Education and Rehabilitation of Adult Persons with Disabilities

Thematic Collection of International Importance

Education and Rehabilitation of Adult Persons with Disabilities Thematic Collection of International Importance

Publishers

University of East Sarajevo, Faculty of Medicine Foča, Bosnia and Herzegovina
University of Belgrade – Faculty of Special Education and Rehabilitation – Publishing Centre of the Faculty (ICF), Serbia

For publishers

PhD Milan Kulić, Dean PhD Jasmina Kovačević, Dean

Editors

PhD Milan Kulić, Associate Professor PhD Danijela Ilić–Stošović, Associate Professor

Reviewers

PhD Goran Nedović, Professor, University of Belgrade – Faculty of Special Education and Rehabilitation, Serbia
PhD Hana Valkova, Professor, Masaryk University, Faculty of Sport Studies, Brno, Czech Republic
PhD Keith Storey, Professor, Touro University, Vallejo, California, United States of America

Processing and printing

Planeta print, Belgrade

Cover design

Milena Milićević Boris Petrović, MA

Technical Editor

Biljana Krasić

Circulation 100

ISBN 978-99955-733-9-3

By decision no. 01-3-169, from September, 16th 2014. The Teaching and Research Council of the Faculty of Medicine of the University of Foča in Eastern Sarajevo has given approval for the printing of Thematic Collection of international importance "Education and Rehabilitation of Adult Persons with Disabilities".

By decision no. 3/9 from March, 8th 2008. The Teaching and Research Council of the University of Belgrade – Faculty of Special Education and Rehabilitation initiated Edition: Monographs and papers.

DEMOGRAPHIC CHARACTERISTICS OF PEOPLE SUFFERING MULTIPLE SCLEROSIS AS DETERMINANTS OF SOCIAL PARTICIPATION

Lidija Ivanović, Danijela Ilić-Stošović & Veselin Medenica¹

University of Belgrade – Faculty of Special Education and Rehabilitation, Belgrade, Serbia

SUMMARY

Multiple sclerosis (MS) causes disability. Participation of people with MS in social activities is insufficiently researched area in special education. Finding the determinants of social participation of persons with MS is the first step to create different forms of intervention.

The aim of the research was to find the determinants of social participation among demographic characteristics of persons with MS.

 $Respondents were surveyed. \ Data were obtained by using \ Demographic question naire and Scale of social participation.$

The results of this study showed that people with MS have a moderate restriction of social participation. We found that age, monthly income, employment status, and living conditions are determinants of social participation.

When creating various social interventions special attention should be paid to the determinants of social participation of persons with MS.

Key words: social participation, multiple sclerosis, demographic characteristics, special education, somatopedia

INTRODUCTION

The World Health Organization (WHO) makes a serious effort in the integration of medical and social model into the bio-psycho-social model (WHO, 2001). Bio-psychosocial model considers disability as a result of the interaction between the poor health of the individual (physical, mental, emotional) and his/her surroundings. Result of these interactions is dysfunction that can manifest as a loss or an abnormality in the body's structure and functioning, limitations in activities, restrictions to participation in life situations.

Within the International Classification of Functioning, Disability and Health (ICF), there was a change of terminology which included replacing the term "disability" by the term "activity limitations" and replacing the term "handicap" by the term "restrictions in participation". Thereby, the term "disability" has a much broader meaning and is an umbrella term for impairments, activity limitations and participation restrictions (WHO, 2001). Changing the terminology and expanded term "disability" open new, so far unexplored areas of defectology.

Literature review (Medenica et al., 2011) shows that research on the social participation of persons with disabilities who are suffering from multiple sclerosis is

very rare. Multiple sclerosis is one of the most common disease is a disorder of the CNS with a slow and often uneven progression. It is characterized by the multiple, sclerotic regions that can occur in the brain, brain cells, or into the spinal cord. The symptoms of MS vary from one person to another, and the condition is usually characterized by exacerbations and remissions, between which sometimes elapse months or years. It usually occurs between 20 and 40 years of age (Stanisavljevic, 2011). It is believed that multiple sclerosis affects about one million people worldwide (Nedović et al., 2008). MS as a result can have different degrees of disability (Medenica et al., 2011).

People with MS have fewer opportunities to actively participate in society (Sibley et al., 2006; Motl et al., 2006; Gray et al., 2006). According to the ICF, social participation is defined as involvement in life situations in relation to the degree to which a person actively is involved, not in relation to degree to which a person can be or want to be involved (WHO, 2001). Therefore, the social participation in this research will be considered through the above definition.

There is speculation on causes of restricted social participation in people with MS (Burnfield, 1984; Holmoy et al., 2012). Finding the determinants of social participation of people with MS is the first step in the development of intervention opportunity that will contribute to a higher level of participation and the implementation of appropriate systematic solutions (Thompson, 1999). Determinants of social participation, as seen through the ICF can be found in the characteristics of disease and impairment, limitation of activities, environmental factors and personal factors (Khan & Pallant, 2007).

The aim of this study is to explore the determinants of social participation in a group of people with MS through the analysis of the impact of demographic characteristics of people with MS on the level of social participation. We assume that some of the personal, socio-economic and educational characteristics of people with MS are the determinants of social participation in these people.

RESEARCH METHODOLOGY

The survey was conducted in the "Multiple Sclerosis Society of Serbia", "Multiple Sclerosis Society of Arandjelovac" and "Nursing Home for Adults with Disabilities" in Belgrade. Collection and processing of data are carried out simultaneously and continuously, with the approval of these institutions and members of the Multiple Sclerosis Society of Serbia.

For the purposes of this study, we used descriptive method. Subjects were interviewed and available medical records were reviewed.

Used instruments included: Socio-demographic questionnaire (includes variables: sex, age, education level, monthly income, marital status and family relations, employment status, employment status before the onset of MS and the environment (living conditions), Protocol for recording data on health status (includes data regarding the presence of MS and additional diseases, time of onset of MS, type of MS, disease symptoms), Participation Scale 6.0 (the participation Scale Development Team, PSDT; The Scale consists of 18 items and allows the quantification of limits in social participation faced by people with disability. It covers eight major life domains defined

by the ICF. Average time of administering the scale of social participation is about 20 minutes. Most of the questions asked respondents to compare their selves with their hypothetical peer or with someone like him in all aspects, except for the aspect of disease and disability. Respondents were asked whether their level of participation is equal to or less than in their peers. If the respondent indicates that there is a potential problem he/her was asked how big the problem was for him/her (it is no problem, a small problem, medium problem, large problem). Psychometric properties - validity, reliability, stability, and responsiveness to change - have been thoroughly tested in 6 languages and have proved to be excellent. The scale has been used in populations of people with leprosy, people with spinal cord injuries, polio and other types of impairments. The scale can be used by professionals in the field of rehabilitation, medical personnel and other sections involved in the socio-economic rehabilitation. Special training is not required for use. The scale was translated into Serbian in the "forward – back – translation" system. The scale is pre-coded and scores for each answer is in the field next to the answer. During the implementation procedure, the responses are recorded by circling the appropriate fields. In this way, each item receives a rating. Adding the score for all items gives a total score on the scale. Each item can be assessed by scores from 0 to 5 depending on the response. Therefore, the total score can range from 0 to 90. If the total score ranges from 0 to 12, it is believed that a person has no restrictions in participation. People scoring more than 12 would be classified as having restrictions in social participation.).

Data analysis was performed using the statistical package SPSS. We used descriptive statistics, correlation analysis and statistical techniques to compare groups.

Sample

The sample consists of people with multiple sclerosis, aged 30 to 65 years, of both sexes. The criteria for the formation of the sample were as follows: that people with MS are members of the Multiple Sclerosis Society of Serbia, they do not suffer from a disease that can affect a person's ability to understand the concept of participation in the study and they have completed at least primary education. The sample was balanced by gender. Of the total number (30) of the respondents, 14 respondents are males (46,7%), while 16 respondents are females (53,3%). Respondents were on average 51,08 (SD=7,70) years old, the youngest respondent was 30,2, while the oldest respondent 64,8. Other characteristics of the sample are presented in Table 1.

Table 1 Characteristics of the sample

| Table 1 Characteri | stics of the san | <i>пріе</i> | |
|--|------------------|-------------|-----------|
| Characteristics | N (%) | AS | SD |
| Age | / | 51,08 | 7,70 |
| Gender | | | |
| Male | 14 (46,7) | / | / |
| Female | 16 (53,3) | / | / |
| Residence | | | |
| Arandjelovac | 9 (30) | / | / |
| Belgrade | 21 (70) | / | / |
| Level of education | | | |
| No formal education | 0 (0) | / | / |
| Basic Education | 0 (0) | / | / |
| Secondary education | 22 (73,3) | / | / |
| Higher Education | 8 (26,7) | / | / |
| Martial status | | | |
| Single-never married | 5 (16,7) | / | / |
| Married / living with partner 15 | 15 (50,0) | / | / |
| Divorced – separated | 8 (26,7) | / | / |
| Widow/widower | 2 (6,7) | / | / |
| Employment status after the onset of MS | | | |
| Unemployed | 4 (13,3) | / | / |
| Employed | 1 (3,3) | / | / |
| Retired | 25 (83,4) | / | / |
| Employment status before the onset of MS | | | |
| Unemployed | 1 (3,3) | / | / |
| Employed | 28 (93,4) | / | / |
| Retired | 1 (3,3) | / | / |
| Average monthly income | / | 22 896,55 | 13 567,09 |
| 0 – 18 000,00 RSD | 11 (37,9) | / | / |
| 18 001 – 30 000 RSD | 10 (34,5) | / | / |
| 30 001 – 50 000 RSD | 8 (8,3) | / | / |
| Living conditions | | ŕ | · |
| Home conditions | 18 (60) | / | / |
| Institutionalized conditions | 12 (40) | / | |
| Year of diagnosis | / | 33,35 | 6,5 |
| MS type | - | | |
| Relapsing-remitting | 10 (41,7) | / | / |
| Primary progressive | 12 (50,0) | | |
| Secondary progressive | 2 (8,3) | | / |

RESULTS

Table 2 shows the results obtained on the scale of social participation in relation to the degree of restriction of participation.

Table 2 The degree of restriction of social participation

| Degree of restriction | N | % |
|-----------------------------------|----|-------|
| No significant restriction (0-12) | 7 | 23,3 |
| Mild restriction (11-22) | 4 | 13,3 |
| Moderate restriction (23-32) | 6 | 20,0 |
| Severe restriction (33-52) | 10 | 33,3 |
| Extreme restriction (53-90) | 3 | 10,0 |
| Total | 30 | 100,0 |

Distribution of social participation of respondents in relation to the age is shown in Table 3. Results of social participation were compared by T-test of independent samples, in a group of younger (aged of 30 to 50,83) and older respondents (aged of 50,84 to 65). There was a statistically significant difference in younger subjects (M = 39,46, SD = 25,89) and older subjects, M = 23,87, SD = 16,07; t (27) = 1,99, p <0,05 (mutually). Size of effect of difference between the mean values of the characteristics by the groups (mean difference = -15,59, 95% Cl: -0,51 to 31,68) was very large (η 2 = 0,12).

Table 3 Social participation in relation to age

| Dograp of restriction | 30- | 49,75 | 49,76 | 5-53,50 | 53,51+ | | |
|-----------------------------------|-----|-------|-------|---------|--------|-------|--|
| Degree of restriction | N | % | N | % | N | % | |
| No significant restriction (0-12) | 2 | 20,0 | 2 | 20,0 | 2 | 22,2 | |
| Mild restriction (11-22) | 2 | 20,0 | 0 | 0,0 | 2 | 22,2 | |
| Moderate restriction (23-32) | 1 | 10,0 | 2 | 20,0 | 3 | 33,3 | |
| Severe restriction (33-52) | 2 | 20,0 | 6 | 60,0 | 2 | 22,2 | |
| Extreme restriction (53-90) | 3 | 30,0 | 0 | 0,0 | 0 | 0,0 | |
| Total | 10 | 100,0 | 10 | 100,0 | 9 | 100,0 | |

Social participation of the respondents with respect to sex is shown in Table 4. Results of the social participation of male and female were compared by T-test of independent samples (Table 4). There were no significant differences found in male (M = 25,14, SD = 25,52) and female (M = 34,56, SD = 18,17), t (28) = -1,18, p = 0, 25 (mutually).

Table 4 Social participation in relation to gender

| Degree of restriction | | Male | Female | | |
|-----------------------------------|----|-------|--------|-------|--|
| Degree of restriction | N | % | N | % | |
| No significant restriction (0-12) | 4 | 28,6 | 3 | 18,8 | |
| Mild restriction (11-22) | 3 | 21,4 | 1 | 6,3 | |
| Moderate restriction (23-32) | 3 | 21,4 | 3 | 18,8 | |
| Severe restriction (33-52) | 2 | 14,3 | 8 | 50,0 | |
| Extreme restriction (53-90) | 2 | 14,3 | 1 | 6,3 | |
| Total | 14 | 100,0 | 16 | 100,0 | |

Among respondents with secondary education there is large degree of restrictions or no restrictions in social participation (by 8 or 36,4%). Among respondents with higher education it can be seen that two respondents (25%) have either small or severe or extreme restriction (Table 5). However, statistical analysis (ANOVA) showed that there was no statistically significant difference between groups on a scale of social participation (F (3) = 1,08, p = 0,37).

Table 5 Social participation in relation to education

| Dogwoo of vestriation | Seconda | ry education | Higher education | | |
|-----------------------------------|---------|--------------|------------------|-------|--|
| Degree of restriction | N | % | N | % | |
| No significant restriction (0-12) | 8 | 27,3 | 1 | 12,5 | |
| Mild restriction (11-22) | 2 | 9,1 | 2 | 25,0 | |
| Moderate restriction (23-32) | 5 | 22,7 | 1 | 12,5 | |
| Severe restriction (33-52) | 8 | 36,4 | 2 | 25,0 | |
| Extreme restriction (53-90) | 1 | 4,5 | 2 | 25,0 | |
| Total | 24 | 100,0 | 8 | 100,0 | |

Table 6 shows the results obtained on the scale of social participation in relation to the marital status of the respondents. The results of social participation in groups of people who currently have a partner and respondents without a partner were compared by T-test of independent samples. There was no statistically significant difference in respondents s without a partner (M = 35,07,SD = 23,89) and respondents with a partner (M = 25,27,SD = 19,59), t (28) = 1,2, p = 0,23 (mutually).

Table 6 Social participation in relation to the marital status

| Daniel Guardinian | Single/hav | ing no parner | Married/having a partner | | | |
|----------------------------------|------------|---------------|--------------------------|-------|--|--|
| Degree of restriction | N | % | N | % | | |
| No significant restriction(0-12) | 3 | 20,0 | 4 | 26,7 | | |
| Mild restriction (11-22) | 1 | 6,7 | 3 | 20,0 | | |
| Moderate restriction (23-32) | 3 | 20,0 | 3 | 20,0 | | |
| Severe restriction (33-52) | 6 | 40,0 | 4 | 26,7 | | |
| Extreme restriction (53-90) | 2 | 13,3 | 1 | 6,7 | | |
| Total | 15 | 100.0 | 15 | 100.0 | | |

Social participation of the respondents in relation to employment status is shown in Table 7. We wanted to compare the achievement of the respondents on a scale of participation by groups in terms of employment, however, the distribution of respondents in relation to employment status is not favourable for further statistical analysis.

Table 7 Social participation in relation to employment status

| Degree of | Current employment status Employment status before onset of MS | | | | | | | | | fore | | |
|----------------------------------|--|-------|------------|-------|----------|-------|---------|-------|------------|-------|---|-------|
| restriction | Employed Retired | | Unemployed | | Employed | | Retired | | Unemployed | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| No significant restriction(0-12) | 0 | 0,0 | 7 | 28,0 | 0 | 0,0 | 7 | 25,0 | 0 | 0,0 | 0 | 0,0 |
| Mild restriction (11-22) | 0 | 0,0 | 4 | 16,0 | 0 | 0,0 | 3 | 10,7 | 0 | 0,0 | 1 | 100,0 |
| Moderate restriction (23-32) | 0 | 0,0 | 5 | 20,0 | 1 | 25,0 | 6 | 21,4 | 0 | 0,0 | 0 | 0,0 |
| Severe restriction (33-52) | 1 | 100,0 | 9 | 36,0 | 0 | 0,0 | 10 | 35,7 | 0 | 0,0 | 0 | 0,0 |
| Extreme restriction (53-90) | 0 | 0,0 | 0 | 0,0 | 3 | 75,0 | 2 | 7,2 | 1 | 100,0 | 0 | 0,0 |
| Total | 1 | 100,0 | 25 | 100,0 | 4 | 100,0 | 28 | 100,0 | 1 | 100,0 | 1 | 100,0 |

ANOVA was used to study the effect of the level of monthly income on degree of social participation, measured by the Participation Scale 6.0. Subjects were divided into three groups according to level of monthly income (group 1: <18000,00 RSD, group 2: 18001,00 - 30000,00 RSD, group 3: 30000,00 - 50000,00 RSD RSD) (Table 8).

It was found that there was no statistically significant difference among members of groups at level p <0,05 on the Participation Scale 6.0 in the three groups: F (2,26) = 6,14, p = 0,007. Difference of effect size, expressed by the use of η 2, is 0,32. Post hoc analysis using Tukey's HSD test says that the mean of group 1 (M = 46,36, SD = 22,55) is significantly different from the mean of group 2 (M = 19,80, SD = 15,61) and group 3 (M = 22, SD = 17,83). Group 2 was not significantly different from group 3.

Table 8 Social participation in relation to the monthly income

| Degree of restriction | | 0-18000,00 | | -30000,00 | 30001-50000,00 | | |
|-----------------------------------|----|------------|----|-----------|----------------|-------|--|
| | | % | N | % | N | % | |
| No significant restriction (0-12) | 1 | 9,1 | 4 | 40,0 | 2 | 25,0 | |
| Mild restriction (11-22) | 0 | 0,0 | 1 | 10,0 | 2 | 25,0 | |
| Moderate restriction (23-32) | 2 | 18,2 | 3 | 30,0 | 1 | 12,5 | |
| Severe restriction (33-52) | 5 | 45,5 | 2 | 20,0 | 3 | 37,5 | |
| Extreme restriction (53-90) | 3 | 27,3 | 0 | 0,0 | 0 | 0,0 | |
| Total | 11 | 100,0 | 10 | 100,0 | 7 | 100,0 | |

Results of social participation in a group of institutionalized and non-institutionalized respondents were compared by T-test of independent samples. There was a statistically significant difference between groups of respondents in non-institutionalized housing (M = 20,22, SD = 17,78) and respondents in institutionalized housing, M = 47,67, SD = 21,64; t (25) = -3,52, p <0,005 (mutually). Difference of effect size between the mean values of the characteristics according to the groups (mean difference = -27,44, 95% CI: -43,50 to -11,38) was very large (η 2 = 0,33).

Table 9 shows the correlation between features of group of people with MS and individual variables within the Participation Scale 6.0.

Table 9 Correlation of characteristics of sample of individual items and Participation Scale 6.0

| Question | Age | Education | Monthly income | Employment status |
|--|--------------------------------|-------------------|-------------------|----------------------|
| | r | r | r | r |
| Do you have equal opportunity as your peers to find work? | -0,40* | 0,32 | -0,46* | 0,09 |
| Do you work as hard as your peers do? (same hours, type of work etc) | -0,40* | 0,07 | - 0,34 | 0,21 |
| Do you contribute to the household economically in a similar way to your peers? | -0,43* | 0,17 | -0,63** | 0,17 |
| Do you make visits outside your village/neighbourhood as much as your peers do? (except for treatment) e.g. bazaars, markets | -0,12 | 0,02 | -0,35 | -0,50 |
| Do you take part in major festivals and rituals as your peers do? (e.g.weddings, funerals, religious festivals) | -0,26 | 0,15 | - 0,34 | 0,09 |
| Do you take as much part in casual recreational/social activities as do your peers? (e.g. sports, chat, meetings) | -0,29 | -0,03 | -0,32 | 0,26 |
| Are you as socially active as your peers are? (e.g. in religious/community affairs) | -0,28 | 0,21 | -0,28 | 0,36* |
| Do you have the same respect in the community as your peers? | -0,27 | 0,45* | -0,43* | 0,52** |
| Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers? | -0,24 | 0,08 | -0,40* | 0,14 |
| Do you have the same opportunities as your peers to start or maintain a long-term relationship with a life partner? | -0,36 | 0,10 | -0,58** | 0,29 |
| Do you visit other people in the community as often as other people do? | -0,26 | -0,008 | -0,49** | 0,11 |
| Do you move around inside and outside the house and around the village/neighbourhood just as other people do? | 0,05 | 0,18 | -0,28 | 0,12 |
| In your village / neighbourhood, do you visit public places as often as other people do? (e.g. schools, shops, offices, market and tea/coffee shops) | 0,08 | 0,21 | -0,22 | -0,02 |
| In your home, do you do household work? | -0,18 | 0,40* | -0,19 | 0,18 |
| In family discussions, does your opinion count? | -0,47* | 0,34 | -0,61** | 0,47** |
| Do you help other people (e.g. neighbours, friends or relatives)? | -0,46* | 0,23 | -0,48** | 0,18 |
| Are you comfortable meeting new people? Do you feel confident to try to learn new things? | -0,46* - 0,30 | 0,42* 0,04 | -0,40* -0,44* | 0,38* 0,29 |

^{*}p<0,05, **p<0,005

DISCUSSION

As already mentioned in the research methodology, we obtained specified data using Socio-demographic questionnaire, while the data on social participation we obtained using the Participation Scale 6.0. Results that respondents achieved on shows that people with MS have average achievement at the Participation Scale 6.0 - 30,17 (SD = 22,04), which means that they have a moderate restriction of social participation. As the standard deviation of the achievements at the Participation Scale 6.0 is large, special attention will be focused on the distribution of respondents according to the restriction of social participation. Only 11 respondents (23,3%) have no restriction of participation while the majority of respondents said they had a severe limitation of participation (33,3%).

There was a statistically significant difference among younger respondents in relation to older respondents. Respondents in the younger age group have a higher level of restrictions in social participation, and older respondents have smaller degree of restrictions in social participation. Analysis of this data has to be very cautiously. It is expected to be that younger people with multiple sclerosis have less restriction in social participation. Questions within the scale of participation are designed in such a way that the respondents are requested to compare the possibility for their own participation in social activities to the opportunities for participation of hypothetical peers, ie. members of their own peer group, who do not differ from the respondents, except for the fact that they do not suffer from the disease. For younger people with MS, hypothetical construct of peer is usually a person who is very active and has a very high ability to participate in social activities. The older person is who completes the questionnaire, construct a hypothetical peer due to age has fewer opportunities of social participation that are close to real possibilities of social participation of people suffering from MS. In other words, distance in the perception of their own participation and the possibility of participation of hypothetical peer decreases with age. Although 56,3% of female sample have a severe or extreme restriction in participation, while only 28,6% of male participants have the same degree of limitation, a comparison of the two groups showed no statistically significant differences between the mean values at the Participation Scale 6.0, and it can not be said that sex determines the social participation of people suffering from MS.

When we observed group of respondents suffering from MS in relation to marital status, we assumed that people who are married or have a partner, have less restrictions in social participation in relation to people having no partners. We considered that there is possibility that people suffering from multiple sclerosis that are married or have a partner get a greater degree of support from family and therefore may have fewer restrictions in the participation than people having no partners. There was no statistically significant difference in respondents having no partners, and respondents having partners. Results of Prodinger et al., (2010) show that the presence of a partner does not have an impact on social participation, however, the quality of family relationships influences. The higher quality of family relationships among the respondents was, the lower restriction of participation was.

It was also found that the level of education of people suffering from MS does not represent a determinant of social participation. It should be noted that the distribution

of the respondents in relation to the level of education is such that most of the respondents, even 73,3% of the respondents have completed secondary education while 26,7% have completed higher education. The results show that the level of education does not represent a determinant of social participation. The level of education could mean greater financial resources, but given that we found that social participation depends on the level of monthly income, and does not depend directly on the level of education we can say that the higher level of education does not mean higher income, and in this sense it is understandable that the level of education does not represent a determinant. What we have not considered in our study, and which should be given special attention in future research is the effect of the cost-effectiveness of education to social participation in people with MS. In fact every kind of education enables person for certain jobs or occupations. There is a possibility that a person due to impairment incurred as a result of the disease is no longer able to perform the occupations that he/ her educated for, it would be important to examine which occupations are indicated for people with MS. In favour to the necessity of need of a further analysis of this issue are the results of our research regarding the employment of people before and after onset of MS. Before the onset of MS 93,4% were employed, 3,3% of respondents were retired and 3,3% unemployed, after the onset of the disease 83,4% were retired, 13,3% were unemployed and 3,3% were employed.

Nedovic et al., (2008) conducted a study in order to determine the characteristics of the social environment of people suffering from multiple sclerosis, to determine the attitudes of society towards these people and to assess the possibilities of social integration of people with multiple sclerosis. The study defined the relevant factors that create barriers and/or prejudices and bring this part of the population in the state of temporary or permanent social incompetence. The sample consisted of 316 patients with multiple sclerosis, of both sexes, aged 20 to 50 years, members of the Multiple Sclerosis Society of Serbia. Respondents were from Belgrade, Gornji Milanovac, Nis, Valjevo and Kragujevac. The results of this study show that in patients suffering from multiple sclerosis there are significantly reduced possibilities for employment, which significantly reduces their quality of life and reduces their social inclusion. The results of their study provide data that 66,6% of individuals with multiple sclerosis does not work and the fact that no one has a part-time job or part-time institutional engagement.

The results of our survey show that the majority of people with MS are in retirement. Prodinger et al., (2010) reported that the Swiss policy is specific because it strives to retain people with MS in employment as longer as possible. This is not true for Serbia, therefore, it would be useful to further study the relation of legislation covering this area in Serbia with the legal requirements in the countries in the region and the world.

Monthly income of people with MS have an average of 23482,00 dinars (SD = 13837,00). Comparing this amount with the minimum wage in Serbia, which is for the month of April 2012 stood at 19320,00 RSD, we can say that the income realized by people with MS are slightly higher. It was found that monthly revenues represent a determinant of social participation of persons with MS, and the greater monthly income is, the lower limitations of social participation are. We found that the main variables from the Participation Scale 6.0 that are correlated with monthly income are the respect in the community and among peers, self-care, the ability to maintain long-

term relationship with a partner, visiting other people, taking the opinions of sufferer into account in family discussions, providing assistance to other people, the level of comfort in meeting new people and confidence in learning new things. These results are consistent to results of Bosme who found that the level of social participation decreases in patients suffering from chronic disease and having a lower income. In fact it has been shown that in patients with rheumatism, multiple sclerosis and pulmonary emphysema score on a scale of social exclusion decreases by 1,47 per euro (Bosma et al., 2005)

We observed a group of respondents housed in institutions of social care and a group of institutions who are outside of institutions that is, living at home. The results show that respondents in social care have greater restrictions in social participation than those living at home. These results were expected and indicate the unenviable position of people with multiple sclerosis in institutionalized housing.

Lesshafft et al., (2010) studied the social participation in people suffering from leprosy. Most respondents (86,0%) received a state pension and were not employed. It is conducted a systematic study of social restrictions in participation in people suffering from leprosy, and who have been or are stationed at the facility, which was a former colony intended to patients with leprosy. Specifically, in Brazil, isolation of these individuals was required from 1920 to 1962, while in practice it hold up to 1980. Lesshafft et al., (2010) came to the result that 40 of 77 (51,9%) patients suffering from leprosy, have restrictions in social participation measured by the Participation Scale. The percentage for people with MS in our study is much higher and amounts 76,7% of respondents. Of those with leprosy who have restrictions in the participation, the greatest number of respondents has mild limitation of participation, while a greater degree of restriction in participation has a very small number of respondents. In people with MS smallest number of respondents have mild restrictions and extensive restriction of participation, while a large number of respondents has moderate and severe restriction of social participation. From the above it can be concluded that greater restrictions on the participation have people with MS and that the distribution of the respondents according to the restriction in social participation is specific, ie. differs from the other types of disability.

It has been shown that there is a difference in the restriction of participation if the leprosy was diagnosed before 1982. Severe restrictions of participation are found in patients in whom the disease is diagnosed before in 1982, ie. in a situation in which people lived within the colony in complete isolation in relation to the period in which isolation developed in institutionalized accommodation. It also showed that people who are currently living at home have less restriction of participation than those living in an institution. In our study scores on the Participation Scale 6.0 differ significantly in a group of patients suffering from MS, and are stationed in institutionalized housing and group of people who suffer from MS, and live at home ie. in a family environment. It can be said that the results are to some extent consistent to research results of Lesshafft et al., (2010). When a person is in a natural environment with numerous social contacts there is less restrictions on participation. Researching the social participation of people with leprosy, the number of patient visits is especially emphasized as a determinant of social participation.

Our results suggest that when it comes to social participation, de-institutionalization would be one of the main forms of social interventions that would contribute to a drastic reduction in restrictions in social participation of individuals suffering from MS. This proposal is consistent with global trend of de-institutionalization of people with disabilities (Kaljaca & Ducic, 2010).

Our research showed some determinants of social participation in the field of demographic characteristics of respondents. It is recommended that future research should be oriented to finding the determinants of social participation in the domain of characteristics of the disease and damage of the structures and/or functions, activity limitations and environmental factors.

CONCLUSION

The results of this research show that people suffering from MS have a moderate restriction of social participation. Authors (PSDT, 2010) of the Participation Scale 6.0 suggest that the existence of any degree of restriction of social participation is an indication of some kind of social intervention. In this study we found that in the area of personal characteristics, social participation of individuals suffering from MS is determined by age. In the field of socio-economic characteristics, social participation of individuals suffering from MS is determined by monthly income, employment status, and living conditions (home, institutionalized). This confirms our assumption.

Young people with MS make a much bigger difference in social participation when their capabilities are compared with the capabilities of their hypothetical peers with respect to the elderly. We believe that the key to improved social participation in this case lies in the understanding of the fact that younger and older adults with MS have different needs and interests. It is necessary that these differences in the needs and interests are recognized by social policy, which will provide access to adequate support services.

When it comes to employment, solution for the inclusion of individual in the labour market should be sought in adaption of workplace and environment. It should ensure re-training and allow changing job types within the same company if possible.

In the process of gaining a higher level of social participation in people with MS should be noted that all team members – therapist, educator, psychologist or social worker, etc. – are adequately educated on the difficulties faced by people with multiple sclerosis (Yorkston et al., 2005; Steultjens et al., 2005).

Family of people with MS is the most important support for overcoming these difficulties. It is very important to prevent the collapse of family relationships and social participation of individual within the family. It should also prevent the family to be the only environment in which individual with MS works.

Since the results of our study indicate the presence of specific determinants of social participation, future research should be oriented to finding the determinants of social participation in the domain of characteristic of the disease and damage to the structures and/or functions, activity limitations and environmental factors.

REFERENCES

- Bosma, H., Diederiks, J.P., van Santen, H.M., & van Eijk, J.T. (2005). [More social exclusion of chronically ill patients with lower incomes]. Ned Tijdschr Geneeskd, 149(34), 1898-1902.
- 2. Burnfield, A. (1984). Doctor-patient dilemmas in multiple sclerosis. *J Med Ethics, 10*(1), 21-26.
- 3. Gray, D.B., Hollingsworth, H.H., Stark, S.L., & Morgan, K.A. (2006). Participation survey/mobility: psychometric properties of a measure of participation for people with mobility impairments and limitations. [Research Support, N.I.H., Extramural Research Support, Non-U.S. Gov't]. *Arch Phys Med Rehabil*, 87(2), 189-197. doi: 10.1016/j. apmr.2005.09.014
- Holmoy, T., Hanssen, K., & Beiske, A.G. (2012). Patient satisfaction in rehabilitation of patients with multiple sclerosis. *Tidsskr Nor Laegeforen*, 132(5), 523-526. doi: 10.4045/ tidsskr.11.1043
- 5. Kaljača, S., & Dučić, B. (2010). Deinstitucionalizacija i kvalitet života u zajednici osoba sa intelektualnom ometenošću. *Beogradska defektološka škola*, (2), 407-417.
- Khan, F., & Pallant, J.F. (2007). Use of International Classification of Functioning, Disability and Health (ICF) to describe patient-reported disability in multiple sclerosis and identification of relevant environmental factors. *J Rehabil Med*, 39(1), 63-70. doi: 10.2340/16501977-0002
- 7. Lesshafft, H., Heukelbach, J., Barbosa, J. C., Rieckmann, N., Liesenfeld, O., & Feldmeier, H. (2010). Perceived social restriction in leprosy-affected inhabitants of a former leprosy colony in northeast Brazil. [Research Support, Non-U.S. Gov't]. *Lepr Rev, 81*(1), 69-78.
- 8. Medenica, V., Ivanović, L., Dragojlović-Ružičić, R., & Arsić-Komljenović, G. (2011). Aktuelna shvatanja o multiploj sklerozi i mogućnosti procene invalidnosti kod obolelih osoba. *Zdravstvena zaštita, 40*(5), 7-12.
- 9. Motl, R.W., Snook, E.M., McAuley, E., Scott, J.A., & Douglass, M.L. (2006). Correlates of physical activity among individuals with multiple sclerosis. *Ann Behav Med*, 32(2), 154-161. doi: 10.1207/s15324796abm3202_13
- Nedović, G., Ilić-Stošović, D., & Ajdinski, G. (2008). Mogućnost socijalne integracije osoba obolelih od multiple skleroze. Beogradska defektološka škola, 3, 183-198.
- 11. Participation Scale Development Team. (2010). *Participation Scale User Manual.* Amsterdam: KIT Leprosy Unit.
- 12. Prodinger, B., Weise, A., Shaw, L., & Stamm, T. (2010). A Delphi study on environmental factors that impact work and social participation of individuals with multiple sclerosis in Austria and Switzerland. *Disability and Rehabilitation*, *32*(3), 183-95.
- 13. Sibley, A., Kersten, P., Ward, C.D., White, B., Mehta, R., & George, S. (2006). Measuring autonomy in disabled people: Validation of a new scale in a UK population. [Research Support, Non-U.S. Gov't Validation Studies]. *Clin Rehabil*, *20*(9), 793-803. doi: 10.1177/0269215506070808
- 14. Stanisavljević, J. (2011): *Kvalitet života osoba obolelih od multiple skleroze*, Diplomski rad, Fakultet za specijalnu edukaciju i rehabilitaciju, Univerziteta u Beogradu.
- 15. Steultjens, E.M., Dekker, J., Bouter, L.M., Leemrijse, C.J., & van den Ende, C.H. (2005). Evidence of the efficacy of occupational therapy in different conditions: an overview of systematic reviews. [Review]. *Clin Rehabil*, 19(3), 247-254.
- 16. Thompson, A.J. (1999). Measuring handicap in multiple sclerosis. [Comparative Study Review]. *Mult Scler*, 5(4), 260-262.
- 17. WHO (2001): International classification of functioning, disability and health: ICF. Geneva.
- 18. Yorkston, K.M., Johnson, K.L., & Klasner, E.R. (2005). Taking part in life: enhancing participation in multiple sclerosis. [Research Support, U.S. Gov't, Non-P.H.S. Review]. *Phys Med Rehabil Clin N Am, 16*(2), 583-594. doi: 10.1016/j.pmr.2005.01.003