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## Perceived health status in multiple sclerosis patients

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**Perceived Health Status  
in Multiple Sclerosis Patients**

**Martina Krokavcová**

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Thesis for the University of Groningen, the Netherlands – with a summary  
in Slovak and Dutch

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# General introduction, aims and structure of the thesis

Multiple sclerosis (MS), with its unknown etiology and still not understood occurrence, has attracted a lot of attention from researchers over the past two decades. This study tries to contribute to the understanding of perceived health status in patients with MS. This first chapter describes the disease, the aim of this study, the theoretical model used, the research questions employed and the structure of this thesis.

## 1.1 Multiple sclerosis

MS is considered an inflammatory neurodegenerative disease of the central nervous system, with onset usually occurring in early adult life. It is characterized by demyelination and primary or secondary axonal degeneration, with the loss of dendrites and neurons contributing to the irreversible functional impairment observed in affected individuals. It attacks more than 2 million people worldwide, the ratio of women to men affected being 2:1. Onset of the illness generally occurs between 20-50 years of age (1-3).

Although descriptions of MS symptoms date back as far as the Middle Ages, MS was first recognized as a distinct disease only in the nineteenth century. The first pathologic report was published in 1868 by J.M. Charcot, a professor of Neurology at the University of Paris. He examined the brain of a young woman and documented the characteristic scars, which he describes as “la sclérose en plaques” (1).

The prevalence of MS varies considerably around the world. It is highest in northern Europe, southern Australia and the middle part of North America. There has been a trend toward an increasing prevalence and incidence, particularly in southern Europe (3, 4, 5). Slovakia has a relatively high rate of MS prevalence, with more than 30 cases reported per 100 000 persons (6). The reasons for the variations in the prevalence and incidence of MS worldwide are not understood, as the etiology of MS is itself unknown. MS is assumed to be a multifactorial disorder, in which environmental factors are hypothesized to interact with genetically susceptible individuals. Pediatric MS and late-onset MS (i.e. clinical onset occurring later than the fifth decade) are rare (4, 7).



### 1.1.1 Diagnostics criteria

The most widely used criteria for the diagnosis of MS are the Poser Committee criteria and a new system of classification, the McDonald criteria. They incorporate magnetic resonance imaging (MRI) to demonstrate multiple areas of involvement and also involvement over time with the appearance of new enhancing lesions. Patients have been diagnosed as having MS or possibly having MS according to these indicators over the past two decades (8, 9). Advanced MRI and spectroscopy may allow clinicians to follow the pathological progression of the disease and to monitor the response to treatment (4).

All patients in this thesis were diagnosed in accordance with the McDonald criteria, which allows for earlier confirmation of a diagnosis of MS and an earlier decision on therapy. This diagnosis was confirmed by one neurologist (8, 9).

### 1.1.2 Clinical course and disability

The clinical course of MS shows heterogeneity among patients and within the same patient. Decisions on the categorization of the clinical course of MS have been made and later on reduced, thus resulting in confusing terminology:

- *relapsing-remitting MS (RR-MS)* – the disease as it occurs in the majority of MS patients (~85%) with relapses with full recovery, or with sequelae upon recovery and periods between relapses characterized by a lack of disease progression. Fifteen percent of patients with RR-MS experience a mild course with minimal disability after 15 years; this is therefore called *benign MS*.
- *progressive-relapsing MS (PR-MS)* – progressive disease from the onset on (~5%), with clear relapses, and periods between relapses showing continuing progression.
- *secondary-progressive MS (SP-MS)* – initially categorized as the RR-MS clinical course (exhibited in ~90% of the 85% RR-MS), followed by progression with or without occasional relapses, minor remissions and plateaus.
- *primary-progressive MS (PP-MS)* – the disease with progression from onset, with plateaus and temporary minor improvements (~10%) (1, 3, 4, 10).

Because of the cross-sectional design of most studies on MS, clinical course is often more simply categorized into RR-MS, SP-MS and PP-MS (7, 11). This categorization of clinical course will be used in this thesis.

The burden of disability in the cross-sectional design of MS studies is most frequently presented as the Kutzke Expanded Disability Status Score. Disability due to MS can be measured within functional neurological systems (pyramidal, cerebellar, brainstem, sensory, bowel

and bladder, visual, other) by assigning each a score. The distribution of the scores over the functional systems combined with their degree is then assigned to one of 20 categories (0, 0.5, 1, 1.5, 2,...10), which indicate the level of disability (12).

### **1.1.3 Treatment**

Patients with MS face enormous prognostic uncertainty, and they should become well informed about their illness. Treatment focuses on acute attacks, prevention of relapses and progression, management of symptoms, and rehabilitation. In recent years advances have been made in all four areas (13). Treating physicians have to continually assess the need for psychological support for patients and their families.

Corticosteroid therapy is often used to treat clinically significant relapses in an attempt to stop the relapse and consequently to hasten recovery. Current therapeutic agents for MS patients are anti-inflammatory or immunomodulatory in nature (1, 4). Treatment with interferon-beta and glatiramer acetate may delay the development of a second, diagnosis-defining bout. Interferon-beta may delay the progression of disability in patients with minor disability who have a relapsing form of MS (3, 4, 14). The advent of natalizumab for the treatment of multiple sclerosis opens up a new era of immune-specific therapy. At present, the available therapeutic repertoire to fight against multiple sclerosis remains limited and is primarily aimed at targeting the activity of the immunocompetent cells (4, 15, 16).

Unfortunately, no proven therapies for PP-MS exist which would be able to reverse the neurological disabilities in MS patients (4). There are, however, moderately effective treatments for several of the complications of MS, like fatigue, pain, gait problems, spasticity, speech and swallowing disorders, weakness of legs, bladder and bowel disturbances, sexual dysfunction, cerebellar tremor, sleep disorders, cognitive and mood disorders, etc. (3, 4).

### **1.1.4 Prognosis**

One limiting factor in determining the potential improvement in outcome with new therapies is the lack of a direct biomarker for disease outcome. Over 120 randomized clinical trials are currently underway in MS involving 30 agents or combinations of agents, so the outlook for better therapies in the future is hopeful. Advances in the understanding of the underlying mechanisms of MS are allowing a more focused approach to the development of the new therapies for MS patients (13). Research and clinical developments in the field of multiple sclerosis appear to be very active and dynamic at present; it is therefore hoped that some of the promising compounds may broaden the still limited therapeutic arsenal for this disabling disease (16).

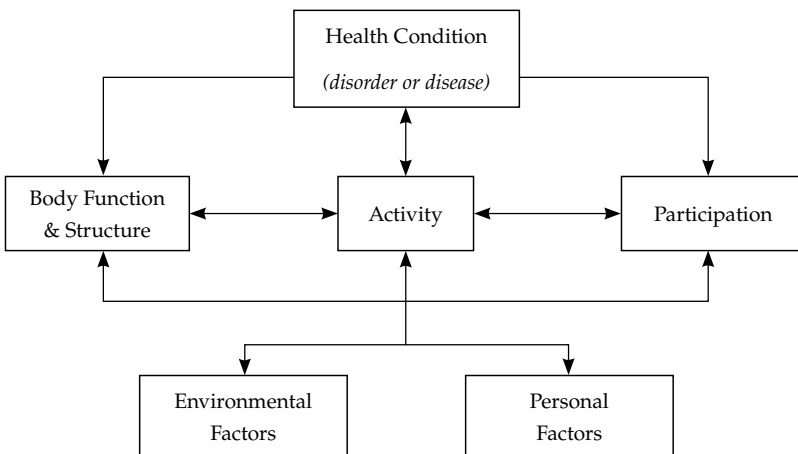
## 1.2 Structure of health status

When trying to explain the structure of health status, some questions on health can be raised: Is health the absence of disease symptoms? Is health the ability to work and carry out one's role? Does health include emotional and spiritual components? What is optimal health? The answers to these questions might only approach an explanation of health, however, because there is not really consensus on the definition of health the content of which has changed over time (17, 18).

The concept of health as well-being was introduced in the World Health Organization (WHO) as a definition of health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (19). Other authors have characterized well-being as being able to feel well during a life of mobility, enjoyment and social relationships (20), and as an optimal individual fitness, so that one lives a full, creative life (21). The WHO definition also provides a popular consideration of several different dimensions of health, such as physical (structure and function), social, role, mental (emotional and intellectual) and general perceptions of health status (17, 19). An important feature of health is its dimensionality. Health has distinct components, as can be derived from the definition of health offered by the WHO (19, 22).

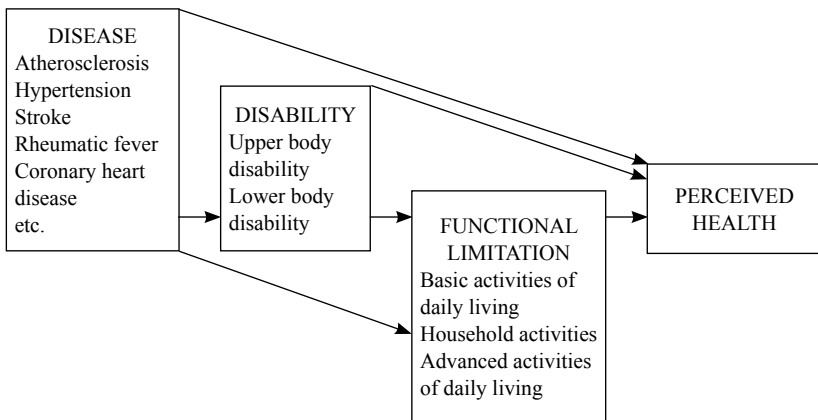
Figure 1 presents a graphic representation of the International Classification of Functioning, Disability and Health (ICF) model formally endorsed as the "International classification of impairment, disability and health" by WHO, in which health conditions interact with environmental and personal factors, and result in functioning or disability in one or more components or levels (23, 24).

**Figure 1** WHO model of the International Classification of Functioning, Disability and Health (24)



As a conceptual framework for disability studies, Nagi's model from 1965 is well-known. When conceptualizing disability, he thought in terms of a four-stage sequential process: *disease – physiological impairment – limitations in the physical and emotional dimensions – disability*. Nagi's model was modified by Johnson and Wolinsky (1993), who used slightly different terminology in some instances. The four terms in their model were substituted: *disease – disability – functional limitation – perceived health* (25) (Figure 2).

**Figure 2** Conceptual model of disability by Johnson and Wolinsky (1993)



Johnson and Wolinsky (1993) expected that all of the dimensions of health status affected an individual's global perception of his or her health status. The concept of perceived health status may reflect the transitional status of acute symptoms unrelated to the more stable influences of chronic disease, disability and functional limitations. That is, perceived health can also be linked to a wider range of health status measures, and therefore is frequently used as a proxy for other physical and mental health status measures (22, 25). Knowledge of the underlying disease, recognition of physical disabilities and awareness of functional limitation affect perceived health status negatively (25).

It is still under debate whether health, defined comprehensively, can be equated with quality of life, which is defined as a much broader concept than health. Quality of life and well-being represent subjective perceptions and expectations of individuals about their health. Perceived health status reflects a complex of internalized calculations based on life experience and knowledge of disease causes and consequences, or the influences of chronic disease, disability and functional limitations (22, 23, 25-32).

Considering the outcome of MS, it is possible to conceptualize the consequences as lying on a continuum of outcome (Figure 3) running

from disease through impairment, disability (activities) and handicap (participation) – formalized in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (33, 34).

**Figure 3** Outcome continuum in MS of the ICIDH (33, 34)

<b>Disease</b>	<b>Impairment</b>	<b>Disability</b>	<b>Handicap</b>	<b>Quality of life</b>
Relapse rate	Weakness	Locomotor	Physical-independence	Well-being
MRI	Sensory dysfunction	Dexterity	Mobility	
	Fatigue	Personal care	Occupation	
	Bladder/bowel dysfunction	Reading	Social integration	
	Imbalance	Sexual function	Economic	
	Visual loss			
	Cognitive decline			

Physical illness, particularly in chronic disorders, can be considered as one of the main causes of a loss of access to valued resources and, consequently, of valued goals. Loss for the individual involves, for example, a loss of independence, a reduced social mobility, reduced capacity to work, exposure to pain, fatigue and threat of disfigurement (and eventually death) (35, 36). The impact of some specific MS disabilities on perceived health status has been studied. Therefore, we now have evidence confirming that cognitive and emotional functions and chronic pain correlate particularly with the physical and mental domains of perceived health status, that depression and anxiety significantly influence the mental domains of perceived health status especially, that bladder, bowel and sexual functioning are related to reduced quality of social functioning, and that fatigue has an important impact on perceived health status in MS patients (26, 30, 37-41).

MS influences a wide range of social and personal dimensions in life. When a person has MS the whole family “is affected” as well. The family of MS patients are often the most immediate and obvious source of social support, and the development of MS has a significant effect on family dynamics as a whole. Patients without family, living alone because they are single, separated, divorced or widowed, may have a sense of isolation and uncertainty about the formation of new relationships. They very often need high levels of physical assistance and emotional support. Moreover, the somatic symptoms involved in MS can cause the loss of current employment and reduce economic status (42-45).

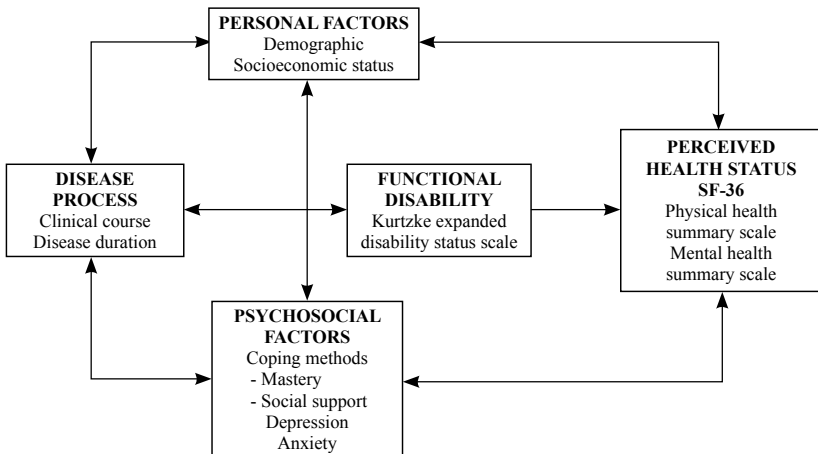
Measures that address impairment and disability have traditionally been referred to as measures of health status (34, 46). It has become common to describe the same dimensions of health status (i.e. impairment,

disability and handicap) as health-related quality of life measures. In this study the construct 'perceived health status' is preferred over the use of 'quality of life', which was more or less 'fashionable' during the last decade. The full SF-36 was originally designed as a generic indicator of health status in the chronically ill (47). *Chapter 2* provides a description of other useful health status measures apart from the SF-36. For example, the Multiple Sclerosis Quality of Life 54 Questionnaire (MSQoL-54) was expanded from the original the SF-36 Health Survey by adding an additional 18 items that were thought by experts to be relevant for patients with MS (34, 48). Items from the SF-36 are also a part of the European Quality of Life Scale (EuroQoL-5D) (49-51). Therefore the SF-36 Health Survey represents the heart of this study with regard to the evaluating the health status of MS patients.

### 1.3 Aims of the study and research questions

The influence of MS on health status has been studied on an individual level. MS, along with its disease symptoms, influences the activity, participation and well-being of patients. The association between MS and social and personal participation in daily activities or with decreased work ability and economic status of whole families is strong. Interaction directions as evaluated in this thesis and arising from the theoretical background of health status, are depicted in Figure 4.

**Figure 4** Design of this thesis



The main objectives of the thesis therefore include:

- 1) To explore the relationships between psychosocial factors and perceived health status in MS patients,
- 2) To study the outcomes in perceived physical and mental health summary scales as measured by the SF-36 in MS patients.

The objectives led to the following general research questions (RQ):

- 1) To review the literature focusing on the associations between disease duration, disability and perceived health status as measured by the SF-36, as well as the psychological well-being related to perceived health status in MS patients (*Chapter 2*).
- 2) To explore the association between self-rated health and employment status in MS patients when controlling for age, gender, functional disability, disease duration and psychological well-being (*Chapter 3*).
- 3) To investigate whether different levels of perceived social support are associated with different levels of perceived health status in MS patients (*Chapter 4*).
- 4) To clarify whether mastery is associated with functional disability and perceived health status in MS patients, and how such an association might function (*Chapter 5*).
- 5) To investigate the discrepancies in the association of depression and anxiety with perceived physical and mental health status, and whether these associations differ in younger (<45 years) and older (≥45 years) MS patients (*Chapter 6*).

## 1.4 Structure of this thesis

The outline of this thesis provides a first insight into the studies addressing the disease of multiple sclerosis, health status with its structure and the specific components of perceived health status in MS patients.

In *Chapter 2* of this study an overview is given of perceived health status as measured using the SF-36 Health Survey in recent studies.

*Chapter 3* will describe the association between self-rated health and employment status in MS patients. The ability to maintain one's job often depends on the progression of disease, and therefore this study sees the subjective assessment of health as a very helpful indicator of the current health status for further work of MS patients. Good self-rated health in association with the ability to work will be studied, and this which association will be controlled for age, gender, functional disability, disease duration, depression and anxiety.

Subsequently, *Chapter 4* will report on social support as a predictor of perceived health status in MS patients. The health status of MS patients may be improved when patients receive social support from their environment. To study this point of view, we will investigate whether

social support from family, friends or significant others associates with different levels of perceived physical and mental health status in MS patients independently from basic demographic variables and functional disability.

*Chapter 5* explores the contribution of mastery and functional disability to perceived health status in MS patients. Next, we are interested in knowing whether younger MS patients (<45 years of age) differ in the evaluation of mastery and in their health status when compared to older MS patients (≥45 years of age).

In *Chapter 6* the study takes into account the relationship between depression and anxiety and perceived health status in the total sample, and possible discrepancies in the levels of depression and anxiety in younger (<45 years) and older (≥45 years) MS patients as well.

Finally, in *Chapter 7* the main results of this study are summarized and discussed, and general conclusions, clinical implications and recommendations for future research are made.

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# **Perceived health status as measured by the SF-36 in patients with multiple sclerosis: a review<sup>1</sup>**

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## **Abstract**

This review of literature gives an overview of recent studies about perceived health status as measured by the SF-36 Health Survey in patients with multiple sclerosis. The SF-36 is one of the tools measuring health status in patients used in international research and clinical practice. It measures two main health concepts - physical and mental. The SF-36 represents a valid instrument able to detect differences in perceived health status in patients. A computer-aided search in Medline and PsycINFO resulted in 504 articles in English published from 1996 to August 2006. After the screening process on the basis of abstracts, 8 articles consisting of empirical studies remained in which perceived health status was evaluated using the SF-36 Health Survey. Seven studies focused on disability and perceived health status in the SF-36. Two studies focused on the relationship between depression and perceived health status. These studies showed that multiple sclerosis patients with low disability and minor depression scored significantly better than patients with high disability and major depression in the SF-36 health dimensions. Gender seems to have no influence on perceived health status in multiple sclerosis patients. The longer the disease duration and the more severe the disease, the lower the patients scored in perceived health status. The more disabled, the more depressive and the older the patients, the poorer their perceived health status was. Health providers supporting appropriate treatment might pay more attention to more disabled and more depressive patients, with longer disease duration. Perceived health status can be a predictor of prognosis and intervention outcomes. The study shows the importance of measuring perceived health status in multiple sclerosis patients with implications for their quality of life and provision of care.

## **Introduction**

Previous studies report that Multiple Sclerosis (MS) patients have reduced quality of life compared with groups from the general population. A large number of studies show that MS has negative effects on both the physical and mental dimensions of health and quality of life (1-3).

MS is a chronic autoimmune disease with an uncertain course, characterized by recurrent patches of inflammation in optic nerves, brain and spinal cord. Symptoms begin between ages 20 and 50 years in 90% of cases, with the peak onset at age 33 years. It is the most common cause of neurological disability in young adults. It is thought to affect over 2 million people worldwide (4, 5).

Perceived health status reflects a complex of internalized calculations based on life experience and knowledge of disease causes

and consequences (6, 7). The concept of perceived health status represents the influences of chronic disease, disability and functional limitations (7). There is uncertainty in definitions in the studies focusing on health status. The researchers study the physical, mental and social domains of health and refer to “quality of life” (1, 2, 8-10), “well-being” (11, 12) or “self-rated health” (13, 14). Despite these interchangeable terms, perceived health status has been identified as the closest in meaning to the self-assessment of health by patients, which allows measurement of the effect of treatment on their overall health-related quality of life, and prediction of other outcomes, including survival in patients with chronic diseases (15, 16).

The SF-36 is evaluated as an appropriate instrument for measuring general health, and is not specific for any age, disease or treatment group (17). The SF-36 assesses 4 physical health domains and 4 mental health domains. This generic indicator allows comparison of the health status of chronic patients with different conditions, and can be a predictor of prognosis and intervention outcomes (17, 18). The benefits of using the SF-36 dimensions in clinical practice could be substantial, e.g. assessment of vitality may indicate exhaustion in MS patients (19).

Perceived health status in MS patients might be affected by disease duration (9). The study by Riazi et al (20) focused on using the SF-36 in patients with MS or Parkinson’s disease, and in the normal population. They found that cross-sectional studies could not define changes in health status according to disease duration (20).

Many neurological scales associated with impairment and disability can measure perceived health status in MS patients (8). When MS patients are compared to controls, they score significantly lower than the general population controls in measures of disability (16, 21, 22). With progression in disability, physical functioning scales show decreases in perceived health status. As previous studies report, a higher level of disability has negative consequences on perceived health status in MS patients (8, 16, 21, 22).

Patients with depression usually suffer from sadness, reduced vitality and fatigue. The symptoms include lower interest, less concentration, insomnia, less appetite, low self-evaluation and self-esteem with feelings of nothingness. Depression is often associated with anxiety in somatic patients. Anxiety often involves obsessive symptomatology, with tension, shakiness, exudation and distraction (23, 24). High depression and anxiety as well were found to be negatively associated with physical and mental health status (25-27). High rates of depression have been found more frequently in MS patients than in comparable groups in some studies. It is suggested that MS patients on average are more depressed than comparable groups (28, 29), but the literature is inconclusive (30, 31). In some studies depression shows one of the strongest links with lower scores in self-reported questionnaires, independent of the clinical course

or disability status of MS patients (1, 32). Patients may develop depression later as an understandable reaction to learning they have a chronic disease and having to live with its consequences (25, 33). Statistically, as many as 60% of patients with MS experience major depression with a suicide rate 7.5 times that of the age-matched general population (33). The negative impact of depressive symptoms on perceived health status in MS patients has been demonstrated (34).

## **Aims**

The aim of this study was to review the literature focusing on the associations between disease duration, disability and perceived health status as measured by the SF-36, as well as the psychological well-being related to perceived health status in MS patients. Since SF-36 has been widely used in clinical and epidemiological studies, the benefits of using the SF-36 and its eight dimensions could be substantial indicators for assessing the physical, mental or social domains in MS patients.

## **Methods**

### **Search strategy and selection criteria**

The computer-assisted literature search covered the years 1996 - August 2006. This search focused on the Medline databases and PsycINFO psychological abstracts, and was performed with a combination of the keywords "multiple sclerosis", "self-reported", "self-evaluation", "self-perception", "self rated", "patient rated", "patient perceive". Our search resulted in 504 hits.

Of these 504 hits, the studies meeting the following inclusion and exclusion criteria are mentioned. Inclusion criteria were: primary studies focusing on perceived health status in MS patients, written in English, published in journals during the search span. The second step was to exclude, on the basis of their abstracts, publications focusing only on the psychometric properties of the measures. Studies with irrelevant content on the basis of their abstracts (focusing on health care services, treatment and biomedical background, and studies comparing MS patients with other chronic diseases) were excluded as well. Furthermore, case studies were omitted. Finally, one study was eliminated in which a self-rating scale on perceived health status was used, but not the SF-36. The reference list of reviewed articles resulted in 8 relevant publications (Table 1).

**Table 1** Results of the screening process

Screening steps	Result	Final Result
1 Medline and PsycINFO retrieval	+ 504	504
2 Excluded articles about measures	- 32	472
3 Excluded for irrelevant content (health care services, treatment and biomedical background, and studies comparing MS patients with different chronic diseases)	- 459	13
4 Excluded case studies	- 4	9
5 Excluded study not using SF-36	- 1	<b>8</b>

## Instruments

### Health measures

Within this review we concentrated on 8 studies measuring perceived health status in MS patients. All studies used as their main measure the Short Form-36 Health Survey (SF-36). This was originally designed as a generic indicator of health status for use in population surveys and evaluative studies of health policy. The SF-36 includes eight multi-item scales to measure the following eight dimensions: physical functioning (ten items), role limitation due to physical health (four items), bodily pain (two items), social functioning (two items), general mental health, covering psychological distress and well-being (five items), role limitations due to emotional problems (three items), vitality, energy or fatigue (four items) and general health perceptions (five items). In addition, one question covers change in health status over the past year (one item). All item scores are coded and transformed into a scale of 0 (poor health) to 100 (optimal health). The SF-36 may be self-administered or used in personal or telephone interviews (8, 17). SF-36 correlations with similar measures are generally consistent with the predictions. Physical function, social function, role limitation-physical, current health and health distress scales distinguish between normal subjects and patients with varying symptom severity (35).

Apart from the SF-36, four of the eight studies used various measures of perceived health status. They include: the European Quality of Life Scale (EuroQoL-5D) which defines health in terms of five dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression); the Sickness Impact Profile (SIP) where higher scores represent greater disease-related dysfunction; the Multiple Sclerosis Quality of Life 54 Questionnaire (MSQoL-54); and finally the Subjective Estimation of Quality of Life (SQoL) (16, 22, 36, 37).



## **Disability**

The Kurtzke Expanded Disability Status Scale (EDSS) is the most frequently used measure of disability in MS patients. Each measured functional system is graded to the nearest possible grade, where 0 means normal grade, 6 means loss of function and V indicates an unknown abnormality. Disability caused by MS is measured on a continuum of 0 (normal neurologic examination) to 10 (death due to MS) according to Kurtzke (38). The Office of Population Census and Surveys (OPCS) presents a disability scale used by a non-medically qualified assistant in the study by Rothwell et al (16). OPCS presents a disability questionnaire based upon a national survey of disability in Great Britain. The scale is used to assess disability in thirteen areas. For each area, a severity score is recorded based on a series of judgements by people with disabilities and those caring for them. The severity categories range from 1 (least severe) to 10 (most severe) (39). The last checklist in the study by Isaakson et al (37), the Self Reported Impairment contains 15 signs of impairment, and patients report if they have no symptoms, moderate or severe, and if the symptoms are constant or fluctuating (37).

## **Psychological well-being**

The Beck Depression Inventory (BDI) is used with patients to explore feelings and attitudes relating to general depressive status and to verify the influence of depression on health status in disabled people. It evaluates 21 symptoms of depression (36, 40). The Center for Epidemiological Studies-Depression Scale (CES-D) is a 20-item self-report measure that yields a numerical estimate of depression severity (36, 41). In the both depression measures, higher scores indicate greater depression (36, 40, 41).

## **Statistics**

Correlation analyses examining the relationships between the study variables were used in all reviewed studies (3, 16, 21, 22, 34, 36, 37, 42). Unpaired t-tests were used to compare MS patients with the general population in one study (42). Univariate analyses were performed using the chi-square test for the proportions (22), and one-way ANOVA (22, 34, 42), the Wilcoxon rank-sum test (22, 37) and Kruskal Wallis test (22) for continuous data. Linear regression analyses were used in three studies (3, 21, 36), and logistic regression analysis in one study (22).

## **Ethical issues**

The reviewed studies were previously approved by the research ethics committees of the universities or institutes where they were performed (3, 16, 21, 22, 34, 37, 42). Information is lacking only for one study (36).

## **Results**

### **Participants, sample size and measures**

A total of 8 studies were found to meet the criteria for inclusion (Table 2). The number of subjects varied between 42 and 261 MS patients. Six surveys were conducted in Europe and two in the USA. In one study data were obtained by postal questionnaires (22) and in one by telephone (36). In the six remaining studies data were collected during the patients' clinic visits (3, 16, 21, 34, 37, 42). Selected studies were grouped into three categories according to the influence on perceived health status: the SF-36 and disease duration, the SF-36 and disability, and finally the SF-36 and psychological determinants (Table 2).

**Table 2** Description of the eight studies grouped into three categories

<b>Disease duration &amp; SF-36</b>			
<b>Author</b>	<b>Study aim</b>	<b>Sample, Measures and Study design</b>	<b>Results</b>
<b>Patti et al. 2003</b> (ref 34)	- To describe the self-assessed burden of MS, to compare these results with those in a general healthy population, to correlate HRQoL of MS patients with disease duration disability and depression.	- 180 patients diagnosed at least 4 years before 1998, in South Italy  - SF-36 Health Survey, the Kurtzke Expanded Disability Status Scale EDSS, Beck Depression Inventory BDI  - Cross-sectional study	- PF & EDSS $r = -.76^{***}$ - D & SF-36 from $r = -.38^{***}$ to $-.65^{***}$
<b>Pittock et al. 2004</b> (ref 42)	- To measure the prevalence of the dimensions of SF-36 in a cohort with MS and compare it with the general population.	- 185 MS patients from Olmsted County, Minn, USA  - The Kurtzke Expanded Disability Status Scale EDSS, SF-36 Health Survey and additional 18 items  - Cross-sectional	- PF & Dis Dur $r = -.37^{***}$ - PF & EDSS $r = -.87^{***}$ - PRL & EDSS $r = -.45^{***}$ - BP & EDSS $r = -.15^*$ - GH & EDSS $r = -.31^{***}$ - V & EDSS $r = -.26^{**}$ - SF & EDSS $r = -.37^{***}$
			<b>Main Findings</b>  - The patients showed significant lower mean score for all SF-36 health dimensions compared with sex- and age-adjusted scores in a healthy general Italian population. - EDSS scores correlated only with physical functioning. - BDI showed high partial correlations with all SF-36 health domains. - MS patients with short time since diagnosis scored worse than the general population in all dimensions of the SF-36.  - MS patients had worse scores than the general US population with respect to physical functioning, vitality and general health dimensions of the SF-36. The majority of MS patients were mostly satisfied or delighted with their quality of life.

### Disability & SF-36

Author	Study aim	Sample, Measures and Study design	Results	Main Findings
<b>Nortvedt et al. 1999</b> (ref 21)	<ul style="list-style-type: none"> <li>- To compare EDSS and perceived health status as measures of disease impact in a representative sample of patients.</li> </ul>	<ul style="list-style-type: none"> <li>- 194 MS patients diagnosed before 1995 in Hordaland County, Norway</li> <li>- The Kurtzke Expanded Disability Status Scale EDSS, SF-36 Health Survey</li> <li>- Cross-sectional</li> </ul>	<ul style="list-style-type: none"> <li>- PF &amp; EDSS <math>r = -.86^{***}</math></li> <li><math>R^2 = .73</math></li> <li>- GH &amp; EDSS <math>r = -.46^{***}</math></li> <li><math>R^2 = .21</math></li> <li>- PRL &amp; EDSS <math>r = -.33^{***}</math></li> <li><math>R^2 = .11</math></li> <li>- V &amp; EDSS <math>r = -.26^{***}</math></li> <li><math>R^2 = .07</math></li> <li>- SF &amp; EDSS <math>r = -.48^{***}</math></li> <li><math>R^2 = .23</math></li> </ul>	<ul style="list-style-type: none"> <li>- The patients had lower mean scores for all eight SF-36 health dimensions compared with sex- and age- adjusted scores in the general population. This difference was especially high for physical functioning: general health; role limitation, physical; vitality, and social functioning.</li> </ul>
<b>Nortvedt et al. 2000</b> (ref 3)	<ul style="list-style-type: none"> <li>- To investigate the predictive value of SF-36 like measure of quality of life on changes in disability.</li> </ul>	<ul style="list-style-type: none"> <li>- Data from 97 relapse-remitting patients with MS from randomised, double-blind, placebo-controlled clinical trial of recombinant human interferon &amp; 2a, Norway</li> <li>- The Kurtzke Expanded Disability Status Scale EDSS, SF-36 Health Survey, gadolinium-enhanced MRI</li> <li>- Longitudinal; follow-up 1 year later</li> </ul>	<ul style="list-style-type: none"> <li>- After 1 year: <ul style="list-style-type: none"> <li>- MH &amp; EDSS <math>r = -.29^{**}</math></li> <li>- ERL &amp; EDSS <math>r = -.22^*</math></li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>- Low scores on SF-36 mental health scale were correlated with increased EDSS scores 1 year later; the results were not altered by adjusting for disease activity at baseline, which was measured by the number gadolinium-enhanced MRI lesions, relapse rate for the preceding 2 years, and baseline EDSS score.</li> <li>- A high score of self-rated health (1<sup>st</sup> question in the SF-36) at baseline was correlated with the decreased EDSS score after 1 year.</li> </ul>

Disability & SF-36			
Author	Study aim	Sample, Measures and Study design	Results
<b>Solari &amp; Radice 2001</b> (ref 22)	- To assess the perceived health status of people with MS.	- 400 people with MS, 261 respondents, randomly selected in Province of Milan and Lombardy Regional Health Service, Italy  - Postal questionnaires - the Multiple Sclerosis Quality-of-Life 54 Questionnaire (MSQOL-54), SF-36 Health Survey, structured demographic and clinical questionnaire	- PF ( $z=-1.3$ ) and PRL ( $z=-.9$ ) most distinguished the groups
<b>Isaksson et al. 2005</b> (ref 37)	- To describe quality of life in MS patients given immunological treatment & non-immunological treatment, to investigate the relationship between impairment and quality of life.	- Cross-sectional study - 29 MS patients with immunological treatment were matched with 29 MS patients not given such treatment, Sweden  - Self-reported impairment checklist, SF-36 Health Survey, the Subjective Estimation of Quality of Life SQuL	- EDSS & PF $r=.62$ - EDSS & BP, GH, SF, PRL $r=.28$ , $r=-.35$
			<p><b>Main Findings</b></p> <ul style="list-style-type: none"> <li>- The three MS groups (EDSS&lt;4.0; 4.0-6.5; &gt;6.5) differed significantly for all domains except cognitive and sexual functions.</li> <li>- Comparisons between the general population SF-36 scales and the EDSS 4.0-6.5 and the EDSS &gt; 6.5 groups are highly significant for all SF-36 scales. Patients had lower scores than the general population.</li> <li>- The EDSS &lt;4.0 group differs significantly in a positive way only for general health and social function. MS population scored worse than the general population in all domains.</li> </ul> <ul style="list-style-type: none"> <li>- In the whole group of MS patients, statistically significant correlation between EDSS and 6 variables of the SF-36 were found.</li> <li>- Physical functioning was associated with walking problems, spasticity and balance.</li> <li>- The physical role limitations were associated with walking, fatigue, concentration/poor memory.</li> <li>- Pain, fatigue, and concentration had the highest impact on vitality, social functioning and mental health in the whole group.</li> </ul>

Psychological determinants & SF-36			
Author	Study aim	Sample, Measures and Study design	Results
<b>Rothwell et al. 1997</b> (ref 16)	- To compare the perceptions of MS patients (and clinicians) as to the relative importance of the 8 different domains of the Short Form 36	- 42 MS patients (28 - 68 years) and control data from survey of health related quality of life in over 6000 people in 1993, UK  - SF-36 Health Survey, EuroQoL-5D; Kurtzke Expanded Disability Status Scale EDSS; the Office of Population Census and Survey `s (OPCS) disability status scale	- V & EuroQoL r= .57*** - GH & EuroQoL r= .49*** - MH & EuroQoL r= .44**
<b>Schwartz &amp; Kraft 1999</b> (ref 36)	- To assess MS patients' disability behaviour and its impact on patient psychological and physical functioning in association with spouse responses to patient disability behaviours and family environment	- Cross-sectional study - 44 individuals with MS and their spouses, USA  - The Kurtzke Expanded Disability Status Scale EDSS, Sickness Impact profile SIP, SF-36 Health Survey, Centre for Epidemiological Studies-Depression Scale CES-D, Family Measures  - Cross-sectional study	- Sollicitous spouse responses to patient disability behaviour were significantly associated with greater MS related physical disability. Poorer psychological functioning was found in patients with families who were reported to have higher conflict and/or who were more controlling.  - MH & family conflict r= -.40** - MH & D r= -.37** - MH & independence in the family r= .44**
			- Patients ` assessment of their physical disability was highly correlated with the clinicians' assessment and the non-clinical assessment. Quality of life (EuroQoL-5D) correlated with vitality, general health, and mental health in the SF-36, each of which patients rated as more important than clinicians; each patient scored lower than the controls.

Note:

\* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ ; SF-36 subscales mentioned in Table: V=vitality, MH=mental health, ERL=emotional role limitation, SF=social functioning, PF=physical functioning, GH=general health, PRL=physical role limitation; BP=bodily pain, higher scores indicate "better functioning"; Dis Dur=disease duration; EuroQoL=quality of life, higher scores indicate "better health"; D=depression measured with BDI or CES-D, higher scores indicate "greater depression"; EDSS=Kurtzke Expanded Disability Status Scale, 0=normal neurologic examination to 10=death due to MS

### **Disease duration and perceived health status**

Health dimensions in SF-36 were negatively correlated with the time since diagnosis. The longer the disease duration, the more severe the disease, and the lower the patients scored in perceived health status (34). Patients with an intermediate time since diagnosis (6-10 years) scored worse than patients with the shortest time since diagnosis (<6 years) for physical functioning, role limitation, bodily pain, vitality, emotional role and mental health. There was no significant difference between the patients with disease duration of over 10 years and those with the disease lasting 6-10 years (34) (Table 3). Compared to the general population and a group of MS patients with whatever disease duration, the patients with a short time since diagnosis (<6 years) already scored worse in all health dimensions in SF-36, except for bodily pain (34) (Table 3). Physical functioning in the SF-36 negatively and significantly correlated with duration of MS from onset ( $r = -0.37$ ;  $p < 0.001$ ) (42) (Table 2).

### **Disability and perceived health status**

Four studies examined the association between disease severity groups and the dimensions of the SF-36. The scores on both the EDSS and the OPCS were highly correlated with physical functioning measured by MS patients on the SF-36 (16). The MS patients with the least disability had a lower mean score than the general population in all health dimensions of the SF-36 (34), except for mental health in the study by Nortvedt et al (21), and explicitly for general health and social functioning in the study by Solari & Radice (22). Similarly, the MS groups with higher disability differed highly significantly for all SF-36 scales compared with the general population (22, 42) (Table 2).

The MS patients in the study by Nortvedt et al (21) were categorized into three EDSS severity groups (Table 3). The patients with low EDSS results scored significantly better than the two groups with higher EDSS scores in all SF-36 dimensions. The SF-36 scores were higher in the groups with EDSS scores between 3.0 and 6.0 than in patients with the highest EDSS scores for physical functioning and social functioning. The EDSS score explained 73% of the variation in physical functioning, 23% in social functioning, and 21% in general health (21).

The study by Patti et al (34) showed that patients with lower EDSS scores scored significantly better than the two groups with higher EDSS scores in all dimensions. The patients with EDSS scores of 3.0 - 6.0 had higher scores on the SF-36 than the patients with the highest EDSS score only for physical functioning (34) (Table 3).

In the study by Pittock et al (42) the dimensions of physical functioning, physical role, general health, social functioning and vitality were significantly correlated with the EDSS score (42). Isaksson et al (37) found almost the same results. In their study a group of MS patients given immunological treatment was compared to a group not given this treatment. Between the two groups no significant differences were found with regard to perceived health status. However, significant correlations were found between disability and six subscales of the SF-36. As they expected, physical functioning, but also bodily pain, general health, social functioning, physical role limitation and emotional role limitation were correlated with the EDSS in the whole group (37) (Table 2).

With regard to change in disability, the change in EDSS score one year later reflects a more progressive disease at baseline among the patients with low scores on the mental health scale. All other subscales were not significantly correlated in this respect (3) (Table 2).

### **Psychological well-being and perceived health status**

Rothwell et al (16) focused on the dimensions in EuroQoL-5D questionnaires where the depression/anxiety subscale was related to perceived health status as measured by the SF-36. The anxiety and depression scale, moreover, correlated significantly with vitality, general health, mental health, and physical role limitation in the SF-36 (16) (Table 2).

Schwartz & Kraft (36) examined the relationship between patients' ratings of their spouses' responses to disability behaviors of MS patients and the impact on patients psychological and physical functioning. Depression was measured using CES-D, and no significant relationship was found between depression and the physical dimension of SF-36, although depression was related significantly with physical functioning as measured by the SIP (36) (Table 2).

Patti et al (34) investigated the relationship between the SF-36 and depression as well. MS patients with lower BDI scores had a lower SF-36 mean score in all dimensions except for bodily pain. These patients with lower scores on depression scored significantly better than the two groups with higher BDI scores in all SF-36 health dimensions. The patients with BDI scores from 11-17 had higher SF-36 scores than the patients with the highest BDI scores for physical functioning, role emotional and mental health, and they had lower scores in all SF-36 health dimensions than the patients with the lowest BDI scores. BDI showed high partial correlations with all SF-36 health dimensions. The highest coefficient was for mental health as measured by the SF-36 (34) (Table 3).



Table 3 Disease duration, disability and depression related to SF-36

Disease duration	Shortest time	Intermediate time	Longest time
Patti et al. 2003 (ref 34)	<6 years	6 - 10 years	> 10 years
In MS patients		Worse than patients < 6 years, for 6 out of 8 dimensions	Worse than patients < 6 years, for 6 out of 8 dimensions
In MS patients compared to the general population	Worse in all health dimensions, except bodily pain	No significance	No significance
<b>Disability</b>	Lowest score	Higher score	Highest score
Nortvedt et al. 1999 (ref 21)	≤ 2.5	3.0 - 6.0	≥ 6.5
EDSS	Better in all dimensions compared with both other groups	Better in physical functioning and social functioning compared with ≥ 6.5	The worst mean scores in all dimensions compared with both other groups
SF-36			
Solari & Radice 2001 (ref 22)	< 4.0	4.0 - 6.5	> 6.5
EDSS	Worse in general health and social function compared with general population	Worse in all dimensions compared with general population	Worse in all dimensions compared with general population
SF-36			
Patti et al. 2003 (ref 34)	< 3.0	3.0 - 6.0	> 6.0
EDSS	Better in all dimensions compared with both other groups	Better in physical functioning compared with > 6.0	Worse in all dimensions compared with both other groups
SF-36			
<b>Depression</b>	Lowest score	Higher score	Highest score
Patti et al. 2003 (ref 34)	≤ 10	11 - 17	> 17
BDI	Better in all dimensions compared with both other groups	Better in physical functioning, role emotional, and mental health compared with the group with BDI > 17	The worst scores in all dimensions compared with both other groups
SF-36			

Note:

SF-36=Short Form-36 Health Survey; EDSS=Kurtzke Expanded Disability Status Scale; BDI=Beck Depression Inventory

## Discussion

The objective of this study was to review and summarize existing literature regarding perceived health status in MS patients measured with the SF-36 Health Survey, with the focus on disability, disease duration and psychological well-being.

The SF-36 was selected as the key measure in this review. Although it was originally designed as a generic measure in population surveys, the reviewed studies confirmed the SF-36 as an appropriate and useful measure of perceived health status in MS patients (3, 16, 21, 22, 34, 36, 37, 42). As most of the instruments in the reviewed studies used ordinal scales, statistics in these studies were mainly performed with using correlation analyses, while some of them used ANOVA and others regression analyses. Causal relationships would need to be confirmed in an intervention study. It follows that these studies' findings should be used for evaluation of health status in MS patients in the treatment process (3).

The results of our review show that time since diagnosis negatively influences perceived health status measured with the SF-36 in patients with MS. After some time from baseline, patients' perceived health status worsens, possibly as a consequence of increasing disability. MS patients with longer disease duration have more physical difficulties than patients with short time from diagnosis. Worsened disability interlocks the mental and other growing symptoms after some time (40). It might be assumed that longer disease duration would be associated with worsening of physical functioning, although only a few studies focus on the association between disease duration and perceived health status in MS patients (34, 42).

A majority of the studies in this review investigated the relationship between disability and perceived health status as measured with the SF-36. Those patients with higher scores in disability assessed their health status as worse, especially in physical functioning. Disability influenced mostly perceived physical health, but determined other dimensions of perceived health status in MS as well. Disability usually changed after some time. EDSS change correlated with the mental health subscale of SF-36 after one year and it was potentially predictive. This may be important in comparing physical health status of MS patients with different conditions or in comparing the same patients after some time. The outcomes in the physical health status domains may predict disease severity and the following intervention. In the report by Hauptz et al (43) the reductions in the eight subscales of SF-36 were even more pronounced in persons with gait impairments. In their study the SF-36 scales only modestly correlated with physical disability. In contrast to Nortverdt et al (21) this indicates that perceived health status does not depend on the physical symptoms of MS (43).

Patti et al (44) demonstrate that disability can be improved by using short outpatient physiotherapy treatment. Treatments in MS are directed at resolving acute attacks, reducing the number of exacerbations, treating the sequels of previous attacks, and preventing progression of disability (44).

Regarding psychological well-being and perceived health status, the latter was better in the patients with less depression (34). MS-depressed patients scored worse on the energy, mental health, cognitive function, overall quality of life, sexual and emotional function dimensions than non-depressed MS patients (10). The study by Benito-Leon et al (45) showed that MS patients currently experiencing depression would give a more negative evaluation of their well-being than those who were not depressed, whether or not a physical illness was also present. There will be some overlap between ratings of low mood and quality of life (45). According to Lamberg (33), depression shows little correlation with deficits in cognitive function, suggesting that it may be an independent indicator of neurological damage. Lamberg (33) complements treatments with cognitive-behavioural, group and family therapy, and the use of antidepressant medications that improve mood and whole perceived health status. MS patients in the study by Schwartz & Kraft (36) who rated their spouses as more negative in response to their disability behaviours had more symptoms of depression. Those MS patients who reported their spouses as more encouraging of "well" behaviours were significantly less depressed. Spousal support had a buffering effect against depression in MS patients. MS patients' depressive symptoms were found to have a moderating affect on the relationship between patients' ratings of spouses' responses and patients' physical functioning (36). Regarding these findings Rudick (4) sees comprehensive MS centers as being extremely helpful to MS patients and their families.

The results of this review may identify potential targets for practice interventions in MS patients. Perceived health status is like a mirror of the way the patient feels about and copes with the disease. Findings from the subscales of SF-36 can be used for observation of MS patients' health status, especially of their disability, as time passes, or psychological symptoms when they are more depressed, anxious or stressed. Sometimes physicians evaluate MS patients as suffering from a handicap from the loss of motor function. But the patients can be distressed more from the cognitive impairment, bad emotional functioning or the loss of social relationships. Assessments of the health professionals do not have to agree with the internal information from MS patients about their health status. For the patients their own perceptions are of higher importance (46). It may be useful to determine the impairments of MS patients using this measurement, and based on its results to recommend appropriate interventions in the practice of nurses, psychologists or physiotherapists.

The SF-36 profile improved for those patients who underwent physiotherapy (10, 34). Nursing care should be part of a continuum of care involving the physiotherapy environment and community and social services sectors.

## **Conclusions**

This study is a review of previous studies examining the association of perceived health status with disability, disease duration and psychological well-being in cohorts of MS patients. We assumed that disease duration, disability and psychological well-being would be significantly associated with perceived health status in MS patients measured with the SF-36 in the eight reviewed studies. This review provided evidence for this hypothesis. The more disabled the patients, the poorer their perceived health status. One study showed MS patients already reporting poorer health status than the general population after very short duration of MS. Perceived health status also significantly correlated with depression: the more depressed the patients, the worse their perceived health status was. Further research should focus on strategies to improve perceived health status in MS patients. Our findings may be useful for evaluating the impairments of MS patients, and for determining the appropriateness of treatment in the practice of nurses, psychologists or physiotherapists. Health care, looking for appropriate treatments, could pay more attention to perceived health status in MS patients by focusing on improved quality of life in these patients. The SF-36 data could be useful, if its results were validated in relation to findings from other specific self-reported instruments used not only in MS, but in other chronic diseases. So the SF-36 outcomes can be important when compared with data from other self-reported measures used in clinical practice.

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## **Author contributions**

Martina Krokavcova, Jitse P. van Dijk, Iveta Nagyova and Jaroslav Rosenberger was responsible for study design and data collection and analyses. Martina Krokavcova, Jitse P. van Dijk, Iveta Nagyova, Jaroslav Rosenberger and Johan W. Groothoff was responsible for drafting of manuscript preparation. Jitse P. van Dijk, Iveta Nagyova, Jaroslav

Rosenberger, Zuzana Gdovinova and Johan W. Groothoff was responsible for supervision. Jitse P. van Dijk, Truus van Ittersum-Gritter and Miriam Gavelova was responsible for material and technical support.

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### **Ethics Committee approval**

Permission for this study was obtained from the local Ethics Committee organized and operated according to ICH Good Clinical Practice.

### **Conflict of interest**

None.

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# **Self-rated health and employment status in patients with multiple sclerosis<sup>2</sup>**

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## Abstract

The aim is to explore the association between self-rated health and employment status in multiple sclerosis (MS) patients when controlling for age, gender, functional status, disease duration, anxiety and depression. 184 MS patients completed a sociodemographic questionnaire that included questions on employment status, the first item of the Short Form-36 Health Survey and the Hospital Anxiety and Depression Scale. Functional disability was assessed using the Expanded Disability Status Scale. The probability of good self-rated health in employed persons was investigated using stepwise logistic regression analyses. MS patients who reported good self-rated health were 2.46 times more likely to be employed (95% confidence interval [CI] 1.08-5.59). MS patients without anxiety were 2.64 times more likely to be employed (95%CI 1.23-5.67). Patients with higher EDSS scores were 0.49 times less likely to be employed (95%CI 0.33-0.70). Age, gender, disease duration and the presence of depression did not show an increased chance of patient employment. Patients with good self-rated health are more likely to be employed, even after adjusting for age, gender, education, functional disability, disease duration, depression and anxiety.

## Introduction

Self-rated health, a subjective assessment of health status, helps predict potential poor health outcomes, mainly in the elderly and in patients with chronic diseases. Several studies have shown the predictive effect of self-rated health on mortality or survival time (1, 2). One large prospective study of healthy individuals showed that self-rated health may be an independent significant predictor for the development of coronary heart disease (3).

Multiple Sclerosis (MS) is a chronic disease with an unpredictable course characterized by recurrent periods of inflammation in the central nervous system, which are followed by diffused changes in the white and grey matter, the breakdown of myelin and damage to axons (4, 5). It is the most common cause of neurological disability in young adults. Symptoms begin between the ages 20 and 50 years in 90% of cases, and the disease strikes individuals during the peak years of their education, career development and family life, significantly impacting their ability to remain in the workforce (4, 6). A study by Nortvedt et al (2000) investigated self-rated health as a predictive factor for the development of MS. The progression of the disease in an MS patient, as measured by the Expanded Disability Status Scale, can be assessed using self-rated health determined by one question from the SF-36 and by evaluating the

change in disability at the baseline measured by EDSS one year later. Since self-rated health is a subjective measure of disease activity, it provides important additional information apart from MRI, EDSS and the relapse rate of clinical course (7).

Measures of functional disability, disease duration and clinical course all reflect health status. A higher level of functional disability and longer disease duration have negative consequences on the health of MS patients (8, 9). Among the commonly described symptoms of MS measured in our study were a depressed mood and a feeling of anxiety. MS patients may develop depression as an understandable reaction to learning that they suffer from a chronic disease and will have to live with its consequences (10, 11). Anxiety, along with a high level of distress, occurs mostly in the first years of diagnosis (12).

Chronic diseases have an enormous impact on the ability to work (13). The relationship between health and employment status has been described in a considerable number of studies, and self-rated health appears to be strongly related to employment status in patients with lower back pain, coronary heart disease and HIV (13-17). A different characterization of job loss due to chronic diseases can be found in the literature. "Unemployment status" and "non-employment status" may have two different meanings. Unemployed people are those who are not active in paid work, but who are looking for jobs and are available for work (18, 19). In contrast, non-employed people are those who are jobless and have the intention to work, but who are unable to work because of serious impairments or disabilities (18, 19).

Numerous factors may be considered when determining the ability to work among individuals with MS. The physical and cognitive functional limitations associated with MS are presumably the primary determinants of employment status in MS patients (20). With each point of increase in the functional disability score, the probability of being employed decreased by 7% when controlling for a large number of sociodemographic variables (21). Disease progression varies between disease courses in ways that could influence employment. Although there is a significant overlap of symptoms between the current clinical courses, the ability to work may vary considerably between them. Study participants with the relapsing-remitting course were found to have a higher frequency of employment than those having the primary-progressive course. An increased degree of disability is typical among individuals with the progressive course of MS (14, 20, 22).

Despite numerous studies on the ability of MS patients to work, it is still not clear whether self-rated health, as the first question in the SF-36 measure, is associated with employment status in MS patients. The direct relationship between disease variables and employment status are well known in MS (23). A similar question can then arise: Does self-rated

health play an important role in relationship to employment status? The aim of this study was to explore the association between self-rated health and employment status in MS patients when controlling for age, gender, functional status, disease duration and psychological well-being. We hypothesized that MS patients with good self-rated health are more likely to be employed when controlling for age, gender, functional disability, disease duration, depression and anxiety.

## **Methods**

### **Study population**

The sample consisted of MS patients from the eastern part of Slovakia. Data were collected from the winter of 2003 to the winter of 2006. MS patients from neurological outpatient clinics and members of MS clubs were included in the study. Patients underwent an interview and a physical examination. They completed several self-reported questionnaires on a voluntary and anonymous basis focusing on sociodemographic data, family life, health-related behaviour and disease history.

The procedure started by sending the questionnaires, invitation letters and a written informed consent form to the participants' homes by postal mail. After two weeks, a trained interviewer interviewed the MS patients personally in a neurologic outpatient clinic. A single neurologist then carried out a physical examination of all the patients. One additional call was made to those patients who did not come in order to arrange another examination. Exclusion criteria included: cognitive impairment determined by a Mini-Mental State Examination (MMSE) score of <24 (24); a history of psychiatric or medical conditions affecting the outcomes of the study; pregnancy; non-Slovak speaking patients.

The local Ethics Committee approved the study before its start. Each patient provided a signed informed consent form to participate in this study.

### **Measures**

Age, gender, marital status (living alone/single or married/cohabiting), education (elementary, secondary and university) and employment status were the variables ascertained from the self-reported questionnaire. Employment status was divided into four groups: 1) employed: full time or part-time, 2) non-employed: not employed or disabled due to MS, 3) unemployed for other reasons than MS, and 4) a group consisting of students, housewives, those on maternity leave and retired persons. The study focused on the first two groups.

Self-rated health was measured using the Short Form-36 Health Survey (SF-36), which was originally designed as a generic indicator of health status for use in population surveys. The SF-36 includes eight multi-item scales used to measure the following eight dimensions: physical functioning, role limitation due to physical health, bodily pain, social functioning, general mental health (covering psychological distress and well-being), role limitations due to emotional problems, vitality and general health perceptions. In addition, one question covers the change in health status over the past year. The reason for only reporting the first item instead of a broader description of perceived health status in MS patients is that self-rated health has been widely used in health studies as an indicator of general health status because it is generally accepted as a good predictor of mortality and morbidity. Self-rated health was assessed on a 5-point scale from 1 (excellent) to 5 (bad). The score was dichotomised into "good health" (excellent, very good, and good) and "fair health" (fair and bad health) (25, 26).

Psychological well-being in MS patients was assessed using the Hospital Anxiety and Depression Scale (HADS) (27). The scale consists of 14 items, 7 of which are related to depression and 7 to anxiety. Patients responded on a 4-point scale (0=absent and 3=definitely present/severe). The scores ranged from 0 to 21, with a higher score implying that depression or anxiety is present to a larger extent. The score identifies non-cases (a score of 7 or smaller), doubtful cases (a score of 8-10), and definitive cases (a score of 11 and higher) (27, 28). Cronbach's alpha was 0.79 for depression and 0.80 for anxiety in this study.

The duration of MS, its clinical course (relapsing-remitting, secondary-progressive and primary-progressive) and functional disability (EDSS) were the MS variables obtained by the same neurologist. The Kurtzke Expanded Disability Status Scale (EDSS) is the most frequently-used measure of disability in MS patients, with disability categories ranging from 1 (least severe) to 10 (most severe) (29).

## **Statistical Analyses**

Firstly, the sociodemographic variables, clinical variables (EDSS, disease duration, and clinical course), psychological well-being and self-rated health were described. Next, subgroups of MS patients with good and fair self-rated health were compared in sociodemographic variables, clinical variables and psychological well-being using an independent *t*-test. Finally, stepwise logistic regression analyses were used to examine the relative effect of self-rated health on employment status in MS patients when adjusting for age, gender, EDSS, disease duration and psychological well-being. Age, gender, self-rated health, EDSS, disease duration, depression and anxiety were independent variables, while employment status was

the dependent variable in these analyses. The results are reported as odds ratios, with 95% confidence intervals (95% CI).

Data were analysed using the Statistical Package for the Social Sciences, v.14.0 (SPSS; SPSS Inc., Chicago, Illinois, USA).

## Results

At first, the study included 223 questionnaires, which represents a response rate of 52.0%. Older MS patients in the study sample were slightly underrepresented, and non-respondents ( $45.1 \pm 10.5$  years) were significantly older than the participants ( $40.5 \pm 9.7$  years) ( $p < 0.05$ ). However, there were no statistically significant differences between non-respondents and participants regarding gender.

Data for 39 MS patients were not included in the analyses because the patients were unemployed for reasons other than MS ( $n=16$ ), were full-time students ( $n=13$ ), were housewives or women on maternity leave ( $n=6$ ) or were on a retirement pension ( $n=4$ ). The activities of these groups differ from the activities we evaluated as being employed, or non-employed due to MS. The study group therefore consisted of 184 MS patients (33.7% male, 66.3% female) who were employed (patients working full-time or part-time due to MS) or non-employed (not employed and disabled due to MS).

A basic description of the sample is given in Table 1 ( $n=184$ ). The MS respondents averaged  $40.5 \pm 9.7$  years old and consisted of more women than men (66.3% female). Of all the participants, 35.9% were employed (29.6% full time), 46.6% were not employed and disabled due to MS, and 17.5% belonged to the excluded groups. The mean EDSS score was  $3.2 \pm 1.4$ , with a mean disease duration of  $6.4 \pm 5.2$  years. The majority of the patients belonged to the relapsing-remitting clinical course (68.0%). Of the sample of MS patients, 78.1% (score  $\leq 7$ ) reported no depression, 48.6% (score  $\leq 7$ ) reported no anxiety, and the mean score for fair self-rated health was  $3.8 \pm 0.9$  (Table 1).

**Table 1** Description of the sample (n=184)

<b>Variables</b>	<b>N (%)</b>	<b>M</b>	<b>SD</b>	<b>Range</b>
<b>Age</b> (years)	184	40.5	9.7	18 - 61
<b>Gender</b>				
Male	62 (33.7%)			
Female	122 (66.3%)			
<b>Marital status</b>				
Living alone/single	31.5%			
Married/cohabiting	68.5%			
<b>Education</b>				
Elementary	27.2%			
Secondary	52.5%			
University	20.3%			
<b>Employment status</b> (n=223)				
Full-time employed	29.6%			
Part-time employed	6.3%			
Student	5.8%			
Housewives/maternity	2.7%			
Unemployed	7.2%			
Retired	1.8%			
Disabled	46.6%			
<b>EDSS</b>		3.2	1.4	1.0 - 8.5
<b>Disease duration</b> (years)		6.4	5.2	0.5 - 37.0
<b>Clinical course</b>				
Relapsing-remitting	68.0%			
Secondary-progressive	14.9%			
Primary-progressive	17.1%			
<b>Depression</b>		4.5	3.5	0 - 18
Not depressed $\leq 7$	78.1%			
Depressed $> 7$	21.9%			
<b>Anxiety</b>		7.8	2.8	2 - 16
Not anxious $\leq 7$	48.6%			
Anxious $> 7$	51.4%			
<b>Self-rated health</b>		3.8	0.9	1 - 5
Good	35.2%			1 - 3*
Fair	64.8%			4 - 5**

Note:

\*Good health, 1-excellent, 2-very good, 3-good; \*\*Fair health, 4-fair, 5-bad

EDSS, Expanded Disability Status Scale



Table 2 presents the differences in subgroups of MS patients defined by employment status with the use of an independent samples *t*-test, where continuous variables were independent variables. Younger MS patients ( $p < 0.001$ ), with lower EDSS scores ( $p < 0.001$ ), shorter disease duration ( $p < 0.001$ ), less depression ( $p < 0.002$ ) and less anxiety ( $p < 0.004$ ) were employed compared to non-employed MS patients. Elementary education was significantly associated with non-employment of MS patients ( $p < 0.001$ ), while university education was associated with employment of MS patients ( $p < 0.001$ ). Better self-rated health was reported by employed patients than by non-employed MS patients ( $p < 0.001$ ) (Table 2).

**Table 2** Means and standard deviations of age, clinical variables, depression, anxiety and self-rated health differences, and numbers and percentages of sociodemographic variables by employed and non-employed MS patients (n=184)

Variables	Employment status		p - value <sup>a</sup> 95% CI <sup>b</sup>
	Employed* Means (±SD) or N (%)	Non-employed** Means (±SD) or N (%)	
Age	37.8 (±8.84)	42.6 (±9.75)	<b>0.001</b>
Gender (%)			
Male	25 (31.2%)	37 (35.6%)	-9.4 - 18.0%
Female	55 (68.8%)	67 (64.4%)	
Marital status (%)			
Married/cohabitating	51 (63.8%)	75 (72.1%)	-22.0 - 5.3%
Living alone/single	29 (36.2%)	29 (27.9%)	
Education (%)			
Elementary	8 (10.8%)	40 (38.8%)	<b>-39.8 - 16.2%</b>
Secondary	38 (51.4%)	55 (53.4%)	-17.0 - 12.9%
University	28 (37.8%)	8 (7.8%)	<b>17.9 - 42.3%</b>
EDSS	2.4 (±1.07)	3.8 (±1.35)	<b>0.001</b>
Disease duration (in years)	4.6 (±4.07)	7.8 (±5.65)	<b>0.001</b>
Depression	3.6 (±3.14)	5.2 (±3.70)	<b>0.002</b>
Anxiety	7.2 (±2.80)	8.4 (±2.65)	<b>0.004</b>
Self-rated health	1.4 (± 0.50)	1.8 (±0.38)	<b>0.001</b>

Note:

EDSS, Expanded Disability Status Scale; Self-rated health, 1(excellent) to 5(bad)

<sup>a</sup> For testing significant differences between subgroups of employed and non-employed MS patients the independent sample *t*-test was used where means for each variable are displayed; significant differences are in bold

<sup>b</sup> Difference of proportions test (30); significant differences are in bold

\* Employed, full-time or part-time employed MS patients; \*\*Non-employed, not employed or disabled due to MS

Logistic regression analyses were used to examine the probability of good self-rated health in the employment status of MS patients. The outcomes of the stepwise logistic regression models indicated that good self-rated health was more likely to be related to employment status when adjusted for age, gender, EDSS, disease duration, depression, and anxiety. The results are presented in Table 3.

MS patients who reported good self-rated health had a 2.46 times greater chance of being employed (95% confidence interval [CI] 1.08-5.59), while patients with higher EDSS scores were less likely to be employed. The odds ratio (OR) of EDSS for employment status was 0.49 (95%CI 0.33-0.70). MS patients without anxiety had a 2.64 times greater chance of being employed (95%CI 1.23-5.67). The results of logistic regression analyses did not show that age, gender, disease duration, nor the presence of depression, increase a patient's chance of being employed (Table 3).

**Table 3** The effect of self-rated health on employment status when adjusted for age, gender, functional disability, disease duration, depression and anxiety (the final table of the stepwise logistic regression)

Variables	B	Odds ratio	95% CI	p-value
Age	-0.001	1.00	0.96-1.04	0.962
Gender				
Male	-0.12	0.89	0.40-1.97	0.766
Female		1		
Self-rated health				
Good health*	0.900	2.46	1.08-5.59	<b>0.031</b>
Fair health**		1		
EDSS	-0.724	0.49	0.33-0.70	<b>0.001</b>
Disease duration	-0.076	0.93	0.84-1.02	0.112
Depression				
Depressed		1		
Not depressed	0.618	1.85	0.73-4.69	0.192
Anxiety				
Anxious		1		
Not anxious	0.972	2.64	1.23-5.67	<b>0.012</b>

Note:

Results were significant at: \*p<.05; \*\*p<.01; \*\*\*p<.001

Significant p-values are in bold

\*Good health, 1-excellent, 2-very good, 3-good; \*\*Fair health, 4-fair, 5-bad

EDSS, Expanded Disability Status Scale

CI, confidence intervals; B, unstandardized coefficient

## Discussion

MS is accompanied by important physical, psychological and social consequences. The present study explores the relationships between self-rated health and employment status according to age, clinical variables and psychological well-being in MS patients.

The results provide support for the hypothesis that good self-rated health was significantly associated with employment status in the MS patients surveyed. The correlation coefficients between the main variables showed that low age, university education, low functional disability, short disease duration, no anxiety, no depression and good self-rated health were all related to employment status in MS patients. MS patients with good self-rated health were more likely to be employed than those who assessed their self-rated health as fair. In this sample, MS patients showed the desire to be employed, but they were not able to work because of the worsened disability caused by MS. Disorders of strength, sensation, coordination and balance, as well as visual, cognitive and effective deficits may lead to severe progressive limitations of functioning in daily life, employment status included (31). Our results are in line with the study by Rietberg et al, which showed that MS patients cannot work when they report poor self-rated health (31).

Although logistic regression analyses showed less significant associations between good self-rated health and employment status when adjusted for functional disability and disease duration, self-rated health still remains a significant indicator for being employed. The results are consistent with studies in which good health was associated with employment status in MS patients (9, 14, 32).

Following the results, self-rated health showed to be a variable more strongly associated with employment status than functional disability. Functional disability caused by MS is measured on a continuum of 0 (normal neurologic examination) to 10 (death due to MS) according to Kurtzke's EDSS score (29). It is reflected in individual physical symptoms, which may vary from patient to patient, and can be compared with outcomes of perceived health status as measured using the SF-36 questionnaire. The SF-36, with its physical and mental summary components, appears to be an appropriate means of measuring the progression of disease and functional abilities in MS patients and can be easily used by healthcare professionals.

The effect of a low level of depression on employment status was weak and was not found to be significant in our study. The absence of anxiety was associated with being employed. The risk factor of major anxiety on low work capability could be demonstrated with its negative impact on work, social and family concerns in MS patients (33). Well-

intentioned family members and employers advise people with MS to leave employment as a way of dealing with the issues of fatigue, pain and stress. Considering the consequences of premature retirement and reduced participation in general, with respect to financial security, the social network, health status and psychological well-being, it may be far more beneficial to assist MS patients who wish to continue employment by following up with coping strategies than to advise them to leave employment (34).

Since this study is based on cross-sectional data, it cannot be determined with certainty whether poor self-rated health is the reason for the inability to work. Therefore, the role of self-rated health as a predictor of employment status in a longitudinal study may be noteworthy and warrant discussion. As several studies have shown a predictive effect of self-rated health on mortality or survival time in chronic diseases (1, 2), it would be worth assessing the role of good self-rated health in predicting the future working ability in MS patients in a longitudinal study. This seems to be useful not only for the patients themselves, but also for their entire families in terms of economic status. Data gathered from MS patients, as well as family members and employers, could provide a great deal of information about the types of work accommodations that are useful and effective for employment status. MS patients with progressive clinical courses may not be able to work when poor health, low functional status and the presence of depression and anxiety could affect work and family life (20, 35). On the contrary, employment status may be a major factor for social support because of its social network supporting adaptation to physical illness. Positive social interaction is associated with better health (36).

The participating MS patients were significantly younger than the non-respondents, which can be considered as a limitation of this study. We may assume that a smaller proportion of the oldest group, probably the group with the longest disease duration, or the most affected group, did not participate. One possible consequence of this might be that outcomes regarding employment status are more related to younger MS patients than to older ones, and that the results cannot be extended and generalized to the whole MS population. MS patients in the study sample were significantly more likely to be working than older patients. We may assume then that older MS patients in the MS population have fewer chances to be employed than younger MS patients.

Regarding future research, other factors not analysed in this study, such as fatigue or cognitive dysfunctions, might also contribute to non-employment in MS patients. Performing subgroup analyses in an attempt to determine factors other than clinical variables or depression and anxiety that could contribute to non-employment in MS patients would be helpful. Furthermore, outcomes concerning the summary scales of the

SF-36, like the summary physical and summary mental scales, or even on a more detailed level the dimensions of the SF-36, such as role physical, role emotional, general mental health, etc., would be interesting to study. Scores ranging from 0 to 100 will be available that should provide the basis for further analysis.

In conclusion, this study supports to some extent existing evidence of the beneficial impact of good health on work ability in patients with MS. Our results showed that MS patients with good self-rated health are more likely to be employed, even after adjusting for age, gender, education, functional disability, disease duration, depression and anxiety. Taking these findings into account, self-rated health may be used as a quick and cheap prognostic marker which can warn about the possible loss of employment, or changes in functional disability. However, these results should be proven in a study that is longitudinal in design. MS patients without anxiety may have increased chances for working. It can be assumed that not only does the employment rate decline with worsening health related to the progression of disease, but that the network of supportive people from work needed for coping decreases as well, although this was not subject of our study. The importance of good health and maintaining employment status for patients suffering from MS could be therefore mutual.

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# **Social support as a predictor of perceived health status in patients with multiple sclerosis<sup>3</sup>**

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## Abstract

*Objective:* The main aim of this study was to investigate whether different levels of perceived social support are associated with different levels of perceived health status in multiple sclerosis (MS) patients.

*Methods:* Two hundred and seven MS patients ( $38.4 \pm 10.6$  years, 66.2% female) completed the Short Form-36 Health Survey (SF-36) as the measure for perceived health status, and the Perceived Social Support Scale (PSSS) as the measure for social support. Functional disability was assessed using Kurtzke's Expanded Disability Status Scale (EDSS). The contribution of EDSS and PSSS for explaining the variance in SF-36 was investigated with multiple linear regression analysis.

*Results:* Demographic variables and EDSS explained 44% of the variance of the physical health summary scale in the SF-36. Demographic variables, EDSS and PSSS from family and friends explained 24% of the variance in mental health summary scale in the SF-36. Results varied according to the multiple linear regression analyses of predictors of variance in the eight dimensions of the SF-36.

*Conclusion:* PSSS from significant others was positively associated with general health dimension of perceived physical health status, while PSSS from family and friends was positively associated with perceived mental health status in MS patients.

*Practice Implications:* The results show the importance of supporting social ties and relationships between MS patients and others.

## Introduction

Multiple sclerosis (MS) is a chronic autoimmune disease with an uncertain course, with symptoms beginning between ages 20 and 50 years in 90% of the cases. It is the most common cause of neurological disability in young adults (1, 2). The socio-medical model of the disablement process explains how chronic and acute conditions affect functioning in specific body systems, physical and mental activities, and activities of daily life in young adults with MS.

Personal and environmental factors can speed up or slow down the disablement of patients. Patients become limited not only in employment but also educational opportunities, or interpersonal relationships as well (3-5). Functional disability has been associated with restricted social participation. The disease usually starts during the first two decades

of employment in a patient's life. Several studies have investigated the relationship between functional disability and perceived health status in MS patients (6-9).

Social support includes the supportive input which different people receive from their social environment, and almost any type of social interaction may be considered as social support (10, 11). It is assumed that social support has two important types of functions: the health-sustaining function has a direct effect on the well-being of individuals. Social support contributes to the positive adjustment and development of personality. On the other hand, social support also has an indirect stress-reducing or buffering function (12-14).

Generally, social support is supposed to influence three basic levels: emotional (love and affection), instrumental (helping hands) and informational (providing information). The final component is the perception of social resources that refer to the subjective evaluation of the level of quality of the support (10, 15). Emotional and informational supports can strengthen the perception that the stressor is not as bad as originally believed. Emotional support is helpful no matter who the source is. Emotional support is helpful when it comes from family and friends or when it comes from healthcare professionals (10). However, patients usually prefer informational support more from the physicians and nurses than from family (10).

Social support has been the most frequently studied psychosocial resource. Structural aspects of social support usually refer to the functions performed for the individual by three groups: family, friends and significant others (16, 17). The group 'significant others' includes persons who are relevant for the patients, in this case for instance co-workers, health care professionals or other MS patients (18); that is to say, relevant persons besides 'family (including partner)', and 'friends'. The authors of the scale of Perceived Social Support presented the importance of exploring specifically whom subjects consider as constitutive of 'special person' in the significant others subscale. The meaning of significant others can be dependent on the patient's age, marital status, social and cultural conditions when interviewed. Significant others could be taken to refer to a number of different individuals. Clarification of this issue would be necessary (16). Apart from these, important sources of informational support could be peer groups or psychotherapeutic groups led by experts (10). Subjects who are employed or studying can feel positive relationships from significant others like colleagues, fellow students and teachers who can provide them social support. When they participate in a work team or study group, they can feel positive relationships with significant others like fellow students, teachers or co-workers who can provide them social support. Koopman et al (19) identified the needs of individuals with MS.

The main aim of this study is to investigate whether different levels of perceived social support are associated with different levels of perceived health status in MS patients. We expected that:

1. Social support provided by family, friends and significant others is positively associated with perceived physical and mental health status in MS patients independently from basic demographic variables and functional disability.
2. Social support provided by family, friends and significant others is positively associated with the separate dimensions of perceived physical and mental health status in MS patients independently from basic demographic variables and functional disability.

## Methods

### Participants and sample size

The sample consisted of 207 MS patients from neurology outpatient clinics and members of MS societies in the eastern part of Slovakia; they were included in the study between December 2003 and July 2006. Exclusion criteria were as follows: cognitive impairment determined by a Mini-Mental State Examination (MMSE) score of  $<24$  (20); history of psychiatric or medical conditions affecting the outcomes of the study; pregnancy; non Slovak speaking patients; under 18 years of age.

Of the 412 MS patients who were deemed eligible for the study, 207 patients were interviewed (50.2%) and 205 MS patients did not respond. The 205 non-responders consisted of 180 patients from outpatient clinics (87.8%), 20 patients from hospitals (9.8%) and 5 non-responders from MS societies (2.4%). There were no statistically significant differences between the non-responders and the participants regarding gender, disease duration and clinical course of MS. However, the non-responders ( $45.1 \pm 10.5$  years) were significantly older than the participants ( $38.4 \pm 10.6$  years) ( $p \leq .05$ ).

#### *Description of sample*

The sample consisted of 66.2% women and 33.8% men with a mean age of  $38.4 \pm 10.6$  years (range 18-65 years). The mean disease duration measured as time from diagnosis was 5.3 years (range 0.5-15.5). Almost three quarters of the sample had the relapsing-remitting course of MS (72.2%). The mean EDSS score was  $3.0 \pm 1.5$  (Table 1). Interferon beta therapy in Slovak MS patients was accessible only for MS patients aged 45 years or less, mostly suffering from relapsing-remitting or secondary-progressive clinical courses. Fifty six per cent of the included MS patients in this study were treated with Interferon beta therapy. Some patients were limited in using

ambulatory devices (30.1%). A smaller group always required assistance always in all daily activities or mechanical devices were necessary (16.9%) and some of them were wheel-chair bound (4.4%).

MS patients in this group mostly lived with a partner (63.8%). Mostly younger MS patients in this sample were never married (30.9%), lived in their own apartment or house (63.4%), and had secondary education (54%). They were currently employed (31.2%). Non-employed were retired due to MS (49.8%), unemployed (8.8%), or had other duties (daily students, those on retirement pension, housewives, women on maternity leave; 10.2%) (Table 1).

Table 2 shows the description of perceived social support and the social networks. MS patients reported small social networks, which consisted of their partner, extended family and friends. MS patients were asked questions which thoroughly described their social network: "How often do you come into general contact with your relatives (personal meeting, phone calls, writing letters, email contacts; the members of household were not meant)? How often do you get into general contact with friends and acquaintances? How often do you go to a club or pub?" At the end of the interview MS patients were asked: "Could you state, that you are hindered by your physical and mental health in maintaining your contacts with other people?" (Table 2).

**Table 1** Description of the sample (n=207)

<b>Variable</b>	<b>%</b>	<b>M</b>	<b>SD</b>	<b>Range</b>
<b>Age</b>		38.4	10.6	18 - 65
<b>Gender</b>				
Male	33.8			
Female	66.2			
<b>Marital status</b>				
Married/cohabiting	63.8			
Living alone/single	36.2			
<b>Education</b>				
Elementary	29.0			
Secondary	54.0			
University	17.0			
<b>Employment status</b>				
Employed	31.2			
Non-employed	68.8			
<b>Clinical course</b>				
Relapsing-remitting	72.2			
Secondary-progressive	10.7			
Primary-progressive	17.1			
<b>Disease duration</b>		5.3	4.1	0.5 - 15.5
<b>EDSS</b>		3.0	1.5	1.0 - 8.5
<b>Treatment</b>				
Disease-modifying drugs	56.0			
Other	44.0			
<b>Type of assistance</b>				
Ambulatory devices	30.1			
Permanent required assistance	16.9			
Wheel-chair bound	4.4			
<b>SF-36</b>				
Physical health summary scale		48.5	20.2	10 - 100
Mental health summary scale		57.0	16.2	13 - 96

Note:

Higher scores indicate more disability (EDSS), more social support (PSSS) and better functioning (SF-36); EDSS-Expanded Disability Status Scale; PSSS-Perceived Social Support Scale; SF-36-Short Form-36 Health Survey

**Table 2** Perceived social support and social networks in the sample (n=207)

<b>Variable</b>	<b>%</b>	<b>M</b>	<b>SD</b>	<b>Range</b>
<b>PSSS</b>				
Family		23.0	4.9	4 - 28
Friends		20.7	5.1	4 - 28
Others		23.2	4.9	4 - 28
<b>Social network</b>				
<b>Contact with relatives</b>				
Never	1.4			
Once per month	8.7			
2-3 times per month	20.3			
Once per week	21.3			
2 or more times per week	42.0			
<b>Contact with friends</b>				
Never	1.0			
Once per month	9.7			
2-3 times per month	20.3			
Once per week	22.7			
2 or more times per week	39.6			
<b>Going to club/pub</b>				
Never	24.6			
Once per month	15.0			
2-3 times per month	10.2			
Once per week	7.7			
2 or more times per week	5.3			
<b>Hindered by health problems in maintaining contacts</b>				
Not at all	61.3			
Little	23.7			
Fairly	9.7			
Very much	4.8			

Note:

PSSS-Perceived Social Support Scale



## *Procedure*

This cross-sectional study consisted of several self-reported questionnaires, a semi-structured interview and a physical examination. The questionnaires, invitation letters and written informed consent were sent to the participants' homes by postal mail. After two weeks a trained interviewer interviewed the MS patients in the neurology outpatient clinic. A neurologist carried out a physical examination. The questionnaires focused on socio-demographic variables like age, gender, partnership, education, employment status and social network.

The local Ethics Committee approved the study before it started. Each patient provided a signed informed consent to participate in this study.

## **Measures**

### *Functional disability*

The most frequently used measure of disability in MS patients is the Kurtzke Expanded Disability Status Scale (EDSS) (21). It is based upon neurological testing of functional systems: pyramidal, cerebellar, brainstem, sensory, bowel and bladder, visual, mental and 'other'. Each functional system is graded to the nearest possible grade, 0 means normal grade, 6 means loss of function and V indicates an unknown abnormality. Disability caused by MS grades on continuum of 0 (normal neurological examination) to 10 (death caused by MS) (21).

### *Self-perceived health status*

The Short Form-36 Health Survey (SF-36) was originally used as a generic indicator of health status for use in population surveys and evaluative studies of health policy (22). The SF-36 includes eight multi-item scales to measure these eight dimensions: 1. physical functioning (ten items), 2. role limitation due to physical health (four items), 3. bodily pain (two items), 4. social functioning (two items), 5. general mental health (five items), 6. covering psychological distress and well-being (five items), 7. role limitations due to emotional problems (three items), 8. vitality, energy or fatigue (four items). In addition, one question covers change in health status over the past year (one item) and the study also focuses on general health perceptions (five items). We used the physical health summary scale (perceived physical health status, dimensions 1-4) and the mental health summary scale (perceived mental health status, dimensions 5-8). All item scores are coded and transformed into a scale of 0 (poor health) to 100 (optimal health) (22, 23). Cronbach's alpha for the SF-36 total score in the present sample was 0.93; for the physical health summary scale 0.89 and for the mental health summary scale 0.89. The physical health

summary scale mean score was  $48.5 \pm 20.2$  and the mental health summary scale mean score from SF-36 was  $57.0 \pm 16.2$  (Table 1).

### *Perceived social support*

The 12-item perceived social support scale was used for measuring the perceived availability and satisfaction with social support. The scale yields three subscale scores for Family, Friends and Significant others, and a total score. Using a 7-point Likert scale, the items should be scored from 1 (very strongly disagree) to 7 (very strongly agree). After this, the value of the items was counted together for each of the three dimensions. A high score means a high level of perceived social support (16, 24). Cronbach's alpha for the total score in the perceived social support scale was 0.93; for social support provided by family members 0.91, by friends 0.93 and by significant others 0.89, indicating very satisfactory reliability. The mean score for perceived social support scale from family was  $23.0 \pm 4.9$ , from friends  $20.7 \pm 5.1$  and from others  $23.2 \pm 4.9$  (Table 1).

### **Statistical analyses**

The relationships between demographic variables, functional disability, perceived health status and social support were examined using Pearson correlations. The relative contributions of social support controlled for demographic variables and functional disability towards explaining the variance in physical and mental health summary scales in MS patients were investigated with multiple linear regression analysis. In these analyses the SF-36 summary scales were dependent variables, whereas age (measured in years), gender, education (categorized into elementary, secondary and university), marital status (categorized into married/cohabiting and living alone/single), employment status (categorized into employed and non-employed), functional disability and perceived social support were independent variables.

Data were analysed using the Statistical Package for the Social Sciences, v.12.0.1 (SPSS).

## **Results**

### **Correlations between the study variables**

The correlation coefficients between the variables showed the significant relationships. Age ( $r = -.44$ ,  $p \leq .01$ ), elementary education ( $r = -.23$ ,  $p \leq .01$ ) and EDSS ( $r = -.53$ ,  $p \leq .01$ ) were negatively associated with the physical health summary scale. Living alone/single ( $r = .20$ ,  $p \leq .01$ ), employed ( $r = .36$ ,  $p \leq .01$ ), social support from family ( $r = .17$ ,  $p \leq .05$ ) and social support from significant others ( $r = .18$ ,  $p \leq .01$ ) were significantly positively

associated with the physical health summary scale. Age ( $r=-.26$ ,  $p\leq.01$ ), elementary education ( $r=-.16$ ,  $p\leq.05$ ) and EDSS ( $r=-.27$ ,  $p\leq.01$ ) were negatively associated with the mental health summary scale. Living alone ( $r=.19$ ,  $p\leq.01$ ), employed ( $r=.36$ ,  $p\leq.01$ ), social support from family ( $r=.34$ ,  $p\leq.01$ ), social support from friends ( $r=.31$ ,  $p\leq.01$ ) and social support from significant others ( $r=.30$ ,  $p\leq.01$ ) were positively significantly associated with the mental health summary scale in MS patients. EDSS, clinical course and disease duration were not significantly associated with the dimensions of perceived social support in MS patients.

### **Multiple linear regression analyses**

With physical and mental health summary scales as dependent variables, multiple linear regression analyses were used to examine the contribution of independent variables to these scales (Table 3).

Dependent variables included physical and mental health status, while independent variables consisted of demographic data, functional disability and social support. Higher age, being unemployed and higher EDSS were negatively associated with a low score in the physical health summary scale. Higher age and worse EDSS were significantly negatively associated with a lower score in the mental health summary scale. Better social support from family and friends was positively associated with a higher score in the mental health summary scale in MS patients.

#### *Multiple linear regression analyses in physical health summary scale SF-36*

Demographic variables, EDSS and social support explained 44% of the variance in the physical health summary scale. Results varied according to the predictors of variance in the single dimensions of SF-36. Social support from significant others significantly explained the variance in general health in the physical health summary scale ( $\beta=.22$ ,  $p\leq.05$ ) (Table 3). Age, elementary education and EDSS were significant predictors of the single dimensions in the SF-36.

#### *Multiple linear regression analyses in mental health summary scale SF-36*

Demographic variables, EDSS and social support from family and friends significantly explained 24% of the variance in the mental health summary scale. Social support provided by family and friends explained more of the variance in the mental health summary scale than in the physical health summary scale of SF-36 ( $\beta=.19$  and  $\beta=.18$ ,  $p\leq.05$ ) (Table 3). Regarding the single dimensions in the SF-36, social support from family significantly explained the variance in social functioning and role-emotional ( $\beta=.23$ ,  $p\leq.05$ ;  $\beta=.26$ ,  $p\leq.05$ ; respectively). Social support from friends explained the variance in the vitality and mental health dimensions ( $\beta=.17$ ,  $p\leq.05$ ;  $\beta=.20$ ,  $p\leq.05$  respectively). Age was a significant predictor of six dimensions, male gender was the significant predictor of one dimension

and EDSS was found to be the significant predictor of five dimensions of the SF-36 (Table 3).

**Table 3** Multiple linear regression analysis: effect of socio-demographic variables, functional disability and social support on the single dimensions and the summary scales of the SF-36 in MS patients

Predictor	PF	RP	BP	GH	PHSS	VT	SF	RE	MH	MHSS
<i>Step 1</i>										
Age	-.28***	-.16*	-.24**	-.18*	-.31***	-.28***	-.08	.09	-.10	-.16*
Male gender	.01	-.08	-.18**	-.04	-.70	-.12	-.02	-.01	-.08	-.10
Living alone / single	-.02	-.06	.11	.11	.04	.05	-.03	.09	.14	.09
Elementary education	-.07	-.08	-.22*	-.06	-.21*	.01	-.01	-.16	-.09	-.05
Secondary education	.04	.13	.04	.00	.05	.12	.06	.02	.05	.09
Employed	.13*	.10	.05	.06	.12*	-.03	.10	.07	.00	.02
<i>Step 2</i>										
EDSS	-.53***	-.15*	.12	-.23**	-.40***	-.20**	-.42***	-.03	-.09	-.21**
<i>Step 3</i>										
Family PSSS	.11	.02	.09	-.11	.05	.05	.23*	.26*	.15	.19*
Friends PSSS	-.03	-.15	-.06	.07	-.02	.17*	.10	-.06	.20*	.18*
Others PSSS	-.01	.16	.01	.22*	.09	-.01	.00	.04	.05	.03
<b>Adjusted R<sup>2</sup></b>	<b>.54</b>	<b>.10</b>	<b>.19</b>	<b>.17</b>	<b>.44</b>	<b>.17</b>	<b>.31</b>	<b>.07</b>	<b>.17</b>	<b>.24</b>

Note:

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

Displayed values are standardized  $\beta$  coefficients, and explained adjusted variances (in bold); EDSS=functional disability, PSSS=Perceived Social Support Scale, PF=physical functioning, RP=role physical, BP=bodily pain, GH=general health, VT=vitality, SF=social functioning, RE=role emotional, MH=mental health, PHSS=physical health summary scale, MHSS=mental health summary scale

## **Discussion and conclusion**

### **Discussion**

The main aim of the study was to investigate whether MS patients with different levels of perceived social support report different levels of perceived health status. Our results provide evidence for the hypothesis that social support given by family, friends and significant others may be positively associated with perceived health status. Social support provided by family and friends was positively associated with five out of eight single dimensions of perceived health status in MS patients.

#### *Social support and perceived physical health status*

Social support explained no variance in the physical health summary scale in MS patients. Results showed that age and functional disability were much stronger predictors than perceived social support in the single dimensions of the physical health summary scale. Social support from significant others contributed to the single dimension, a general health, in the physical health summary scale.

The participants in this study were in regular contact with the MS outpatient clinic, with its neurologist and nurse. Significant others like healthcare professionals can be an important resource of social support. They provide information, knowledge and encouragement (19, 25). Moreover, MS patients rely on the help of neurologists in a confidential relationship. The feeling of confidence in patients can significantly reduce the effects of stress experiences on their physical and psychological outcomes (26, 27).

Patients with the same diagnosis can help each other and can support the health status using exchanged information and tips for coping with disability due to MS. They tend to meet each other in MS societies around the whole country. Thoits (18, 28) underlined that the most effective support-givers were similar others. They are the patients who have successfully faced the same stressful circumstances that other MS patients are currently facing (18, 28).

Other studies have consistently shown that social support may be a major factor in adaptation to physical illness and positive social interaction is associated with better physical functioning (26, 29-32).

#### *Social support and perceived mental health status*

The expectation that positive social support from family and from friends would explain the mental health summary scale variance was confirmed. The more social support from family MS patients perceived, the better their assessments were of their social and emotional functioning. The

more social support from friends MS patients reported, the higher their assessments were of their vitality and better mental health in the dimensions of the SF-36. No single dimension of perceived health status was explained by social support from significant others.

The explanation may be that MS patients, who look for support from family and friends, report the feeling as being strengthened and encouraged more than when they look for social support from significant others. The results of this study are in line with findings that more social support contributes to better mental health status. Willingness to talk openly about MS on the part of spouses leads towards positive coping (25, 33).

Families who talk about MS do better at living with MS. The more patients reach out for help when they need it, the better. It is vital as a protection against isolation that family and friends understand the patients with MS. The sense that patients belong to others promotes positive well-being. Social support enhances patients' psychological well-being directly by fulfilling their need for belonging, and thus counteracting feelings of loneliness (33, 34).

The most important predictors of physical health status seem to be age, elementary education and functional disability, while mental health status is associated also with social support. It appears that there is a little change in the contribution of social support with regard to the dimensions of physical health status. For the dimensions of mental health status, the contribution of social support was more visible. Our results are in line with previous studies (18, 25) which consider social support mainly as a psychosocial and not as a physical construct.

It has been pointed out that different types of social support are necessary for different dimensions of health in MS patients. The partner relationship is generally thought to be one of the most important resources of social support, because the partner is the main provider of emotional and instrumental support (34). Similarly, the effects of perceived social support have been most frequently examined, especially the effects of perceived emotional support (beliefs that love and caring, sympathy and understanding, esteem and value are available from family members) (18).

Because the data in this study are cross-sectional, the observed results merely reflect associations, and issues of causality cannot be adequately addressed. Speculating about the findings in a more causal way might imply that more perceived social support could have a positive influence on perceived physical and mental health status in MS patients. Each health dimension in the SF-36 could be influenced by a different type of social support and could have an additive effect on particular perceived health values in MS patients. The inspection of bivariate correlations between the study variables did not confirm significant associations between functional disability, disease duration, or clinical course of MS on the one hand and

social support dimensions on the other hand. In addition, the possible interaction effect of functional disability and social support was analysed using multiple regression analysis. The interactions were computed for functional disability and each dimension of social support separately, but no significant interactions were revealed. There is still a need to examine the role of perceived social support in a prospective design to better assess the buffering effects of perceived social support on physical and mental health status in MS patients.

This study has primarily focused on the positive consequences of social support in MS patients and interactions with other people. The consequences of social support may not necessarily be positive. MS patients may experience negative aspects from the social environment. Negative interactions are salient and unexpected, so they can have a stronger impact on the perceived health status in MS patients (35).

There is a growing body of literature about the importance of psychosocial recourses in the disablement process. The studies highlight the influence of social support in promoting individuals' well-being under the conditions of disability (36, 37). On the other hand, there is still a lack of studies about the effect of social support provided by family, friends and significant others on health status in MS patients in the literature (25).

Participating MS patients were significantly younger than the non-responders. We may assume that non-responders were a proportion of the oldest MS group with the longest disease duration, and possibly the most affected group, which might have prevented them from the participating. The possible consequence might be that outcomes are more related to the younger MS patients than to the older ones, and that the results cannot be extended and generalized to the whole MS population.

## **Conclusion**

This study demonstrates that social support provided by significant others is positively associated with general health dimension of perceived physical health status measured with SF-36, while social support provided by family and friends was found to have a positive relationship with perceived mental health status in MS patients. Furthermore, the more social support from family MS patients perceived, the better their assessments were of their social and emotional functioning in the SF-36 dimensions. The more social support from friends MS patients reported, the better their assessments were of their higher vitality and better mental health in the single dimensions of the SF-36. The study revealed that social support provided by family and friends was mainly related to perceived mental health status. A different basis of social support is necessary for different dimensions of perceived health status in MS patients.



### *Practice implications*

The study shows that social support is associated with perceived health status in MS patients. Strengthening recommendations for social support is connected with effective coping with MS. A good family background and network of friends is most important for the mental health status. If social support is lacking, supplying effective prevention and intervention programmes by healthcare professionals as significant others could be helpful. Group therapy would be appropriate for expressing and sharing problems of MS patients lacking social support. MS patients could thus participate in programmes focusing on developing self-management skills and providing social support (38).

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# **Mastery, functional disability and perceived health status in patients with multiple sclerosis<sup>4</sup>**

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## Abstract

*Background:* Multiple sclerosis (MS) is a chronic disease that is difficult to predict and to cope with. Mastery refers to the extent to which patients see themselves as being in control of the forces that affect their lives. It may play an important role in perceived health status and well-being. The purpose of this study was to clarify whether mastery is associated with functional disability and perceived health status in MS patients and how such an association might function.

*Methods:* Two hundred and three MS patients completed the Short Form-36 Health Survey as well as the Pearlin-Schooler Mastery Scale. Functional disability was assessed using the Kurtzke Expanded Disability Status Scale. Hierarchical multiple linear regression analyses were performed on the data from two MS age groups: <45 and ≥45 years of age.

*Results:* Functional disability was negatively associated with perceived physical health status in both age groups and with perceived mental health status in younger age group. Mastery was positively associated with perceived health status in older age group.

*Discussion:* The findings confirm that mastery might be helpful for older MS patients. Education strategies for MS patients aimed at personal empowerment for the maintaining of physical and mental well-being may be important.

## Introduction

Multiple sclerosis (MS) is a chronic disease that follows an unpredictable course as it affects the central nervous system. It is the most common cause of neurological disability in young adults, with the incidence of symptoms appearing and varying over time (1, 2). Functional disability has been associated with restricted participation in employment, educational opportunities, interpersonal relationships and leisure-time activities for MS patients (3-5). A socio-medical model of the disablement process explains how chronic and acute conditions affect the functioning of specific bodily systems, physical and mental activities and the activities of daily life. Personal and environmental factors can speed up or slow down the disablement of patients (6, 7).

Disablement status has been found to be reflected in the perceived health status of the chronically ill (6, 7), and several studies have also investigated this relationship in patients with MS. With the progression

of a disability, it is primarily physical functioning that shows a decrease in perceived health status. As previous studies have reported, a higher level of functional disability has negative consequences on perceived health status in MS patients (5, 8, 9). Quantifying the clinical impact of MS on perceived health status can be assessed in clinical trials and in everyday practice in order to optimize individual patient care (10-12).

Mastery as a part of a patient's self-concept could be useful in achieving better health status. Mastery refers to the extent to which people see themselves as being in control of the forces that significantly affect their lives. It is considered as responsive to the conditions of people's lives (13). Mastery is studied from the perspective of ways of coping with a progressing chronic disease (14, 15). The positive effect of higher mastery on physical and mental health in disabled elderly persons has been shown in many studies (16-18). Low mastery has been identified as a risk factor for functional decline in older people in The Netherlands (19). Mastery, or perceived control in elderly persons, is crucial for maintaining functional ability in later life. It makes a unique contribution to changes in functional disability (19, 20).

Lower levels of mastery are associated with greater depression. Mastery shows a significant interaction with functional disability in predicting depression, and it has a protective role with regard to mental health in older people. Similarly, mastery and perceived health status of senior adults with orthopaedic disabilities have been studied, with mastery correlating positively with positive health perceptions and relating inversely to depression. Higher levels of mastery buffer against the anxiety associated with greater impairment in physically disabled adults as well (16, 17, 21).

There is inconsistency in the findings about the associations between age and mastery. Increasing mastery with increasing age may reflect the attainment of personal and institutional resources that contribute to greater mastery (17, 22). However, there are also studies that report decreasing mastery with increasing age (16, 17, 22, 23). Functional disability is seen as being more related to mastery for older people because it occurs in the context of other negative changes. Some studies have found the influence of disability on mastery to be affected by age, and their interaction differs across age groups (14, 23, 24). Older and younger MS patients may differ in coping strategies in their lifetime, therefore there is an assumption that they differ in self-concept, including mastery.

Within the context of this study age is an important factor that might play a role in the perception of health, disability and mastery. To improve functioning or just to stop the decrease in functional disability, different therapeutic strategies are used in MS patients. New disease-modifying drugs are the most commonly used approach (25). In Slovakia, these disease-modifying drugs are accessible predominantly for MS patients



aged 45 year or younger, suffering mainly from relapsing-remitting or secondary-progressive clinical courses (26).

The study was conducted because, thus far, little research has been done with MS patients regarding the associations between mastery, functional disability and perceived health status. Younger MS patients (<45 years of age) might differ in the evaluation of mastery and their health status when compared to older MS patients ( $\geq 45$  years of age). The aim of this study was to clarify whether mastery is associated with functional disability and perceived health status in MS patients and how such an association might function. We expected better mastery and less functional disability to be associated with higher perceived physical and mental health status in MS patients even when controlled for relevant sociodemographic and clinical variables. We also expected that the relationship between mastery and functional disability, with its associations to perceived physical and mental health status, would differ between younger and older age groups of MS patients.

## **Methods**

### **Patients**

The sample consisted of MS patients from the eastern part of Slovakia. Data were collected from December 2003 to January 2006. MS patients from neurology outpatient clinics and members of MS clubs were included in the study. Outpatient clinics were addressed and MS patients were recruited from those who were eligible to participate. Firstly, questionnaires, invitation letters and written informed-consent forms were sent to the participants' homes by postal mail. After two weeks, a trained interviewer spoke with the MS patients personally in the neurological outpatient clinic. A neurologist then carried out neurological examinations immediately after the interview. These examinations were done by the same neurologist for all patients. One phone call to arrange one more interview was made to those who did not come.

Out of 405 adult MS patients addressed, 214 patients responded and returned the questionnaires (a crude response rate of 52.8%). From these, 11 patients were excluded because of low MMSE or other exclusion criteria. Finally, 203 were included in the study (for an effective response rate of 50.1%; males 35.7%, females 64.3%). There were no differences between the non-responders and the participants regarding gender. A significant difference was found in age ( $p < 0.05$ ); the non-responders (mean age  $45.1 \pm 10.5$  years) were significantly older than the participants (mean age  $38.3 \pm 10.6$  years).

During the interview, patients completed several self-reporting questionnaires and went through physical examinations on a voluntary and anonymous basis. Sociodemographic data, including gender, age, marital status, living situation, education level, employment status, family life and disease history were derived from the interview. Mastery and perceived health status were obtained from the questionnaires. Clinical data, including functional disability, disease duration and clinical course, were assessed by the neurologist, who was the same for all outpatient clinics. The duration of MS was assessed during the interview and neurological examinations by the same neurologist and compared with data in the patient's medical file. The framework of formal procedure of translation and adaptation of questionnaires to the Slovak language was respected. Questionnaires were translated from English into Slovak, and then the Slovak version was translated back into English and compared with the original version. Measures were tested in a pilot study with 10 MS patients. Exclusion criteria were as follows: non-Slovak-speaking patients, cognitive impairment determined by a Mini-Mental State Examination (MMSE) score of <24 (27), history of psychiatric or medical conditions affecting the outcomes of the study, and pregnancy. In MS pregnancy has been a matter of controversy for a long time. Pregnancy can modify the clinical course of disease with a reduced relapse rate, or on the other hand, can cause an increased relapse rate after delivery (28, 29). Symptoms like pain, fatigue, anxiety or less participation in daily activities may occur during pregnancy and are similarly described in MS patients. The responses may thus misrepresent perceived health status and may change the study outcomes in women with MS.

## **Ethics**

Each patient provided a signed informed-consent form before participation in the study. The local Ethical Committee approved the study.

## **Measures**

The Kurtzke Expanded Disability Status Scale (EDSS) is based on the neurological testing of functional systems: pyramidal, cerebellar, brainstem, sensory, bowel and bladder, visual, mental and "other" (30). Each functional system is graded to the nearest possible grade, where 0 means normal grade, 6 means loss of function and "V" indicates an unknown abnormality. Disability caused by MS is graded on a continuum from 0 (normal neurological examination) to 10 (death caused by MS) (30). This measure, with its widespread use, remains the most frequently-used scoring system in MS in neurological practice (25). It belongs in the category of physician-oriented measures, as information is based on an

objective neurological examination, which in this study was performed by the same neurologist on all respondents.

The Short Form-36 Health Survey (SF-36) was originally designed as a generic indicator of health status for use in population surveys and evaluative studies of health policy (31). The SF-36 consists of eight dimensions which can be summarized into two health summary scales to measure those eight dimensions. The first, the physical health summary scale, contains four dimensions: 1. physical functioning (ten items), 2. role – physical (four items), 3. bodily pain (two items) and 4. general health (five items). The second, the mental health summary scale, also contains four dimensions: 5. vitality (four items), 6. social functioning (two items), 7. role – emotional (three items) and 8. mental health (five items). In addition, one question covers changes in health status over the past year (one item), and the study also includes general health perceptions (five items). All item scores are coded and transformed into a scale from 0 (poor health) to 100 (optimal health). Higher scores on the physical and mental health summary scales indicate better functioning (31, 32). Cronbach's alpha for the total score in the present research was 0.93; for the physical health summary scale it was 0.89 and for the mental health summary scale 0.89.

The Pearlin-Schooler Mastery Scale (PMS) measures the global sense of personal control (33). It consists of seven items in which high scores represent a strong sense of mastery. Patients responded on a 5-point Likert scale about the extent to which they agreed (5=strongly agree) or disagreed (1=strongly disagree) with statements such as "I can do just about anything I really set my mind to" and "I often feel helpless in dealing with the problems of life." A PMS score ranges from 7 to 35, with higher score reflecting greater mastery. The PMS was applied to a sample of MS patients providing information about its validity ( $r=0.73$ ) (34). In the present study, Cronbach's alpha for this measure was 0.75.

## **Statistical analyses**

To examine the relationships between mastery, functional disability and perceived health status the following steps were taken. Firstly, mean scores, standard deviations and ranges of scores were calculated for all variables. Next, Pearson's correlations were used for testing the associations amongst socio-demographic factors, disease duration, functional disability, disease course, perceived physical and mental health status and mastery. Third, hierarchical multiple regression analyses with the 'enter method' were performed in order to identify how much of the variance of the dependent variable (SF-36) may be explained by sociodemographic factors, functional disability and mastery. The block of sociodemographic variables (age, education, gender, marital status, employment) were entered into the equation at Step 1; functional disability (as measured by the EDSS) was

entered at Step 2 and finally, mastery was entered into the equation at Step 3 in the total sample (Table 3). In the groups of younger (<45) and older ( $\geq 45$ ) MS patients functional disability (as measured by the EDSS) was entered at Step 1 and mastery was entered into the equation at Step 2 separately (results presented in Table 4). Hierarchical multiple regression analyses were performed for the total sample (results presented in Table 3) as well as for samples of younger (<45) and older ( $\geq 45$ ) MS patients (results presented in Table 4). The age cut-off of 45 years was based on accessibility to disease-modifying drugs in this sample (26, 35).

Data were analyzed using the Statistical Package for the Social Sciences 12.0 (SPSS Inc., Chicago, IL, USA).

## Results

### Basic description of the sample

A basic description of the sample is given in Table 1 (n=203). In general, the MS responders were of middle age (mean age  $38.3 \pm 10.6$  years), consisted of more women than men (64.3% females), were married or cohabiting (64.1%), had secondary education (51.7%) and were not employed (65.5%).

Almost three quarters of the sample had the relapsing-remitting course (72.3%). The average duration of disease, measured as time from diagnosis, was  $5.3 \pm 4.1$  years (range 0.5-15.5). The mean EDSS score was  $3.0 \pm 1.5$ . The physical health summary scale mean score was  $48.6 \pm 20.2$ , and the mental health summary scale mean score of SF-36 came to  $57.0 \pm 16.1$ . The mean score for mastery was  $21.5 \pm 5.5$  (Table 1).

The subgroup of the younger MS patients (<45 years old; mean age  $32.6 \pm 6.9$  years; 69.0% female) had predominantly the relapsing-remitting course (82.7%) with a mean duration of illness of  $4.7 \pm 3.7$  years. The subgroup of older MS patients ( $\geq 45$  years old; mean age  $50.8 \pm 4.9$  years; 53.1% female) had the relapsing-remitting course in 48.4% and the mean duration of illness was  $6.8 \pm 4.4$  years. The main study variables with means and standard deviations for the two age groups of MS patients are described in Table 1.

**Table 1** Description of the study sample and two age groups of MS patients: <45 years of age and ≥45 years of age

Variable	Total sample (n=203) n (%) or mean±SD	<45 age group (n=139) n (%) or mean±SD	≥45 age group (n=64) n (%) or mean±SD
<b>Gender</b>			
Women	130 (64.3)	96 (69.0)	34 (53.1)
<b>Age</b>	38.3±10.6	32.6±6.9	50.8±4.9
<b>Marital status</b>			
Living alone/single	73 (35.9)	61 (43.9)	12 (18.8)
Married/cohabiting	130 (64.1)	78 (56.1)	52 (81.2)
<b>Living situation</b>			
Own apartment/house	126 (62.1)	49 (35.3)	45 (70.3)
<b>Education</b>			
Elementary	58 (28.6)	38 (27.3)	20 (31.3)
Secondary	105 (51.7)	75 (53.9)	30 (46.9)
University	33 (16.3)	26 (18.7)	7 (10.9)
<b>Employment status</b>			
Employed/studying	69 (40.0)	53 (38.1)	16 (25.0)
Not employed	133 (65.5)	86 (61.9)	47 (73.4)
<b>Disease duration</b>	5.3±4.1	4.7±3.7	6.8±4.4
<b>EDSS</b>	3.0±1.5	2.7±1.5	3.7±1.3
<b>Clinical course</b>			
Relapsing-remitting	146 (72.3)	115 (82.7)	31 (48.4)
Secondary-progressive	21 (10.3)	6 (4.3)	15 (23.4)
Primary-progressive	35 (17.2)	17 (12.2)	18 (28.1)
<b>SF-36</b>			
Physical <sup>a</sup>	48.6±20.2	53.4±19.9	37.6±16.4
Mental <sup>a</sup>	57.0±16.1	58.7±16.6	53.1±14.2
<b>Mastery</b>	21.5±5.5	21.2±5.6	22.0 ±5.3

Note:

EDSS, Expanded Disability Status Scale; SF-36, Short Form-36 Health Survey

<sup>a</sup>Higher scores indicate 'better functioning'

## Correlations between study variables

Table 2 demonstrates the significant cross-sectional relationships between variables. EDSS and clinical course are strongly positively correlated with disease duration; EDSS is strongly negatively correlated with physical and mental health status in MS patients. Disease duration and clinical course are negatively associated with the physical summary scale. Regarding the mental summary scale, clinical course is negatively correlated with this scale, while mastery positively correlates with it. Mastery appeared not to

be associated with the main variables of interest, EDSS and the physical health summary scale in the total sample (Table 2). When comparing the correlations in younger and older MS patients, mastery was significantly associated with EDSS ( $r=-0.33$ ;  $p\leq 0.01$ ), clinical course ( $r=-0.34$ ;  $p\leq 0.01$ ), physical summary scale ( $r=0.39$ ;  $p\leq 0.01$ ) and mental summary scale ( $r=0.33$ ;  $p\leq 0.01$ ) only in the older MS age group. Significant relationships between EDSS and the physical health summary scale in the SF-36 were found (Table 2;  $r=-0.53$ ;  $p\leq 0.01$ ).

**Table 2** Pearson's correlations between the studied variables

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. Age	-										
2. Education	ns	-									
3. Gender	ns	ns	-								
4. Marital status	-.42**	ns	ns	-							
5. Employment	.14*	.42**	ns	ns	-						
6. Disease duration	.29**	ns	ns	ns	.20**	-					
7. EDSS	.33**	-.21**	-.15*	ns	.31**	.36**	-				
8. Clinical course	.35**	ns	ns	ns	.19**	.32**	.63**	-			
9. Physical SF-36	-.43**	.24**	ns	.19**	-.35**	-.23**	-.53**	-.38**	-		
10. Mental SF-36	-.25**	.18*	ns	.19*	-.21**	ns	-.30**	-.27**	.64**	-	
11. Mastery	ns	ns	ns	ns	ns	ns	ns	ns	ns	.18*	-

Note:

\* $p<0.05$ ; \*\* $p<0.01$

Marital status 1=married/cohabiting, 2=living alone/single; Employment 1=employed/studying, 2=not employed; Gender 1=men, 2=women; ns=no significance; for abbreviations see Table 1

### Physical health status

In the whole group of MS patients, 41.6% of the variance in perceived physical health status was explained by a model consisting of age, gender, marital status, education, employment, EDSS and mastery ( $p\leq 0.001$ ). EDSS was the strongest variable associated with perceived physical health status in these patients ( $\beta=-0.34$ ;  $p\leq 0.001$ ) (Table 3).

Table 4 presents the explained variance of the model consisting of EDSS and mastery in the age groups  $<45$  years and  $\geq 45$  years. The larger variance of perceived physical health status was explained in the age group  $\geq 45$  years (adjusted  $R^2=0.24$ ;  $p\leq 0.01$ ). EDSS was significantly associated with perceived physical health status in both age groups. Mastery was significantly associated with perceived physical health status in older MS patients ( $\geq 45$  years old), but not in younger ones ( $<45$  years old) ( $\beta=0.31$ ,  $p\leq 0.01$ ;  $\beta=0.01$ , not significant; respectively).

**Mental health status**

With regard to perceived mental health status, 14.6% ( $p \leq 0.001$ ) of the variance was explained by a model consisting of age, gender, marital status, education, employment, EDSS and mastery in the total sample (Table 3).

Table 4 presents the results of the analyses for two age groups. The examined model consisting of EDSS and mastery explained the largest variance in perceived mental health status in the group of MS patients  $\geq 45$  years (adjusted  $R^2 = 0.12$ ,  $p \leq 0.01$ ). EDSS appeared to be significant variable related to perceived mental health status in younger MS patients ( $< 45$  years old), but not in older ones ( $\geq 45$  year old) ( $\beta = -0.19$ ,  $p \leq 0.05$ ;  $\beta = -0.19$ , not significant). In contrast, in the group of older MS patients, mastery was significantly associated with perceived mental health status ( $\beta = 0.28$ ;  $p \leq 0.05$ ) (Table 4).

**Table 3** Hierarchical multiple regression analysis: sociodemographic variables, EDSS and mastery on perceived physical and mental health status

		Physical health status		Mental health status	
		SF-36 <i>Adjusted R<sup>2</sup></i>	$\beta$	SF-36 <i>Adjusted R<sup>2</sup></i>	$\beta$
1 <sup>st</sup> step	Age		<b>-.33***</b>		<b>-.25**</b>
	Education		.11		.06
	Gender		-.06		-.10
	Marital status		.03		.06
	Employment	32.0	<b>.14*</b>	12.7	.14
2 <sup>nd</sup> step	EDSS	41.9	<b>-.34***</b>	13.5	-.08
3 <sup>rd</sup> step	Mastery	41.6	.01	14.6	.13

Note:

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

Adjusted R2 are displayed; significant values are displayed in bold; for abbreviations see Table 1

**Table 4** Hierarchical multiple regression analyses: EDSS and mastery on perceived physical and mental health status in younger (<45) and older (≥45) MS patients

<i>Physical health status SF-36</i>		Age groups			
		<45		≥45	
		R <sup>2</sup>	β	R <sup>2</sup>	β
1 <sup>st</sup> step	EDSS	<b>.22***</b>	<b>-.48***</b>	<b>.17**</b>	<b>-.43**</b>
2 <sup>nd</sup> step	EDSS	<b>.22***</b>	<b>-.48***</b>	<b>.24**</b>	<b>-.34**</b>
	Mastery		.01		<b>.31**</b>
<i>Mental health status SF-36</i>		<45		≥45	
		R <sup>2</sup>	β	R <sup>2</sup>	β
1 <sup>st</sup> step	EDSS	<b>.03*</b>	<b>-.19*</b>	<b>.06*</b>	<b>-.27*</b>
2 <sup>nd</sup> step	EDSS	<b>.04*</b>	<b>-.19*</b>	<b>.12**</b>	-.19
	Mastery		.15		<b>.28*</b>

Note:

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

EDSS, Expanded Disability Status Scale; adjusted R<sup>2</sup> values and β values are displayed; significant values are displayed in bold

## Discussion

This study aimed at examining the association between mastery, functional disability and perceived health status in MS patients. Better mastery and less functional disability were expected to be associated with better perceived physical and mental health status.

The results provide support for the hypothesis that the negative association between functional disability and perceived health status was significant. This finding is in line with existing studies on functional disability and perceived health status (6, 11, 36). Our results also show that better mastery is associated with a higher perceived physical health status and perceived mental health status. These results are in line with previous findings in other chronically disabled patients, where mastery predicts rising levels of psychological well-being and quality of life among these people (15, 37).

Although mastery was not correlated with the variables of interest when examining the sample as a whole, when looking at the specific age groups, mastery was associated with perceived health status for the older participants but not for the younger ones. Multiple linear regression analyses performed separately for the two age groups clearly showed that mastery explained more variance in the perceived physical and mental health status in older MS patients than in younger ones. Similarly, in a study by Forbes, mastery was significantly related to health status and perceived health in a group of elderly community-dwelling people (18).



For the younger age group functional disability appeared to be the most important variable for explaining variances in the physical health status of MS patients.

The SF-36 as a generic indicator allows for the comparison of the health status of chronic patients with different conditions and can be related to the prognosis of disease and intervention outcomes (31, 38). The outcomes of the perceived physical and mental health summary scales in the present study are comparable to the findings of other European studies focusing on health status in MS patients. Perceived health status in MS patients inevitably worsens due to MS, and thus the scores in the dimensions of perceived physical and mental health status are low (3, 5, 10).

The findings show that functional disability is positively associated with the age of MS patients. This is a consequence of MS being a progressive chronic disease, although a direct association between functional disability and mastery was not confirmed. To summarize the results, worse functional disability, higher mastery and worse perceived health status in the older age group than in the younger one could suggest that the progress of MS should be taken into account. Patients may adapt to the conditions of their lives with MS, and older MS patients perhaps know better what to expect and how to behave in response to possible deterioration of their health status. They may undergo a psychological adjustment process enabling them to cope with impairment (39). This adjustment is important for coping with the disease, for the feeling of having control of one's life.

Our findings confirm that mastery might be helpful for older persons with MS. Individuals with greater mastery are more likely to use preventive care, have good health behaviours, seek treatment early and use health services properly (17, 40, 41). Patients with a strong self-concept (high self-esteem and mastery) may be more likely to "see the light at the end of the tunnel" and consequently predict positive outcomes for themselves despite their current problems (42).

Some limitations should be noted in the generalisation of our results. MS patients participating in this study were significantly younger than the non-responders. We may assume that the non-responders were a proportion of the oldest MS group, with the longest disease duration and possibly the most affected group, which might have prevented them from participating. The results cannot be therefore extended and generalized to the whole MS population, as the oldest group of MS patients was missing from this study. Also, the existence of unique features of the national health care system may lead to a certain limitation of this study. In particular the inaccessibility to disease-modifying drugs in MS patients over age 45 may lead to differences when outcomes are compared with patients from other countries. In addition, the outcomes of this cross-sectional study cannot be causally determined. Mastery and its stability is a subject of

controversy. In order to clarify stability or changes in mastery over time in MS patients, a longitudinal study design is needed. Longitudinal data are needed to further unravel the complex interplay between functional disability, perceived health status and mastery in MS patients.

The clinical importance of this study is that older patients possessing higher levels of mastery have a greater likelihood of perceiving mental health status more positively than those who are less disabled but have lower mastery. This may be assumed to involve individuals' mastery in making personal choices and deciding the level of participation in health care and society (22). In the end, their quality of life might be better.

## **Clinical implications**

The results of our analyses suggest that mastery can be a variable important for perceived mental health status, especially in MS patients aged 45 years and over. The consequences for clinical practice are aimed especially at the group of older MS patients who are less likely to experience a significant improvement of their health status. On the other hand, these patients report more physical and psychological health complaints. Therefore, more intensive medical and psychological attention should be paid mainly to older MS patients. Education strategies for groups of MS patients, provided by psychologist or trained nurses and focused on personal empowerment for maintaining physical and mental well-being in the face of MS, may be important. A collaborative strategy during group psychotherapy may allow MS patients to share their knowledge regarding how to influence attitudes and to improve physical and mental health. MS patients may effectively mobilize personal resources better and cope with the disease and thus may perceive their mental health as better with a higher level of mastery. Hence, there is a challenge for future research to measure self-efficacy and social support like other related variables associated with perceived health status in MS patients. Neurologists' education and counseling supporting the coping strategies of MS patients are essential for good patient management.

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## Disclosure

The authors declare that they have no conflicts of interest.

## Author contributions

Data collection: M. Krokavcova, M. Gavelova; Manuscript writing: M. Krokavcova, I. Nagyova, J.P. van Dijk, J. Rosenberger, M. Gavelova, Z. Gdovinova, J.W. Groothoff; Design of study: M. Krokavcova, I. Nagyova, J.P. van Dijk, J. Rosenberger, B. Middel, J.W. Groothoff; Statistical analysis: M. Krokavcova, I. Nagyova, J. Rosenberger.

All authors contributed to the structure, revision and writing of the article.

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# **The importance of depression and anxiety for perceived health status in younger and older patients with multiple sclerosis<sup>5</sup>**

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## Abstract

Higher levels of depression and anxiety have a negative impact on the disease process in multiple sclerosis (MS) patients. The aim of this study was to explore whether there are the discrepancies in the association of depression and anxiety with perceived physical and mental health status, and whether these associations differ between younger and older MS patients.

The study sample consisted of 223 MS patients who were divided into two age groups: those under 45 years ( $n=149$ ) and those age 45 years or older ( $n=74$ ). A model consisting of age, gender, marital status, EDSS, depression and anxiety explained 46.6% of the variance in perceived physical health status and 60.8% of the variance in perceived mental health status in the total sample. Depression was significantly associated with perceived physical health status in both younger ( $p\leq 0.05$ ) and older ( $p\leq 0.001$ ) MS patients. Depression was also significantly related to perceived mental health status in both age groups ( $p\leq 0.001$ ). Anxiety, however, was significantly associated with perceived physical and mental health status in the younger age group ( $p\leq 0.05$ ;  $p\leq 0.001$ ), but not in the older one.

The role of depression is always present in MS patients with regard to their perceived health status, mainly to perceived physical health status in the older group and to perceived mental health status in the younger one. The role of anxiety is more important in younger MS patients than among older patients with regard to their perceived health status.

## Introduction

Multiple sclerosis (MS) is a chronic and unpredictable neurological disease that varies from a mild course with minimal disabilities to a rapidly progressing or fluctuating course resulting in disabilities. No reliable indicators exist to assure patients that their status will remain stable or that disabilities will not arise or progress. Furthermore, patients are confronted with symptoms that frequently and unpredictably vary with respect to their form and intensity, sometimes even daily (1). Symptoms include sensory and motor loss, fatigue, difficulties with balance, ataxia, muscular weakness, pain, cognitive impairments and mood disorders. MS is the most common cause of neurological disability in young adults (2).

Disablement status has been found to be reflected in the perceived health status of the chronically ill (3). With the progression of a disability, it is primarily physical functioning that shows a decrease in perceived health status in patients with MS. As previous studies have reported,

a higher level of functional disability has negative consequences on perceived health status in MS patients (4, 5). The clinical impact of MS on perceived health status can be quantified and assessed in clinical trials and in everyday practice in order to optimize individual patient care (6, 7). Many neurological scales associated with functional disability are used to measure perceived health status in MS patients (8). When MS patients are compared to controls, they score significantly lower than the general population in disability measures (4, 8-10).

Depressed mood and anxiety are among the most commonly described symptoms of MS. MS patients may develop depression as an understandable reaction to their experiencing a chronic disease and having to live with its consequences (11, 12). Anxiety, along with a high level of distress, occurs mostly in the first years of diagnosis (13). High levels of depression and anxiety were found to be negatively associated with physical and mental health status in chronically ill patients (14-16). The negative impact of depressive symptoms on perceived health status in MS patients has also been demonstrated (7). In some studies, depression seems to be associated with worse scores in self-reported questionnaires, independent of the clinical course or disability status of the MS patients (5, 17). Statistically, as many as 60% of patients with MS experience major depression, and the suicide rate among those with MS is 7.5 times higher than that of the age-matched general population (12).

Perceived health status, measured using the SF-36 questionnaire, has been evaluated as an appropriate instrument for measuring general health. It assesses four physical health domains and four mental health domains, and MS patients show lower scores for both the physical health summary scale and for the mental health summary scale in the SF-36 than the general population (18).

Within the context of this study, age is an important factor that might play a role in perceiving health, assessing functional disability and evaluating psychological well-being. Older age seems to be related to lower scores in perceived health status (7), though the association of depression and anxiety with age in MS patients is still unclear. Some studies have reported the prevalence of a greater risk of depression in younger MS patients. When younger and older MS patients are compared, the younger patients appeared to be more depressed than the older ones. Other studies have revealed a high rate of anxiety prevalence, with higher levels of anxiety at disease onset (19-21).

This study was conducted because younger and older MS patients might differ in evaluating their psychological well-being and health status. The aim of this study was to explore whether there are discrepancies in the association of depression and anxiety with perceived physical and mental health status, and whether these associations differ in younger (<45 years) and older (≥45 years) MS patients. We expected depression

and anxiety in MS patients to be significantly associated with perceived physical and mental health status, even when controlled for the relevant sociodemographic and clinical variables. We also expected this relationship to differ between younger (<45 years) and older ( $\geq$ 45 years) MS patients.

## **Methods**

### **Patients and procedures**

MS patients from neurology outpatient clinics and members of MS clubs were included in the study. Outpatient clinics were addressed and MS patients were recruited from those who were eligible to participate. The sample consisted of 223 MS patients from the eastern part of Slovakia. Data were collected from December 2003 to January 2006. Firstly, questionnaires, invitation letters and written informed-consent forms were sent to participants' homes by post. After two weeks, a trained interviewer spoke with the MS patients personally in a neurological outpatient clinic. A neurologist then carried out a neurological examination immediately after each interview. These examinations were performed by the same neurologist for all patients. One phone call to again arrange an interview was made to those patients who did not come the first time.

This cross-sectional study consisted of several self-reported questionnaires, a semi-structured interview and physical examinations on a voluntary and anonymous basis. Socio-demographic data, including age, gender, marital status, living situation, education level, employment status, family life and disease history, were ascertained from the interview. Depression, anxiety and perceived health status were obtained from the questionnaires. Clinical data, including functional disability, disease duration and clinical course, were assessed by the neurologist. Questionnaires were translated from English into Slovak, and then the Slovak version was translated back into English and compared with the original version. Measures were tested in a pilot study with 10 MS patients. Exclusion criteria were as follows: non-Slovak-speaking patients, cognitive impairment determined by a Mini-Mental State Examination (MMSE) score of <24 (22), a history of psychiatric or medical conditions affecting the outcomes of the study and pregnancy.

Each patient provided a signed informed-consent form before participating in the study. The local Ethics Committee of the University Hospital approved the study on December 17<sup>th</sup>, 2002.

### **Measures**

The Kurtzke Expanded Disability Status Scale (EDSS) is based on the neurological testing of functional systems: pyramidal, cerebellar,

brainstem, sensory, bowel and bladder, visual, mental and "other". Disability caused by MS is graded on a continuum from 0 (normal neurological examination) to 10 (death caused by MS) (23). This measure, with its widespread use, remains the most frequently used scoring system in MS in neurological practice. It belongs to the category of physician-oriented measures, as information is based on an objective neurological examination, which in this study was performed by the same neurologist on all respondents (24).

Psychological well-being was assessed with the Hospital Anxiety and Depression Scale (HADS) (25). The scale consists of 14 items, 7 of which are related to depression and 7 to anxiety. Patients respond on a 4-point scale (0=absent and 3=definitely present/severe), and the score ranges from 0 to 21, with a higher score implying that depression or anxiety is present to a larger extent. The score identifies non-cases (a score of 7 or smaller), doubtful cases (a score from 8-10) and definitive cases (a score of 11 or higher) (25). Cronbach's alpha for depression was 0.79 and for anxiety 0.81 in this study.

The Short Form-36 Health Survey (SF-36) was originally used as a generic indicator of health status in population surveys and evaluative studies of health policy (26). The SF-36 includes the measurement of the eight dimensions of health: 1. physical functioning (ten items), 2. role limitation due to physical health (four items), 3. bodily pain (two items), 4. social functioning (two items), 5. general health (five items), 6. mental health, covering psychological distress and well-being (five items), 7. role limitations due to emotional problems (three items), and 8. vitality, energy or fatigue (four items). In addition, one question covers changes in health status over the past year (one item). We used the physical health summary scale (perceived physical health status) and the mental health summary scale (perceived mental health status). All item scores were coded and transformed into a scale of 0 (poor health) to 100 (optimal health) (26, 27). Cronbach's alpha for the SF-36 total score in the present sample was 0.93; for the physical health summary scale it was 0.90, and for the mental health summary scale 0.89.

To improve functioning or to simply stop the decrease in functional ability, different therapeutic strategies are used in MS patients (24). Disease-modifying drugs (DMD) are a commonly used approach, and in Slovakia DMD were, until recently, accessible predominantly for MS patients aged 45 year or younger suffering mainly from relapsing-remitting or secondary-progressive clinical courses (28). This is the reason why we chose 45 years old as our cut-off point. All patients in our sample of <45 years used DMD's.

It is important to control for variables that can frequently influence study outcomes. Many studies in recent years have found associations between sociodemographic variables, functional disability and health

status in patients with MS. Patients who were younger, were male, were engaged and who had low functional disability reported better perceived health status (4, 29-31).

### **Statistical analysis**

Firstly, the sociodemographic variables (age, gender, marital status), clinical variables (EDSS, disease duration, clinical course), psychological well-being (depression, anxiety) and perceived health status (physical and mental health summary scales) were described. Pearson's correlations were used for testing the associations between the examined variables. The cut-off age of 45 years in this sample was based particularly on the prescription of DMD to MS patients. The Mann-Whitney U test was conducted to determine the differences in scores between younger (<45 years) and older ( $\geq 45$  years) age subgroups of MS in sociodemographic variables, clinical variables, psychological well-being and perceived health status. Finally, hierarchical multiple regression analyses were performed using the "enter method" in order to identify how much of the variance of dependent variables (physical and mental health summary scales) may be explained by age, gender, marital status, functional disability, depression and anxiety. Hierarchical multiple regression analyses were performed for the total sample, as well as for samples of younger (<45 years) and older ( $\geq 45$  years) MS patients (final results presented in Table 3).

Data were analysed using the Statistical Package for the Social Sciences, v.16.0 (SPSS).

## **Results**

### **Basic description of the sample**

In general, the respondents (n=223) were of middle age (mean age  $38.9 \pm 10.8$  years), consisted of more women than men (67.3% females), were married or cohabiting (64.6%), had secondary education (54.6%) and were not employed (59.4%). The main study variables with means and standard deviations for the whole sample and for the two age groups of MS patients (<45 years and  $\geq 45$  years) are described in Table 1. The younger group significantly differed statistically from the older age group in more often living alone/single, shorter disease duration, lower EDSS and a more frequent a relapsing-remitting course. Furthermore, the younger group had less depression, better perceived physical health status and better perceived mental health status (Table 1).

The 223 questionnaires represented a response rate of 52.0%. Non-respondents ( $45.1 \pm 10.5$  years) were significantly older than the participants ( $38.9 \pm 10.8$  years) ( $p < 0.05$ ), though there were no statistically significant

differences between the non-respondents and the participants regarding gender.

**Table 1** Description of the study sample and two age groups of MS patients: <45 years of age and ≥45 years of age

Variables <sup>a</sup>	Total sample (n=223)	<45 age group (n=149)	≥45 age group (n=74)
	n (%) or mean±SD	n (%) or mean±SD	n (%) or mean±SD
<b>Age</b>	38.9±10.8	32.7±6.9***	51.2±4.9***
<b>Gender</b>			
Women	67.3%	69.8%	62.2%
<b>Marital status</b>			
Living alone/single	35.4%	44.3%***	17.6%***
Married/cohabiting	64.6%	55.7%	82.4%
<b>Disease duration</b>	5.8±5.2	4.9±4.4***	7.6±6.3***
<b>EDSS</b>	3.1±1.5	2.7±1.5***	3.7±1.3***
<b>Clinical course</b>			
Relapsing-remitting	70.9%	83.7%***	45.2%***
Secondary-progressive	13.2%	4.8%	30.1%
Primary-progressive	15.9%	11.6%	24.7%
<b>HADS</b>			
Depression	4.5±3.6	4.2±3.5*	5.3±3.8*
Anxiety	7.1±4.2	6.8±4.2	7.6±4.2
<b>SF-36</b>			
Physical Summary <sup>b</sup>	48.1±20.4	53.0±20.1***	37.7±16.7***
Mental Summary <sup>b</sup>	56.7±16.0	58.6±16.6**	53.0±14.0**

Note:

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

<sup>a</sup>The significance test on the differences between subgroups of younger and older MS patients was on the Mann-Whitney U test on continuous variables; <sup>b</sup>higher scores indicate “better functioning”; EDSS=Expanded Disability Status Scale; HADS=Hospital Anxiety and Depression Scale; SF-36=Short Form-36 Health Survey

### Correlations between study variables

Table 2 demonstrates the significant cross-sectional relationships between the variables used in this study. Marital status (married/cohabiting) is significantly correlated with better physical and mental health status in MS patients. Age, disease duration, EDSS, clinical course, depression and anxiety are strongly associated negatively with the physical summary scale. Age, EDSS, clinical course, depression and anxiety are strongly associated negatively with the mental summary scale.

Table 2 Pearson's correlations between the studied variables

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. Age	-									
2. Gender	ns	-								
3. Marital status	-.42***	ns	-							
4. Disease duration	.34***	ns	ns	-						
5. EDSS	.33***	ns	ns	.40***	-					
6. Clinical course	.36***	ns	ns	.31***	.64***	-				
7. Depression	.23***	ns	ns	ns	.18**	.18**	-			
8. Anxiety	.13*	ns	-.14*	ns	ns	ns	.55***	-		
9. Physical Summary	-.42***	ns	.17*	-.23***	-.54***	-.37**	-.44***	-.37***	-	
10. Mental Summary	-.25***	ns	.16*	ns	-.27***	-.26***	-.72***	-.63***	.64***	-

Note:

\*p&lt;.05; \*\*p&lt;.01; \*\*\*p&lt;.001

Gender 1=men, 2=women; Marital status 1=married/cohabiting, 2=living alone/single; ns=no significance; EDSS=Expanded Disability Status Scale

### **Perceived physical health status**

Table 3 shows that 46.6% of the variance of perceived physical health status in the whole group of MS patients was explained by a model consisting of age, gender, marital status, EDSS, depression and anxiety. EDSS appeared to be the strongest variable associated with perceived physical health status in the total sample ( $\beta = -0.44$ ,  $p \leq 0.001$ ) (Table 3).

The variance in perceived physical health status explained in both age groups was very similar: 39.8% in the younger group and 38.8% in the older group of MS patients. Discrepancies were found with regard to the importance of EDSS and anxiety in the younger group (<45 years) and of depression in the older ( $\geq 45$  years). EDSS was the strongest variable associated with perceived physical health status in the younger age group (<45 years) ( $\beta = -0.47$ ,  $p \leq 0.001$ ), while depression was the stronger variable related to perceived physical health status in the older age group ( $\geq 45$  years) ( $\beta = -0.39$ ,  $p \leq 0.001$ ). Anxiety was significantly associated statistically, albeit weakly, with perceived physical health status in the younger age group (<45 years) ( $\beta = -0.16$ ,  $p \leq 0.05$ ), but not in the older one ( $\geq 45$  year) ( $\beta = -0.17$ , not significant) (Table 3).

### **Perceived mental health status**

In the total sample of MS patients, 60.8% of the variance in perceived mental health status was explained by a model consisting of age, gender, marital status, EDSS, depression and anxiety. Anxiety appeared to be the strongest variable associated with perceived mental health status in the sample of all MS patients ( $\beta = -0.32$ ,  $p \leq 0.001$ ) (Table 3).

In younger MS patients (<45 years), 65.0% of the variance in perceived mental health status was explained by a model consisting of age, gender, marital status, EDSS, depression and anxiety, while the same model explained 47.2% of the variance in perceived mental health status in older MS patients ( $\geq 45$  years). Depression appeared to be the strongest variable associated with perceived mental health status in both age groups ( $\beta = -0.49$ ,  $p \leq 0.001$ ;  $\beta = -0.47$ ,  $p \leq 0.001$  respectively), with higher explained variance in younger MS patients (<45 years). Anxiety was significantly associated with perceived mental health status in the younger age group (<45 years) ( $\beta = -0.37$ ,  $p \leq 0.001$ ), but not in the older one ( $\geq 45$  years) ( $\beta = -0.20$ , not significant) (Table 3).



**Table 3** Final results from the hierarchical multiple regression analyses: sociodemographic variables, EDSS, depression and anxiety on perceived physical and mental health status in the total sample, and in younger (<45) and older (≥45) MS patients

Total sample			Age groups			
			<45		≥45	
<b>Physical health</b>						
<b>status SF-36</b>	<i>Adjusted R<sup>2</sup></i>	<i>β</i>	<i>Adjusted R<sup>2</sup></i>	<i>β</i>	<i>Adjusted R<sup>2</sup></i>	<i>β</i>
Age	16.7%	-.19***	6.0%	-.20**	0.3%	.07
Gender	0.0%	-.03	0.0%	-.07	0.0%	-.03
Marital status	0.0%	.05	0.0%	-.02	3.6%	.17
EDSS	19.0%	-.44***	24.2%	-.47***	13.7%	-.38***
Depression	3.6%	-.24***	2.3%	-.20*	10.3%	-.39***
Anxiety	7.3%	-.15*	7.3%	-.16*	10.9%	-.17
Σ Adjusted R <sup>2</sup>	46.6%		39.8%		38.8%	
<b>Mental health</b>						
<b>status SF-36</b>	<i>Adjusted R<sup>2</sup></i>	<i>β</i>	<i>Adjusted R<sup>2</sup></i>	<i>β</i>	<i>Adjusted R<sup>2</sup></i>	<i>β</i>
Age	6.4%	-.05	3.9%	-.09	3.7%	-.02
Gender	0.6%	-.03	0.0%	.00	4.0%	-.15
Marital status	0.0%	.04	0.0%	.02	3.3%	.11
EDSS	4.3%	-.16***	3.0%	-.13*	4.1%	-.21*
Depression	16.4%	-.50***	42.6%	-.49***	16.0%	-.47***
Anxiety	33.1%	-.32***	15.5%	-.37***	16.1%	-.20
Σ Adjusted R <sup>2</sup>	60.8%		65.0%		47.2%	

Note:

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

EDSS=Expanded Disability Status Scale

## Discussion

The aim of this study was to explore whether there are discrepancies in the association of depression and anxiety with perceived physical and mental health status, and whether these associations differ in younger (<45 years) and older (≥45 years) MS patients. Less depression and less anxiety were associated with better perceived physical and mental health status in the total sample. MS patients without depressed mood and anxiety reported significantly better perceived physical health status than those with depression and anxiety when controlled for age, gender, marital status and EDSS. Similarly, less depressed and less anxious MS patients assessed perceived mental health status as significantly better when controlled for age, gender, marital status and EDSS. Our results regarding perceived health status as a dependent variable are in line with previous findings (4, 29-32).

The described model, which includes depression and anxiety, explained the lower variance in the difference in perceived physical health status (46.6%) compared with perceived mental health status (60.8%) in the total sample. While EDSS was the strongest variable explaining perceived physical health status, depression and anxiety appeared to be the main variables explaining most of the variance in perceived mental health status. Janssens et al (33) showed that the EDSS explained much, but not all, of the variance in the physical scale of SF-36, suggesting that other additive determinants were involved. An important difference between the instruments is that the EDSS aims to assess objective clinical status, whereas the SF-36 is a subjective evaluation of physical functioning as perceived by the patient (33).

A low score in depression was associated with better perceived physical health status, while a low score in anxiety appeared to be significantly related to better perceived physical health status in younger MS patients, but without significant association in the older age group. These findings provide some support for the results of more recent studies, which have suggested that more symptoms of depression and anxiety were significantly associated with worse perceived physical and mental health status presented by the SF-36 health summary scales and with poorer quality of life in MS patients (17, 30, 33).

A low score in depression was associated with better perceived mental health status in both age groups, with a higher explained prevalence of depression in younger MS patients. This finding is comparable to the results of some studies in which younger adults reported higher levels of depressive symptoms than older adults with MS (34, 35). Depression can result from individual reactions to MS-related disability, its symptoms and from the disease process itself (14). A low score in anxiety was significantly related to perceived mental health status only in the younger age group. The relationship between anxiety and mental health in younger patients was studied in a survey of recently diagnosed MS patients whose mean age was  $37.5 \pm 9.5$  years. More symptoms of anxiety were associated with poorer physical and mental health in this sample (33).

The existence of unique features in the national health care system in the past may lead to a certain limitation of this study. In particular, the inaccessibility to DMD for MS patients over age 45 may affect the differences when evaluating symptoms of depression and anxiety in comparison to patients from other countries in this age cohort. Also, the MS patients participating in this study were significantly younger than the non-respondents. We may assume, then, that the non-respondents were largely members of the older MS group and with the longest disease duration, and that they were possibly the most affected group, a fact that might have prevented them from participating in the study. The results therefore cannot be extended and generalized to the whole MS population,

as a larger proportion of the oldest group of MS patients compared with the younger group was missing from this study. In addition, the outcomes of this cross-sectional study cannot be causally determined. The current survey can only imply causal pathways, not prove them. Longitudinal data are needed to further unravel the complex interplay between psychological well-being and changes in perceived health status during and after DMD treatment in Slovak MS patients.

### **Summary and implications**

In a summary of the study findings, depression showed its importance for evaluating the perceived health status in all MS patients. Therefore depression should be carefully screened for in all MS patients, regardless of sociodemographic factors and clinical variables. Among the most used therapeutic agents,  $\beta$ -interferon (a DMD) is being widely adopted in relapsing-remitting MS (28). In our sample, patients below the age of 45 years had been treated with  $\beta$ -interferon 1a or 1b. It was recognized that among the potential drug-related side effects, there was a possible association with an increased risk of depression, a fact which has been debated (36). If depression occurs in MS patients, it is hard to conclude that the reason is as a side effect of DMD or no accessibility to using DMD or any other reason. As DMD moderately reduces the number and severity of attacks, the number of new lesions on magnetic resonance imaging and progression (37), it may be that older MS patients who had no access to DMD feel the impossibility of coping with the disease as their younger colleague patients are able to, which might lead to a depressed mood. Symptoms of anxiety could be connected with perceived physical and mental health in younger MS patients, despite their use of DMD. This could be explained by distress caused by possibly worsening functional disability at a younger age, which was significantly associated with impairment, and its consequences on education, employment and leisure-time physical activity, and with the restricted social network. With regard to older MS patients, they could have built up during treatment with DMD useful coping strategies during the years of disease and thus are able to cope with anxiety when older. Determining the factors that could have an impact on an MS patient's perceived health status might help with decision-making during the planning of interventions, treatments and services aimed at enhancing health status or quality of life (30).

The clinical importance of this study is that MS patients possessing higher levels of depression and anxiety have a greater likelihood of perceiving health status more negatively than those who are less depressed and less anxious. According to the result of the study, health care providers would expect that MS patients suffering from depression and anxiety may

evaluate their health as worsened. It may be therefore important to assess the symptoms of depression and anxiety of MS patients and to treat them in order to contribute to a patient's perceived health status.

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# General discussion and implications for future research and practice

In the first part of this chapter general considerations regarding perceived health status and its association to the main variables of the study will be discussed. Later, the strengths and some limitations of the study will be reviewed. The chapter will end with some suggestions about directions for future research on perceived health status in MS patients and with a discussion about the implications of the findings for clinical practice.

## 7.1 Discussion of the main findings

Perceived health status focuses on two areas: physical health status and mental health status. In medical patients, including MS patients, the physical and mental dimensions of perceived health status are related to one another. Many MS patients report a fear of sudden relapses and anxiety about disease progression (4). Consequently, they must resist the intrusion of negative thoughts that result in a bad mood or the stress that comes from the progressive decline in their physical health status. Regarding the aims of this work, Chapter 1 contains the theoretical model used in the study. We focused on the outcomes of the physical and mental health summary scales with the disease process and the functional disability associated with physical health status, as well as the psychosocial factors related to mental health status.

Regarding physical health status, the studies reviewed here provided support for the negative association of disease duration and a higher score in functional disability with the physical health dimensions of the SF-36 (1, 2). Patti et al (2) actually reported a significant association between all SF-36 health dimensions and disease duration. Similarly, Nortvedt et al (5), in a study of 194 MS patients, revealed significantly lower scores in all health dimensions of perceived health status and higher scores in functional disability (5).

The first item of the SF-36 appeared, in a statistical sense, as a strong predictor of employment status in MS patients. In terms of premature retirement, non-employment status mainly affects financial security and leads to a reduced social network and a worsened perceived health status. Despite these results, experience shows that society and employers assess the efforts of MS patients to work as marginal, and a patient's



opportunities for being employed full-time or part-time are genuinely limited. In line with this statement, only about one-third (35.9%) of all patients surveyed were employed full-time or part-time, although the majority of MS patients had the relapsing-remitting clinical course.

The next step focused on psychological well-being and perceived health status in MS patients. Our results show that less depressed and less anxious MS patients assessed their perceived physical and mental health status as significantly better, and that results regarding perceived health status as an important dependent variable related to depression and anxiety are in line with previous findings (5-7).

Social support is considered primarily as a psychosocial construct and to a lesser extent, a physical construct. In line with this statement, our outcomes did not reveal a strong relationship between social support and physical health status. But some studies have consistently shown that social support may be a major factor in adaptation to physical illness, and that positive social interaction is associated with better physical functioning (8, 9). In spite of this fact, social support provided by family and friends was positively associated with all of the individual dimensions of mental health status in MS patients. Thus, the results of this study are in line with the finding that more social support contributes to better mental health (8, 9). Many authors have shown that social support functions as a protective factor against mental health problems (10-12).

Another psychosocial factor studied was mastery. We concluded that higher mastery was associated with better mental health status in MS patients. The fact that worse functional disability, higher mastery and worse perceived health status are more frequently present in the older age group ( $\geq 45$  years) than in the younger one ( $< 45$  years) might suggest that the progress of MS should be taken into account. Other authors have also found that individuals with greater mastery are more likely to use preventive care, have good health behaviours, seek treatment early and use health services properly (13-15).

At the end of the discussion of our main findings, we would like to come back to our earlier statement regarding the fear of sudden relapses and disease progression that deeply affects MS patients. The described variables, including low functional disability, short disease duration, the ability to work and social support provided by significant others, could be factors mainly associated with perceived physical health status in MS patients. Secondly, the studied psychosocial factors, including social support provided by family and friends, higher mastery and the absence of depression and anxiety, could be important determinants of mental health status in MS patients. Our study showed that the physical and mental health dimensions of perceived health status can only be divided for analytical reasons; in reality they operate in patients as a whole.

## **7.2 Study strengths and limitations**

### **Strengths**

With regard to the functional disability of MS patients, not only subjective data on physical health status was collected. EDSS, a measure of functional disability, was used as an objective health indicator focusing on the level of disease severity and was assessed by a neurologist. EDSS was significantly correlated in the total sample of MS patients with the dimensions of the physical health summary scale of the SF-36. This scale therefore could be recognized as an appropriate measure of perceived physical health status. Neurologists, nurses, psychologists and psychiatrists might use it as a quick tool for measuring perceived physical health in MS patients.

Since published studies were lacking on the effect of perceived social support on the health status of MS patients, our study tried specifically to shed more light on this topic. In doing so it revealed that the health dimensions of the SF-36 might be associated with a different type of social support and could contribute to better perceived health determinants. Similarly, little research has thus far been conducted on MS patients regarding the associations between mastery, functional disability and perceived health status.

### **Limitations**

Each of the studies described in this thesis contain a section in which the strengths and limitations of the study have already been discussed, therefore these factors will only be mentioned here very briefly. The studies are cross-sectional, so causal relationships cannot be concluded from the findings. The significantly older age of the non-respondents suggests more disease severity among this group, which affects the ability to generalize from our study outcomes. A further limitation of our outcomes could be the exclusive access of patients under the age of 45 to disease-modifying agents.

However, there are additional issues that should be mentioned. Firstly, the study was carried out in a population of MS patients, but not in a healthy or general population. It is well known from many previous studies on quality of life that MS patients report their health status worse than the general population (5, 16-18). Secondly, we agree with the authors of Perceived Social Support scale that clarification is needed regarding who actually belongs to the significant others subscale (19).

A number of disease-modifying drugs (DMD) have been developed over the past 20 years. Although these drugs have been introduced in Central and Eastern Europe, their high cost means many patients do not have access to them. The unavailability of DMD for patients over the age

of 45 in Slovakia might lead to a certain limitation of this study. There is no doubt that a significant treatment gap exists in approaches to MS between countries. DMD are also costly, requiring € 15.000 to € 26.300 per annum per patient, and are beyond the reach of many patients (20). On 1 July 2008, the Slovak Ministry of Health cancelled the age restriction on the use of DMD. As a result, every MS patient for whom DMD might be helpful now has, according to a neurologist's decision, the opportunity to use this medicine and have the cost covered by their health insurance provider.

## **7.3 Implications of the findings**

### **Recommendations for future research**

As with many neurological diseases, MS is difficult to study. Even after several decades of intensive research activity, it remains a condition with no known pathogen, and there is no consensus on its origin or accepted determinants of its severity. Below are some suggestions for future research based on the findings of this thesis.

Some neuropsychological studies suggest that 40-65% of MS patients show some cognitive dysfunction, prominently involving memory, sustained attention and information processing speed. Cognitive functioning has a dramatic impact on a patient's well-being, influencing role fulfillment in both work and social life (21-23). A patient's cognitive dysfunction could be assessed by specific neuropsychological measures (23). Thus, researchers might want to study how cognitive functioning is associated with perceived health status in MS patients. We might expect some limitations in the dimensions of the mental health summary scale depending on its linkage with cognitive functioning.

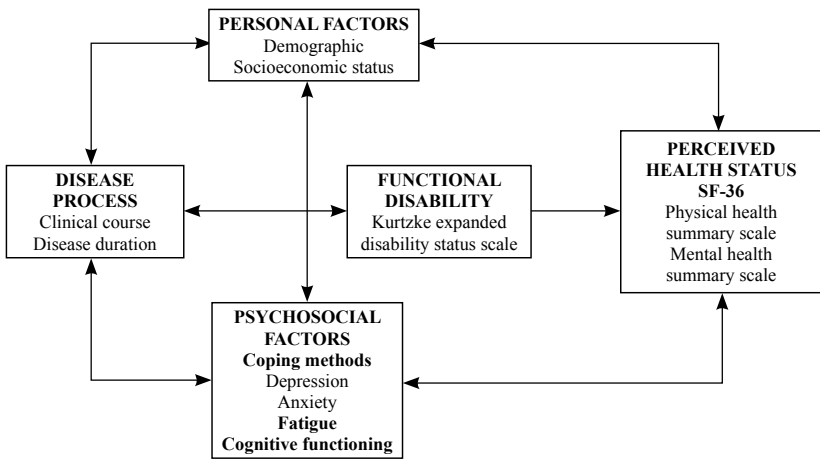
Physical fatigue and mental fatigue are frequently reported negative factors in people with MS. The symptoms of depression and fatigue are very similar, however, and it may be difficult to differentiate them; sometimes a trial of antidepressants may be necessary (20). As the subjective experience of fatigue is one of the most common symptoms in MS patients and is certainly associated with reduced health, the association in which fatigue impacts perceived health status has not yet been clearly defined (24-26). We can assume that since the score in functional disability is influenced by limb and gait dysfunction, fatigue might very well be linked with the physical domain of perceived health status.

It would be interesting to ascertain whether positive experiences directly enhance the perceived physical and mental health status of MS patients. How MS patients cope with stressors may be affected not only by their mastery over life circumstances but also by the social support

provided. People with a diagnosed disorder might differ from those who score high on psychological symptom scales in social characteristics and in life event experiences. Additionally, hardiness, a sense of coherence, and Type A characteristics such as impatience and hostility have been studied as factors relevant for coping with disease. Pearlin and Schooler (27) distinguished between perception-focused coping strategies and emotion-management strategies. Furthermore, behavioral self-efficacy has been related to health-promoting behaviour and to positive physical health outcomes (27-30). Focusing more on stress and the coping strategies used by MS patients could be a very important part of future research.

The extended model, with elements of cognitive functioning, fatigue, stress and coping strategies, might serve as a framework for future research on MS patients (Figure 1). This model with perceived health status might also be studied in a comparison of MS patients and the general population within a cross-sectional theoretical framework.

**Figure 1** Framework for future research



MS patients are usually diagnosed in the first part of their life trajectories, when career and starting a family are major issues. With a renewal of the theoretical framework, future research could focus on if and how the life plans of younger MS patients might change and be affected by such a distressing factor. A longitudinal study would be appropriate for revealing these changes in MS patients over time. Furthermore, longitudinal data would be needed to further unravel the complex interplay between psychological well-being and changes in perceived health status in MS patients during and after treatment with the disease-modifying agents.

## **Clinical implications**

MS patients achieved an average score in perceived physical and mental health status; thus, many MS patients experienced good health status. But a minority of them, mainly older people with MS, does not experience a satisfactory physical health status.

Even though drug treatment options are relatively limited, significant improvements in the well-being of people with MS might be supported by more intensive rehabilitation approaches. For patients with relatively moderate disability, both aerobic and non-aerobic exercise, for example, has been found to be very useful. There is a need for more studies evaluating the rehabilitation needs of MS patients experiencing with more severe disability. Similarly, neuro-rehabilitation aiming to improve independence leads individuals with MS to adapt their lifestyle.

People with MS might also benefit from psychosocial intervention. Cognitive-behavioural therapy focuses on unrealistic beliefs and replaces them with realistic beliefs. Such therapy might help patients adapt to life circumstances that are beyond their control. A good family background and a network of friends have been shown to be important for mental health status. If social support is lacking, intervention programmes might therefore be of help. Additive psychosocial treatment, including support groups and family therapy, should focus not only on patients, but also on wider family interactions.

There is still a need for a multidisciplinary MS service and multimodal approach to symptom management. Caring for MS patients used to increase in line with worsened functional disability. Uncertainty over the origin or progression of MS indicates that prevention is currently not a realistic option. An approach in managing treatment, centered on MS patients should include medication appropriate to the level of functional disability, followed by management of additive symptoms, mainly including fatigue, spasticity, pain, anxiety, depression, bladder and bowel dysfunction, imbalance, visual loss, cognitive impairment, etc. (20).

National MS societies, MS patients, their families, governments, health, social and care providers, employers, researchers and others might try to use services and improvements in their programmes which include independence, medical care, long-term care and social care, health promotion, support for family members, transportation, employment and volunteer activities, disability benefits, cash assistance and education for MS patients. MS patients should be educated about the possibilities of MS development and regarding how to adopt satisfactory coping strategies. Such a health care network should consist not only of neurologists, but also nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists, social workers and psychiatrists who should stress this goal (20).

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# Summary

Most people live with an ‘illusion of invulnerability’. After diagnosis of a chronic disease like MS, this illusion is broken, and this loss of perspective may be devastating, particularly in early or middle adulthood. Disease onset of MS before the age of 10 or after the age of 50 is considered rare. A number of large epidemiological studies, but not all, on the natural history of MS have found that late age of onset, male gender and a short interval between onset and first relapse are associated with a poor prognosis. The progression of MS has been related to worsened functional disability as expressed in MS patients by Kurtzke’s EDSS scale. As the measures of perceived health status include physical health dimensions, functional disability and health status outcomes reported by MS patients may be linked very closely.

Chapter 1 of this thesis elaborates on the background of MS, with its clinical criteria, treatment and prognosis. This is followed by a general model of disability and by health status as applied in MS. Terms like *disease, impairment, disability, handicap* and *quality of life* established in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) might be considered in the context of MS outcomes. At the end of this chapter, the aims of the study and research questions are formulated, focusing on a review of the literature on disease duration, functional disability, psychological well-being and perceived health status in MS (Chapter 2); self-rated health and its association to employment status in MS (Chapter 3); social support provided by family, friends and significant others and its positive associations with perceived physical and mental health status (Chapter 4); the associations of mastery, functional disability and perceived health status in MS (Chapter 5); and finally, the relationships between depression, anxiety and perceived health status in the whole sample as well as separately in the younger and older groups of MS patients (Chapter 6).

Chapter 2 reviews recent studies concerning perceived health status in MS patients as measured by the Short Form-36 Health Survey (SF-36). The study focuses on the use of the physical and mental health dimensions of the SF-36 that are linked to clinical data (disease duration and functional disability) and psychological well-being (depression). A computer-aided search in Medline and PsycINFO resulted in 504 articles in English published from 1996 to August 2006. Just 8 articles consisted of empirical MS studies in which perceived health status was evaluated using the SF-36. MS patients with low functional disability, shorter disease duration and minor depression scored significantly better than

patients with high functional disability, long disease duration and major depression in the SF-36 health summary scales.

Chapter 3 focuses on the association between the self-rated health of MS patients and employment status. Self-rated health was chosen as the first item of the SF-36 for a short subjective screening of health status. In addition to self-rated health, other important variables, including functional disability, disease duration, depression and anxiety, were examined as independent variables, while employment status was treated as a dependent variable. Results showed that MS patients who reported good self-rated health were more likely to be employed, less disabled and less anxious. Age, gender, disease duration and depression showed no statistically significant association with employment or non-employment in MS patients. It should be mentioned that only about half of the surveyed MS patients were employed full-time or part-time, although 68% of all patients belonged to the relapsing-remitting clinical course. This means that the possibilities of MS patients of being employed are really limited.

Perceived social support has shown its usefulness in the chronically ill as a psychosocial factor and coping strategy. People who look to others to support them report feeling strengthened and encouraged. Having someone who openly and willingly talks about MS and its challenges provides a patient with a positive coping style. The first aim of the study, described in Chapter 4, was to assess the association between social support provided by family, friends and significant others and perceived physical and mental health status in MS patients. The second aim focused on evaluating the social support provided by family, friends and significant others in association with the separate dimensions of perceived physical and mental health status. Social support from significant others was positively associated with the general health dimension of perceived physical health status, while social support from family and friends was positively associated with all four dimensions of perceived mental health status. The results show the importance of supporting social ties and relationships between MS patients and others.

Along with social support, mastery, as in having a sense of control, was identified as an important variable in a patient's psychological well-being. Chapter 5 deals with the associations between mastery, functional disability and perceived health status in MS patients. With regard to age and the use of disease-modifying drugs, differences were expected in mastery, functional disability and perceived health status between younger and older age groups of MS patients (<45 and ≥45 years of age). Patients with low functional disability reported better physical health status in both age groups and better mental health status in the younger age group. Mastery was positively associated with perceived health status in the older age group. The findings confirmed that mastery might be

helpful for older MS patients, while functional disability appeared to be the most important variable for younger age group.

Depression and anxiety were found to be significant variables associated with perceived health status, as described in Chapter 6. Comparable to Chapter 5, the study sample consisted of 223 MS patients who were divided into two age groups (<45 and ≥45 years of age). The role of depression was present with regard to perceived health status, mainly to perceived physical health status in the older group and to perceived mental health status in the younger one. The role of anxiety was more important in younger MS patients than among older patients with regard to their perceived health status.

Finally, in Chapter 7 the main findings of the studies described in this thesis are discussed and placed within a broader context. This chapter also reflects the importance of the model used as the framework for this thesis. The chapter ends with a discussion on the clinical implications of the work.

Several recommendations are made about directions for future research and practice: to continue this research in a longitudinal study in order to compare both cross-sectional data and longitudinal data; to extend the theoretical framework by adding new variables; to support better perceived health status in MS patients through rehabilitation and neuro-rehabilitation approaches; to follow up with psychosocial interventions, including cognitive-behavioural therapy, social support, group therapy etc.; to provide a multidisciplinary approach in symptom treatment that would be directed toward patients with MS.

Unexpected worsened disability may affect patients with MS fearing prognostic uncertainty, and they should thus become well informed about their illness. Collaboration is essential in the plan of care between patient, family and health care providers. Treating physicians should continually assess the need for psychological support for patients and their families, since depression is common and the rate of suicide is relatively high in this population of patients. Therefore, a multidisciplinary approach is needed for several of the complications of MS that may involve specialists in physical medicine and rehabilitation. Recent progress in treatment showed that advanced magnetic resonance imaging (MRI) and spectroscopy may allow clinicians to follow the pathological progression of the disease and to monitor the response to treatment. In parallel with the development of new diagnostics methods and clinical treatments, researchers have recently begun to recognize the association between disease progress and the psychosocial factors of MS.



# Samenvatting

Veel mensen leven met een soort 'illusie van onkwetsbaarheid'. Na de diagnose van een chronische ziekte zoals MS gaat deze illusie teloor, en het verlies van perspectief kan aanzienlijk zijn, speciaal in de periode van jong of middenvolwassenheid. Het begin van MS voor het tiende of na het vijftigste levensjaar is zeldzaam. Uit een aantal epidemiologische studies met betrekking tot het natuurlijk verloop van MS, maar niet uit alle, blijkt dat het late optreden ervan, het mannelijke geslacht en een kort interval tussen begin van de ziekte en de eerste terugval gerelateerd is met een slechte prognose. De progressie van MS wordt gewoonlijk gekoppeld aan functionele beperkingen tengevolge van de ziekte, uitgedrukt door Kurtzke's Expanded Disability Status Scale (EDSS) schaal. Naast deze door de arts vastgestelde gezondheidstoestand is er de door de patient 'ervaren gezondheidstoestand'; omdat deze ook betrekking heeft op de lichamelijke gezondheidsdimensies, zijn functionele beperkingen en de uitkomsten van de gezondheidstoestand nauw aan elkaar verwant.

In Hoofdstuk 1 van dit proefschrift wordt ingegaan op de achtergrond van MS en de klinische criteria, de behandeling en de prognose ervan. In een erop volgend algemeen model met betrekking tot beperkingen wordt dat toegepast op MS. Termen zoals *ziekte*, *stoornissen*, *beperkingen*, *handicap* en kwaliteit van leven, genoemd in de International Classification of Impairments, Disabilities and Handicaps (ICIDH) kunnen ook in de context van MS uitkomsten worden gebruikt. Aan het eind van dit hoofdstuk worden doelen van het onderzoek en de onderzoeksvragen genoemd. Ze zijn gericht op een review van de literatuur over ziekteduur, functionele beperkingen, psychisch welbevinden en ervaren gezondheidstoestand bij MS (Hoofdstuk 2); op ervaren gezondheidstoestand en de relatie ervan met het hebben van werk bij MS (Hoofdstuk 3); op sociale steun door familie, vrienden, en belangrijke anderen en de relatie ervan met ervaren fysieke en psychische gezondheidstoestand (Hoofdstuk 4); op de verbanden tussen mastery, functionele beperkingen, en ervaren gezondheidstoestand bij MS (Hoofdstuk 5); en tenslotte op de verbanden tussen depressie, angst, en ervaren gezondheidstoestand in de hele steekproef, en afzonderlijk in de oudere en jongere groep MS patiënten (Hoofdstuk 6).

In Hoofdstuk 2 wordt de literatuur met betrekking tot ervaren gezondheidstoestand gemeten met de Short Form-36 Health Survey (SF-36) gereviewed. Het hoofdstuk is gericht op het gebruik van de fysieke en psychische dimensies van de SF-36 die gerelateerd zijn aan klinische data (ziekteduur en functionele beperkingen) en psychisch welbevinden (depressie). Een zoekstrategie met behulp van de computer in Medline

en PsycINFO resulteerde in 504 Engelstalige artikelen, gepubliceerd van 1996 tot augustus 2006. In slechts 8 artikelen werden empirisch onderzoek onder MS patiënten gerapporteerd waarbij ervaren gezondheidstoestand was gemeten met behulp van de SF-36. MS patiënten met een gering aantal functionele beperkingen, een korte ziekte duur, en weinig depressieve klachten scoorden significant beter op de fysieke en psychische dimensies van de SF-36 dan patiënten met een groot aantal functionele beperkingen, een lange ziekte duur, en veel depressieve klachten.

In Hoofdstuk 3 wordt het verband tussen ervaren gezondheidstoestand bij MS patiënten en het hebben van werk beschreven. De ervaren gezondheidstoestand werd gemeten met de eerste vraag van de SF-36 om een korte subjectieve indruk van de gezondheidstoestand te krijgen. Naast de ervaren gezondheidstoestand werden de variabelen functionele beperkingen, ziekte duur, depressie en angst gebruikt als onafhankelijke variabelen, terwijl het hebben van werk als afhankelijke variabele werd behandeld. MS patiënten met een goede ervaren gezondheidstoestand en die minder beperkt en minder angstig waren bleken meer kans op van werk te hebben. Er bestond geen statistisch significant verband tussen leeftijd, geslacht, ziekte duur en depressie en het hebben van werk van MS patiënten. Ongeveer de helft van de onderzochte MS patiënten hadden full time of parttime werk hoewel 68% van alle patiënten tot het 'relapsing-remitting' type behoorde. Kansen voor MS patiënten om werk te krijgen zijn zeer beperkt.

Van ervaren sociale steun als een van de psychosociale factoren en coping strategieën is bekend dat het nuttig is bij chronisch zieken. Mensen die op anderen gericht zijn en hun steunen, geven aan zich daardoor gesterkt en bemoedigd te voelen. Er is sprake van een positieve coping stijl als de patient iemand heeft met wie hij openlijk en vrijwillig kan spreken over MS en de problemen die zich erbij voordoen. Het eerste doel van het onderzoek dat is beschreven in Hoofdstuk 4 was het nagaan van het verband tussen sociale steun geboden door familie, vrienden, en belangrijke anderen en ervaren fysieke en psychische gezondheidstoestand in MS patiënten. Het tweede doel was gericht op het onderzoeken van het verband tussen sociale steun geboden door familie, vrienden, en belangrijke anderen en de verschillende dimensies van ervaren fysieke en psychische gezondheidstoestand. Sociale steun afkomstig van belangrijke anderen was positief geassocieerd met de algemene gezondheidsdimensie van de ervaren fysieke gezondheidstoestand, terwijl sociale steun van familie en vrienden positief geassocieerd was met alle vier dimensies van ervaren psychische gezondheidstoestand. De resultaten laten het belang van steunende sociale verbanden zien tussen MS patiënten en anderen.

Naast sociale steun bleek mastery - het gevoel controle te hebben - een belangrijke variabele voor het psychisch welbevinden van de patiënt. In Hoofdstuk 5 wordt ingegaan op de verbanden tussen mastery, functionele

beperkingen en ervaren gezondheidstoestand bij MS patiënten. Vanwege de leeftijd en het toegestane gebruik van disease modifying drugs werden verschillen verwacht tussen mastery, functionele beperkingen en ervaren gezondheidstoestand tussen jongere en oudere MS patiënten (<45 en ≥45 jaar). Patienten met geringe functionele beperkingen gaven in beide leeftijdsgroepen aan een betere ervaren fysieke gezondheidstoestand te hebben, en in de jongere leeftijdsgroep ook een betere ervaren psychische gezondheidstoestand. Mastery bleek geassocieerd met een betere ervaren gezondheidstoestand de oudere leeftijdsgroep. De resultaten lijken te suggereren dat mastery van nut is voor oudere MS patiënten, terwijl functionele beperkingen de belangrijkste variabele is voor de jongere leeftijdsgroep.

Uit Hoofdstuk 6 blijkt dat tussen depressie en angst enerzijds en ervaren gezondheidstoestand anderzijds een significant negatief verband bestaat. Net als in Hoofdstuk 5 werd de onderzoeksgroep van 223 MS patiënten verdeeld in twee leeftijdsgroepen (<45 en ≥45 jaar). Met betrekking tot ervaren gezondheidstoestand was de rol van depressie aanwezig, in het bijzonder bij ervaren fysieke gezondheidstoestand in de oudere leeftijdsgroep en ervaren psychische gezondheidstoestand in de jongere leeftijdsgroep. De rol van angst bleek meer van belang bij jongere dan bij oudere MS patiënten met betrekking tot hun ervaren gezondheidstoestand.

Tenslotte worden in Hoofdstuk 7 de belangrijkste bevindingen van dit proefschrift beschreven en in een bredere context bediscussieerd. Ook wordt ingegaan op het belang van het model dat gebruikt werd als kader voor dit onderzoek. Het hoofdstuk eindigt met een discussie over een aantal klinische aanbevelingen.

Verschillende aanbevelingen worden gedaan inzake toekomstig onderzoek en de praktijk. Dit onderzoek behoeft een longitudinale voortzetting om cross-sectionele en longitudinale data te kunnen vergelijken; voorts zouden nieuwe variabelen aan de opzet moeten worden toegevoegd. MS patiënten zouden een betere ervaren gezondheidstoestand kunnen bereiken door meer gerichte revalidatie en neuro-revalidatie; voorts zouden ze psychosociale interventie kunnen volgen met daarin cognitieve gedragsbehandeling, sociale steun, groepstherapie etc; en tenslotte zou een multidisciplinaire aanpak bij de behandeling van symptomen aangeboden moeten worden aan MS patiënten.

Onverwachte verslechtering kan MS patiënten confronteren met onzekerheid over de prognose en ontwikkeling van hun beperkingen; om die reden moeten ze goed geïnformeerd zijn over wat hun te wachten staat. Samenwerking is essentieel in het behandelplan tussen patiënt, diens naaste familie en de zorgverleners. Behandelende artsen dienen ook continu de behoefte aan psychische steun bij patiënten en hun families na te gaan, aangezien depressie frequent en ook suïcide relatief vaak voorkomt



in deze patiëntencategorie. Daarnaast is een multidisciplinaire aanpak nodig vanwege de complicaties van MS, met inbreng van de deskundigheid van fysiotherapeuten en revalidatie-artsen in het begeleidingsproces. Een recente ontwikkeling in de behandeling is de advanced magnetic resonance imaging (MRI) en spectroscopie die klinici in staat stelt het pathologische substraat van het voortschrijden van de ziekte zichtbaar te maken alsmede het effect van de behandeling te volgen. De ontwikkeling van nieuwe diagnostische middelen en klinische behandelwijzen laat onverlet het belang van onderzoek naar het voortschrijden van de ziekte en de psychosociale factoren bij MS.

# Zhrnutie

Mnohí ľudia sú presvedčení, že im sa nemôže stať, že ochorejú. Po diagnostikovaní chronického ochorenia, akým je skleróza multiplex (SM), sa táto ilúzia rúca. Strata ďalšej perspektívy, najmä v období mladšieho a stredného dospelého veku, môže byť zničujúca. Nástup SM pred desiatym rokom alebo po päťdesiatom roku života sa považuje za ojedinelý. Veľký počet rozsiahlych epidemiologických štúdií o pôvode SM uvádza, že neskorší nástup ochorenia, mužské pohlavie, krátky interval medzi nástupom a prvým relapsom sa spája s horšou prognózou ochorenia. Progress SM sa pripisuje zhoršenému funkčnému stavu, ktorý sa u pacientov so SM vyjadruje pomocou Kurtzkeho škály EDSS. Keďže metódy sebaopisovania zdravotného stavu zahŕňajú dimenzie fyzického zdravia, výsledky sebaopisovaného zdravia sa môžu úzko prelínať s funkčným stavom ako odrazom zhoršenie fyzického zdravia.

V kapitole 1 je opísané pozadie vzniku SM, vrátane klinických kritérií, liečebných postupov a prognózy ochorenia. Sleduje všeobecne uplatňovaný model funkčnej neschopnosti a zdravotného stavu, ktorý možno aplikovať u SM. Terminológia v tejto kapitole zahŕňa pojmy ako choroba, postihnutie, neschopnosť, hendikep a kvalita života, čo sú pojmy zavedené v medzinárodnej klasifikácii *International Classification of Impairments, Disabilities and Handicaps (ICIDH)*. Tieto pojmy možno uplatniť v kontexte výskumu SM. V závere tejto kapitoly sa uvádzajú ciele štúdie a jej výskumné otázky, prehľad doteraz publikovanej literatúry o dĺžke ochorenia, funkčnom stave, psychickej pohode a sebaopisovanom zdraví (Kapitola 2); sebaopisované zdravie ako jedna položka a jeho vzťah k zamestnanosti (Kapitola 3); sociálna opora, ktorú poskytuje rodina, priatelia a iní významní ľudia a jej pozitívny vzťah k sebaopisovanému fyzickému a duševnému zdraviu (Kapitola 4); súvislosti medzi mastery, funkčným stavom a sebaopisovaným zdravím (Kapitola 5); a nakoniec, vzťahy medzi depresiou, anxiétou a sebaopisovaným zdravím v celom skúmanom súbore SM pacientov, ako aj osobitne v dvoch skupinách pacientov rozdelených podľa veku (Kapitola 6).

Kapitola 2 zobrazuje prehľad posledných článkov, ktoré sú orientované na sebaopisované zdravie merané dotazníkovou metódou Short Form-36 Health Survey (SF-36). Tento prehľad literatúry zdôrazňuje fyzické a mentálne dimenzie dotazníka SF-36 v súvislosti s využitím klinických údajov (dĺžka ochorenia, funkčný stav) a psychickej pohody (depresia). Elektronické vyhľadávanie v databázach Medline a PsycINFO vyústilo do výsledkov v podobe 504 článkov, ktoré boli publikované v anglickom jazyku v období januára 1996 až augusta 2006. Len 8 nájdených článkov

obsahovalo empirické štúdie o SM, v ktorých sa sebaopisované zdravie hodnotilo prostredníctvom metódy SF-36. Tento prehľadový článok uvádza, že SM pacienti s dobrým funkčným stavom, krátkou dĺžkou ochorenia a nízkou depresiou skórovali štatisticky lepšie v škálach dotazníka SF-36 než pacienti so zhoršeným funkčným stavom, zdlhávajúcim ochorením a zvýšenou depresiou.

Kapitola 3 sa zaoberá vzťahom medzi sebaopisovaným zdravím a zamestnanosťou pacientov so SM. Sebaopisované zdravie odzrkadľuje v tejto práci 1. otázka z dotazníka SF-36 ako rýchly a subjektívny opis zdravotného stavu pacienta. Okrem sebaopisovaného zdravia hodnotili pacienti ďalšie dôležité premenné vrátane funkčného stavu, dĺžky ochorenia, depresie a anxiety, ktoré boli v tomto prípade nezávislými premennými. Zamestnanosť hodnotili potom ako závislú premennú. Výsledky ukázali, že pacienti so SM, ktorí označili svoje zdravie ako dobré, boli menej zneschopnení, menej úzkostní a mali väčšiu šancu zamestnať sa. Vek, pohlavie, dĺžka ochorenia a depresia nesúviseli štatisticky významne so zamestnanosťou alebo nezamestnanosťou v dôsledku ochorenia. Treba spomenúť, že v čase snímania údajov v priemere asi polovica skúmaných pacientov so SM pracovala na celý alebo čiastočný úväzok, hoci 68% všetkých skúmaných pacientov malo diagnostikovanú relaps-remitujúcu formu ochorenia. Tento rozpor svedčí o pretrvávajúcej obmedzenej možnostiach nájsť si prácu s touto diagnózou.

Sociálna opora ukázala svoju opodstatnenosť pri skúmaní chronických ochorení ako psychosociálny faktor a copingová stratégia. Ľudia, ktorým sú ostatní oporou, hovoria o pocitoch väčšej sily a odvahy. To vedie k pozitívnemu štýlu zvládania ochorenia, najmä ak pri pacientovi stojí niekto, kto s ním otvorene a ochotne hovorí o problémoch so SM. Prvá hypotéza v kapitole 4 sa zamerala na hodnotenie vzťahu medzi sociálnou oporou poskytovanou rodinou, priateľmi a inými dôležitými ľuďmi a sebaopisovaným fyzickým a duševným zdravotným stavom. Druhá hypotéza sa dotýkala hodnotenia sociálnej opory v súvislosti s jednotlivými dimenziami sebaopisovaného zdravotného stavu. Výsledky analýz ukázali, že sociálna opora poskytovaná inými dôležitými ľuďmi súvisela pozitívne s jednou z ôsmich dimenzií, a to so „všeobecným zdravím“. Sociálna opora od rodiny a priateľov pozitívne významne súvisela so všetkými štyrmi dimenziami v rámci sebaopisovaného duševného zdravia. Tieto výsledky poukazujú na dôležitosť podporovať sociálne putá a vzťahy medzi pacientami so SM a ostatnými ľuďmi.

Okrem sociálnej opory, za ďalšiu podstatnú premennú pre psychickú pohodu pacientov so SM možno považovať mastery ako zmysel mať pod kontrolou udalosti života. Kapitoly 5 skúma vzťahy medzi mastery, funkčným stavom a sebaopisovaným zdravím u pacientov so SM. Vzhľadom na vek a užívanie liekov ovplyvňujúcich priebeh choroby sa dali očakávať rozdiely medzi mastery, funkčným stavom a sebaopisu-

dzovaným zdravím medzi mladšími a staršími pacientami so SM (<45 a ≥45 rokov). Pacienti s lepším funkčným stavom udávali lepšie fyzické zdravie v oboch vekových skupinách a lepšie duševné zdravie udávali mladší pacienti so SM. Mastery pozitívne súviselo so sebaopisovaným zdravím v staršej vekovej skupine pacientov. Tieto zistenia potvrdili, že mastery môže byť užitočné u starších pacientov, kým funkčný stav sa zdá byť zo skúmaných premenných najdôležitejšou premennou v mladšej vekovej skupine.

V kapitole 6 sa sledoval vzťah depresie a anxiety v súvislosti so sebaopisovaným zdravím u pacientov so SM. Skúmaný súbor pozostával z 223 pacientov so SM. Podobne ako v kapitole 5, pacienti boli rozdelení do dvoch vekových skupín podľa užívania liekov ovplyvňujúcich prebeh ochorenia (<45 a ≥45 rokov). Významnosť depresie sa ukázala vo vzťahu k sebaopisujúcemu fyzickému zdraviu v skupine starších pacientov a voči sebaopisujúcemu duševnému zdraviu v skupine mladších pacientov so SM. Anxieta sa prejavila ako dôležitejší faktor sebaopisovaného zdravia v mladšej vekovej skupine pacientov so SM.

Nakoniec, kapitola 7 zahŕňa hlavné zistenia tejto štúdie a rozpracováva ich v širšom kontexte. Tak isto reflektuje opodstatnenosť teoretického modelu, ktorý slúžil ako podklad pre túto prácu a končí diskusiou o možnostiach uplatnenia poznatkov v klinickej praxi.

Táto práca poskytuje niekoľko odporúčaní pre budúci výskum a prax: pokračovať v longitudinálnom výskume a porovnať údaje z prierezovej štúdie a longitudinálneho výskumu; rozšíriť teoretický rámec výskumu o skúmanie ďalších faktorov; podporovať rehabilitačné a neurorehabilitačné aktivity pacientov pre zlepšenie sebaopisovaného zdravotného stavu; podieľať sa na psychosociálnych intervenciách napr. kognitívno-behaviorálnej terapii, sociálnej opore a skupinovej psychoterapii; zabezpečiť multidisciplinárny prístup k liečbe symptómov u pacientov so SM.

Nečakané zhoršenie funkčného stavu môže spôsobiť pacientom so SM obavy z neistej prognózy. Preto by mali byť veľmi dobre informovaní o svojom ochorení. Základom v starostlivosti o pacienta je spolupráca medzi ním, rodinou a zdravotníckym personálom. Lekári by mali neustále sledovať, či je potrebné poskytnúť pacientovi a jeho rodine psychologickú pomoc, keďže depresia býva častá a výskyt samovrážd v tejto skupine pacientov býva relatívne vysoký. Kvôli mnohým komplikáciám v dôsledku SM je v medicínskej a fyzioterapeutickej liečbe potrebný multidisciplinárny prístup. Nedávny pokrok v liečbe ukázal, že magnetická rezonancia (MRI) a spektroskopia umožňujú lekárom sledovať patologický postup ochorenia a reakcie pacientov na liečbu. Paralelne s vývojom nových diagnostických metód a liečby začali vedci viacej chápať súvislosti medzi progresom ochorenia a vplyvom psychosociálnych faktorov u pacientov so SM.



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Martina Krokavcova was born on October 22, 1975, in Hnusta, Slovak Republic. After completing secondary school in Rimavska Sobota she studied psychology at the Department of Psychology, University of PJ Safarik, Kosice. Her Master's dissertation "Psychological well-being among cancer patients and patients after heart attack" dealt with mental health status in two most occurring chronic diseases. In the years 1999-2001 she worked for the high school in Tisovec as a school psychologist and teacher. She delivered lectures on psychology, prepared Slovak students for attending US high schools and was involved in diagnostics and psychological counselling. In the following two years she was a psychologist for the Pedagogical, Psychological and Consulting Centre in Kosice. She cooperated with teachers and parents of students with mental problems. In 2003 she started her work at the University of PJ Safarik as a researcher while also starting her PhD studies at University of Groningen, The Netherlands. In addition, she delivered lectures on developmental psychology for students of nursing at the Faculty of Medicine, at social-psychological training sessions, supervised students' bachelor degree dissertations and participated in an international research project. During this time she finished training in relaxation-imaginative psychotherapy. At present she is working at the 1<sup>st</sup> Department of Psychiatry, Faculty of Medicine, University of PJ Safarik as a university teacher, and for the University Hospital as a clinical psychologist. Her professional interests focus on research on the psycho-social determinants of health behaviour in patients with multiple sclerosis and mental disorders, social-psychological training and improving communication skills in medicine.



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