


Self-esteem, social participation, and quality of life in patients with multiple sclerosis

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Abstract

The aim of this study is to explore whether self-esteem and social participation are associated with the physical and mental quality of life (Physical Component Summary, Mental Component Summary) and whether self-esteem can mediate the association between these variables. We collected information from 118 consecutive multiple sclerosis patients. Age, gender, disease duration, disability status, and participation were significant predictors of Physical Component Summary, explaining 55.4 percent of the total variance. Self-esteem fully mediated the association between social participation and Mental Component Summary (estimate/standard error = -4.872; $p < 0.001$) and along with disability status explained 48.3 percent of the variance in Mental Component Summary. These results can be used in intervention and educational programs.

Keywords

multiple sclerosis, physical and mental domain of health-related quality of life, self-esteem, social participation

Introduction

Symptoms of multiple sclerosis (MS) are of both physical (Miller et al., 2014) and mental (Briones-Buixassa et al., 2015; Ensari et al., 2015; Stepleman et al., 2014) nature. The impact of these symptoms makes the life of MS patients different from healthy people. Along with social well-being, physical and mental aspects are crucial for health (World Health Organization (WHO), 1946). MS patients report their health-related quality of life (HRQoL) as worse compared to the general population in both the

physical (Physical Component Summary (PCS)) and the mental (Mental Component Summary

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(MCS)) domains (Gedik et al., 2015; Klevan et al., 2014; Senders et al., 2014).

MS patients differ from the general population in several ways. Level of self-esteem, lower in MS patients, is one of these differences (Sarisoy et al., 2013). Self-esteem is the result of a personal self-view, the assessment of oneself, and it is prone to changes over time (Kernis et al., 1989). The diagnosis of a chronic disease might be a driver of change in self-esteem (Nosek et al., 2003). The level of self-esteem is also associated with other concepts shaping HRQoL, such as depression, with evidence supporting the vulnerability model of their association in which low self-esteem contributes to depression (Orth and Robins, 2013), or with anxiety which also shows an association with low self-esteem (Sowislo and Orth, 2013).

Social participation is another concept associated with self-esteem (Geyh et al., 2012; Suzuki et al., 2011), and satisfactory social participation is important for HRQoL in various health conditions (Cooper et al., 2014; Yeung and Towers, 2014). Social participation is responsive to health impairments and limitations arising in physical activity over time, along with environmental and personal factors (Dijkers, 2010). It is also closely intertwined with HRQoL, and engagement with various activities of the social community, friendships or work is perceived as helpful and health persevering (Andonian and MacRae, 2011). Specifically for MS population, previous results showed that social participation is positively associated with certain aspects of HRQoL (Mikula et al., 2014).

Social participation and self-esteem both seem to be protective factors for HRQoL in chronic and general populations (Black and Dorstyn, 2015). These two concepts differ in few key aspects. Self-esteem is internal protective factor built around image of oneself, which although can be influenced by other individuals, but is always constructed internally and is intrapersonal (Judge et al., 1998). Social participation, on the other hand, is defined by social inclusion/exclusion and as so is dependent on interpersonal relationships (Levasseur et al., 2010).

The aim of this study is thus to explore whether self-esteem and social participation are associated with the physical and mental domains of quality of life and whether self-esteem can mediate the association between social participation and HRQoL. Self-esteem was chosen as the possible mediator because of the intraindividual nature of this variable. While social participation can be somewhat influenced by outside factors like distance, peers themselves, and lack of time, self-esteem is always with the person and may affect decision-making process when it comes to social participation. Also, to our knowledge, no other research focused on this particular mediation before.

Methods

Participants

Patients meeting the McDonald criteria were asked to participate in the study (Polman et al., 2005). Out of 155 consecutive MS patients from the Department of Neurology of the Louis Pasteur University Hospital in Košice, 37 refused to participate in the study (response rate, 76.1%). Exclusion criteria were applied to the rest of the sample. These were as follows: presence of a psychiatric diagnosis in the medical record, the Mini-Mental State Examination (MMSE) <24, pregnancy, and the inability to speak Slovak. The final sample ($N=118$) consisted of 72.2 percent women, with a median age of 41.5 years (range, 18–61 years). There were no statistically significant differences between respondents and non-respondents in terms of gender or age.

Procedure

This cross-sectional study consisted of a semi-structured interview, self-reported questionnaires, and a neurological examination. The invitation letter, the written informed consent form, the non-response sheet, and the questionnaires were sent to participants' homes by postal mail. After 2 weeks, patients were reminded about the questionnaire by a phone call. During this phone call,

the interview and neurological examination were arranged as well. The same neurologist carried out the neurological examinations on all patients, and a trained interviewer conducted the semi-structured interview, acquiring information on age, gender, and education among other variables. Examinations took place at the Neurology Outpatient Clinic.

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

Measures

Sociodemographic and clinical variables. Sociodemographic variables were retrieved during interview, including information on age, gender, and education (elementary, secondary, and university). Clinical variables were retrieved from medical records, including disease duration (in years), Expanded Disability Status Scale (EDSS; score ranges from 0.0 to 10.0, with a higher score indicating more severe disability), and type of MS.

Self-esteem. The self-esteem of patients was measured by the Rosenberg Self-Esteem (RSE) scale (Rosenberg, 1965). It consists of 10 items assessing global self-esteem (Robins et al., 2001). Examples of items include "On the whole, I am satisfied with myself," or "At times I think I am no good at all." Five items are worded negatively and five positively, which were then recoded. The score ranges from 10 to 40, with a higher number indicating a higher level of self-esteem. In our study, self-esteem was treated as a continuous variable. Cronbach's alpha for RSE in our sample was 0.87.

Social participation. This variable was measured using the Participation scale (P-scale). It includes 18 items, and its use is intended for people in stigmatized conditions (Van Brakel et al., 2006). Each item includes two questions. The first question goes into some aspect of social participation in comparison with one's peers, for example, "Do you take part in as many casual recreational/social activities as your peers?" If participants

answer "Yes" or "Irrelevant/I don't want to, I don't have to," their answer is scored 0. If the answer is "Sometimes" or "No," the next question is "How big a problem is this for you?" Participants then choose from four options: "No problem," "Small," "Medium," or "Large," which are scored 1, 2, 3, or 5, respectively. The summary score can range from 0 to 90, with a higher score indicating more restriction in social participation. Based on the score, the authors sort respondents into five categories of restrictions in social participation: no restrictions, mild restrictions, moderate restrictions, severe restrictions, and extreme restrictions (Van Brakel et al., 2006). We treated participation as a continuous variable. Cronbach's alpha for the P-scale in our sample was 0.89.

HRQoL. HRQoL was assessed using the 36-item Short-Form (SF-36) health survey (Ware and Sherbourne, 1992). The SF-36 includes multiple items to measure eight scales: (1) physical functioning (10 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) psychological distress and well-being (five items), (7) role limitations due to emotional problems (three items), and (8) vitality, energy, or fatigue (four items). The questionnaire additionally includes one question which covers changes in health status over the past year. All item scores are coded and transformed into a scale ranging from 0 (poor health) to 100 (optimal health). The PCS and the MCS were calculated. The component summary scores are normalized to a general population mean of 50 and a standard deviation of 10. A higher score indicates better HRQoL in both dimensions. Cronbach's alpha was 0.92 for the PCS and 0.93 for the MCS.

Statistical analyses

Descriptive analyses of the study variables were carried out first, followed by linear regression analysis (the enter method), which examined the variance of the dependent variables (PCS, MCS) explained by studied variables and

Table 1. Description of the study population ($N=118$).

Variables	<i>N</i> (%)	Median	95% CI	Range
Age (years)		40.5	37–43	18–61
Gender				
Male	34 (28.8%)			
Female	84 (72.2%)			
Education				
Elementary	6 (5.1%)			
Secondary	86 (72.9%)			
University	26 (22.0%)			
Disease duration (years)		6	5–8	1–28
MS course				
CIS	14 (13.9%)			
RRMS	71 (70.3%)			
SPMS	16 (15.8%)			
EDSS		3	2.5–3.5	1.0–7.0
RSE		29	27–30	18–49
Participation		16	9–22	0–60
Quality of life				
PCS		38.1	33.7–41.6	18.5–60.0
MCS		43.1	38.4–48.0	18.8–67.2

CIS: Clinically isolated syndrome; RRMS: relapse-remitting multiple sclerosis; SPMS: simple progressive multiple sclerosis; EDSS: Expanded Disability Status Scale; RSE: Rosenberg Self-Esteem; PCS: Physical Component Summary; MCS: Mental Component Summary; CI: confidence interval; MS: multiple sclerosis.

Missing values: EDSS: 12.7 percent; disease duration: 4.2 percent; and MS course: 14.4 percent.

controlled for sociodemographic and clinical variables. Next, the mediating effect of self-esteem on the association between social participation and HRQoL was examined by structural equation modeling, controlled for sociodemographic and clinical variables. Statistical analyses were performed in IBM SPSS 20 and Mplus 7.1.

Results

A basic description of the study population is given in Table 1 ($N=118$). The median age of the MS respondents was 40.5 years, and the sample consisted of 72.2 percent women. The median EDSS score was 3, and median disease duration was 6 years. The majority of the patients (70.3%) belonged to relapse-remitting clinical course (Table 1).

After having described the study sample, we proceeded with multiple linear regressions (the

enter method) for both dimensions of HRQoL, PCS and MCS. Results of these analyses showed that age, disease duration, EDSS, and participation explained a significant amount of the total variance in PCS, while in MCS only EDSS and self-esteem were found to be significant in the final model (Table 2).

Finally, to assess the effect of self-esteem on the association between participation and both dimensions of HRQoL, we used structural equation modeling. Results showed that in PCS, no mediation by self-esteem was present and that only a direct association between participation and PCS was significant. In the second model, however, self-esteem showed full mediation and had a statistically significant indirect effect on the association between participation and MCS (Table 3).

These mediations were controlled by sociodemographic and clinical variables. Beta coefficients were statistically significant for age,

Table 2. Correlations of the variables under study.

	Age	Gender	Education	Disease duration	EDSS	Participation	Self-esteem	PCS
Age								
Gender	0.10							
Education	-0.12	-0.14						
Disease duration	0.24*	-0.03	-0.08					
EDSS	0.39*	0.21*	-0.24*	0.45*				
Participation	0.24*	0.08	-0.24*	0.33*	0.38*			
Self-esteem	0.02	0.01	0.03	-0.18*	-0.07	-0.44*		
PCS	-0.46*	-0.07	0.14	-0.22*	-0.59*	-0.60*	0.21*	
MCS	-0.01	0.02	0.10	-0.10	0.05	-0.29*	0.62*	0.10

EDSS: Expanded Disability Status Scale; PCS: Physical Component Summary; MCS: Mental Component Summary; bold values: $p < 0.05$.

Table 3. Total, indirect (mediation by self-esteem), and direct effects of the studied models.

	PCS				MCS			
	Est.	SE	Est./SE	Sig.	Est.	SE	Est./SE	Sig.
Total	-0.387	0.072	-5.406	0.000	-0.316	0.096	-3.291	0.001
Specific indirect	-0.013	0.033	-0.407	0.684	-0.313	0.064	-4.872	0.000
Direct	-0.373	0.081	-4.594	0.000	-0.003	0.088	-0.033	0.974

PCS: Physical Component Summary; MCS: Mental Component Summary; Est.: estimate; SE: standard error; Sig.: significance; bold values: $p < 0.05$.

disease duration, and EDSS in PCS (Figure 1). In MCS, mediation of study variables by self-esteem was present. Beta coefficient was significant only in case of EDSS (Figure 2).

Discussion

The aim of this study was to explore whether self-esteem and social participation are associated with the physical and mental domains of quality of life and whether self-esteem can mediate the association between social participation and HRQoL.

The association between social participation and PCS did not seem to be mediated by self-esteem. The final model in the linear regression showed that age, disease duration, EDSS, and participation are significantly associated with PCS, explaining 55.4 percent of its total variance in the model. The reason for this result may be

the very physical nature of the variables. Age and disease duration are closely associated with deterioration over time and with more symptoms as the disease progresses (Scalfari et al., 2011). EDSS as a measure of functional disability has always been very strongly associated with PCS (Vermersch et al., 2002). Social participation to our knowledge has not been studied in this context before, although partial aspects of social life were examined before (Benka et al., 2012; Krokavcova et al., 2010; Turner et al., 2009; Van der Mei, 2007), and in association with barriers that can prevent participation in certain activities (Stroud et al., 2009). This is also a possible explanation as to why social participation is statistically significant in explaining PCS and not MCS. Participation in social life is dependent on the objective ability to physically meet with people. Patients cannot participate if their health status prevents it. On the other hand, the recent

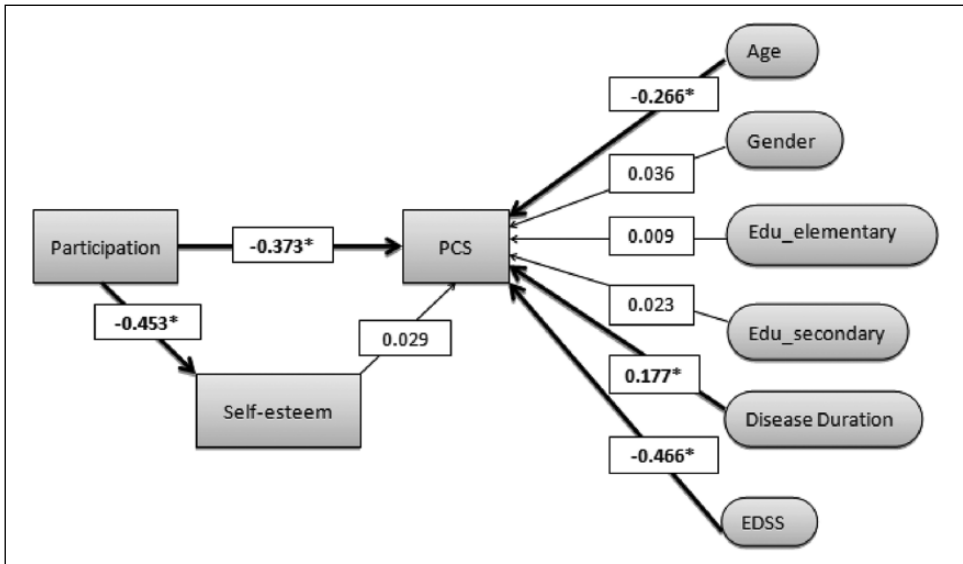


Figure 1. Mediation of self-esteem on the association between participation and PCS controlled for sociodemographic and clinical variables.

PCS: Physical Component Summary; Edu: education; EDSS: Expanded Disability Status Scale.

* $p < 0.05$.

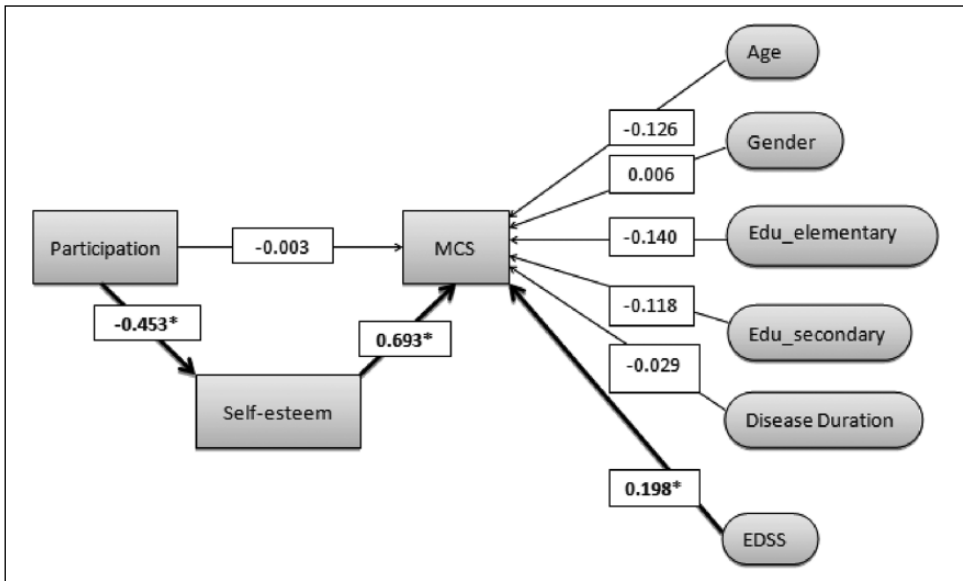


Figure 2. Mediation of self-esteem on the association between participation and MCS controlled for sociodemographic and clinical variables.

MCS: Mental Component Summary; Edu: education; EDSS: Expanded Disability Status Scale.

* $p < 0.05$.

expansion of social networking can possibly allow higher social participation even for people with more severe disabilities.

In MCS, self-esteem, along with EDSS, explained 48.3 percent of the total variance in our model and also fully mediated the association between participation and MCS. Self-esteem thus seems to be important in MCS, which is in line with previous findings in other chronic conditions (Bartoces et al., 2009; Garcia-Martinez et al., 2012; Platten et al., 2013). Being an integral part of how people see themselves, perceive their self-worth, and interact with others, self-esteem has an important role in mental well-being and MCS.

Strengths and limitations

Strengths of this study include a relatively high response rate (76.1%), the consecutive way of collecting data, as well as the complex modeling of variable interactions. Some limitations should be noted, however. The women-to-men ratio in MS is 2:1 (in our sample 72.2% women); our results may better explain the relationship between studied variables of women than that of men. Another limitation is that patients with a lower disease severity (mean EDSS, 3.2) were more likely to participate in the study than patients with a higher disability, who were more likely to refuse to participate. In addition, due to the cross-sectional design, any causal relationships drawn from our results should be interpreted with caution as the data are not longitudinal and are based on self-report, despite the complex statistical approach we used.

Implications

Various ways of improving self-esteem can be possibly applied for the benefit of MCS. It can be modified, for example, by social support (Dlugonski and Motl, 2012). Social support has been found to have a protective effect from various adverse effects on MCS (Eom et al., 2013), so encouraging and education of caregivers and relatives about positive social support for self-esteem may be beneficial. Encouraging MS

patients to engage in social participation can be also helpful, since we found an association with PCS. Social participation and leisure-time management associated with it (Dinas et al., 2011; Motl and McAuley, 2009) have potential to bring results, as self-esteem seems to be very responsive to educational programs and can be improved (Dinas et al., 2011; Hall-McMaster et al., 2015; Hughes et al., 2004; Madan and Pakenham, 2015; Motl and McAuley, 2009), thus educating patients, their caregivers, nurses, relatives, and physicians about this topic can help improve patients' self-esteem.

Such information can also be used in MS clubs, where seminars and educational lectures can help patients to increase their self-esteem and social participation. Psychotherapists working with MS patients can also use these data in their work and focus on increasing the level of self-esteem in order to improve MCS. Future research is needed, however, especially longitudinal studies which would give us more information about the causality of the associations between the studied variables.

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