

RESEARCH PAPER

Coping and its importance for quality of life in patients with multiple sclerosis

Pavol Mikula^{1,2}, Iveta Nagyova^{1,2}, Martina Krokavcova^{1,2,3}, Marianna Vitkova^{2,4}, Jaroslav Rosenberger^{1,2}, Jarmila Szilasiova⁴, Zuzana Gdovinova⁴, Johan W. Groothoff⁵, and Jitse P. van Dijk^{2,5}

¹Institute of Public Health – Department of Social Medicine, Faculty of Medicine, Safarik University, Kosice, Slovakia, ²Graduate School – Kosice Institute for Society and Health, Safarik University, Kosice, Slovakia, ³1st Department of Psychiatry, Faculty of Medicine, Safarik University, Kosice, Slovakia, ⁴Department of Neurology, Faculty of Medicine, Safarik University, Kosice, Slovakia, and ⁵Department of Community and Occupational Health, University Medical Center Groningen, University of Groningen, The Netherlands

Abstract

Purpose: The aim of this study was to analyse whether problem-focused coping, coping focused on getting support and coping focused on stopping unpleasant emotions and thoughts are associated with different levels of physical and mental quality of life (PCS, MCS), controlling for gender, age and disease severity among MS patients. **Method:** The sample consisted of 113 consecutive MS patients (response rate: 79.6%; 77.0% women; mean age 40.8 ± 9.2). Patients completed the Short-Form Health Survey (SF-36) and the Coping Self-Efficacy Scale (CSE). Disability was assessed by Expanded Disability Status Scale (EDSS). The associations between CSE and PCS and MCS were analysed using linear regression. **Results:** EDSS and age were significantly associated only with PCS. The regression model for problem-focused coping, coping focused on getting support and coping focused on stopping unpleasant emotions and thoughts explained 29%, 24% and 35% of the variance in MCS, respectively. In PCS coping was not significant. **Conclusions:** Coping is significantly associated with MCS, but not with PCS. Stopping unpleasant emotions and thoughts seems to be the most important type of coping in MS patients. Thus, patients, their caregivers and their physicians should be educated about this type of coping and its positive association with MCS.

Keywords

Coping, mental component of quality of life, multiple sclerosis, physical component of quality of life

History

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► Implications for Rehabilitation

- All types of coping are associated positively with mental component of Quality of life.
- Coping focused on stopping negative emotions and thoughts seems to be very adaptive for patients with MS.
- This type of coping can help patients with chronic conditions when problem-focused coping can not effectively solve the problem.

Introduction

Multiple Sclerosis (MS) is the most common neurological disease that occurs in young adults with disabling consequences, more often affecting women than men. It is a chronic disease characterised by diffuse changes in the white and grey matter, the breakdown of myelin and damage to axons within the central nervous system (CNS) [1]. Its various symptoms can occur anywhere in the CNS and include fatigue, pain, loss of function or sensitivity in the limbs, dizziness and loss of balance, loss of bowel or bladder control, sexual dysfunction and a variety of cognitive and emotional changes. These disabling symptoms pose multiple challenges for both physical and psychological

well-being [2] and have a negative impact on a patient's quality of life [3].

The symptoms and limitations associated with MS cause high levels of distress which patients need to cope with. Coping is defined as an effort to manage a situation and involves various cognitive and behavioural efforts to overcome external or internal demands which are appraised as either taxing or exceeding the person's resources [4]. To manage the stress caused by MS, patients can use, for example, problem-focused coping, which can be described as an effort to remove a threatening event or to diminish its impact. There is also coping focused on getting support, which can be described as an effort to reduce the negative feelings that arise in response to a threat or as seeking emotional support. Another way of coping with stress is to stop or avoid unpleasant thoughts about the problem in order to stop or prevent negative emotions. Problem-focused and emotion-focused coping can easily occur simultaneously. Emotion-focused coping can even facilitate problem-focused coping by removing some of the distress that can hamper problem-focused efforts; similarly,

problem-focused coping can render the threat less forbidding, thereby diminishing distress emotions [5]. Problem-focused coping was found to contribute positively to the health-related quality of life (HRQoL) of patients with various conditions. The positive effect of coping can appear either in the mental health component of HRQoL only [6], or in both the physical and mental components (PCS, MCS) [7]. Men use more problem-focused coping than women at work and in situations requiring acceptance and requiring more information [8]. Increasing age is usually associated with a decline in the use of both problem-focused and emotion-focused coping strategies [9].

MS influences a person's life for a very long time. For a patient it is vital that HRQoL should be improved by all means possible, including the most suitable way of coping. Thus far, little research has been done among MS patients regarding the association between coping and HRQoL. The studies that have been carried out on this topic are different from ours. Some of the studies dealing with the association between coping and HRQoL in MS patients have a significantly lower number of participants [10–12] or focused on women only [13]. Some of them use variables that are only partly responsible for overall HRQoL such as fatigue [14], coping in dyadic relationships [15] or focusing only on positive effect of problem-focused coping [16]. However, there is no study addressing all these three types of coping at once so this study tries to put another piece of the puzzle into the overall picture of this field of research. Thus, the aim of this study is to explore whether problem-focused coping, coping focused on getting emotional support and coping focused on stopping unpleasant emotions and thoughts are associated with PCS and MCS, controlling for gender, age and disease severity.

Methods

Participants

Of the 157 consecutive MS patients from neurology outpatient clinics in the eastern part of Slovakia, 32 (21 women and 11 men) refused to participate in the study (response rate 79.6%). Patients who met the McDonald criteria were eligible for the study [17]. Exclusion criteria were psychiatric diagnosis, Mini-Mental State Examination (MMSE) <24, pregnancy, diagnosis of Clinically Isolated Syndrome (CIS) [18], and the inability to speak Slovak. Based on these criteria 12 patients were excluded from the study. The final sample ($N = 113$) consisted of 77.0% women and 23.0% men, with a mean age of 40.8 ± 9.2 years (range 20–59 years).

Procedure

The data collection took place between September 2010 and May 2012. This cross-sectional study consisted of a self-reported questionnaire, a semi-structured interview and a neurological examination. The invitation letter, the informed consent form, the non-response sheet and the questionnaires were sent to participants' homes by postal mail. Patients were reminded about the questionnaires by a phone call 2 weeks later. During this phone call, their interview and neurological examination were scheduled as well. These then took place at the Neurology Outpatient Clinic. One neurologist carried out the neurological examination and a trained interviewer conducted the semi-structured interview.

The Ethics Committee of the Medical faculty of PJ Safarik University approved the study before it started. Each patient provided a signed informed consent form prior to the study.

Measures

All questionnaires used in this study were translated from original language. Next, backwards translation was made to ensure that

meaning was not lost in translation. Final changes in translated version were made accordingly.

Health-related quality of life

HRQOL was assessed using the 36-item Short-Form (SF-36) health survey [19]. The SF-36 includes multi-item scales to measure 8 dimensions: (1) physical functioning (10 items), (2) role limitation due to physical health (4 items), (3) bodily pain (2 items), (4) social functioning (2 items), (5) general mental health (5 items), (6) psychological distress and well-being (5 items), (7) role limitations due to emotional problems (3 items), (8) vitality, energy or fatigue (4 items). In addition, one question covers changes in health status over the past year (1 item). All item scores are coded and transformed into a scale of 0 (poor health) to 100 (optimal health). PCS and MCS summaries were calculated. A higher score indicates better health in both dimensions. Cronbach's alpha was 0.91 for the PCS and 0.93 for the MCS for our sample.

Coping self-efficacy

Coping self-efficacy was measured using the 26-item Coping Self-Efficacy Scale (CSE) developed specifically for chronically ill populations [20]. Coping self-efficacy is prerequisite for using actual coping strategies as patients need to be sure, they can perform coping actions before they act upon them. That is why in this article we treat terms coping and coping self-efficacy as equivalent because in our opinion, those concepts are closely tied to each other.

Patients were asked respond to the following question: "When things are not going well for you, or when you're having problems, how confident or certain are you that you can do the following?". They then had to give the extent to which they believe they could perform each coping behaviour on an 11-point scale. The instrument consists of three subscales representing self-efficacy for the use of problem-focused coping strategies (ranging from 0 to 120), the ability to stop unpleasant emotions and thoughts (ranging from 0 to 90), and finally the ability to get support from friends and family (ranging from 0 to 50). A higher score indicates a higher ability to cope with the situation described in the question. Cronbach's alpha was 0.94 for problem-focused coping in the sample, 0.85 for coping focused on getting support and 0.93 for stopping unpleasant emotions and thoughts for our sample.

Clinical variables

We used medical records to obtain information on EDSS (score ranges from 0.0 to 10.0, with a higher score indicating more severe disability) [21] and the course of MS. Patients were categorized in the relapse-remitting (RRMS) course of MS or the secondary-progressive (SPMS) course of MS [22].

Data on socio-demographic variables were retrieved from the interview.

Statistical analyses

First, descriptive analyses of the study variables were carried out. Next, multiple linear regression analysis (the enter method) was used to examine the relationship between the three coping strategies and both PCS and MCS. The associations between the variables were controlled for gender, age and EDSS. These demographic and neurological variables were assessed as independent variables along with the three mentioned coping strategies, the effect of which was observed on the dependent variables (PCS, MCS). Statistical analyses were performed in IBM SPSS 20.

Results

A basic description of the study population is given in Table 1 ($N = 113$). The MS respondents averaged 40.8 ± 9.2 years old and consisted of 77.0% women. The mean EDSS score was 3.3 ± 1.3 , with a mean disease duration of 8.4 ± 6.7 years. The majority of the patients (84.9%) belonged to relapse-remitting clinical course (Table 1).

Linear regression analyses (Table 2) were used to examine the associations between coping strategies and PCS and MCS, controlled for gender, age and EDSS. The outcomes of the multiple linear regressions indicate that all three types of coping are associated with MCS, but not with PCS. In PCS, EDSS explained the most variance in the model regardless of which type of coping was analysed. Also, all three types of coping showed a similar explanation of variance in their respective models. There were no differences between coping focused on stopping

unpleasant emotions and thoughts and problem-focused coping focused on getting support in terms of significance, but in the MCS, coping focused on stopping unpleasant emotions and thoughts explained most of the variance in the model (Table 2).

Discussion

The aim of this study was to explore whether problem-focused coping, coping focused on getting emotional support and coping focused on stopping unpleasant emotions and thoughts were associated with different levels of physical and mental quality of life when controlling for demographic and clinical data in patients with MS. Our results provided evidence that all types of coping were associated with mental component of quality of life out of which stopping unpleasant emotions and thoughts was the most strongly associated with MCS. Regarding PCS coping was not significant, while EDSS showed the highest explanation of variance in this quality-of-life component.

The mental component of quality of life was for the most part determined in our models by coping. All three types of coping explained large portions of the overall variance in the mental component, and in contrast with the physical component, the disability (contribution of EDSS) was in this case not significant. In general, these results correspond with recent studies about the association of coping with the mental component of quality of life [6,23,24]. On the other hand, some studies dealing with chronic conditions have claimed that coping was not significantly associated with HRQoL at all [25] or even that coping focused on getting support is negatively associated with quality of life [26]; this is not in line with our findings.

Coping focused on stopping unpleasant emotions and thoughts in our sample explained the most variance of all the coping strategies in the mental component of quality of life. One possible explanation why stopping unpleasant emotions and thoughts might be adaptive as a coping strategy in patients with MS is that the patients have very little control over their disease. MS is in most patients a chronic progressive disease and no optimal cure has thus far been found. When patients lose the ability to control the disease and have to learn how to live with it, this kind of

Table 1. Characteristics of the study population.

Variables	N (%)	Mean	SD	Range
Age (years)	113	40.82	9.22	20–59
Gender				
Male	26 (23.0%)			
Female	87 (77.0%)			
Disease duration (years)		8.40	6.75	1–28
MS form				
RRMS	96 (84.9%)			
SPMS	17 (15.1%)			
EDSS		3.31	1.37	1.0–8.0
Coping				
Problem-focused		77.54	22.70	22–120
Getting support		32.90	10.00	3–50
Stop emotions and thoughts		57.01	19.56	4–90
Quality of life				
PCS		37.11	11.08	16.0–60.0
MCS		42.60	12.38	17.3–69.8

CIS, clinically isolated syndrome; RRMS, relapsing-remitting MS; SPMS, secondary progressive MS; PCS, physical component scale; MCS, mental component scale.

Table 2. Multiple regression analyses: coping types, sociodemographic variables and clinical variables on HRQoL.

	PCS			MCS		
	Beta	F Change	Adjusted R ²	Beta	F Change	Adjusted R ²
Model 1		12.50*	0.17		0.10	–0.01
Age	–0.39*			–0.04		
Gender	–0.13			0.02		
Model 2		22.07*	0.39		0.16	–0.02
Age	–0.16			–0.06		
Gender	0.02			0.04		
EDSS	–0.55*			0.00		
Model 3 A		15.05*	0.37		10.68*	0.29
Age	–0.15			0.01		
Gender	0.00			–0.06		
EDSS	–0.54*			0.00		
Problem focused coping	0.06			0.57*		
Model 3 B		15.93*	0.38		8.94*	0.24
Age	–0.15			0.06		
Gender	0.02			0.00		
EDSS	–0.55*			–0.03		
Getting support	0.04			0.53*		
Model 3 C		15.11*	0.37		13.85*	0.35
Age	–0.15			0.00		
Gender	0.01			0.03		
EDSS	–0.55*			–0.08		
Stopping emotions and thoughts	0.07			0.61*		

R², explained variance; Gender, male gender was set as reference; EDSS, expanded disability status scale; * $p < 0.05$.

coping can help them to reduce the stress that MS brings and thus improve their mental quality of life. This interpretation is in line with previous works which suggest that this type of coping is more adaptive when little control is possible [27,28]. De Groot et al. also add that this type of coping seems to be more adaptive when patients have to cope with the emotional value of the problem [27].

On the other hand, our results showed that regarding the physical component of quality of life, the role of coping was not significant. It did not add to the explained variance of this variable, as EDSS did. This result is in line with existing studies dealing with coping and quality of life [6,23,29,30]. The reason why the physical component of quality of life was not associated with any type of coping might be the fact that residual persisting neurological symptoms cannot be suppressed by coping strategies. Clinical neuropsychological symptoms appear even if patients use coping strategies effectively to deal with stress. The physical component of quality of life might be barely modified by psychological resources.

Strengths and limitations

One of the strengths of this study is the high response rate within our sample (79.6%). Some limitations should be noted, however. Although the women-to-men ratio in MS is 2:1, in our sample the ratio was higher (77.0% women), so the results may better explain the quality of life of women than men. Also, patients with a lower disease severity (mean EDSS 3.2) were more likely to participate in the study, while patients with a more serious disability were more likely to refuse to participate. We expect the results would be even worse in the total MS patients group, although the high response rate might mitigate this effect.

Implications

This study is beneficial in bringing a new view on avoidance coping. Stopping unpleasant emotions and thoughts or not thinking about the disease showed in our results to be an adaptive and helpful for patients with MS. Although this type of coping may seem maladaptive, in our sample it helped to improve the mental component of quality of life. It is possible that this type of coping would also be adaptive in other patients with chronic conditions, but future research is needed to confirm this.

The clinical importance of this study is that patients should consider using this type of coping in dealing with their condition. Physicians, caregivers and patients themselves should be educated about various ways of coping with their disease and encouraged to live a life without constant worries about their symptoms or the progress of their disease and thus improve their mental quality of life. MS clubs could apply these outcomes during discussions/educational programs with MS patients, where psychologists or trained caregivers could talk with patients about the various ways of coping with their disease. Physicians could also benefit from the knowledge about different ways of coping with stress, especially in the early stages of the disease when patients are still learning how to live with a new diagnosis of MS. Even patients with longer disease duration could make use of these findings if their coping strategies have so thus proved to be ineffective. These findings can also be implemented into the psychological therapy process. Cognitive Behavioural Therapy may especially work with stopping unpleasant emotions and thoughts in patients with MS [31].

Extreme usage of this coping strategy should not be encouraged though. Stopping unpleasant emotions and thoughts should not impact treatment adherence; therefore, education may focus on the long-term effects of the coping strategy used

in situations where one's behaviour cannot change the situation, and where treatment adherence requires a more active approach.

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Declaration of interest

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