

DOI: 10.15225/PNN.2014.3.4.6

## Ways of Describing the Degree of Physically Impaired Children, the Classification of Everyday Communication Skills and the Quality of Life Children with Cerebral Palsy

### Sposoby opisywania stopnia niepełnosprawności motorycznej, klasyfikacji umiejętności codziennej komunikacji oraz oceny jakości życia dzieci z mózgowym porażeniem dziecięcym

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#### Abstract

Cerebral palsy (CP) is a chronic and incurable disease, in which there is high possibility to significantly improve the patient's condition. The formation of ways of describing the degree of physical impairment, the classification of everyday life communication skills or scales thanks to which there is high possibility to measure the quality of life in that specific group of patients, allows for thorough understanding of the needs, as well as systematic evaluation of therapeutic actions taken with respect to the patient with cerebral palsy.

This work aims to provide the ways of describing a degree of physical impairment, the classification of everyday communication skills and the specific scales used to describe the quality of life patients with cerebral palsy.

Research in the group of patients with ICP allows to learn the needs of patients and may be useful in channeling into development of the patients' life quality from both clinical and social aspects. (JNNN 2014;3(4):183–187)

**Key Words:** cerebral palsy, child, physican impairment, quality of life

#### Streszczenie

Mózgowe porażenie dziecięce (mpd) jest chorobą przewlekłą i nieuleczalną, w której możliwe jest znaczne usprawnienie chorego. Powstanie sposobów opisywania stopnia niepełnosprawności motorycznej, klasyfikacji umiejętności komunikacji codziennej czy też skal pozwalających na ocenę jakości życia specyficznych dla tej grupy chorych, pozwala na dogłębne poznanie potrzeb pacjentów z mózgowym porażeniem dziecięcym, a także systematyczną ocenę podjętych działań terapeutycznych względem chorego.

Niniejsza praca ma na celu przedstawienie sposobów opisywania stopnia niepełnosprawności motorycznej, klasyfikacji umiejętności codziennej komunikacji oraz skal specyficznych używanych do opisu jakości życia w grupie chorych z mózgowym porażeniem dziecięcym.

Prowadzenie badań w grupie chorych z mpd pozwala na poznanie potrzeb pacjentów, a następnie może okazać się pomocne w ukierunkowywaniu poprawy rozwoju jakości życia chorych, zarówno ze strony klinicznej jak i społecznej. (PNN 2014;3(4):183–187)

**Słowa kluczowe:** mózgowe porażenie dziecięce, dziecko, niepełnosprawność, jakość życia

#### Introduction

In recent years, we can observe the versatile attention to the needs and care of chronically ill patients [1]. Cerebral palsy (CP) is a chronic and incurable illness, in

which it is possible to significantly improve the patient's condition [1–7]. The classification of everyday life communication skills or scales thanks to which there is high possibility to measure the quality of life in that specific group of patients, allows for thorough understanding of

the needs, as well as systematic evaluation of therapeutic actions taken with respect to the patient with cerebral palsy. The versatile interest with proven research methods may also affect the life extension and its quality. There are few publications in Polish literature concerning the life quality of patients with cerebral palsy, although the children with developmental disorders, including cerebral palsy, are a vast majority in child health clinics [1].

This work aims to provide the ways of describing a degree of physical impairment, the classification of everyday communication skills and the specific scales used to describe the quality of life patients with cerebral palsy.

### Characteristics of cerebral palsy

Current knowledge development and discussions among researchers during the International Workshop about Definition and Classification of Cerebral Palsy among Children in Bethesda (USA), July 2004 resulted in cerebral palsy definition and classification upgrade. These discussions were a response to the need of summarizing the state of knowledge about cerebral palsy and a fresh look at the language of illness description. In accordance with the definition the term: “cerebral palsy” describes a group of permanent non-progressive movement and posture disorders, causing physical limitation that may arise in the fetus or infant brain development. The cerebral palsy is often characterized by sensory, perception, cognition, communication and behavior disturbances, epilepsy and musculoskeletal problems [8,9]. “The new definitions and functioning scales applied in cerebral palsy” by Gajewska took comments (following Rosenbaum) on the cerebral palsy definition. Thanks to them, there is a possibility to clarify the concept of CP among many connected areas [8,9].

The frequency of cerebral palsy has not changed for many years — 1–2 cases per 1000 live births worldwide [4,8,9]. It was estimated that in the Polish population there are born approximately 1200–1300 children each year, which based on occurring symptoms are diagnosed with cerebral palsy. Development of newborns monitoring and life-saving technologies, including those born prematurely, with low birth weight did not contribute to the illness diminution [2,10]. Some researchers believe that the increase of medical care for mother and child, caused a greater survival of children with potential cerebral complications [1,3].

The illness image in case of CP is very diverse. A common feature of each sick person is motor neuron damage that permanently reduces physical abilities. The degree of physical limitation is different and multifactorial according to each patient, depends on the stage of cerebral palsy, its topography and paresis severity, and

also on its accompanying symptoms [4], such as mental retardation, hearing, speech and vision impairments or epilepsy [3–6].

A patient afflicted with cerebral palsy requires a comprehensive therapeutic process led by various specialists, physical therapists, nurses, speech therapists and pedagogues. Many researchers pay attention to the good cooperation between the various members of the care team and parents of a sick child — the task of the therapeutic team at first, is to provide the family with necessary knowledge, and to save them from the social isolation or a sense of loneliness after the diagnosis. In the literature, it is emphasized that parents should be aware as soon as possible that cerebral palsy is a disorder for which there is no cure, and the rehabilitation process is long [4,11]. The parents of a sick child should also be informed that the initially proposed therapy may change due to numerous discoveries and new reports in this field. Burke-Taylor and their associates in their study from 2009, pointed to the fact that parents are the best source of information about child development for the therapeutic team, so they should be aware of possible home activities which can be performed at home and on what to pay attention [4,12].

### The scales used to assess the functioning of a patient with cerebral palsy

Physical impairment associated with daily activities, is inextricably linked with cerebral palsy, being its main symptom. Today, the main measure of progress in the therapy or rehabilitation is to assess the gross motor skills.

Gross Motor Function Measure (GMFM) scale was developed in the 90's of the last century by Russell and co-authors as a response to the need for a standardized assessment tool to classify the movement severity patients with CP. GMFM method is based on the principles of neurophysiology development — examines the functional behavior in the field of gross motor skills from infancy to 16. Thanks to high sensitivity and reproducibility allows for a thorough assessment of the different treatments effectiveness.

Scale GMFM-66 has been designed exclusively for children with cerebral palsy. It is based on the GMFM-88 — version for assessing patients with Down Syndrome — as a result it also helped to assess a difficulty to complete each task by children with cerebral palsy. To test the children with cerebral palsy there were only selected tasks that most reflect the capabilities of the child and those which should be monitored [1,13]. During the test, the child is subjected to 66 motor tests conducted on the five levels: A) Lying and rotating B) Seating C) Walking on hands and knees D) Standing E) Walking, running, jumping. Each test is rated on a scale of 0 to 3, where

0 means no movement is initiated, 1 point — action performed in the range of less than 10% (initiation of motion), 2 points — partly traverses between 10–100%, 3 points — the action performed at 100%. There is also a term NTM — Non tested movement. Obtained points are summarized and subjected to the conversion by a computer program GMAE (Gross Motor Ability Software) that provides the result in percentages with 95% confidence region [8,13].

There is another scale called the GMFCS (Gross Motor Function Classification System), developed by Palisano and his coworkers. Thanks to it, there is possibility to classify a child with cerebral palsy to the corresponding development level of motor skills, depending on age (there are five age groups: up to 2 years, 2–4 years, 4–6 years, 6–12 years, 12–18 years) and palsy severity (I–V levels). Children in Level I are able to perform the same actions as healthy peers — only the rate of motion, balance and coordination are the problem. In turn, children in Level V have difficulty in controlling the position of the head and trunk and the conscious physical control. Today, GMFCS is the main source of describing motor disability children with cerebral palsy [2,8,14].

The GMFM-66 and GMFCS scales are not applied to assess the direct quality of life patients with CP, but may be useful as an auxiliary tool in the assessment of the issue [2].

Based on the functional diagnosis patients with CP-GMFCS scale and information about the proper functional development of the hand there has been developed by a group of Swedish doctors a manual abilities classification system, called MACS (Manual Ability Classification System). This system allows for the provision of systematic method to assess how children with CP use their hands using the objects in daily activities. This method is intended for patients aged 4 to, taking into account the difference on between holding them by a 4-year old child and a teenager.

It should be emphasized that the MACS includes a variety of functional limitation among children with cerebral palsy and all subtypes. Some subtypes are sorted by MACS at several levels, such as binaural CP. The first level includes children with minor motor limitations, while children with severe motor limitations are classified into levels IV and V. Level “0” would be necessary if we would classify by MACS healthy developed children [15].

CFCS (Communication Function Classification System) is an system everyday communication skills classification system children with cerebral palsy. There are V levels, where I is the highest level of communication skills, and level V the lowest. This method is focused on activity and participation, defined by the World Health Organization in the International Classification of Functioning Disability and Health.

During determining the level of CFCS there are taken into account all types of communication (verbal communication, gestures, behavior, gaze, facial expression and supporting and alternative communication — augmentative and alternative communication — ACC). The ACC includes manual signs, logos, communication boards, communication books, and devices capable to communicate — called voice communication aids (VOCAs) or devices that generate speech (SGDs).

The difference between particular levels is based on the ability to adopt the role of the sender and the recipient, the pace of communication and type of partner [16].

According to Hidecker and coauthors of CFCS can be useful in researches and in providing services, in which there is important communication effectiveness classification [17].

### **Polish versions of specific scales for assessing the quality of life patients with cerebral palsy**

The concept of quality of life determined by the state of health — HRQOL (health related quality of life) — has been introduced to modern medicine in 1990 by Schipper. HRQOL study is based on a subjective assessment of the three dimensions of life: physical, mental and social. Assessment of motor impairment, pain level, the scope of daily activities, the overall level of life energy, cognitive functioning, emotional and social functioning, the range of social roles and relationships with others is assessed by the patient and in case of children by a parent or guardian. The quality of life in holistic terms, remains strictly dependent on developed by the World Health Organization definition of health, which is defined as a state of complete mental and social wellbeing and not only the disease [2,7,18]. In assessing the children quality of life there are applied both general (non-specific, generic) and specific questionnaires, designed to study HRQOL in specific disease entities [2,7].

We can find below the specific questionnaires used for children with cerebral palsy, with Polish language version available that were passed through validation process.

Pediatric Quality of Life Inventory — Cerebral Palsy Module (PedsQL — CP Module) is a standardized research tool by James W. Varni from the Department of Pediatrics, College of Medicine in the USA. It has been developed for the assessment of the life quality for children with cerebral palsy.

PedsQL-CP Module consists of 35 questions that relate to the seven life spheres of the patient: daily life activities, school activity, move and balance maintenance, pain, fatigue, eating, speech and communication. The questionnaire is designed for children between: 5–7 years, 8–12 years and adolescents 13–18 years. There are also, according to the different age groups, questionnaires for

parents and additional questionnaires for guardians of children aged 2–4 years. The content of the questions in each questionnaire are similar to each other. The tool is based on studies of representative groups of patients, in which the reliability analysis was performed using the internal consistency index Cronbach's  $\alpha$  — on level 0.79 — in the group of the children and 0.91 — for their parents [19].

CPQOL-Child is test used to assess the life quality of children with cerebral palsy. It was created by a group of Australian and international scientists. It is based on three essential pillars that form:

1. International Classification of Functioning Disability and Health (ICF — International Classification of Functioning, Disability and Health)
2. Experiences and international studies
3. Equal treatment and evaluation of the responses received from parents and children [20–22].

The questionnaire completed by the parent, refers to children between 4–12. It consists of 66 questions. Patients aged between 9–12 receive their own questionnaire consisting of 52 questions. Each of the questions is divided into seven ranges: welfare and social acceptance, child's functioning, physical health, emotional well-being, access to services/medical care (questions are only directed to guardians). CPQOL-Child questionnaire is evaluated in the literature as an extremely valuable and reliable.

Validation of the Polish language version is only available for CPQOL-Child Head Guardian Questionnaire (4–12 years). Research on the Polish version of the questionnaire published by Dmitruk and coauthors in 2013 shows that the rate of internal consistency of Cronbach's  $\alpha$  — is above 0.77 for each of the rated range, and the rate of internal consistency of Cronbach's  $\alpha$  — calculated for the entire questionnaire is 0.82 [23].

An important advantage of CPQOL-Child is that it focuses on the welfare of the child, and not on the level of his impairment. It also allows to reveal how a child perceives various aspects of life [20–22,24,25].

There is also available CPQOL-Teen version for patients aged between 13–18, and a version for their guardians, but as a questionnaire for patients aged 9–12 is not available in Polish version [20].

## Summary

People affected by cerebral palsy in addition to numerous health problems, often have difficulty in performing simple everyday life activities. Problems which they need to face decrease their life quality and functioning level. Apart from scales and questionnaires described in the study, there are many others, but do not have a Polish version validation. Children with cerebral palsy, are

a large group of patients in Polish health care system, hence it seems necessary to conduct studies on obtaining standardized research tools to meet their needs, and then provide the best treatment solution, rehabilitation, the communication and functioning level improvement in the community. These activities certainly can help to increase the self-esteem of patients with cerebral palsy.

## References

- [1] Sienkiewicz D., Kułak W., Buzalska A., Okurowska-Zawada B., Paszko-Patej G. Skale funkcjonalne stosowane u dzieci z mózgowym porażeniem dziecięcym. *Neurol Dziec.* 2009;35(18):73–78.
- [2] Topór E., Kułak W. Jakość życia dzieci z mózgowym porażeniem dziecięcym. *Neurol Dziec.* 2010;19(37):61–66.
- [3] Michałowicz R. *Mózgowe porażenie dziecięce*. PZWL, Warszawa 2001.
- [4] Andruszczak B., Buraczyńska-Andrzejewska B., Krauss H. i wsp. Wielopłaszczyznowa opieka nad dzieckiem z mózgowym porażeniem dziecięcym. *Medycyna Ogólna i Nauki o Zdrowiu.* 2012;18(4):314–318.
- [5] Rosińczuk J., Kołtuniuk A., Księżyc M., Wolniak M. Rodzice dziecka z mózgowym porażeniem dziecięcym wobec problemów dnia codziennego. *Pielęgniarstwo Neurologiczne i Neurochirurgiczne.* 2013;2(4):149–54.
- [6] Czupryna K., Nowotny-Czupryna O., Nowotny J. Stopień niepełnosprawności dzieci z mózgowym porażeniem dziecięcym i jakość ich usprawniania a ograniczenia życia rodziny. *Rehabilitacja Medyczna.* 2012;16(2):22–28.
- [7] Michalska A., Boksa E., Wendorff J., Wiktor P.J. Jakość życia dzieci i młodzieży z mózgowym porażeniem dziecięcym i niepełnosprawnością intelektualną. Wybrane uwarunkowania społeczno-demograficzne. *Neurologia Dziecięca.* 2012;21(42):35–44.
- [8] Gajewska E. Nowe definicje i skale funkcjonalne stosowane w mózgowym porażeniu dziecięcym. *Neurol Dziec.* 2009;18(29):67–71.
- [9] Rosenbaum P., Paneth N., Leviton A. et al. A report: the definition and classification of cerebral palsy April 2006. *Dev. Med. Child. Neurol.* 2007;49(suppl):480.
- [10] Harat M., Radziszewski K., Rudaś M. et al. Kliniczna ocena głębokiej stymulacji mózdzku w leczeniu spastyczności u chorych na mózgowe porażenie dziecięce. *Neurol Neuroch Pol.* 2009;43(1):36–44.
- [11] Donovan J.M., VanLeit B.J., Crowe T.K., Keefe E.B. Occupational goals of mothers of children with disabilities: influence of temporal, social and emotional context. *Am J Occ Ther.* 2005;59:249–61.
- [12] Bourke-Taylor H.M., Law M., Howie I., Pallant J.F. Development of Assistance to participates Scale (PAS) for children's leisure activities. *Child Care Health Dev.* 2009;35:739–45.
- [13] Kwestionariusz GMFM-66. Retrieved July 22, 2014, from <http://www.canchild.ca/en/measures/gmfm.asp>
- [14] Kwestionariusz GMFCS. Retrieved July 22, 2014, from [http://www.motorgrowth.canchild.ca/en/GMFCS-resources/GMFCS\\_English.pdf](http://www.motorgrowth.canchild.ca/en/GMFCS-resources/GMFCS_English.pdf)

- [15] Kwestionariusz MACS. Retrieved July 22, 2014, from <http://www.macs.nu>
- [16] System klasyfikacji CFCS. Retrieved July 22, 2014, from <http://www.cfcs.us>
- [17] Hidecker M.J.C., Paneth N., Rosenbaum P.L. et al. Development and validating the Communication Function Classification System (CFCS) for Individuals with Cerebral Palsy. *Developmental Medicine and Child Neurology*. 2011;53(8):704–710.
- [18] Oleś M. *Jakość życia młodzieży w zdrowiu i chorobie*. Wydawnictwo KUL, Warszawa 2010.
- [19] Kwestionariusz PedsQL: <http://www.pedsqol.org/index.html>
- [20] Kwestionariusz CP QOL: <http://www.cpqol.org.au>
- [21] Waters E., Davis E., Mackinnon A. et al. Psychometric properties of the quality of life questionnaire for children with CP. *Dev Med Child Neurol*. 2007;49:49–55.
- [22] Waters E., Davis E., Ronen G.M. et al. Quality of life instruments for children and adolescents with neurodisabilities: how to choose the appropriate instrument. *Dev Med Child Neurol*. 2009;51:660–669.
- [23] Dmitruk E., Mirska A., Kułak W. et al. Psychometric properties and validation of the Polish CP QOL Child questionnaire: a pilot study. *Scand J Caring Sci*. 2013;11. DOI:10.1111/scs.12095.
- [24] Davis E., Shelly A., Waters E. et al. Quality of life of adolescents with cerebral palsy: perspectives of adolescents and parents. *Dev Med Child Neurol*. 2009;51:193–199.
- [25] Davis E., Shelly A., Waters E. et al. Measuring the quality of life of children with cerebral palsy: comparing the conceptual differences and psychometric properties of three instruments. *Dev Med Child Neurol*. 2009;52:174–180.

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**Conflict of Interest:** None**Funding:** None**Author Contributions:** Marta Grabinska<sup>A, B, C, E, F</sup>, Andrzej Kurylak<sup>A, G, H</sup>, Ewa Barczykowska<sup>A, G, H</sup>

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

**Received:** 11.08.2014**Accepted:** 12.09.2014