



ACTIVITIES OF DAILY LIFE OF CHILDREN AND YOUTH WITH CEREBRAL PALSY

AKTIVNOSTI SVAKODNEVNOG ŽIVOTA DJECE I MLADIH SA CEREBRALNOM PARALIZOM

Adis Zukić¹, Dževad Hadžić², Edina Kuduzović³, Dženana Radžo Alibegović³, Azra Kurtić⁴, Benjamin Avdić⁵

¹ Mental Health Center, Brčko District

² PI Department of Special Education and Upbringing of Children „Mjedenica“, Sarajevo

³ Faculty of Education and Rehabilitation, University of Tuzla

⁴ Faculty of Medicine, University of Tuzla

⁵ Center for Special Education and Rehabilitation “Vladimir Nazor”, Sarajevo

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ABSTRACT

The main goal of this paper is to determine the level of independence in performing daily activities in children and youth with cerebral palsy who are included in the regular education and rehabilitation program and to see their progress in relation to children and youth with cerebral palsy who are occasionally included or not included in the education and rehabilitation program. The research was conducted in the Center for Children with Multiple Disabilities "Koraci Nade (eng. Steps of Hope)" in Tuzla as well as in practice with the mobile team of the Centre. Total of 40 respondents were included. Respondents were divided into two groups: respondents who were included in the program and respondents who were occasionally or not at all included in the program. The results of the research indicate that the respondents who were included in the regular program of education and rehabilitation achieve better results in performing activities of everyday life in relation to the respondents who are occasionally or not at all included in the program.

Key words: cerebral palsy, motor functioning, daily life activities, treatment.

SAŽETAK

Glavni cilj ovog rada je bio utvrditi nivo samostalnosti u obavljanju svakodnevnih aktivnosti kod djece i mladih s cerebralnom paralizom koja su uključena u redovni program edukacije i rehabilitacije, te sagledati njihov napredak u odnosu na djecu i mlade s cerebralnom paralizom koja su povremeno uključena ili nisu uključena u program edukacije i rehabilitacije. Istraživanje je provedeno u Centru za djecu s višestrukim smetnjama „Koraci nade“ u Tuzl.

Obuhvaćeno je ukupno 40 ispitanika. Ispitanici su podijeljeni u dvije skupine: ispitanici koji su bili uključeni u program i ispitanici koji su povremeno ili uopće nisu uključeni u program. Rezultati istraživanja pokazuju da ispitanici koji su uključeni u redovni program edukacije i rehabilitacije postižu bolje rezultate u obavljanju aktivnosti svakodnevnog života u odnosu na ispitanike koji su povremeno ili uopće nisu uključeni u program.

Ključne riječi: Cerebralna paraliza, motoričko funkcionisanje, aktivnosti svakodnevnog života, tretman.

INTRODUCTION

A group of non-progressive movement and position disorders caused by a defect or damage to the immature brain in the early stages of development is called cerebral palsy (Punda, 2017). Cerebral palsy, as the most common cause of severe neuro-motor abnormalities in children, is not only a medical, but also a social and psychological problem. Although cerebral palsy is primarily a movement and posture disorder, that is, damage that is limited to the motor system, many children with cerebral palsy suffer from a number of other associated health impairments and problems that make the clinical picture of cerebral palsy even more difficult and complicated for adequate care and treatment. The quality of life of these children, as well as their entire families, is extremely impaired (Kraguljac et al., 2018). The definition and classification of cerebral palsy (CP) is constantly being reconsidered. According to Katušić (2012), previous definitions of cerebral palsy did not take into account non-motor neurodevelopmental difficulties or the progression of musculoskeletal problems. Today, more emphasis is placed on assessing the limitations that people with cerebral palsy have in performing daily activities (Erdeš, 2017). The therapy of a child with cerebral palsy has a functional goal, that is, it is aimed at achieving a given goal. The two main goals of habilitation are to reduce the complications caused by cerebral palsy and to improve the ability to acquire new skills. Additional goals include caregiver education, reduction of physical deformities and improvement of mobility (Kraguljac et al., 2018).

Activities of everyday life

In children with cerebral palsy, developmental specifics can occur, which significantly affect their training for everyday activities and schooling (Mahmutagić, Prstačić et al. 2006). Cerebral palsy often causes multiple disabilities that affect a person's functioning in all areas of daily life. As the most common motor disorder in childhood (Pakula, Braun, & Yeargin Allsopp, 2009), or one of the most common etiological factors of motor behaviour disorder, cerebral palsy limits the development of abilities with all the consequences that accompany, hinder or disable motor, cognitive, intellectual, emotional and social functioning of these persons and leads to a constant need for intensive and continuous somatopedic support (Milićević, Potić, & Trgovčević, 2011).

Motor functioning

Cerebral palsy is clinically manifested by a neuro-motor disorder of control of body position and movement, tone and reflexes from infancy, often with variable symptoms, but there is always a slow development of motor skills (Mejaški Bošnjak, Đaković 2013). Although a fundamental characteristic of children with cerebral palsy is motor deviation and delay, their overall health status should be viewed in the context of medical, developmental, and psychosocial issues. Early recognition and involvement in rehabilitation treatments significantly increases the possibility of the child's general status progressing. It is necessary to include all members of the multidisciplinary health care team in the method of treatment, in order to increase the quality of the final outcomes of treatment, which has been verified to date by the results of recent scientific research (Knežić, 2015). The main difficulties in motor development of children with cerebral palsy are: abnormal muscle tone, the existence of primitive reflexes intertwined with voluntary movements, poorly developed voluntary motor skills, including balance reactions, muscle weakness and poor development of skills and voluntary movements (Katušić, 2012). The measures implemented in the treatment of children with cerebral palsy are aimed at improving their quality of life and daily activities. Parents are actively involved in the overall care of the child (feeding, dressing, hygiene procedures) and are learning to communicate with their children. With growth and development, the child must gain maximum independence in these activities, taking into account its real possibilities. All this is largely feasible with a systematic and multidisciplinary approach that includes physicians of higher specialties (paediatrician, ophthalmologist, audiologist, physiatrist, orthopaedist, speech therapist, and child psychiatrist), a social worker, an occupational therapist, a psychologist etc. A prerequisite for any significant treatment success was and still remains an early diagnosis of a neurodevelopmental disorder (Križ and Prpić, 2005).

The research subjects in this paper are children and youth with cerebral palsy and their level of independence in performing activities of everyday life.

The aims of this research are:

1. To determine the level of independence in performing activities of daily living in children and youth with cerebral palsy who are included in the regular program of education and rehabilitation.
2. To determine the level of independence in performing activities of daily living in children and youth with cerebral palsy who are occasionally included or not at all included in the regular program of education and rehabilitation.

MATERIAL AND METHODS

Sample of respondents

This study included a sample of 40 respondents, children and adolescents with cerebral palsy, aged between 1 and 30. There were 20 male and 20 female respondents in the sample. Considering the set goals of the research, the respondents from the sample were divided into two groups. The first group consisted of children and youth with cerebral palsy who were included in the regular education and rehabilitation program (20) and the second group consisted of children and youth with cerebral palsy who were occasionally or not at all included in the regular education and rehabilitation program (20).

Measuring instrument

For the purposes of this study, the FIM test was used for evaluation. The FIM test measures functional independence and functional adaptation. The FIM examines 18 functions, and for each of them the grades are set from 1 to 7 so that the total score can range from 18 to 126. (FIM. Instrument. Copyright © 1997 Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc. Reprinted with the permission of UDSMR, University at Buffalo, 232 Parker Hall, 3435 Main St., Buffalo, NY 14214).

Method of conducting research

The research was conducted in a time span from two months in the "Centre for Children with Multiple Disabilities Koraci Nade (eng. Steps of Hope)" in Tuzla, as well as in practice when visiting the respondents by the mobile team of the Centre. In this research, secondary data obtained by reviewing medical records (respondents' files) and primary data obtained using a measuring instrument were used. The research was performed using the test method. All respondents were individually examined, in a pleasant environment in a room that serves for education and rehabilitation of users of the Centre, and during practice work in their homes in the presence and with the consent of parents to participate in the research.

Data processing methods

The standard Statistical Package for Social Research (SPSS) version 20.0 was used to analyze the results. A t-test for independent samples was used to examine the differences between the two groups of subjects in the stratified sample. The significance of the obtained results was set at the level of $p < 0.05$.

RESULTS AND DISCUSSION

Using the t-test, we examined the significance of the differences in the arithmetic means of the observed variables between the group of respondents covered by the treatment program and the group of respondents covered occasionally or not at all covered by the treatment program.

The analysis of the results shown in Table 1, indicate that the respondents included in the treatment program registered better results ($p < 0.05$) on the functional independence test (FIM) in the part related to motor skills, except in the area of independent bathing activities ($p = 0.396$) and climbing stairs ($p = 0.171$).

Table 1. Differences in the achievement on the functional independence test (FIM)

Areas of activity	Respondents covered by the treatment		Respondents not covered by the treatment		t	p
	M	SD	M	SD		
Feeding	2.05	1.84	3.35	2.87	19.58	.000
Personal hygiene	1.25	1.11	2.15	1.78	11.26	.002
Bathing	1.50	1.23	1.75	1.61	.737	.396
Putting on upper clothes	1.10	0.44	2.50	2.43	34.50	.000
Putting on underwear and lower clothes	1.20	0.89	2.00	1.91	9.17	.004
Toilet	1.25	0.91	2.00	2.10	11.29	.002
Bladder control	1.10	0.30	1.00	0.00	10.68	.002
Bowel emptying control	1.10	0.30	1.00	0.00	10.68	.002
Transfer / bed, chair, wheelchair	1.00	0.00	1.05	0.22	4.45	.041
Transfer/ toilet	1.20	0.89	1.00	0.00	4.45	.041
Transfer/ bathtub, shower	1.05	0.22	1.00	0.00	4.46	.041
Movement / walk, wheelchair	1.10	.44	1.00	.00	4.47	.042
Movement / stairs	2.00	1.77	1.55	1.43	1.94	.171
Communication / understanding	1.20	.52	1.70	1.59	6.59	.014
Communication / expression	1.55	1.27	1.60	1.56	.05	.815
Social interaction	1.45	1.14	1.00	.00	16.79	.000
Understanding of a problem	1.25	.91	1.15	.67	.555	.461
Memory	1.05	.22	1.15	.67	1.78	.190

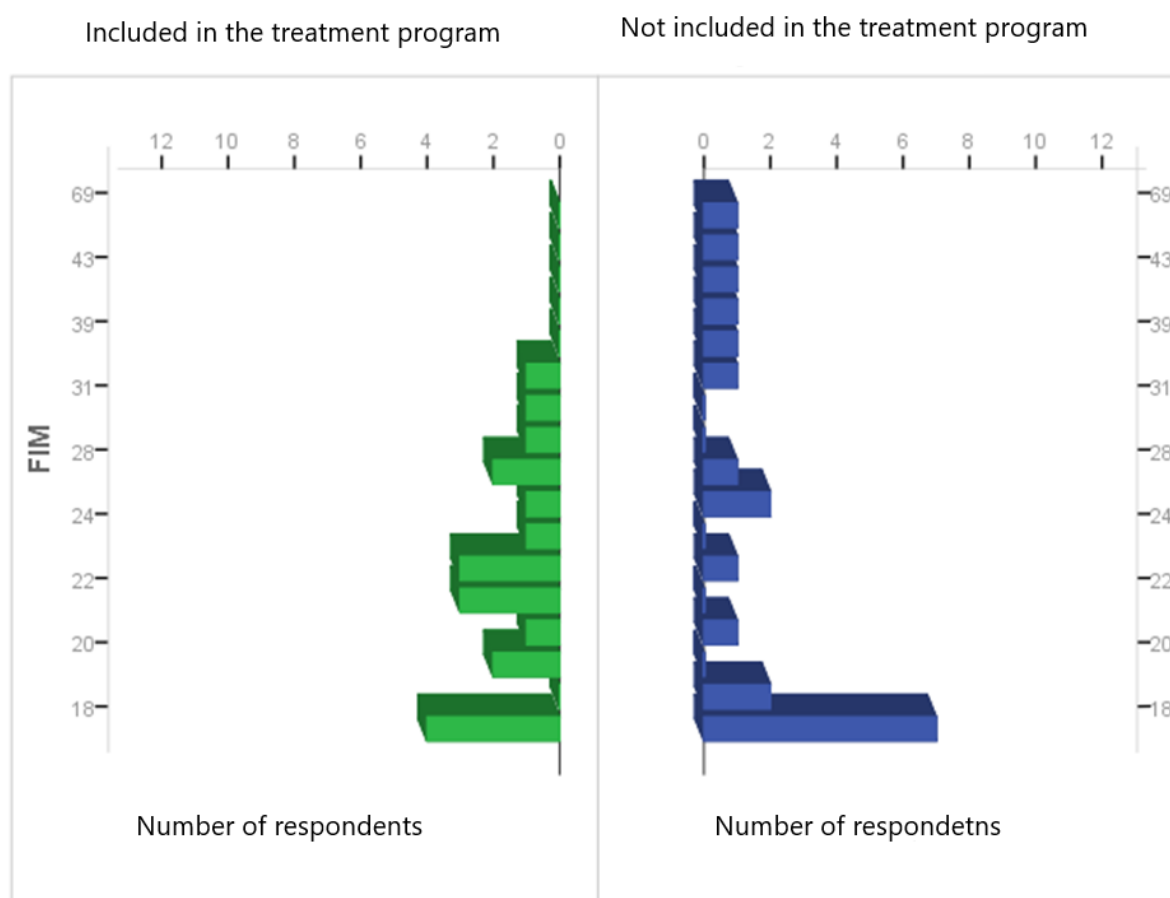
In our study, in general, persons included in the treatment program registered better results in motor activities compared to persons who were occasionally included or not at all included in the treatment program. Training a child to feed itself requires patience, time, energy, knowledge and determination, but it is useful and valuable for a child with cerebral palsy because this way we give it the opportunity to become independent within its capabilities. The therapy of a child with cerebral palsy has a functional goal, i.e. it is aimed at achieving the set goal. The two main goals of habilitation are to reduce the complications caused by cerebral palsy and to improve the ability to acquire new skills. Additional goals include caregiver education, reduction of physical deformities and improvement of mobility (Kraguljac et al., 2018). Positioning is the foundation and beginning of the feeding activity itself. With good positioning, all parts of the body come into the right relationship and become stable. All that affects the improvement of oral motor skills (tonic bite, protruding tongue, lip compression).

Proper positioning of the child affects the quality of performance of activities. You can also make feeding easier for your baby if you use the various aids available. A light, thickened handle on cutlery, a cuff around the metacarpal bones of the hand to which the cutlery is attached, a curved spoon attached to the cuff - are some of the aids that facilitate coordination of movements and prevent food spillage (Šantek, 2008).

In our study, persons included in the treatment program achieved better results in feeding activities compared to persons who were occasionally included or not at all included in the treatment program. The goal of dealing with a child with cerebral palsy is to achieve maximum independence in movement and activities of everyday life. In addition to the habilitation treatment, which is carried out in specialized institutions, the child learns through routine daily activities (taking/picking up, carrying, changing clothes, bathing, etc.). Therefore, constant communication and exchange of information between parents and all members of the habilitation team is important (Savić and Milić Rašić, 2017). Analysis of the results shown in Graph 1 showed that the group of respondents included in the treatment program achieved better results in lying, standing and walking activities compared to the group of respondents who were occasionally included or not at all included in the treatment program. Due to the high connection between motor development and the development of learning and comprehension skills, a number of aids and techniques are used that enable learning through exercise. Practice shows that in addition to therapy, children must exercise at home. Therefore, in addition to working with the child, the kinesiologist must be able to educate parents and introduce them to the exercise techniques they can perform at home (Šarčević, 2016). And this research shows that people who are included in the treatment program achieve better results in standing and walking activities compared to people who are occasionally included or not at all included in the treatment program. Children with cerebral palsy should be able to walk independently before they are integrated into school and society. Independent walking plays an important role in the activities of everyday life, improves bone density and cardiopulmonary endurance, reduces obesity, etc. Therefore, independent walking is the most important goal of rehabilitation for many children with cerebral palsy. Therapeutic methods to improve the walking ability of children with cerebral palsy include strength exercises, cardiopulmonary endurance exercises, functional electrical stimulation approaches, task-oriented exercises, neurological developmental approaches, and proprioceptive neuromuscular facilitation (Cho et al., 2016).

The measures implemented in the treatment of children with cerebral palsy are aimed at improving their quality of life and daily activities of those children. Parents are actively involved in the overall care of the child (feeding, dressing, hygiene procedures) and learn to communicate with their children. With growth and development, the child must gain maximum independence in these activities, taking into account its real possibilities. All this is largely feasible with a systematic and multidisciplinary approach that includes physicians of more specialties (paediatrician, ophthalmologist, audiologist, physiatrist, orthopaedist, speech therapist, child psychiatrist), a social worker, an occupational therapist, a psychologist etc. A prerequisite for any significant treatment success was and remains an early diagnosis of a neurodevelopmental disorder (Križ, Prpić, 2005). It is necessary that all neurodevelopmental children are provided with opportunity for greater involvement in the activities of everyday life and

thus also relieve the parents in order for the child to be as independent as possible (Matijević, Marunica Karšaj, 2015).



Graph 1. Distribution of respondents in relation to the FIM

In the research conducted by Joković Turalija et al. (2004), the results obtained in the field of Communication show that 45% of the respondents do not have greater needs for expression, understanding, and speech in social situations. The least progress in functional independence was recorded in the sphere of cognitive functioning, where the respondents included in the treatment program differed significantly ($p < 0.05$) in the area of understanding and social interaction, while in other areas (expression, understanding of problems and memory) the differences were statistically insignificant. Parents most often react to the diagnosis by denying and setting unrealistic expectations related to the child's abilities and capabilities (Igrić, Cvitković, Jakab, 2009). Such an unrealistic attitude of parents leads to a lack of self-confidence in children. Children cannot achieve what is expected of them and then they create a negative image of themselves. Lack of self-confidence leads to feelings of loneliness, which prevents them from developing emotional and social competencies (Mandić, 2015). The quality of life of children with cerebral palsy depends on access to products, information and support. Access to products means the availability of specialized aids that make everyday life easier for children with cerebral palsy and their families, e.g. electric wheelchairs, special computers, cutlery etc. Access to information includes notions where parents can get advice on caring for a child with cerebral palsy, where they can find out all about their rights.

Likewise, the approach to support involves forming a community support network that includes organizations, families, and children with cerebral palsy to share experiences and advice (Punda, 2017).

CONCLUSION

It can be concluded that cerebral palsy is a very complex condition that affects a number of developmental areas of the child, the level of its functional abilities and quality of life, which indicates the importance of habilitation treatment.

There is a unique model of functioning for each person, so an individual re / habilitation program should be created in accordance with the diagnosis.

The family of the child or their immediate and wider environment should be given useful advice on the need to include children and youth with cerebral palsy in regular individually tailored education and rehabilitation programs and thus contribute to improving their quality of life.

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