

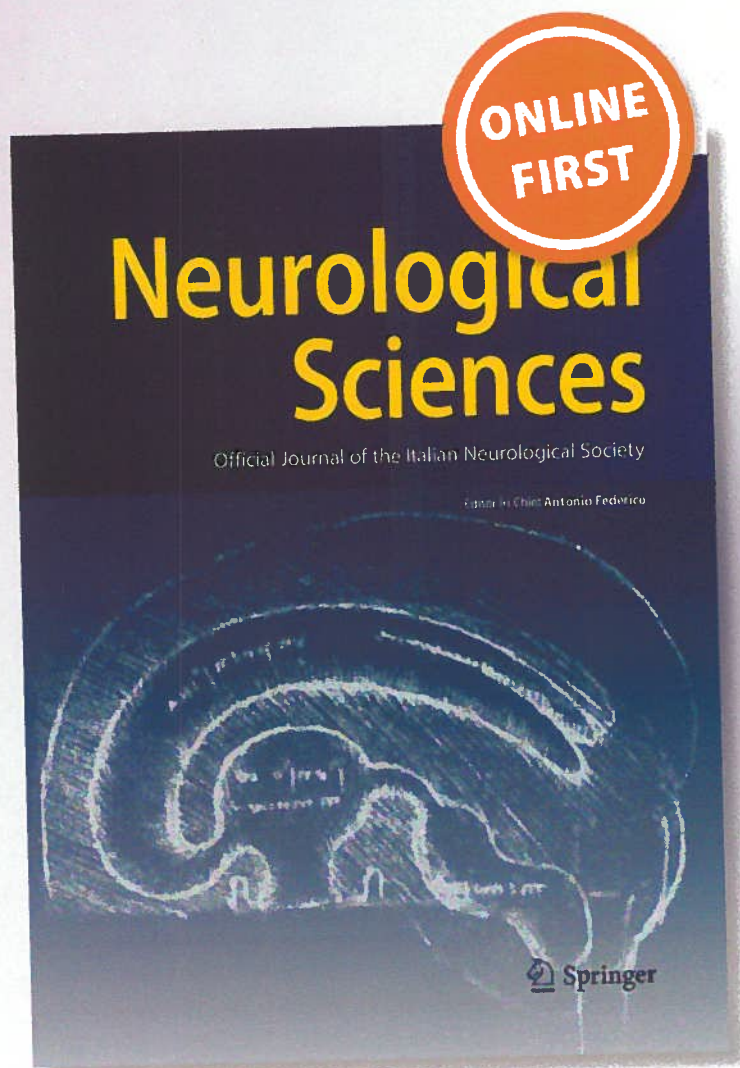
*Improving the quality of life of multiple sclerosis patients through coping strategies in routine medical practice*

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**Neurological Sciences**  
Official Journal of the Italian  
Neurological Society

ISSN 1590-1874

Neurol Sci  
DOI 10.1007/s10072-014-1900-8



 Springer

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# Improving the quality of life of multiple sclerosis patients through coping strategies in routine medical practice

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Received: 24 March 2014 / Accepted: 18 July 2014  
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**Abstract** Multiple sclerosis (MS) has a major impact on quality of life (QoL). Coping strategies which may influence QoL have not been identified. Furthermore, there is no coping scale designed to measure coping in MS patients and concise enough for routine medical practice. We used 46 items and 7 coping dimensions; we successively reduced the minimum number of dimensions through confirmatory factor analysis (CFA) and Rasch modelling. The resulting scale was submitted to psychometric validation via an independent cross-sectional analysis. After administration to 331 MS patients, we eliminated 10 of the 46 initial items; a CFA iterative algorithm identified a positive coping (PC) group and a negative coping (NC) group; an iterative reduction algorithm led to a final 10 items questionnaire, which was tested in an independent, new cross-sectional sample of 457 patients. Psychometric tests, including the Rasch model and CFA, successfully validated the scale, confirming the two dimensions and the

absence of differential item functioning. The correlation between coping and QoL increased to 0.59 and 0.62 for NC and PC, respectively, compared with 0.33 found with existing scales. Our findings justify a one-dimensional overall coping scale (PC + NC). The effect of coping on QoL can be evaluated simply by adding together a positive and a negative coping strategy, for which we developed a short 10-item scale, which can be considered as an effective means of measuring the impact of coping on QoL and is ideal in routine medical practice.

**Keywords** Coping · Quality of life · Multiple sclerosis · Routine medical practice

## Introduction

Multiple sclerosis (MS) severely affects quality of life (QoL) [1]. Although current treatments have known clinical benefits, no significant effect on maintaining QoL in MS patients has been demonstrated.

Coping is the cognitive and behavioural efforts of a patient to adjust to disease [2] and it may impact QoL. Independent cross-sectional studies on MS patients found that emotional and avoidance coping strategies were associated with depression while patients developing problem solving strategies were less liable to experience depression [3–5]. While coping impacts QoL [5], positive strategies influence both mental and overall QoL [6], wishful thinking being the most negative strategy [5]. The high prevalence of emotional and avoidance negative coping strategies in MS has been confirmed [3, 6].

As a spontaneous adjustment is not expected for all patients, the question is whether a particular therapeutic intervention may trigger patient's adaptation. Adequate

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methodology and appropriate scales for QoL and coping measurement are required to evidence the efficacy and detect potential deficient strategies of such interventions.

Naturalistic trials reproduce the conditions of routine medical practice (RMP) and are suitable for measuring QoL and coping which are influenced both by the patient's characteristics and his relationship with the therapist. Adequate coping scales must be accurate, short and easy to use and interpret. For QoL measurement, a short specific tool applicable to RMP has been suggested [7]. In this study, we attempted to define a coping scale appropriate for MS patients in RMP.

We first conducted a literature search on coping scales. The most used 32-item self-reported Coping with Health, Injuries and Problems Solving (CHIP) [8] covers four dimensions and has been validated in MS. Other scales such as the Ways of Coping Checklist and its derived scale [9], the Coping Strategy Indicator [10], the Coping Inventory for Stressful Situations [11], the Coping Strategies Questionnaire [12], the Coping Orientation to Problems Experienced [13], or the Stress and Coping Process Questionnaire [14] are not validated in MS patients. Of these scales, CHIP and Coping with MS Scales have been validated in MS [15, 16].

These tools provide various possible dimensions and types of coping strategies, but these scales do not explore the same number of dimensions, the coping strategies studied target various problems and not only QoL concerns and their length is not suitable in RMP context.

Our objective was to identify and define a coping measurement tool addressing only those dimensions of coping strictly related to QoL and short enough for use in RMP.

## Materials and methods

We developed the scale in three stages

A first stage (item generation) produced a patient-reported outcome questionnaire gathering a set of coping-related items from all items of CHIP and adding three dimensions [8]: avoidance, energy conservation and problem-solving and 14 additional items resulting from interviews of MS patients and experts' opinions. The final questionnaire consisted of 46 items and was pre-tested on 25 randomly selected MS patients. We added patient identification variables and the QoL questionnaire previously validated for MS [7].

The second stage consisted in the scale development, based on a national cross-sectional multi-centre survey of consecutively-selected anonymously-collected MS patients, approved by the local health authorities. The item reduction

step consisted in excluding items which did not fit the Polytomous Rasch Model [17] (mean square fit residual  $>2.5$ ),  $>5\%$  of observed missing data, floor-ceiling effects  $>25\%$ , linear correlation ( $r$ ) of each item with its own corrected dimension  $r < 0.30$  (convergent validity) [17],  $r$  between each item with its own scale  $\leq \times 2$  standard errors than  $r$  between any item of any other dimension (discriminant validity), and  $r$  between two items of the same dimension  $< 0.85$  (redundancy). We used exploratory factor analysis (EFA, Maximum Likelihood search) to identify the overall factor structure of QoL and coping dimensions. We then identified the minimum number of useful dimensions by using a backward hierarchical confirmatory factor analysis (CFA) aggregating at each iteration the two most correlated dimensions that were not significantly separable ( $\chi^2$  nested hierarchical test) [17]. Our sample size of 435 patients provided a 95% power to detect a significant difference at comparison-wise error with a risk  $\alpha = 0.05$ , with a minimum clinically meaningful value of the correlation coefficient  $\leq 0.7$ , for a two-nested model with RMSEA (root mean square error approximation) at 0.05 and 0.005, respectively [17].

The smallest subset of items was identified using an iterative algorithm and removing, at each iteration, the least relevant item with the weakest convergent validity or uncorrelated with overall QoL ( $r < 0.2$ ). The iteration was continued for as long as the internal consistency of each dimension was  $>0.7$ .

We assessed the validity of the new scale in an independent, new, cross-sectional study. Goodness-of-fit to the Rasch model and differential item functioning (DIF), particularly geographical and cultural factors and illness severity, were validated by CFA. We predicted the effects of coping strategies on QoL, adjusting for severity of the illness (EDSS, illness stage), age, gender, active job and living conditions. Finally, we conducted a 1-week longitudinal study during which the scale was re-administered to 60 patients selected for test-retest reproducibility.

## Results

A total of 36 neurologists in 20 centres were involved (4 academic hospitals, 4 general hospitals, 3 clinics, 9 private practices). A total of 390 questionnaires were distributed, 331 were completed by patients. The sample included 232 women (70.1%) with a median age of 38 years (interquartile range 32–46). Overall, 79 patients (23%) were in relapse phase, 182 (55%) worked outside the home, 101 (30%) lived alone and 144 (43%) had children; 234 patients (71%) had relapsing remitting MS (RRMS), 42 (13%) Secondary progressive MS (SPMS) and 55 (16%) Primary progressive MS (PPMS).

**Table 1** Summary of the seven, a priori selected coping dimensions and the 46 initial items

Coping dimensions	Cronbach $\alpha^a$	Number of items	Number of items correlated with QoL <sup>b</sup>			Correlation with QoL scores <sup>c</sup>			Total
			$r > 0.2$	$-0.2 < r < 0.2$	$R < -0.2$	Physical	Mental	Energy	
Emotional	0.71	8	7	0	1	-0.32***	-0.38***	-0.29***	-0.33***
Avoidance	0.69	4	3	1	0	-0.25***	-0.35***	-0.28**	-0.31***
Palliative	0.53	7	3	2	2	-0.22***	-0.20**	-0.21**	-0.21**
Instrumental	0.67	8	2	4	2	-0.07 <sup>ns</sup>	-0.06	0.04	-0.07
Distractive	0.59	10	2	4	4	0.10*	0.16	0.06	0.11*
Energy	0.66	4	0	1	2	0.37***	0.39***	0.43***	0.39***
Problem-solving	0.78	5	0	1	4	0.35***	0.39***	0.41***	0.39***

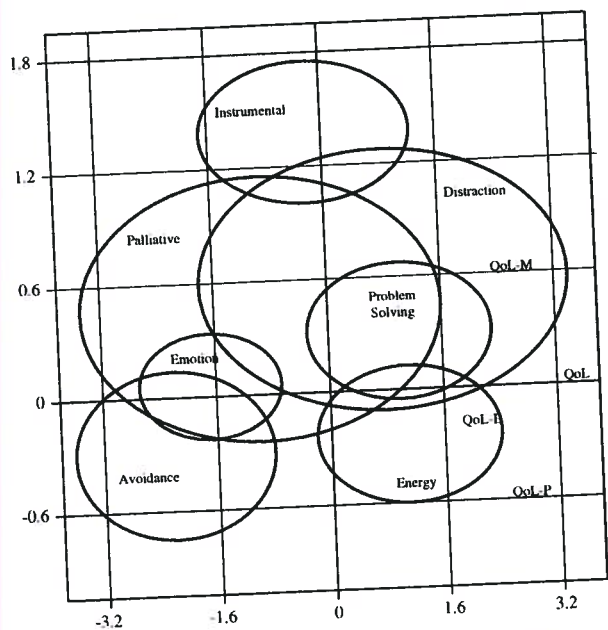
Dimensions are sorted by order of increasing correlation with total QoL (last column)

Correlation significance: \*\*\* < 0.001, \*\* < 0.01, \* < 0.05, otherwise NS

<sup>a</sup> Internal consistency (Cronbach  $\alpha$ )

<sup>b</sup> Number of items correlated negatively ( $r < -0.2$ ), positively ( $r > 0.2$ ), or non-significantly ( $-0.2 < r < 0.2$ ) with QoL

<sup>c</sup> Correlation with physical, mental, and energy domains and total QoL, measured by QoL Scores



**Fig. 1** Exploratory factor analysis (EFA) on coping and QoL items. The first factor is essentially associated with QoL, the second factor (19 % of the variance) differentiating mental and physical QoL. Avoidance and emotion strategies are inversely correlated with QoL, whereas problem-solving and energy conservation are directly correlated. The discriminant validity of each dimension is described by the radius of each circle, suggesting very heterogeneous values of palliative and distractive dimensions

Poor internal consistencies were found for almost all the coping dimensions and discordances in the direction of the correlation between QoL items were found for the palliative, instrumental and distractive dimensions (Table 1).

**Table 2** Final list consisting of 10 items scale (DC10)

Items	Rasch analysis			Correlations with dimensions	
	<i>p</i> value	Outfit MSQ	Infit MSQ	PC	NC
Do you spend time doing sport?	1.000	0.704	0.705	0.539	-0.103
Do you want to fight your illness?	0.384	1.017	0.996	0.523	-0.223
I have fun whenever I can.	0.999	0.799	0.825	0.523	-0.010
Do you have personal projects?	1.000	0.751	0.754	0.623	-0.234
If I organise my life better, could I improve my health?	0.998	0.808	0.794	0.685	-0.284
I ask for help from people I trust.	0.726	0.954	0.960	0.743	-0.307
Do you feel guilty?	0.059	1.151	1.182	-0.177	0.683
I tend to lie in bed.	0.065	1.107	1.113	-0.158	0.599
Do you feel frustrated with your disease?	0.278	1.038	0.999	-0.297	0.761
I feel sorry for myself.	0.365	1.021	1.034	-0.250	0.707

Rasch analysis of the selected items for dimensions of positive coping (PC) and negative coping (NC), outfit and infit mean squares. Correlations between each item and the two dimensions. DC10: Will be defined after acceptance of the manuscript to preserve anonymity

**Item reduction**

Ten of the 46 initial items were excluded: one due to missing data, one as the overall misfit to the Polytomous Rasch Rating Scale Model (RSM) was significant (<0.05),



one with an absolute value of fit residual  $>2.5$ , two with floor-ceiling effects  $>30\%$ , and five for lack of convergent/discriminant validity. For the 36 remaining items, the selection of psychometric conditions was achieved in terms of distribution, comparable means, and any item-own scale correlations in the range (0.27; 0.68).

#### Dimension extraction

EFA detected one predominant factor (63% variance, Fig. 1), essentially associated with QoL, highlighting that problem-solving and energy conservation had a positive effect on QoL (linear correlation,  $r = 0.38$  and  $0.39$ , respectively; Table 1); emotional ( $p = -0.33$ ) and avoidance ( $p = -0.31$ ) strategies were found to have a negative effect. Using the CFA iterative algorithm, the seven separate coping strategies were considered as not significantly different ( $\chi^2$  nested test,  $p < 0.001$ ) and converged into two significantly distinct clusters: emotional, palliative and avoidance dimensions opposed to others. The correlations with QoL (Table 1) led to refer them as positive coping (PC) and negative coping (NC) groups, respectively.

#### Item final reduction

Based on PC and NC, the iterative removal of items resulted in a final selection of 10 items, six for PC and four for NC (Table 2).

#### Validation study

An independent new sample involved 58 neurologists in 40 centres (8 academic hospitals, 7 general hospitals, 4 clinics, and 21 private practice). A total of 531 questionnaires were distributed and 457 were completed. The sample included 343 women (75.1%), with a median age of 44 years (interquartile range 36–52); 247 (54%) worked outside the home, 107 (23.4%) were living alone and 231 (51%) had children. 314 patients had RRMS, 50 SPMS and 93 PPMS. The mean (SD) duration of illness since diagnosis was 10.5 years (7.9) and the mean (SD) Kurtzke EDSS index was 1.6 (0.79). A total of 223 patients (49%) had medullar lesions and 56 (12%) were in relapse.

The internal consistencies of the PC and NC dimensions were 0.73 and 0.70, respectively. Test-retest reproducibility was measured on 60 other patients during a longitudinal study, leading to intra-class correlation coefficients (ICC) of 0.81 and 0.87 for PC and NC, respectively.

Construct validity was assessed by CFA assuming the existence of the two reliable and separable dimensions. A goodness-of-fit test provided evidence at the 95% confidence level that the model was consistent with the study sample (implied parameters = 55, estimated parameters = 20,

**Table 3** Correlations between the two subscales (PC, MC) and total scale (TC) with QoL measurement and patient identification variables

	PC	NC	TC
QoL	0.59***	-0.62***	0.68***
Age	-0.26**	0.07	-0.20**
Gender	0.10	0.03	0.03
Relapse	-0.03	-0.01	-0.02
Living	0.02	-0.05	0.05
Job	0.26**	-0.17**	0.28**
Stage (SPMS compared with RRMS)	-0.20**	0.17**	-0.23**

\*\*\*  $<0.001$ , \*\*  $<0.01$ , otherwise NS

DF = 35,  $\chi^2 = 46.26$ ,  $p = 0.09$ ). MS stage, gender, and age groups did not differ significantly between groups (DIF:  $p = 0.09$ , 0.12 and 0.045, respectively).

We successfully tested standardised residuals with the Polytomous Rasch model, extreme values of the mean square, or differences of item locations when splitting the sample (Wald test) [17] (Table 2), the equality of all items amongst person random splits ( $\chi^2$ ,  $p = 0.098$ ) [18], and the equality of person parameters among any split of items ( $\chi^2$ ,  $p = 0.24$ ) [17].

The original scale was tested according to four ordinal categories (as used by CHIP [8]), replacing them by two categories (severe/not severe), resulting in a correlation  $r = 0.85$  between original and simplified values.

We observed a strong correlation between QoL scores and PC, NC and the combined score (TC) (Table 3), with some differences among patients: PC is higher in patients with a steady job; it lowers with increasing age and with progressive types of MS (SPMS or PPMS) compared with RRMS.

The predictive value of coping dimensions on QoL was evaluated via a stepwise regression (Table 4), considering PC and NC dimensions and patient mix (age, gender, EDSS, duration of illness, living alone, active job). In referring to patients aged 45 years, with RRMS, without a job, and not currently in relapse, a mean QoL score of 6.18 was found. A positive effect of 0.75 per level [95% CI (0.45; 1.04);  $p < 0.001$ ] and a negative effect of -1.68 [95% CI (-1.94; -1.42)] per level were estimated for PC and NC, respectively. When RRMS, SPMS and PPMS were taken as three ordinal levels, a decrease in QoL of -0.41 [95% CI (-0.60; -0.22)] per level was found; age decreased QoL by -0.02 (-0.03; -0.01) per year, whilst having a job increased QoL by 0.34 [95% CI (0.04–0.64);  $p = 0.027$ ] versus being unemployed. Being in relapse decreased QoL by -0.38 [95% CI (-0.8; 0.02);  $p = 0.067$ ], whereas the other variables (living conditions and gender) were not significant.

**Table 4** Linear predictive model of overall QoL as a function of the two coping dimensions and patient mix

	Coefficient	(95 % CI)	P
QoL: mean value of the reference population	6.18	(5.04; 6.90)	<0.001
PC (continuous, range 0–6, reference = 0)	0.75	(0.45; 1.04)	<0.001
NC (continuous, range 0–4, reference = 0)	–1.68	(–1.94; –1.42)	<0.001
Stage (0 = RRMS, 1 = SPMS, 2 = PPMS)	–0.41	(–0.60; –0.21)	<0.001
EDSS (range = 0–4)	–0.88	(–1.08; –0.68)	<0.001
Age (continuous, reference = 45 years)	–0.02	(–0.03; –0.01)	0.004
Job (employed versus unemployed)	0.34	(0.04; 0.64)	0.027
Relapse (relapse versus no relapse)	–0.38	(–0.80; 0.02)	0.067
Living (couple versus living alone)	0.19	(–0.12; 0.51)	0.240
Gender (women versus men)	–0.13	(–0.44; 0.18)	0.425

Adjusted  $R^2 = 0.4684$ , sample size = 457

## Discussion

Our objective was to devise a coping scale designed to measure the link between coping and QoL in MS patients in RMP. We used the extensive information provided by CHIP, interview of MS patients and expert opinions and retained seven coping dimensions and 46 items. We then reduced the number of coping dimensions related to QoL to the strict minimum. We developed this approach based on an initial sample, and validated the results on a new independent sample. Our results take into account the data generated by 847 patients in 40 centres.

We wished to explore the feasibility of adapting a scale to MS patients characterized by the minimum number of dimensions necessary to predict QoL, and a shortest possible self-administered questionnaire compatible with RMP.

First, through independent statistical methods (EFA, CFA), we demonstrated that the classification of coping types/dimensions as a function of their QoL consequences can be reduced to a distinction into positive (problem solving, energy), negative (emotional, avoidance, palliative) and neutral (instrumental, distraction) dimensions. Similarly, McCabe [19] suggested that particular types of coping strategies affect particular types of QoL. Pakenham [16] also showed positive and negative effects, and outlined various coping strategies, whereas Schwartz [20] concluded that teaching coping skills enhanced QoL. We found that, compared with our approach, CHIP is unnecessarily complex in RMP to measure coping strategy impact on QoL. Similarly, Pakenham [16] refers to more dimensions, but all are not required to assess QoL, and the length and complexity of the scale limits its use in RMP.

Our 10-item scale significantly improved the correlation between coping strategy and QoL from maximum values of

0.33 for CHIP dimensions, the correlation between coping strategy and QoL increased to 0.59 and 0.62 for NC and PC, respectively.

Another question is the real effect of coping strategy on QoL. We compared the effect of coping strategy with other influences by considering coping dimensions as potential QoL predictors, but also for patient oriented variables such as EDSS, MS stage or patient age, variables that are expected to have a marked influence on QoL.

Our model demonstrated the additive contribution of PC and NC, with two coefficients of opposite sign (0.75 and 1.68, respectively), justifying the assimilation of the two components to one overall sum-score (TC). However, with this model, coping effect can be compared with patient variables: EDSS, MS stage, age and having a steady job were shown to have a determinant effect. These results have already been suggested elsewhere [7, 16] and provide additional evidences of the validity of the QoL scale used. However, this model allows a comparison of effects: the maximum effect of positive coping ( $0.75 \times 6 = 4.5$ ) reaches the maximum values of the scale (10), whilst the extreme effect of negative coping ( $1.68 \times 4 = 6.72$ ) is linked with a total collapse of QoL [7]. We conclude that compared with all the other possible predictors of QoL, coping is associated with a potentially powerful effect and that a low expected QoL resulting from a negative mix can be compensated by appropriate coping strategies.

## Implication for therapy

Monitoring QoL may be a simple and inexpensive way of detecting a possible downturn in a patient's condition which standard clinical measurements may identify too late, resulting in delayed response to therapy and reduced treatment efficacy. Similarly, it ought to be possible to detect a sustained period of negative coping via similar monitoring of coping strategies, making it possible to decide on the intervention required to convert negative into positive coping, with expected QoL benefits. Monitoring QoL and coping strategies is particularly useful once MS has been diagnosed, when patients are most liable to develop negative emotional coping strategy.

Both our previously validated QoL scale [7] and the current coping scale were developed in the same context of regular monitoring of MS patients in RMP, with the primary purpose of helping the therapist contribute to maintaining QoL of their patients.

## Conclusions

Apart from clinical considerations, QoL is the primary concern of MS patients. Although pharmacological agents

failed to prove an effect, an adaptive positive coping strategy may definitely improve QoL. Psycho-social interventions must be evaluated to help the patient develop adequate coping strategies, but the Quality of life and coping of MS patients must be monitored regularly so that adequate therapy can be started to help improve the way these patients cope with their disease. We refer to our short form scale constitutes an adequate measurement tool, both for testing therapies and regular patient monitoring in routine medical practice.

**Conflict of interest** No conflict of interest was declared.

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