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Perceived health status in multiple sclerosis patients

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Social support as a predictor of perceived health status in patients with multiple sclerosis³

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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 ± 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 ± 10.5 years) were significantly older than the participants (38.4 ± 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 ± 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 ± 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)

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

Variable	%	M	SD	Range
PSSS				
Family		23.0	4.9	4 - 28
Friends		20.7	5.1	4 - 28
Others		23.2	4.9	4 - 28
Social network				
Contact with relatives				
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			
Contact with friends				
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			
Going to club/pub				
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			
Hindered by health problems in maintaining contacts				
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 ± 20.2 and the mental health summary scale mean score from SF-36 was 57.0 ± 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 ± 4.9 , from friends 20.7 ± 5.1 and from others 23.2 ± 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
Adjusted R²	.54	.10	.19	.17	.44	.17	.31	.07	.17	.24

Note:

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

Displayed values are standardized β 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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