



Univerzitet u Tuzli
Edukacijsko-rehabilitacijski fakultet



Udruženje za podršku i kreativni
razvoj djece i mladih

V Međunarodna
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Unapređenje kvalitete života djece i mladih

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COMPARISON OF THE LIFE QUALITY OF PERSONS WITH ACQUIRED AND INBORN DISABILITY

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ABSTRACT

Considering the numerous findings and results obtained by evaluations and researches it can be concluded that disability, inborn or acquired, significantly changes the quality of life of the individual, affecting her behavior, ability to perform daily activities and social competencies. Main goal of our research was to determinate whether there are differences in every day functioning and social activities in persons with acquired disability and persons with inborn disability. There was convenient sample of the research, including 32 subjects with multiple sclerosis and 25 examinees with cerebral palsy, older than 18 years and with normal IQ. Methodological structure is based on the methods of structural, descriptive and functional analysis, method of generalization and comparison method, and as techniques were used analysis of documentation, scaling and survey. We used a questioner composed by a combination of several assessment scales and indexes. Collected data were processed by standard statistical program SPSS 11 for Windows HP, with usage of the chi square tests. The analysis of the results confirmed that the persons with MS have bigger problem and difficulties in dealing with the disease and adaptation to the remaining abilities, which leads to the psychical barrier, apathy and withdrawal from the cultural-societal and social life. Twenty percentages of persons with cerebral palsy at least once a week participate in socio-cultural activities, versus 3,13% of persons with multiple sclerosis. It can be concluded that persons with inborn disability have better life quality because they learn how to deal with their disability from the birth.

Key words: inborn and acquired disability, daily activities, socio-cultural participation, multiple sclerosis and cerebral palsy.

INTRODUCTION

The meaning of "quality of life" varies from person to person, and so is contextually fluid: it may be shaped by health status, presence or absence of pain, happiness and acceptance, or fluctuations in social and economic status. More specifically "quality of life" is thus understood in terms of how people live their lives in correlation with the resources available to them, where beside economic and financial resources, also includes socio-cultural, psychological, environmental and interpersonal resources¹. Chronic conditions and degenerative illness with their long-term accompanying symptoms and physical impairments can take a psychological, social and economic toll, and are assumed to diminish a person's quality of life. For an individual with a disability, the most important domains of the quality of life, as identified in the literature are: physical health which enables greater mobility and activity, psychological well-being necessary for successfully dealing with the impairments, family and social support, which impact at the

acceptance and coping with the disability, as well as physical and care environment^{2,3}. Beside the structure of an individual's person, that influences the coping with the impairments and everyday activities, it is also necessary to point the influence of the type and degree of impairments, especially underlying the time of occurrence, inborn disability, or acquired later in the life. In that way we set our research, in order to emphasize the difference in the way of functioning and dealing with the daily problems, between persons with acquired impairment during the life and persons with inborn impairment, or impairments of the central nervous system occurred in the early childhood. More exactly we included persons with multiple sclerosis (MS) and persons with cerebral palsy (CP). Multiple sclerosis is chronic, unpredictable disease which presents the heterogeneous spectrum of an idiopathic, inflammatory, demyelination disease of the central nervous system (CNS). The term multiple sclerosis is composed according the pathoanatomical findings and originate from the terms "sclerosis" that means hardened plate (plaques) scar tissue, located in more areas of the CNS, named as "multiple"^{4,5}. In worldwide frames the borders of most common occurrence of the first MS symptoms are between 25.3 and 31.8 years, with a mean age of 29.2 years. As a result of high prevalence of the pathological process in the cranial and spinal brain, as well in the optical neurons, the symptoms of multiple sclerosis vary, but the first ones that most frequently dominated are: sensory abnormalities, locomotors problems, pain in the eyes and vision lost^{6,7}. Defining of the multiple sclerosis as progressive disease with an unpredictable prognosis has great impact on the emotional sphere of the patient, causing difficulties in psychological adaptation of the illness. Life with MS requires constant struggle with the symptoms during the relapses and coping with the impairments and the progression of the disease, leading to greater impairments and restrictions, which directly change the quality of life⁸. Despite multiple sclerosis, which presents acquired illness that causes disability, cerebral palsy (CP) presents group of unprogressive disorders of the movements and posture, caused by the damage of the developing brain, more precisely it presents the sum of motor impairments caused by the brain damages occurred before, during or after the birth, and according the literature has an incidence of 2 cases per 1000 live born persons. The term "cerebral" refers the brain, and the term "paralysis" refers the movement and posture impairments. Opposite of the persons with multiple sclerosis, those with cerebral palsy from the same beginning, from their birth or early childhood, learn how to deal with everyday life situations, according to their abilities^{9,10}.

METHODOLOGY OF THE RESEARCH

The main goal of the paper was to determinate the quality of life of the individuals with disabilities, by making a comparison between persons with acquired disability (persons with MS) and persons with inborn disability or occurred in the early childhood (persons with CP). More concretely the research was directed toward determination of the differences in the way of functioning and adjusting to the personal conditions, realization of daily activities and participation in social-cultural events. Perceiving the similar pathophysiological base of damages in

patients with multiple sclerosis and persons with cerebral palsy, destructed structure of the white brain mass by the process of demyelization or hypomyelination, the sample included 32 examinees with diagnosed multiple sclerosis at the age above 18 years, with the gender distribution of 12 males (37%) and also 25 examinees with cerebral palsy, older than 18 years and normal intellectual functioning, including 11 males or 44%. In the research there were applied the methods of structural, descriptive and functional analysis, method of generalization and comparison method, and from the techniques, analysis of the documentation, scaling and inquiry. In the research we used a questioner composed by a combination of several scales and indexes for assessments, adjusted to the specifics and characteristics of the sample and research conditions: Bartell index, Berg balance scale, Functional status questionnaire – FSQ, Frenchay Activities Index - FAI and the Index of disability. Once the data were collected, grouped and tabled, we approached to calculate the frequencies and percentages of the structure of the obtained results, as well statistical analysis of the results. The nature of the data imposed application of the Chi square tests: Pearson chi square test, Likelihood-ratio (LR) and Linear by linear association (G2). The mentioned analysis was performed with standard computer statistical program SPSS 11 for WindowsXP. For statistically significant difference we considered the difference at the level of significance $p < 0,05$.

RESULTS AND DISCUSSION

Application of the extensive questioner enabled detailed analysis of the quality of life of persons with multiple sclerosis and cerebral palsy, giving us clear presentation of their physical condition, mobility, completion of daily duties, their social life and etc. But we will present just some of the results. Knowing that the level of acquired education and professional training impact on the employment, and indirectly on the quality of life, we compared the level of acquired education in both groups examinees. From the table 1 can be noticed that bigger part of the examinees with multiple sclerosis, 20 (62%) have finished secondary school, with equal gender distribution, while 38% have finished graduated level, in which 10 females and two male respondents. In the control group, respondents with cerebral palsy, four examinees (16%) have primary education, where two are only basically literate, 12 examinees (48%) are with secondary education and nine examinees (36%) are with high education and most of them are females, 7. Considering the education structure of both groups of examinees, can be noticed that there is a statistically significant difference ($p = 0,030$), in the group of persons with multiple sclerosis there are not examinees with completed only primary school, and also in comparison to the group of cerebral palsy, in the first one there are more examinees with a graduate degree of education. We consider that this difference is a result of a later occurrence of the multiple sclerosis symptoms and subsequent reduction of the MS patients' capabilities, which enables them to complete their education before occurrence of the illness.

Table 1. Educational degree of examinees with multiple sclerosis and cerebral palsy

Education	N %	Disease			χ^2	df ^a	p ^{**}
		MS	CP	Sum			
Primary school	N	0	5	5	7,046625	2	0,030
	%	0	20	8,77			
High school	N	20	12	32			
	%	62,5	48	56,14			
Graduated level	N	12	8	20			
	%	37,5	32	35,09			
Sum	N	32	25	57			
	%	100	100	100			

^adf-degrees of freedom; ^{**}p -probability

Although there is a statistically significant difference in the educational structure of both groups of examinees, the further analysis showed that there is no difference in the percentages of employed and unemployed respondents with multiple sclerosis and cerebral palsy (Figure 1 and 2). The difference can be observed only in the group of respondents with multiple sclerosis, linking the educational degree with the employment, it can be seen that most of the employees, 6 examinees (67%) have graduated level of education, and only three respondents have finished secondary schools, which points to the fact that higher degree of education offers greater choices of job possibilities, and directly leads to greater employment of the examinees. The obtained results are indicators of the societal structure, persons with disabilities are not sufficiently integrated in the society, there are insufficient the models of adjusting to the workplace or prequalification according to the remaining abilities are missing, which on the other side changes the quality of life. Buchanan, Huang and Haufman long period, from 1993 to 2010 year, provided the study with young people with multiple sclerosis, in order to assess the quality of their lives. In their study they find a high correlation between the constancy of the workplace (employment), course and symptoms of the multiple sclerosis and dimensions of the quality of life based on the health status¹¹ Rocka with her coworkers in their research determinate that 90% of persons diagnosed with multiple sclerosis were employed before getting the diagnosis, and only 20% to 40% of them kept their workplace in duration of five years after the diagnosis. According to that, that job loss presents a very stressful situation for patients with multiple sclerosis thereby causing loss of the professional identity as well as financial power, Rocka believes that employment is directly related to the overall quality of life of the people with multiple sclerosis and their families¹².

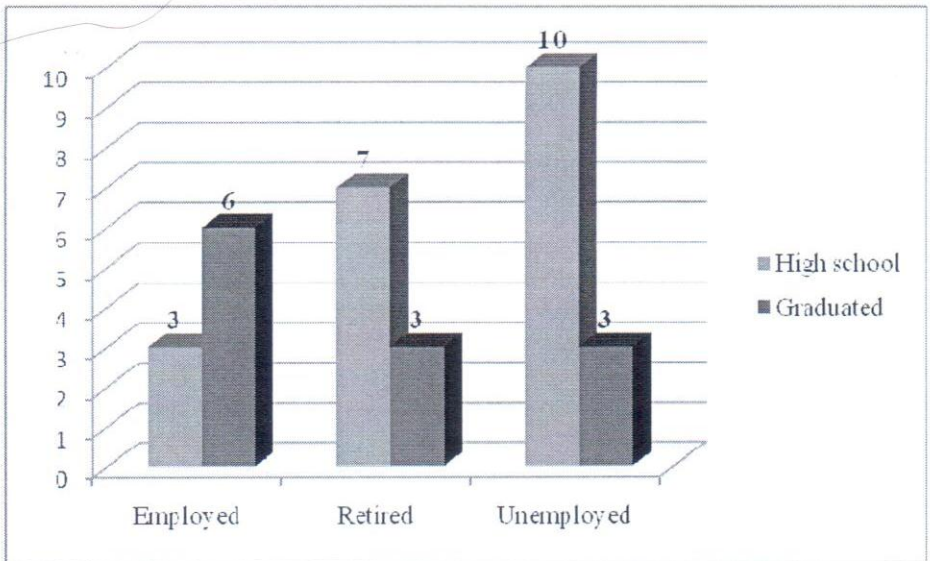


Figure 1. Correlation between the educational level and employment status of the examinees with multiple sclerosis

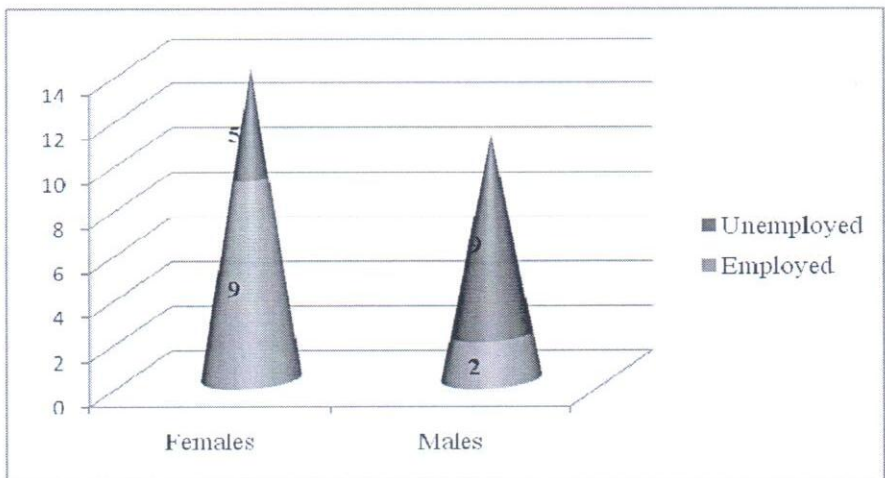


Figure 2. Employment status of the respondents with cerebral palsy

Knowing that daily activities and the degree of social-cultural life depend on the degree of impairments and disabilities, before we present the results we will give a brief review of the both groups respondents, according to the Disability index. Among individuals with multiple sclerosis the biggest part, 53.12% don't have need of any assistance during realization of everyday tasks, but parallel with increasing of the age there is also increasing of the degree of disability and need of assistance. While in group of respondents with cerebral palsy 44% or the biggest part use different equipment and prompts in realization of the activities, and here

there is no correlation between the age and the degree of disability, because cerebral palsy does not progress (Table 2).

Table 2. Differences in the respondents' answers on the Disability Index

Disability Index		There is not need of assistance	Uses prompts and equipment in the realization of the activities	Needs a help from the other person	Can not realize the activity
		to 25 points	26-42 p.	43-65 p.	66-88 p.
MS	N	17	7	4	4
	%	53,125	21,875	12,5	12,5
CP	N	9	11	3	2
	%	36	44	12	8
Sum	N	26	18	7	6
	%	46	32	12	10

Although the respondents with multiple sclerosis are more independent than the respondents with cerebral palsy, which can be affirmed with the answer of one of the questions, about driving capabilities, 12 (37%) from the examinees answered that can drive by themselves, in opposite of only three driving examinees with cerebral palsy, the second group of examinees, those with cerebral palsy are more included and active in the social-cultural life, what can be seen in the next table (Table 3).

Table 3. Differences in the answers of both groups examinees in relation to the socio-cultural life and participation at the socio-cultural manifestations.

Participation at socio-cultural manifestations	N %	Disease			χ^2	df	p
		MS	CP	Sum			
Once a week	N	1	5	6	8,34	3	0,039
	%	3,13	20,00	10,53			
Few times in the month	N	5	7	12			
	%	15,63	28,00	21,05			
Rare	N	19	12	31			
	%	59,38	48,00	54,39			
Not at all	N	7	1	8			
	%	21,88	4,00	14,04			
Sum	N	32	25	57			
	%	100,00	100,00	100,00			

Among the persons with multiple sclerosis the biggest part, 19 (59,38%), answered that very rare visit cultural-recreate manifestations, 7 respondents or 21.88% answered that do not attend that kind of events, five persons (15.63%) visit cultural manifestations several times in the month and only one person, once a week participate at different social events. Unlike persons with multiple sclerosis, in the group of respondents with cerebral palsy there is a bigger number of persons which answered that at least a few times in the month or once a week participate in

different socio-cultural events. Five individuals (20%) once a week visit socio-cultural manifestations, 7 persons (28%) these activities realized several times in the month, and the biggest part of the group 12 persons (48%) similarly as in the group with multiple sclerosis, rare visit social manifestations.

From these and the rest obtained results, got at the research but not presented in the paper, we concluded that persons with cerebral palsy more often can be seen at the organized cultural-recreate manifestations, than the persons with multiple sclerosis. This occurrence can be due to the habit of persons with cerebral palsy to participate at different kind of social-cultural events, from their earliest age, while in patients with multiple sclerosis there is a need for long-term adaptation and acceptance of the disease during the adult period of life. Our consideration is also affirmed by the study provided in Mexico in 2008 year, which assessed the mental (psychical) destructions in persons with multiple sclerosis. The results from the study pointed that the disease multiple sclerosis reducing the functional capabilities of the examinees do even greater psychical restrictions and problems, which indirectly leads to withdrawal and isolation of the patients from all daily and socio-cultural events¹³. There is also an evident difference among the respondents with multiple sclerosis and cerebral palsy referring to the self-perception about the quality of the realization of the activities (Table 4).

Table 4. Differences in the answers of both groups examinees in relation to the self-perception of the realization of daily activities comparing to other colleagues

Work same as others, similar activities and tasks	N %	Disease			χ^2	df	p
		MS	CP	Sum			
Never	N	12	0	12	14,26	3	0,0025603
	%	38,71	0	23,08			
Sometimes	N	8	4	12			
	%	25,81	19,05	23,08			
Almost always	N	3	8	11			
	%	9,68	38,10	21,15			
Everytime	N	8	9	17			
	%	25,81	42,86	32,69			
Sum	N	31	21	52			
	%	100,00	100,00	100,00			

The biggest part, 12 (38,71%), of the group of examinees with multiple sclerosis answered that they never work same or with similar tasks as other colleagues or people, eight examinees (25.81%) answered that sometimes work same as others, and three respondents pointed that almost always realized the tasks with the same quality as other people. Opposite of patients with multiple sclerosis, in the control group, individuals with cerebral palsy, 42.86% (9 persons) answered that always realized the tasks with the same quality as others, eight examinees (38.10%) answered that almost always work in the same way with the general population,

and only four respondents (19.05%) pointed that only sometimes realized the tasks with the same quality. We supposed that the differences in the answers of both groups' participants in the research can be a result of the higher level of self-perception and self-evaluation in examinees with cerebral palsy than in the examinees with multiple sclerosis, or can be a result of their greater adjustment to their restrictions and remaining abilities.

CONCLUSIONS

In the analysis of the obtained data we found that 62% of examinees with acquired disability due to the progressive disease multiple sclerosis, have secondary education, and 38% have graduated. Compared to the control group, persons with cerebral palsy, the first group have higher educational level, thanks to later onset of the symptoms of the disease and later functional restriction. If quality of life is seen through the prism of achieving personal satisfaction and revenue contribution in the family, then we can conclude that compared with the general population the both categories of respondents have significantly changed and poor quality. An insufficient adaptation of the societal system toward the needs of the persons with disabilities, does not allow an equal struggle in the labor market. The Frenchay activity index show that one of the consequences of the disability acquired due to the disease is isolation of the patients and decreasing of the activity frequencies and intensity, as well as duties. Persons with multiple sclerosis are less active in the social sphere than the persons with cerebral palsy, 20% of examinees with cerebral palsy participate in the social-cultural manifestations at least once a week, opposite of 3.13% of respondents with multiple sclerosis, which need a longer period of acceptance of the disability, adjusting to the new created situation as adaptation to the environment, in order to facilitate the physical and social integration. Overall we can conclude that people with acquired disabilities, multiple sclerosis, are more withdrawn, depressed, less active in daily life with greater dependence on others, compared to the people with cerebral palsy (congenital disability or acquired in early childhood), which allows us to conclude that quality of life drastically changes and declines in individuals with acquired disabilities after the occurrence of the disease.

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