive tasks were hardly related to physical disease characteristics. In the regression analyses, the SIP-subscale somatic autonomy, mobility control and mobility range and disease duration were not related to any of the adaptive tasks. The number of MS-related symptoms is among the significant predictors of the task of 'Defining new challenges' and 'Preserving autonomy'. More significant regression coefficient correlations were found in the psychosocial domain, with seven out of ten adaptive tasks being related to at least one of the psychosocial SIP-subscale or depression. Psychological autonomy was associated with 'Maintaining emotional balance' and 'Maintaining self-esteem', 'Learning to be a patient' and 'Looking at the bright side'. Depression was related to 'Giving up ordinary activities' and 'Facing an uncertain future'. Zero to twenty percent of the variance in adaptive tasks was explained by disease-related characteristics with depression being the strongest predictor.

Adaptive Tasks and Coping

With the exception of 'Learning to be a patient' all adaptive tasks were associated significantly with at least one coping or coping resource variable. Self-efficacy is explaining variance in five out of ten tasks such as 'Defining new challenges', 'Acknowledging one's limits', 'Maintaining emotional balance', 'Maintaining self-esteem', and 'Looking at the bright side'. Optimism is a significant predictor of the tasks of 'Re-establishing social relationships' and 'Looking at the bright side'.

'Defining new challenges', 'Preserving autonomy' and 'Looking at the bright side' were predicted by task-oriented coping, while emotion-oriented coping was related to 'Maintaining self-esteem' and 'Facing an uncertain future'. An avoidant coping style was negatively associated to 'Giving up ordinary activities' and positively to 'Acknowledging one's limits', 'Maintaining an emotional balance' and 'Re-establishing social relationships'. Coping and coping resources explained up to 10% of variance in adaptive tasks.

DISCUSSION

The objective of this study was to develop a valid and reliable instrument for measuring adaptive tasks encountered by patients dealing with chronic illness in general and dealing with MS in particular. The results of this study demonstrate that adaptive tasks indeed can be measured in a psychometrically appropriate way. Moreover, the study has shown that adaptive tasks can be distinguished both conceptually and empirically from related concepts like coping and quality of life. A first indicator of the validity of the QuAT-MS lies in its correspondence with the adaptive tasks identified in an unrelated sample employing a different (concept mapping) procedure (De Ridder *et al.*, 1998). Additional evidence for the validity of the QuAT is provided by the literature, where typologies based on clinical experience (Cohen and Lazarus, 1979; Moos and Schaefer, 1984; Miller *et al.*, 1992) show a remarkable resemblance to the adaptive tasks presented by the MS-patients in this study (see Appendix 1). The only new element in the QuAT-MS is the adaptive task of 'Defining new challenges' which is a growth-oriented task not mentioned earlier in the literature. The emergence of this scale may be explained by the wording of the focus question, which specifically asked for positive (challenges) as well as negative (threats and losses) tasks. However, positive adaptive tasks are recognized by patients as important for their sense of control and fit in Folkman's (1997) observation that serious diseases like MS are not an entirely devastating experience but may have positive aspects as well (cf. Sodergren and Hyland, 2000). Taken together, the QuAT-MS covers a wide range of adaptive tasks, reflecting the meaning of disease-related stress quite well.

The MS-patients in this study considered 'Preserving autonomy' as the most important task in dealing with illness. Further, in descending order of importance, they indicated 'Re-establishing social relationships', 'Looking at the bright side', 'Acknowledging one's limits', 'Maintaining emotional balance', 'Maintaining self-esteem', 'Learning to be a patient', 'Defining new challenges', 'Giving up ordinary activities', and 'Facing an uncertain future'. It is remarkable that dealing with an uncertain future is considered the least important as in the literature on chronic diseases, MS is considered the classic example of an unpredictable disease resulting in uncertainty (e.g., Antonak and Livneh, 1995) which generally leads to greater emotional disturbance (Wineman *et al.*, 1994). Our results may be interpreted as an indication that it may be adaptive to relegate the unchangeable aspects of MS to a less important position in dealing with illness.

Adaptive tasks bear more relationship to psychological and psychosocial characteristics than to disease-related characteristics and physical functioning of patients. From a stress-coping perspective, adjustment to disease starts when disease

disrupts valued goals in life. Therefore, the weak associations of physical functioning with adaptive tasks correspond with the observation that adaptation to MS is only weakly related to biomedical disease characteristics (Wineman, 1990; Warren *et al.*, 1991; Antonak and Livneh, 1995). In contrast, coping styles and coping resources such as optimism and self-efficacy show significant and meaningful relationships with a number of adaptive tasks. Self-efficacy and optimism were related to tasks representing opportunities such as 'Defining new challenges', 'Re-establishing social relationships' and 'Looking at the bright side'. In addition, self-efficacy was related to the tasks of maintaining emotional balance and self-esteem. Emotion-oriented coping was related to adaptive tasks associated with threat or loss such as 'Facing an uncertain future' while task-oriented coping was associated with opportunity-related tasks such as 'Defining new challenges' and 'Preserving autonomy'. Similar relationships have been reported in a study among MS-patients in which appraisal of opportunity was related to problem-focused coping and appraisal of danger to emotion-focused coping (Wineman *et al.*, 1994). Possibly, it is easier for those patients who can build upon a high level of coping resources to emphasize the opportunities in their lives. In contrast, the perception of inevitable loss may call for emotion-oriented coping.

Our study also demonstrated that the salience of adaptive tasks varies with the social background of patients, most remarkably gender. It appeared that female patients attach more importance than male patients to 'Preserving autonomy', 'Acknowledging one's limits', 'Defining new challenges' and 'Re-establishing social relationships'. This gender difference cannot be explained straightforwardly although women may be more prepared than men to admit the impact of disease on their lives and take subsequent action.

The relevance of the adaptive tasks identified by the QuAT-MS for patients with a chronic disease other than MS remains to be determined. Adaptive tasks may vary according to disease characteristics, such as the availability of adequate treatment or the social response the disease evokes. This is demonstrated in studies on stressors which are typical for particular diseases, like cancer (Schag *et al.*, 1990; Dunkel-Schetter *et al.*, 1992), rheumatoid arthritis (Van Lankveld *et al.*, 1993), Parkinson's disease and the Chronic Fatigue Syndrome (De Ridder *et al.*, 1998), renal disease (Littlewood *et al.*, 1990), HIV-infection (Siegel and Krauss, 1991), or parents of children with chronic conditions (Canam, 1993). Some adaptive tasks will be highly specific for the disease under study, while others will be shared over various disease categories. 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 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 and Schaefer, 1984). Although these tasks proposed by Moos and Schaefer appear to be an adequate listing of potential stresses facing chronic patients, it does not make clear whether these tasks are equally relevant for different types of chronic diseases. The results of these studies on disease-related stressors suggest that a systematic investigation of adaptive tasks may further our understanding of adjustment processes in chronic illness.

The study had some limitations, the most important being that the MS patients in this study were not a random selection. While comparison of background data with samples from other studies did not reveal significant differences – except a slight over-representation of female patients in the middle age groups – participants were members of a patient organization and as such may have been more involved in dealing with their illness compared to non-members. This means that the results of this study can only be considered as a test on the validity of the QuAT-MS, and not as a description of the adaptive tasks facing MS patients in general. Another limitation is the rather low amount of explained variance with the variables used. Taken together, about 4–27% of the variance in adaptive tasks could be explained from the demographic, disease-related and psychological variables employed in this study. This is a modest result, implying that other factors have a considerable influence on the adaptive tasks which patients define for themselves when confronted with MS. However, this is not uncommon in psychological research. Notwithstanding these critical comments, we feel that the adaptive tasks questionnaire described here offers a fruitful step in the empirical study of an adaptive tasks framework. This framework offers insight in the focus of patients' coping efforts, has the advantages of a goal-related approach which can be utilized by professionals involved in care for chronically ill patients and which may function as a starting point for developing disease-specific problem-oriented approaches for clinical intervention (Somerfield, 1997).

References

- Antonak, R.F. and Livneh, H. (1995). Psychosocial adaptation to disability and its investigation among persons with multiple sclerosis. *Social Science and Medicine*, **40**, 1099–1108.
- Aronson, K.J. (1997). Quality of life among persons with multiple sclerosis and their caregivers. *Neurology*, **48**, 74–80.
- Beck, A.T., Ward, C.H., Mendelsohn, M., Mock, J.E. and Erbaugh, J.K. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, **4**, 561–571.
- Bouman, T.K., Luteijn, F., Albersnagel, F.A. and Van der Ploeg, F.A.E. (1985). Enige ervaringen met de Beck Depression Inventory (BDI). [A Dutch experience with the Beck Depression Inventory] *Gedrag: Tijdschrift voor Psychologie*, **3**, 13–24.
- Canam, C. (1993). Common adaptive tasks facing parents of children with chronic conditions. *Journal of Advanced Nursing*, **18**, 46–53.
- Cantril, H. (1965). *The Pattern of Human Concerns*. Rutgers University Press, New Brunswick, NJ.
- Carver, C.S. and Scheier, M.F. (1998). *On the Self-regulation of Behavior*. Cambridge University Press, Cambridge, UK.
- Cela, D.F. and Tulskey, D.S. (1990). Measuring quality of life today: Methodological aspects. *Oncology*, **4**, 29–39.
- Cohen, F. and Lazarus, R.S. (1979). Coping with the stresses of illness. In: Stone, G.C., Cohen, F. and Adler, N.E. (Eds.), *Health Psychology*, pp. 217–254. Jossey-Bass, San Francisco.
- De Bruin, A.F., Buys, M., De Witte, L.P. and Diederiks, J.P.M. (1994). The Sickness Impact Profile: SIP 68, a short generic version. First evaluation of reliability and reproducibility. *Journal of Clinical Epidemiology*, **47**, 863–871.
- De Ridder, D., Schreurs, K. and Bensing, J. (1998). Adaptive tasks, coping and quality of life of chronically ill patients: The cases of Parkinson's disease and chronic fatigue syndrome. *Journal of Health Psychology*, **3**, 87–101.
- Donker, G.A., Foets, M. and Spreeuwenberg, P. (1996). Multiple Sclerosis: Management in Dutch general practice. *Family Practice*, **13**, 439–443.
- Dunkel-Schetter, C., Feinstein, L.G., Taylor, S. E. and Falke, R.L. (1992). Patterns of coping with cancer. *Health Psychology*, **11**, 79–87.
- Eklund, V. and MacDonald, A. (1991). Descriptions of persons with multiple sclerosis. With an emphasis on what is needed from psychologists. *Professional Psychology: Research and Practice*, **22**, 277–284.
- Endler, N.S. and Parker, D.A. (1994). Assessment of multidimensional coping: Task, emotion, and avoidance strategies. *Psychological Assessment*, **6**, 50–60.

- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine*, **45**, 1207–1221.
- Lazarus, R. and Folkman, S. (1984). *Stress, Appraisal and Coping*. Springer, New York.
- Littlewood, J., Hardiker, P., Pedley, J. and Olley, D. (1990). Coping with home dialysis. *Human Relations*, **43**, 103–111.
- Maes, S., Leventhal, H. and De Ridder, D. (1996). Coping with chronic diseases. In: Zeidner, M. and Endler, N.S. (Eds.), *Handbook of Coping: Theory, Research, Applications*, pp. 221–251. Wiley, New York.
- Miller, D.H., Hornabrook, R.W. and Purdie, G. (1992). The natural history of multiple sclerosis: A regional study with some longitudinal data. *Journal of Neurology, Neurosurgery and Psychiatry*, **55**, 341–346.
- Moos, R.H. and Schaefer, J.A. (1984). The crisis of physical illness: An overview and conceptual approach. In: Moos, R.H. (Ed.), *Coping with Physical Illness. 2: New Perspectives*, pp. 3–25. Plenum, New York.
- Morse, J.M. and Johnson, J.L. (1991). Towards a theory of illness: The illness constellation model. In: Morse, J.M. and Johnson, J.L. (Eds.), *The Illness Experience*, pp. 315–342. Sage, London.
- O'Brien, M.T. (1993). Multiple sclerosis: The relationship among self-esteem, social support and coping behavior. *Applied Nursing Research*, **2**, 54–63.
- Peters, V. and Wester, F. (1990). *Qualitative Analysis in Practice: Including User's Guide, Kwalitan Version 2*. University of Nijmegen.
- Pollock, S.E., Christian, B.J. and Sands, D. (1990). Responses to chronic illness: Analysis of psychological and physiological adaptation. *Nursing Research*, **39**, 301–304.
- Schag, A., Heinrich, R.L., Ganz, P.A. and Aadland, R.L. (1990). Assessing problems of cancer patients: Psychometric properties of the cancer inventory of problem situations. *Health Psychology*, **9**, 83–102.
- Scheier, M.F. and Carver, C.S. (1985). Optimism, coping and health: Assessment and implications of generalized outcome expectancies. *Cognitive Therapy and Research*, **16**, 201–228.
- Siegel, K. and Krauss, B.J. (1991). Living with HIV Infection: Adaptive tasks of seropositive gay men. *Journal of Health and Social Behavior*, **32**, 17–32.
- Sodergren, S.C. and Hyland, M.E. (2000). What are the positive consequences of illness? *Psychology and Health*, **15**, 85–97.
- Somerfield, M.R. (1997). The utility of systems models of stress and coping for applied research. *Journal of Health Psychology*, **2**, 133–151.
- Sprangers, M.A.G. and Schwartz, C.E. (1999). Integrating response shift into health-related quality of life research: A theoretical model. *Social Science and Medicine*, **48**, 1507–1515.
- Van Buuren, S., Zaadstra, B.M. and Van Noort, J.M. (1998). Clusterstudie naar perinatale infecties met MS patiënten. [A study of perinatal infections in MS patients] *Tijdschrift Sociale Gezondheidszorg*, **8**, 442–445.
- Van Lankveld, W., Näring, G., Van der Staak, C., Van 't Pad Bosch, P. and Van de Putte, L. (1993). Stress caused by rheumatoid arthritis: Relation among subjective stress of the disease, disease status, and well being. *Journal of Behavioral Medicine*, **16**, 309–321.
- Warren, S., Warren, K.G. and Cockerill, R. (1991). Emotional stress and coping in multiple sclerosis (MS) exacerbations. *Journal of Psychosomatic Research*, **35**, 37–47.
- Wineman, N.M. (1990). Adaptation to multiple sclerosis: The role of social support, functional disability, and perceived uncertainty. *Nursing Research*, **39**, 294–299.
- Wineman, N. M., Durand, E.J. and Steiner, R.P. (1994). A comparative analysis of coping behaviors in persons with multiple sclerosis or a spinal cord injury. *Research in Nursing and Health*, **17**, 185–194.
- Zwanikken, C.P. (1997). *Multiple sclerose: epidemiologie en kwaliteit van leven* [Multiple sclerosis: Epidemiology and quality of life]. Thesis Rijkuniversiteit Groningen.

APPENDIX 1

Comparison of the adaptive tasks in the QuAT-MS with typologies of the literature on chronic diseases

<i>QuAT-MS</i>	<i>Cohen and Lazarus (1979)</i>	<i>Moos and Schaefer (1984)</i>	<i>Miller (1992)</i>
Acknowledging one's limits	Reduce harmful environmental conditions and enhance prospects of recovery	Dealing with symptoms	Adjusting life-style. Knowledge and skill for self-care Complying with prescribed regimen Handling physical discomfort
Giving up ordinary activities	Tolerate or adjust to negative events and realities		Grieving over losses
Maintaining self-esteem	Maintain a positive self-image	Preserving a satisfactory self-image and maintaining a sense of competence and mastery	Positive self-concept
Maintaining emotional balance	Maintain emotional equilibrium	Preserving a reasonable emotional balance	
Re-establishing social relationships	Continue satisfying relationships with others	Sustaining relationships with family and friends Developing and maintaining relationships with health care staff	Altered social relations Dealing with role change
Learning to be a patient		Dealing with hospital environment and treatment procedures	Dealing with social stigma
Facing an uncertain future		Preparing for an uncertain future	
Preserving autonomy			Maintaining a sense of normalcy Maintaining control Maintaining hope
Looking at the bright side			
Defining new challenges			

APPENDIX 2

Correlations of demographic variables, disease-related characteristics and coping variables with adaptive tasks

	Defining new challenges	Acknowledging one's limits	Giving up ordinary activities	Maintain. emotional balance	Maintain. self-esteem	Facing an uncertain future	Preserving autonomy	Learning to be a patient	Reestablishing soc. relationsh.	Looking at the bright side
Age	-0.08	-0.06	0.03	0.08	-0.05	-0.14*	0.11	-0.02	0.11	0.07
Gender ^a	0.25***	0.25***	0.06	0.06	0.17**	0.09	0.19**	0.21**	0.15*	0.13*
Partner ^b	-0.07	-0.15*	-0.07	-0.06	0.02	-0.01	-0.03	-0.04	-0.09	-0.13*
Education	0.01	-0.11	-0.16**	-0.25***	-0.09	0.02	-0.24***	-0.12	-0.07	-0.09
Work ^b	0.18**	0.11	0.08	0.03	0.14*	0.01	0.08	0.14*	0.13*	0.12
Somatic autonomy	-0.00	0.01	0.10	0.04	0.07	0.10	0.01	0.09	0.07	0.00
Mobility control	0.01	-0.03	0.05	-0.02	0.02	0.03	0.04	0.02	0.05	0.02
Mobility range	-0.10	0.07	0.17**	0.04	-0.05	0.12	0.03	0.06	-0.02	-0.05
Psychological autonomy	0.11	0.08	0.11	0.18**	0.21**	0.20**	0.18**	0.17**	0.06	0.16*
Emotional stability	0.06	0.11	0.16**	0.07	0.18**	0.28***	0.15*	0.07	-0.06	-0.06
Social behaviour	0.05	0.14*	0.11	0.06	0.13*	0.18**	0.06	0.07	-0.06	-0.01
Depression	0.10	0.13*	0.27***	0.08	0.19**	0.46***	0.12	0.11	-0.07	-0.01
Number of symptoms	0.18**	0.13*	0.22**	0.12	0.14*	0.23**	0.18**	0.08	0.03	0.09
Disease length	0.06	-0.02	-0.03	0.07	-0.01	-0.12	0.16**	0.07	0.05	0.03
Optimism	0.07	0.03	-0.20**	0.03	0.12	-0.40***	0.07	-0.11	0.20**	0.24***
Self-efficacy	0.13*	0.09	0.04	0.18**	0.11	-0.03	0.04	-0.04	0.07	0.24***
Task-oriented coping	0.28***	0.14*	-0.09	0.07	0.12	0.03	0.19**	-0.02	0.06	0.19**
Emotion-oriented coping	0.16*	0.13*	0.24***	0.11	0.30***	0.46***	0.18**	0.17**	-0.01	0.02
Avoidant coping	0.20**	0.18**	-0.14*	0.14*	0.16**	0.05	0.15*	0.07	0.19**	0.19**

^a0 = male, 1 = female; ^b 0 = no, 1 = yes;* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.