

DOI: 10.15225/PNN.2014.3.2.1

Daily Functioning Problems in Children with Cerebral Palsy (CP) Aged 5 and More

Problemy dnia codziennego dzieci z mózgowym porażeniem dziecięcym powyżej piątego roku życia

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Abstract

Introduction. Children with CP struggle with various problems in daily living due to diverse symptomatology which accompanies the central nervous system (CNS) damage. The problems concern both basic self-care activities like dressing, grooming or bathing as well as more complicated activities like reading or social interactions — starting and maintaining relationships.

Aim. This study aims to identify and present daily living problems experienced by the children with CP aged 5 or more.

Material and Methods. The study was conducted among a group of 130 randomly selected participants, 50 participants were children with CP aged 5–19 and 80 participants were their parents. The author's self-designed questionnaire was used to collect data in the study. Results. Analysis of the collected data shows that:

- according to surveyed parents the most common disorders characteristic for their children are: visual disturbance (75%), speech disorder (65%) and intellectual disability (65%),
- one fourth of children with CP are non-ambulant, wheelchair provides independent mobility for the children or they require personal assistance from another person,
- problems with balance in vertical position are the most problematic limitation in daily living for the group of surveyed children (68%).

Conclusions.

1. Children with CP struggle with various problems concerning daily living functioning.
2. Small percentage of children with CP are able to move independently.
3. Majority of children with CP are not able to function independently due to the disorders resulting from the brain damage.
4. Management of associated conditions through motor rehabilitation has improved mobility and motor skills in daily functioning of children with CP. (JNNN 2014;3(2):52–57)

Key Words: cerebral palsy, daily living problems in children with cerebral palsy

Streszczenie

Wprowadzenie. Ze względu na bogatą symptomatologię i objawy towarzyszące uszkodzeniu OUN dzieci z MPD borykają się z wieloma problemami w życiu codziennym, poczynając od tych związanych z samodzielnym wykonywaniem podstawowych czynności higieniczno-pielęgnacyjnych, poprzez naukę czynności złożonych, np. czytania, aż do problemów natury psychospołecznej — nawiązanie i utrzymanie kontaktów interpersonalnych z innymi osobami. **Cel.** Poznanie i przedstawienie problemów dnia codziennego dzieci z mózgowym porażeniem dziecięcym, które ukończyły 5 rok życia.

Materiał i metody. Badanie zostało przeprowadzone wśród losowo dobranej grupy 130 osób, w której 50 osób stanowiły dzieci z MPD w wieku 5–19 lat, a rodzice stanowili 80 osób. Do zebrania danych posłużono się autorskim kwestionariuszem ankiety.

Wyniki. Z analizy materiału badawczego wynika, że:

- według ankietowanych rodziców najczęściej występującymi schorzeniami u ich dzieci są: zaburzenia wzroku (75%), zaburzenia mowy (65%) oraz upośledzenie umysłowe (65%),
- co czwarte dziecko porusza się przy pomocy wózka inwalidzkiego i drugiej osoby,
- dla ankietowanych dzieci zaburzenie równowagi w pozycji stojącej jest najbardziej utrudniającym funkcjonowanie ograniczeniem (68%).

Wnioski.

1. Dzieci z MPD borykają się z wieloma problemami w życiu codziennym.
2. Tylko niewielki odsetek dzieci z MPD jest w stanie samodzielnie się poruszać.
3. Ze względu na istniejące u nich zaburzenia zdecydowana większość z nich nie jest w stanie samodzielnie funkcjonować.
4. Wskutek prowadzonej rehabilitacji ruchowej u dzieci z MPD poprawiła się sprawność wykonywania różnych czynności dnia codziennego. (PNN 2014;3(2):52–57)

Słowa kluczowe: mózgowie porażenie dziecięce, problemy dzieci

Introduction

CP is not a single condition, it is rather a term for a group of non-progressive neurological disorders caused by damage to the motor control centers. CP is usually caused by brain lesion that occurs during pregnancy, delivery or the first month of life [1]. It is a serious neurological disorder which appears all over the world in every ethnic group [2]. In CP, the movement disorders are accompanied by other symptoms associated with the brain damage including epilepsy, intellectual disability, vision, hearing, and speech problems, and behavioral disorders — irritability, irascibility and aggressive behavior [2–4]. CP occurrence is estimated at 1.5–2.5/1000 live births. The risk of developing CP increases in children with intrauterine trauma during pregnancy, intoxication (i.e. alcohol and drugs) or infections (rubella, toxoplasmosis and viral infections including HIV) [1]. Children with CP struggle with various problems in daily living due to diverse symptomatology which accompanies the CNS damage. The problems concern both basic self-care activities like dressing, grooming or bathing as well as more complicated activities like reading and even social interactions.

The objective of this paper was to identify and present daily living problems experienced by the children with CP aged 5 or more.

Material and Methods

The study was conducted among randomly selected group of children with CP who stay in Zakład Opiekuńczo-Lecznicy dla Dzieci, run by Sisters of St. Joseph congregation, and their parents and among children with CP associated at Dolnośląskie Stowarzyszenie Pomocy Dzieciom i Młodzieży z Mózgowym Porażeniem Dziecięcym „Ostoja” from Ośrodek Rehabilitacyjno-Edukacyjny. The study was carried out among the group

of 130 randomly selected participants, 50 participants were children with CP aged 5–19 and 80 participants were their parents.

The study was conducted using a diagnostic survey method with questionnaire technique. Author's self-designed questionnaire was developed to collect data in the study. The questionnaire for children includes 24 questions (18 closed-ended and 7 open-ended), and the questionnaire for parents includes 31 questions (10 open-ended and 21 closed-ended). The survey was anonymous and voluntary. At the beginning of the study participants were informed about possibility to resign at any stage.

Bioethical Commission at the Medical University of Wrocław issued the permission 48/XV R/2012 for the research.

Microsoft Office Excel and Microsoft Office Word were used to process the data collected for the study.

Results

Data analysis showed that majority of mothers (87.5%) did not take any medication during pregnancy. Other women admitted taking medications such as: Zyrtec, Euthyrox, Fenoterol, No-spa, Asparagin, Nootropil, iron and vitamins. All surveyed women declared they did not take any alcohol during pregnancy, unfortunately one fourth of them smoked and 7.5% was exposed to radiation. 25% of women in the study had various infections when pregnant and 2.5% caught infections like rubella, toxoplasmosis and herpes zoster. The results show that 22.5% of children experienced severe blood and oxygen deprivation in prenatal period.

The study shows that 24% of children considered their health to be very good. In contrast, only 5% of parents described their children's health as very good. 60% of parents described the health condition of their children as average and only one third of children has the same opinion. Only 27.5% of parents do not know

what type of CP their children have and 64% of children do not possess this knowledge. According to surveyed parents their children most often suffer from vision and speech disorders as well as intellectual disability. From the children's point of view, most frequently they observe problems with poor coordination, vision and speaking. Detailed data is presented in Table 1.

In the opinion of surveyed parents, their children ambulate with the aid of a wheelchair and assistance (45%) or they ambulate with assistance (20%). However, according to children they ambulate with the use of wheelchair and assistance 40% or independently with the use of a wheelchair (28%). Unfortunately, only 10% of children are able to ambulate without any physical assistance or equipment.

Parents who took part in the study claim that they assist their children mostly with more precise activities e.i. fastening buttons or zipper (97.5%) and nail care (95%). As to the children's opinion, they claim their parents assist them with nail care (96%) and making bed (92%). Over three-fourths of surveyed parents declared

help for their children in brushing teeth and hair. 68% of children claim they require help when dressing as opposed to 85% according to parents. 60% of children claim they have problems with morning-evening hygiene whereas 77% of surveyed parents give the same response. According to both groups 80% of children are not able to wash the whole body without the assistance. Only 48% of children admit they need help to meet physiological needs. However, 70% of parents answered they assist their children in the above activities.

The study findings show that parents observe the most frequent limitations in daily functioning and these are: problems with coordination (65%) and abnormal muscle tone (55%). For surveyed children, difficulties in maintaining balance in standing position is perceived as the biggest obstacle in daily functioning. Detailed information is presented in Table 2.

Both in the opinion of surveyed parents and their children the most problematic obstacles when leaving the house are architectural barriers (almost 60%) and the requirement of a second person assistance (approximately 55%). Unfortunately

Table 1. Coexisting conditions in children with CP in the opinions of children and their parents

Coexisting conditions	Number of parents (n)	The percentage of parents (%)	Number of children (n)	The percentage of children (%)
Vision disorder	60	75	22	44
Hearing disorder	6	7,5	0	0
Speech disorder	52	65	18	36
Epilepsy	46	57,5	6	12
Concentration disorder	42	52,5	32	64
Intellectual disability	52	65	12	24
Others	8	10	2	4

Table 2. Health conditions affecting children with CP in the opinion of children and their parents

Functional limitations	Number of parents (n)	The percentage of parents (%)	Number of children (n)	The percentage of children (%)
Difficulties with maintaining balance in a standing position	42	52,5	34	68
Low muscle tone	16	20	8	16
High muscle tone	44	55	22	44
Difficulties with maintaining head stabilization	16	20	6	12
Lack of balance in a sitting position	22	27,5	12	24
Coordination problems	52	65	18	36
Limited joint movement	22	27,5	22	44
Others	22	27,5	2	4

for 12% of children going out is connected with the feeling of shame. Despite many obstacles, almost three quarters of children with CP leave the house every day. Over 90% of children participate in rehabilitation. The most common form of rehabilitation according to the parents is the Bobath therapy (42.5%) and Vojta therapy (17.5%). The vast majority of surveyed children do not know the name of the method they are rehabilitated with. Both surveyed parents and their children, among other rehabilitation methods used in their own children usually mention therapeutic massage and kinesitherapy. One in three children claim they are treated with music therapy, however their parents do not confirm that.

Both surveyed groups (over 80%) notice that due to run rehabilitation the efficiency of performing various activities of daily living has improved.

Table 3. Attitude of able-bodied persons towards children with CP in the opinion of surveyed parents and children (more than one answer was possible)

Attitude of society to the children with CP	Number of parents (n)	The percentage of parents (%)	Number of children (n)	The percentage of children (%)
Tolerant	46	57,5	26	52
Helpful	36	45	18	36
Mocking	4	5	18	36
Ignoring	8	10	10	20
Friendly	32	40	26	26
Hard to say	8	10	8	16
Other attitude	0	0	0	0

More than three quarters of parents declare their children are under the care of the specialists: physiotherapist, neurologist and speech therapist.

The findings on the social relationships show that children with CP mainly socialize with their family members (85% parents and 72% children admit so). A big number of children (72.5% as to parents and 60% of children) maintain direct contacts with peers when staying in a big group e.g. during lessons. 50% of parents say their children maintain contact with friends via the Internet, however, only one fifth of children mention this form of communication with friends.

Children with CP (over 90%) feel safest at home (in the opinion of both parents and their children). In second place, both groups mentioned a school (65% of surveyed parents and 40% of surveyed children). The least safe place according to both groups is a shop, supermarket.

Both in the opinion of surveyed parents and children, able-bodied persons are tolerant to children with CP (57.5% v 52%) and offer assistance (45% v 36%). Unfortunately, every third child declared that able-bodied persons laugh at them. Among parents, only 5% of respondents drew attention to this problem. Detailed data is shown in Table 3.

Discussion

Difficulties that children with CP encounter every day depend on the severity of brain damage or the kind of developmental disorders of the immature brain. CP is not a single condition but a group of many disorders. Brain damage can occur during fetal life, infancy, until the age of three [5]. There is still no cure or one proper method of treatment of CP in children, which is why many professionals are interested in this issue trying to invent the most effective therapeutic approaches [6]. Issues concerning the etiology of CP and its pathogenesis have been the subject of research for many years. According to the literature, there are several causes contributing to

the development of CP [1]. These include the infections that occurred in the mother during pregnancy [7]. In the studied group, 25% of mothers during pregnancy had infections of various etiologies with 7.5% of them suffering from herpes infection, toxoplasmosis or shingles.

Smoking during pregnancy increases the risk of premature birth, very low

birth weight, causes abnormal diffusion of oxygen through the placenta, carbon monoxide poisoning, ischemia and hypoxia of the fetus, thereby contributing to the development of risk factors of CP [8]. Unfortunately, every fourth surveyed mother smoked during pregnancy.

One of the factors influencing the development of CP is fetal hypoxia and/or ischemia [8]. Also, perinatal hypoxia, which is reflected in low Apgar scores, has an impact on the frequency of incidence of CP in children [9]. The studies show that fetal hypoxia or ischemia were diagnosed in 22.5% of all pregnancies.

Due to the occurrence of various diseases connected with CP, children face numerous problems in daily functioning.

One of the most common consequences of CP, apart from the motor dysfunctions, are speech disorders [10]. According to Obrębowskiego and Auriga [11] delayed speech development is found in 96% of children with CP. Among the respondents, 52% of parents notice abnormal speech in children with CP, while only 36% of children have the same observations. The inability to express themselves through the speech affects daily life at the level of interpersonal contacts. It often causes the feeling of resignation due to the lack of understanding.

Approximately 50% of children with CP experience visual problems [12,13]. This study findings show that visual disturbances occur in children with CP in the opinion of three quarters of parents. In contrast, only 44% of children declared having visual problems.

Mental retardation is seen in half of children with CP [5,13], which may take the form of mild to severe disability [2]. In our study, 65% of parents and only 24% of children declared the occurrence of mental retardation.

Hearing disorders occur in children with CP in 25% of cases [13]. In our study, the percentage of children who have experienced hearing loss is only 7.5 (according to parents).

Approximately every third child with CP has epilepsy [14,15], which is a particularly unfavorable symptom affecting psychomotor development and leading to secondary changes in the CNS — to hypoxia and injuries,

in the case of severe epilepsy it may cause regression of child development and the loss of previously learned functions [14]. The presence of epilepsy causes additional problems and affects the daily life of children with CP. The analysis of the collected material shows that, according to the parents 57.5% of children have been diagnosed with epilepsy. In contrast, only 12% of the children were aware of the disease diagnosed called epilepsy.

In the case of people with disabilities, leaving the house requires more than just good intentions and enthusiasm, often additional conditions have to be fulfilled. Patients with CP (50%) often ambulate with the aid of special equipment such as wheelchairs, walkers and crutches [2]. This study shows that the vast majority of children with CP (almost 90%) ambulate with the help of special equipment or with the assistance of another person. However, the biggest obstacle when leaving the house are architectural barriers (according to 60% of children and 75% of parents). Problems with independent mobility and architectural barriers are a significant problem in the daily life of children with CP and their families. Despite this problem, more than half of respondents go out every day.

Everyday problems of children with CP also refer to difficulties with performing basic nursing and hygiene activities including dealing with physiological functions. When dressing, 68% requires help (according to children) to 85% (according to parents). Help with brushing teeth is needed by 36% of surveyed children, and according to parents by over 70%. Morning-evening hygiene is a problem for 60% of children, and 77% of parents. Both groups (80%) reported problems with washing the whole body. In the opinion of children only 48% of them admit the need for assistance in performing physiological functions. In contrast, nearly 70% of surveyed parents claim they need to assist their children in such situations. These differences are probably due to the fact that children refuse to admit that they cannot cope with certain activities. In contrast, making bed, nail care or performing precise activities such as fastening buttons or zipper seem to be less “embarrassing” activities — that is why in both groups over 80% of respondents reported problems with these activities on a daily basis. Unfortunately, as research has shown, a high percentage of children need assistance in the performance of nursing and hygiene activities of daily living. It is the consequence of various disorders accompanying CP such as imbalance in the standing position experienced by more than 50% (in the opinion of parents) to 68% (in the opinion of children). Half of the children with CP also have a problem with high muscle tone. It is also difficult to self-maintain a head or body balance in a sitting position. Lack of coordination is a problem in more than half of surveyed children with

CP. All the above disorders impair daily functioning of children with CP.

Analysis of data on social contacts showed that in the opinion of both groups, children with CP frequently maintain relationships mainly with family members and peers, if they find themselves together in a big group. The research by Rosińczuk et al [16] shows that only half of the children with CP is involved in social and cultural life of the family. The research conducted by Michelsen [17] showed that children with CP spend less time with friends compared to their able-bodied peers.

Rehabilitation of children with CP is about focusing on the proper mental and physical development of the child so that in the future, they can achieve the most optimal level of functioning, i.e. eliminate pathological patterns and manage compensation in such a way that the developing movement patterns resemble natural ones [18].

In this study, the majority of children with CP was rehabilitated (over 90%). In contrast, over 80% of respondents in both groups noticed significant progress in performing daily functions as a result of rehabilitation. The surveyed children with CP are involved in various forms of rehabilitation. Apart from motor rehabilitation, children with CP improve their physical condition through therapeutic massage (67.5%), kinesitherapy (56.25%), dog therapy (40%) and hippo-therapy (30%) and hydrotherapy (30%). The research conducted by Nawrocka [19] proved that dog therapy is an effective method to aid development of children with a variety of disorders, including CP.

Implications for Nursing Practice

A child with CP, due to the complexity of symptoms, faces many problems in daily life. A nurse as a member of the interdisciplinary team who takes care of a child with CP should be in accordance with their knowledge and scope of the duties, participate in the care and the entire rehabilitation process and parental education. Both children and their parents require special care, emotional support and information from the nursing staff.

Conclusions

1. Children with CP are exposed to many problems in daily life.
2. Only a small percentage of children with CP is able to ambulate independently.
3. Due to the existing disorders, the vast majority of children with CP are not able to function without assistance.

4. A result of rehabilitation, children with CP have improved the efficiency of performing various activities in daily functioning.

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Conflict of Interest: None

Funding: None

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(A — Concept and design of research, B — Collection and/or compilation of data, C — Analysis and interpretation of data, D — Statistical Analysis, E — Writing an article, F — Search of the literature, G — Critical article analysis, H — Approval of the final version of the article)

Received: 18.02.2014

Accepted: 23.04.2014