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Research Paper

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

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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.

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 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

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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 concept[13]; only physical handicaps related to social participation were taken into account, including mobility[14] 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,