

Research Paper

Social participation and health-related quality of life in people with multiple sclerosis

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Abstract of this article was presented at conference of European Health Psychology Society titled: Well-being, Quality of Life and Caregiving in Bordeaux, France, 2013.

Abstract

Background: Social participation is an integral part of everyday life in society; however, evidence about its association with health-related quality of life (HRQoL) in people with multiple sclerosis (MS) is lacking.

Objective: The aim of this study is to explore whether social participation is associated with the Physical Component Summary of HRQoL (PCS) and Mental Component Summary of HRQoL (MCS) in people with MS, controlled for age, gender, disease severity and disease duration.

Methods: The sample consisted of 116 consecutive people with MS (response rate: 75.8%; 72.4% women; mean age 40.3 ± 9.8). People with MS completed the Short-Form Health Survey (SF-36) for measuring PCS and MCS and the Participation Scale, which measures the level of social participation. Disability was assessed using the Expanded Disability Status Scale (EDSS). The associations between social participation, PCS and MCS, were analyzed using linear regression that controlled for sociodemographic and clinical variables.

Results: PCS was significantly associated with age, disease duration, EDSS and social participation. MCS did not show significant association with the studied variables. Overall, a multiple regression model explained 48% of the PCS variance, while the proportion of MCS variance explained was not significant.

Conclusions: Social participation was significantly associated with PCS, suggesting a possibility for intervention in this domain. © 2015 Elsevier Inc. All rights reserved.

Keywords: Multiple sclerosis; Social participation; Health-related quality of life

Multiple sclerosis (MS) is the most common neurological disease with disabling consequences in young adults. MS is a chronic progressive disease, with diffuse changes

This work was supported by the Slovak Research and Development Agency under contract APVV-0220-10 (80%). Furthermore, this work was partially supported by the Agency of the Slovak Ministry of the Education, Science, Research and Sport of the Slovak Republic for the Structural Funds of the EU under project no. ITMS: 26220120058 (20%).

Declaration of interest statement: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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in the white and gray matter, the breakdown of myelin and damage to axons.¹ These changes are manifested in a wide range of symptoms, depending on the location of the process in the central nervous system (CNS). They may include immobility, loss of eyesight, loss of independence and problems in relationships or in sexual intimacy, with these symptoms having the worst impact on health-related quality of life (HRQoL).²

HRQoL is a multidimensional concept that includes an individual's perception of the physical and mental components of HRQoL. In the case of MS, this concept is especially relevant, as the physical limitations inherent to the disease, such as the loss of personal independence, the loss of a job, fatigue, etc., are closely tied to social functioning

as well. The physical and mental functioning of people with MS is decreased in comparison with the general population.³ With the progression and longer duration of MS, neurological disability rises, causing in later stages not only physical, but also mental impairments.⁴

Social participation is associated with HRQoL in people with disabilities.^{5–7} Social participation is defined by the World Health Organization's International Classification of Functioning, Disability and Health (ICF) as involvement in life situations.⁸ It is affected by impairments and activity limitations interacting with environmental and personal factors.⁹ Social participation is closely linked to self-esteem, life satisfaction and mental health status, which makes it a very important factor for HRQoL.^{10,11} Engagement with community activities, friendships and meaningful volunteer work are perceived as strategies for maintaining social participation, especially for people with a chronic disease.¹²

Thus far, little research has been conducted among people with MS regarding the association between their social participation and HRQoL. In some studies, social participation was measured merely as a part of the general quality of life concept¹³; only physical handicaps related to social participation were taken into account, including mobility¹⁴ and communicative participation.¹⁵ A number of studies have focused on the psychometric properties of the social participation measurement instruments^{16–18} but not on the association between social participation and the actual HRQoL. Thus, the aim of this study is to explore the association of social participation with the physical and mental dimensions of HRQoL in people with MS, controlled for sociodemographic variables, disease duration and disease severity.

Methods

Participants

People who met the McDonald criteria (objective clinical findings, dissemination of specific lesions in the central nervous system and a paraclinical examination which helps to exclude false-positive and false-negative diagnoses of MS) were eligible for the study.¹⁹ A total of 153 consecutive people with MS from the Neurology Department of the L. Pasteur University Hospital in Košice were asked to participate in the study. There was no selection based on age, gender or other variables. All people meeting the inclusion criteria (diagnosis of MS) who were scheduled for their regular neurological examination were asked to participate; 37 people (64.8% women and 35.2% men) refused to participate (a response rate of 75.8%). Exclusion criteria were psychiatric diagnosis, a Mini-Mental State Examination (MMSE) score <24, pregnancy, the inability to speak Slovak and diagnosis of clinically isolated syndrome.²⁰ Data collection took place between April 2011 and December 2012. 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 self-reported questionnaire, a semi-structured interview 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. People in the study sample were reminded about the questionnaire by a phone call two weeks later. During this phone call, the interview and neurological examination were arranged. The same neurologist carried out the neurological examinations on all people and a trained interviewer conducted the semi-structured interview, acquiring information on age, gender, education and disease duration among other variables. Examinations took place at the Neurology outpatient clinic.

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

Measures

All questionnaires used in this study were translated from the original language. A back translation was then done to ensure that no meaning was lost in the translation. Final changes in the translated version were made accordingly.

Sociodemographic and clinical variables

Sociodemographic and clinical variables were retrieved from medical records and via the interview. During statistical analyses, the age of participants at the time of data collection was used. Besides disease duration (in years), EDSS (score ranges from 0.0 to 10.0 with higher score indicating more severe disability) and type of MS were retrieved from medical records, while information on age and education (elementary, high school and university) was gathered from the interview. People in the sample were diagnosed with the relapse-remitting (R–R) type of MS and the secondary-progressive (S–P) type of MS.²¹

Social participation

This variable was measured by the participation scale (p-scale), which includes 18 items and is intended for people with stigmatized conditions.²² Each item consists of 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 as 1, 2, 3 or 5,

respectively. The summary score can range from 0 to 90, with a higher score indicating more restriction and greater dissatisfaction with the amount of social participation. Based on the final score the authors also created five categories of restrictions in social participation: No restrictions (0–12), Mild restrictions (13–22), Moderate restrictions (23–33), Severe restrictions (34–53) and Extreme restrictions (54–90).²² We treated social participation as a continuous variable. Cronbach's alpha for the *p*-scale in our sample was 0.88.

Health-related quality of life

HRQoL was assessed using the 36-item Short-Form (SF-36) health survey.²³ The SF-36 includes multi-item scales used to measure 8 dimensions: 1. Physical functioning (ten items), 2. Role limitation due to physical health (four items), 3. Bodily pain (two items), 4. General health (five items), 5. Social functioning (two items), 6. Psychological distress and well-being (five items), 7. Role limitation 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). All item scores are coded and transformed into a scale of 0 (poor health) to 100 (optimal health). The Physical Component Summary (PCS), which includes dimensions one through four (21 items), and the Mental Component Summary (MCS), which includes dimensions five through eight (14 items), were calculated and also range from 0 to 100, with a higher score indicating better health in both dimensions. In our study Cronbach's alpha was 0.92 for the PCS and 0.93 for the MCS.

Statistical analyses

Firstly, descriptive analyses of the study variables were carried out (elementary and high school education were coded as dummy variables and university education was used as the reference category). Next, PCS and MCS were regressed on social participation and controlled for age, gender, education, disease duration and EDSS. Statistical analyses were performed in IBM SPSS 20.

Results

A basic description of the study population is given in Table 1 (*n* = 116). The respondents averaged 40.35 years old and consisted of 72.4% women. The mean EDSS score was 3.08, and the mean disease duration was 7.04 years. The majority of people (79.2%) were diagnosed with the relapse-remitting clinical type (Table 1).

Before we proceeded with the regressions, we prepared the data, starting with the correlations, which indicated that EDSS correlated strongly with the sociodemographic data. PCS correlated with age, EDSS and social participation, and MCS correlated only with social

Table 1
Characteristics of the study population (*N* = 116)

Variables	<i>N</i> (%)	Mean	SD	Range
Age (years)	116	40.35	9.89	18–61
Gender				
Male	32 (27.6%)			
Female	84 (72.4%)			
Education				
Elementary	6 (5.2%)			
High school	83 (71.6%)			
University	26 (22.4%)			
Disease duration (years)		7.04	5.80	1–28
MS type				
CIS	8 (9.7%)			
RRMS	65 (79.2%)			
SPMS	9 (10.9%)			
EDSS		3.08	1.27	1–6.5
Participation	116	20.37	18.07	0–60
1	54 (46.6%)			
2	15 (12.9%)			
3	13 (11.2%)			
4	25 (21.6%)			
5	9 (7.8%)			
Quality of life				
PCS	116	38.59	11.25	18.56–60.0
MCS	116	42.91	12.19	18.88–67.24

CIS – clinically isolated syndrome; RRMS – relapse-remitting multiple sclerosis; SPMS – simple progressive multiple sclerosis; EDSS – Expanded Disability Status Scale; 1 – no restrictions; 2 – mild restrictions; 3 – moderate restrictions; 4 – severe restrictions; 5 – extreme restrictions; PCS – Physical Component Summary; MCS – Mental Component Summary; Missing values: EDSS: (23.2%), Education: (0.9%), Disease duration: (12.9%), MS type: (29.3%).

participation. The subscales of the SF-36 did not correlate (Table 2).

In linear regression analyses (Table 3) PCS and MCS were regressed on social participation and controlled for age, gender, education, disease duration and EDSS. The outcomes of multiple linear regression analyses indicate that social participation is an important factor associated with PCS, where its statistically significant contribution added another 14% to the previous model, so that the final variance of the model was 48%. EDSS and disease duration seem to be important only for PCS as well. In MCS only the beta coefficient of social participation showed significance, but the overall variance of the whole model was not significant.

Discussion

The aim of this study was to determine if there is an association between social participation and the physical and mental components of health-related quality of life in people with MS. These associations were controlled for demographic and clinical variables. Our results provide evidence that social participation is an important factor associated with PCS, while in MCS it was not significant.

According to our results, higher PCS scores are associated with higher levels of peoples' satisfaction with the

Table 2
Correlations between the variables under study

	Age	Gender	Edu_elem	Edu_HS	EDSS	Disease duration	Participation	PCS
Age								
Gender	0.13							
Edu_elem	0.13	0.11						
Edu_HS	-0.01	-0.00	-0.40					
EDSS	0.35	0.26	0.14	0.03				
Disease duration	0.15	-0.04	0.02	0.00	0.24			
Participation	0.18	0.12	0.10	0.17	0.25	0.26		
PCS	-0.43	-0.11	-0.04	-0.10	-0.54	-0.04	-0.57	
MCS	0.02	0.06	0.02	-0.10	0.09	-0.18	-0.27	0.03

Edu_elem – Elementary education; Edu_HS – High School education; EDSS – Expanded Disability Status Scale; PCS – Physical Component Summary; MCS – Mental Component Summary.

Bold indicates significant at $P < 0.05$.

amount of social participation they engage in. A similar result was found on the other side of the scale, where low levels of social participation were associated with lower levels of PCS. In previous studies authors have suggested that the association between PCS and social participation is present because people with chronic diseases often experience some form of mobility impairment and thus consider their HRQoL to be better when they can still manage to integrate into the community compared with those whose social activity is low.¹⁴ People with increased social participation can have a higher PCS because they are more involved in social life, or this involvement may result from the minimal obstacles in PCS, thus allowing for more social participation. Satisfaction with social participation, as a subjective variable, may reflect various physical and

environmental factors that influence social participation.²⁴ Age, EDSS and disease duration showed a significant amount of variance in the final model, as expected, as they are closely tied to physical functioning and physical roles.²⁵

Our findings indicate that in MCS our proposed model is not significantly associated with this domain of quality of life, although the beta coefficient in social participation suggests that some weak association with social participation is present. But in interaction with other variables it does not add to the overall variance. The reason for this may be rooted in other variables and their effect on MCS, such as appropriate coping strategies,²⁶ lower levels of apathy and depression and higher levels of cognition and self-efficacy in people who agreed to participate in the study.²⁷

Table 3
Multiple linear regression analyses (enter method): PCS and MCS regressed on social participation and controlled for age, gender, education, EDSS and disease duration

	PCS				MCS			
	Beta	<i>p</i> -values	F/F change	Adjusted R^2	Beta	<i>p</i> -values	F/F change	Adjusted R^2
Model 1			5.80/5.80	0.15			0.48/0.48	-0.02
Age	-0.40	0.00			0.02	0.78		
Gender	-0.04	0.61			0.07	0.46		
Elementary education	-0.03	0.69			-0.03	0.74		
Secondary education	-0.12	0.21			-0.12	0.25		
Model 2			7.61/14.14	0.34			1.34/2.63	0.02
Age	-0.21	0.03			-0.10	0.40		
Gender	0.09	0.33			0.07	0.51		
Elementary education	0.01	0.87			-0.05	0.62		
Secondary education	-0.01	0.90			-0.14	0.26		
EDSS	-0.56	0.00			0.17	0.18		
Disease duration	0.14	0.15			-0.25	0.03		
Model 3			11.12/19.66	0.48			2.01/5.53	0.08
Age	-0.16	0.06			-0.06	0.57		
Gender	0.08	0.34			0.06	0.55		
Elementary education	0.07	0.42			-0.02	0.86		
Secondary education	0.08	0.38			-0.07	0.55		
EDSS	-0.50	0.00			0.22	0.08		
Disease duration	0.20	0.02			-0.20	0.08		
Participation	-0.40	0.00			-0.28	0.02		

R^2 – explained variance; Gender – male gender was set as reference; Education – university education was set as reference; EDSS – Expanded Disability Status Scale.

Bold indicates significant at $P < 0.05$.

Strengths and limitations

The main strength of this study is the approach regarding social participation on the basis of peer comparisons with the HRQoL. This, although without a control group, gives us a better understanding of social participation in one's specific conditions and not only a comparison with the general average population. Some limitations should be noted, however. Although the women-to-men ratio in MS is generally 2:1, in our sample this ratio was higher (72.4% women); thus, the results may be better applied to HRQoL among women than among men. Also, people with a lower disease severity (mean EDSS 3.24) were more likely to participate in the study, while people with a more serious disability were more likely to refuse to participate. Thus, the findings can be generalized to people with lower disease severity and not to the whole populations of people with MS. Another limitation of the study is a similar focus of the *p*-scale, which refers to the phenomenon of performing one's role in society or taking part in activities in a group situation, and the role limitations subscale of the SF-36, which is focused on problems with work or other daily activities as a result of physical limitations. On the other hand, it measures social participation with far fewer items, does not involve the concept of peer comparison and is only a small part of the MCS dimension, with no links to PCS, which is the reason why we decided to use this measurement. Finally, HRQoL measured by the SF-36 can be considered as not entirely accurate, as this measurement is closely linked with functional status rather than with health, and functional limitation may be the reason for the negative bias.²⁸

Conclusion

This study is beneficial in that it shows that social participation is very important for PCS in people with MS. According to our results, isolation and avoiding social activities are associated with lower HRQoL in people with MS. Hiding from social activities may seem comfortable and easy, as it eliminates the stress from obstacles to social participation caused by health problems, but this study indicates that there is an association between social participation and PCS. This could be the basis for an intervention program for people with MS, where they could be educated about ways in which social activities can benefit them and can be encouraged to engage in social participation even if physical obstacles make it more difficult. This can also be beneficial for caretakers of these people, who can encourage them to engage in social activities and to visit family, friends or clubs for people with MS. Future research is needed, however, to determine the causality of the relationship between PCS and social participation. These recommendations can be included in intervention programs focused on social participation and tested by experimental design.

Acknowledgments

We wish to thank the people with multiple sclerosis who participated in this study.

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