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Functional characteristics of school age children with cerebral palsy*

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Children with cerebral palsy are one of the largest, but also very heterogeneous category in the population of people with motor disabilities. In the school environment, children achieve their functioning and behavior through motor activity, cognitive activity, communication and adaptation. The aim of the study was to evaluate the functioning of students with cerebral palsy in school and social activities. The basic assumption is that functional deficits that accompany cerebral palsy limit students' participation in school and social activities and lead to the need for continued professional support. The sample consists of 27 participants with cerebral palsy (59.3% boys), aged 9 to 16 years ($M = 12.48$, $SD = 4.89$). The sample was uniform in gender structure ($\chi^2 = .926$, $df = 1$, $p = .336$) and calendar age ($\chi^2 = 1.556$, $df = 2$, $p = .459$). For the purposes of the research, a Protocol for assessment the functioning of the students at school was developed. This protocol contains tests for assessment functional status, subjects participation and their needs. The results of the study showed that severe motor disorder (irreversible) is present in 22.2% of children with cerebral palsy. In relation to the level of realization of activities of daily living, 59.3% partially accomplish activities of daily living. 37% of the subjects participate in school activities independently, while 51.9% of the subjects with cerebral palsy have independent participation in social

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activities. At the same time, the need for a personal companion is recorded in 33.3% of children, while the need for support in development and learning is identified in almost 97% children from our sample. The variability of results indicates that the degree of functional ability and functional characteristics is an important criterion for defining the program of rehabilitation and education of children with cerebral palsy.

Key words: *education, motor disorders, participation, rehabilitation*

Introduction

Cerebral palsy (CP) is a chronic non-progressive disorder caused by brain damage in the early developmental period. Since brain damage usually occurs intrauterine or at birth, the peculiarities of the development of children with cerebral palsy are quite specific. Cerebral palsy is a biologically changed condition, that in the social context acquires the attributes of incapacity (disability) and in education it leads to learning problems or difficulties (Rapaić&Nedović, 2011).

Cerebral palsy can also be viewed as one of the etiological factors in motor behavior disorders with all the consequences that follow, make it difficult or impossible motor, cognitive and social functioning of these individuals, and therefore their participation in school and social activities. Motor functioning determines the possibility of children's participation in teaching and extracurricular activities, while cognitive functioning defines the specifics of learning (Nedovic et al., 2012).The tendency of our research is not to cover all the relevant consequences of cerebral palsy, but only a part of those that at school age represent an obstacle to participation in school and social activities and require continuous professional intervention.

The impact of cerebral palsy is not only observed through the prism of medicine and the possibilities provided by medical interventions, but that impact also has its social, psychological and economic consequences that reflect on the overall quality of life of persons and their immediate and distant surroundings. Therefore, research is important not only on the epidemiology of cerebral palsy, but also on its etiology and the consequences it brings with it.

Of the total number of children with neurological disorders who have difficulties in daily activities, 80% are children with cerebral palsy (Gladstone, 2010). Functional problems, as well as learning problems,

upper extremity motor problems and various transient diseases have been identified. The epidemiology and etiology of cerebral palsy are influenced by health, education, and social factors (Pharoah et al., 1996).

The available research literature related to the issue of cerebral palsy and its impact on functional abilities is very diverse in terms of methodology, age and classification system of subjects with cerebral palsy. Diversity in research can contribute to a broader view of one issue and lead to the development of different models of support. However, so many different methodological approaches can create aggravating circumstances in terms of comparison and interpretation of the obtained findings.

The aim of the study was to evaluate the functioning of students with cerebral palsy in school and social activities. The basic assumption is that functional deficits that accompany cerebral palsy limit students' participation in school and social activities and lead to the need for continuous professional support.

Method

Sample

The research was carried out in Belgrade, on the sample of 27 participants with cerebral palsy (59.3% boys), aged 9 to 16 years ($M=12.48$, $SD=4.89$). At the time of testing, all participants attended the primary school "Dr Dragan Hercog". The sample was uniform in gender structure ($\chi^2 = .926$, $df=1$, $p = .336$) and calendar age ($\chi^2 = 1.556$, $df=2$, $p = .459$).

Instruments

For the purposes of the research, a Protocol for assessment the functioning of the students at school was developed. This protocol contains tests for assessment functional status, subjects participation and their needs. The Protocol for Assessment the Functioning of the Students at School is constructed on the basis of parameters from the following tests: Facilitators and Barriers Survey/Mobility (FABS/M), Participation Survey/Mobility (PARTS/M), Berg Balance Scale, International Classification of Functioning, Disability and Health – World Health Organizations (applied for the analysis of medical documentation and medical history and coding of

variables of functioning of a child with cerebral palsy), as well as parameters from the test for determining somatic status. The general functional characteristics of students with cerebral palsy and the level of participation in school and social activities were tested according to the methodology of the International Classification of Functioning, Disability and Health. Based on the obtained assessment results, we determined whether (and to what extent) the form of manifestation and the level and quality of motor disorders of the selected sample directly and/or indirectly determine school activities, lifestyle and level of social participation. Relevant factors that prevent participation in school and social activities have been singled out.

Research procedure

Prior to the start of the research, the consent of the parents/guardians of children with cerebral palsy, the consent of the school principal, as well as the positive opinions of the ethics committee of the Special Hospital for Cerebral Palsy and Developmental Neurology were obtained.

Statistical data processing

The statistical program for social sciences, SPSS v.21, was used for the analysis of the obtained data. Measures of descriptive statistics were applied: frequencies and percentages, mean values and standard deviations, and from the inference statistics Chi square test, Independent samples T-test and One-factor analysis of variance (ANOVA) with subsequent post-hoc tests (Scheffe post-hoc test).

Results with discussion

Cerebral palsy can be considered as one of the etiological factors of motor behavior disorders with all the consequences that accompany, hinder or disable the motor, cognitive and social functioning of these persons, and thus their participation in school and social activities.

In this section we will present the results related to the average achievements of the participants in relation to gender and age.

Table 1 shows the average achievements of boys and girls on the Protocol for Assessment the Functioning of the Students at School.

Table 1

Average achievements of boys and girls on the Protocol for Assessment the Functioning of the Students at School

		Gender						<i>p</i>
		Boys			Girls			
		N	M	SD	N	M	SD	
Somatic status	Senses	16	1.68	.946	11	2.63	1.12	.025
	Sphincter control	16	1.12	.341	11	1.27	.467	.351
	Physical/body integrity	16	1.25	.447	11	1.27	.467	.900
	Anomalies and deformities	16	1.25	.447	11	1.09	.301	.280
	Accompanying problems	16	2.81	.910	11	2.54	.687	.418
	Health status	16	1.37	.500	11	1.81	.873	.150
Functional status	Change and maintain position	16	1.43	.813	11	1.72	.904	.393
	Movement	16	1.87	1.45	11	2.36	1.68	.429
	Communication	16	1.62	.885	11	1.81	1.25	.642
	Degree of motor disorders	16	2.56	.813	11	2.27	.904	.393
	Degree of realization of activities of daily living	16	2.12	.619	11	2.27	.646	.555
Participation	In school activities	16	1.87	.806	11	1.72	.646	.618
	In extracurricular activities	16	2.31	.873	11	2.18	.750	.690
	Social participation	16	1.56	.512	11	1.45	.687	.644
	Visits to public events	16	1.81	.981	11	2.00	1.00	.632
	Use of public services	16	1.50	.516	11	1.72	.467	.254
	Going to visit friends, relatives	16	1.56	.629	11	2.00	1.00	.174
	Arrival of friends, relatives in their house	16	1.75	.683	11	2.00	.894	.418
Needs	Personal needs	16	2.37	1.40	11	2.27	1.19	.845
	Development and learning support	16	2.06	1.12	11	2.09	1.04	.948

Independent samples T-test determined that there is a statistically significant difference between boys ($M = 1.68$, $SD = .946$) and girls ($M = 2.63$, $SD = 1.12$); $t(25) = -2.37$, $p = .025$ in the area of somatic status on the parameter – senses (sensory impairment). The difference between the mean values of the features by groups (mean difference = $-.948$, $CI: -1.77$ to -0.12) was large ($\eta^2 = 0.18$). Also, there are differences in other variables and parameters, but not at the level of statistically significant differences between the groups (Table 1).

Table 2 shows average achievements of participants of different calendar ages on the Protocol for Assessment the Functioning of the Students at School.

Table 2

Average achievements of participants of different calendar ages on the Protocol for Assessment the Functioning of the Students at School

		Age									P
		to 9			to 13			over 13			
		N	M	SD	N	M	SD	N	M	SD	
Somatic status	Senses	11	2.00	1.09	6	2.00	.894	10	2.20	1.31	.909
	Sphincter control	11	1.09	.301	6	1.00	.000	10	1.40	.516	.082
	Physical/body integrity	11	1.09	.301	6	1.00	.000	10	1.60	.516	.005
	Anomalies and deformities	11	1.18	.404	6	1.50	.547	10	1.00	.000	.043
	Accompanying problems	11	2.54	.687	6	2.83	.752	10	2.80	1.03	.724
	Health status	11	1.54	.687	6	1.33	.516	10	1.70	.823	.613
Functional status	Change and maintain position	11	1.36	.674	6	1.16	.408	10	2.00	1.05	.098
	Movement	11	1.90	1.44	6	1.33	.816	10	2.70	1.82	.212
	Communication	11	1.54	.934	6	1.16	.408	10	2.20	1.22	.120
	Degree of motor disorders	11	2.63	.674	6	2.83	.408	10	2.00	1.05	.098
	Degree of realization activities of daily living	11	2.18	.404	6	1.83	.752	10	2.40	.699	.217
Participation	In school activities	11	1.72	.646	6	1.50	.547	10	2.10	.875	.261
	In extracurricular activities	11	2.27	.646	6	1.83	.983	10	2.50	.849	.293
	Social participation	11	1.45	.687	6	1.33	.516	10	1.33	.516	.439
	Visit to public events	11	2.09	1.22	6	1.83	1.16	10	1.70	.483	.665
	Use of public services	11	1.63	.504	6	1.66	.516	10	1.50	.527	.771
	Going to visit friends, relatives	11	1.54	.522	6	1.66	.816	10	2.00	1.05	.444
	Arrival of friends, relatives in their house	11	1.90	.831	6	2.00	.632	10	1.70	.823	.730
Needs	Personal needs	11	2.00	.894	6	2.83	1.32	10	2.40	1.64	.459
	Development and learning support	11	2.09	1.04	6	1.66	1.03	10	2.30	1.15	.537

Table 2 shows the average achievements of the subjects in relation to age. In the area of somatic status, a statistically significant difference at the level $p < .05$ was recorded on the parameters of body integrity ($F(2, 24) = 6.803$, $p = .005$) and anomalies and deformities ($F(2, 24) = 3.588$, $p = .043$). Further

analysis, by using a Post hoc test (Scheffe post-hoc test) on the parameter of physical/body integrity, determined the difference between the group up to nine ($M = 1.09$, $SD = .301$) and group over 13 years ($M = 1.60$, $SD = .516$), as well as in the group up to 13 ($M = 1.00$, $SD = .000$) and over 13 years ($M = 1.60$, $SD = .516$), whereby in both groups students over 13 years have more impaired physical integrity compared to younger participants. At the same time, the difference was recorded between students up to 13 ($M = 1.50$, $SD = .547$) and over 13 years ($M = 1.00$, $SD = .000$) when it comes to the presence of anomalies and deformities. Students up to 13 years have more anomalies and deformities.

Functional limitations of children with cerebral palsy correlated with the level of involvement in some community-based activities (Milićević, 2020), or in other words functional status is a significant indicator of social participation. It is also pointed out, that it is necessary to focus on the factors that are considered to influence participation, such as age, gender and the already mentioned level of functional abilities (Law et al., 2004).

Further, in this section we will narratively present distribution of the results of the sample as a whole in specific areas of the Protocol.

The analysis of data related to the area of somatic status showed that 25.9% of our students have impaired physical/body integrity. When it comes to sensory impairments, 14.8% of students have hearing impairment, 29.6% visual impairment, and 11.1% of students have combined sensory impairment. Hearing impairment in children with cerebral palsy ranged from hard of hearing to deafness in one or both ears (Neil & McKinlay, 1986; Rosen, 1956, cited in Rapačić & Nedović, 2011), as 50% of children with CP had strabismus, 36% of children squint, and 9.9% of children had atrophy of optic nerve (Rapačić & Nedović, 2011).

In 44.4% of participants, epilepsy or some other chronic disease is present, and in 51.9% there are accompanying problems such as speech disorders, perceptual dysfunction, psychophysical problems. Savić (2002) states that in children with CP, the most common disorders are articulation and rhythm of speech (dyslalia, dysarthria, dyspraxia), phonation disorders (dysphonia), as well as underdeveloped speech (dysphasia).

Impaired motor skills are the primary feature of children with cerebral palsy. It affects the upper or lower extremities, and often all four extremities. The degree of damage ranges from discrete (light) to extremely conspicuous (severe). Severe motor disorder (irreversible) is present in 22.2% of children

with cerebral palsy, severe motor disorder (reversible) was recorded in 11.1%, and mild motor disorder (corrective) is present in 66.7% of children. When it comes to functional status, 22.2% of students cannot maintain and/or change their basic positions, while about 37% of subjects use a wheelchair or some other aids.

In relation to the degree of realization of activities of daily living, 59.3% partially realize activities of daily living, and only 11.1% of them realize them completely. Research findings in the field of activities of daily living of children with cerebral palsy confirm the great variability of motor functioning in terms of mobility, personal care and social engagement as a consequence of the heterogeneity of this population (Ostensjo et al., 2003). Donkervoort et al. (2007) found that in the domain of life habits, most children with CP reported difficulties in movement, personal care, community living, responsibility, and leisure. In the area of participation, 37% of our subjects participate in school activities independently, 22.2% in extracurricular activities, while 51.9% of subjects with cerebral palsy have independent participation in social activities. About 40% of subjects attend public events and visit relatives, while about 37% of subjects are visited by relatives or friends. Our data are not comparable to the results found in the available literature. Some authors identified that more than 85% of children with CP participate in informal activities such as hanging out, visiting and entertaining others (Longo et al, 2013). On the other side, the results of a study conducted on a sample of children with CP and typical development children, in order to investigate participation in extracurricular activities, showed that children with CP compared to their peers participate less in these activities. It was found that children with CP independently engage in activities or with some of the family members, and these activities taking place in the child's home rather than in the wider community (Imms et al., 2008).

At the same time, the need for a personal companion is recorded in 33.3% of children, while 97% of children need support in development and learning. These are the data refer to the area of needs.

Conclusion

Based on the obtained results, we can say that a significant number of children with cerebral palsy at school age have impaired somatic and functional status that determine the functioning and participation of

these children in school and social activities. The degree of functional abilities and functional characteristics are important criteria for defining rehabilitation and education programs (organizing schooling) of children with cerebral palsy. Functional deficits that accompany cerebral palsy limit the participation of these children in school and social activities, as well as in activities of daily living, which leads to the need for continuous professional intervention and support. As children with cerebral palsy are a very heterogeneous group at school age, it also indicates the complexity of organizing rehabilitation, education and social integration programs.

Some limitations and recommendations of our research should be mentioned. The sample include a small number of participants. It was formed by the children who are attended the same primary school at the time of testing. For that reason, we cannot draw generalized conclusions. So, some future research should be conducted on a larger sample. Next, there is little of the same or almost similar research, especially in our area. It is necessary to study the functional characteristics of people with cerebral palsy, to provide adequate intervention and support.

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FUNKCIONALNE KARAKTERISTIKE UČENIKA SA CEREBRALNOM PARALIZOM

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Apstrakt

Deca sa cerebralnom paralizom su jedna od najbrojnijih, a istovremeno i veoma heterogenih kategorija u populaciji osoba sa motoričkim poremećajima. Deca u školskoj sredini svoje funkcionisanje i ponašanje ostvaruju kroz motoričku aktivnost, kognitivnu aktivnost, komunikaciju i adaptaciju. Cilj istraživanja je bio procena funkcionisanja učenika sa cerebralnom paralizom u školskim i socijalnim aktivnostima. Osnovna pretpostavka je da funkcionalni deficiti koji prate cerebralnu paralizu ograničavaju participaciju učenika u školskim i socijalnim aktivnostima i vode ka potrebi za kontinuiranom stručnom podrškom. Uzorak istraživanja čini 27 ispitanika sa cerebralnom paralizom (59,3% ispitanika muškog pola), uzrasta od devet do 16 godina (AS = 12,48, SD = 4,89). Uzorak je ujednačeni u odnosu na polnu strukturu ($\chi^2 = 0,926$, df = 1, p = 0,336) i u odnosu na kalendarski uzrast ($\chi^2 = 1,556$, df = 2, p = 0,459). Za potrebe istraživanja kreiran je Protokol za procenu funkcionisanja učenika u školi. Ovaj protokol sadrži testove za procenu funkcionalnog statusa, procenu participacije ispitanika i procenu potreba. Rezultati istraživanja pokazuju da je teški poremećaj motorike (ireverzibilan) prisutan kod 22,2% dece sa cerebralnom paralizom. U odnosu na stepen ostvarivanja aktivnosti svakodnevnog života, 59,3% delimično ostvaruje aktivnosti svakodnevnog života. U školskim aktivnostima samostalno participira 37% ispitanika, dok samostalnu participaciju u socijalnim aktivnostima ostvaruje 51,9% ispitanika sa cerebralnom paralizom. Istovremeno, potreba za ličnim pratiocem evidentirana je kod 33,3% dece, dok je kod skoro 97% utvrđena potreba za podrškom u razvoju i učenju. Varijabilnost rezultata ukazuje na to da su stepen funkcionalnih sposobnosti i funkcionalne karakteristike bitan kriterijum za definisanje programa rehabilitacije i edukacije (organizovanja školovanja) dece sa cerebralnom paralizom.

Ključne reči: edukacija, motorički poremećaji, participacija, rehabilitacija