

THE USE OF THE FUNCTIONAL ASSESSMENT OF PATIENTS – PAEDIATRIC VERSION IN THE STUDY OF THE FUNCTIONAL STATUS OF CHILDREN WITH CEREBRAL PALSY AND PROFOUND INTELLECTUAL DISABILITIES

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ABSTRACT

Introduction. The study of the functional status of children with Cerebral Palsy (CP), along with the concomitant profound intellectual disability is a complex process, both in terms of organizational and methodological aims. Particularly troublesome is the assess of the motor skills development and motor skills themselves and changes that may occur in the course of therapy and rehabilitation.

Aim. Determination of the diagnostic accessibility of the Functional Assessment of Patients – OFC – paediatric versions for the rehabilitation process as a method determining the degree of impairment and recovery of function for daily life activities in children with the cerebral palsy and profound intellectual disabilities.

Material and methods. The study involved 17 children aged from 7 to 17 years. Methods of testing using OFC paediatric version relied on observation of the patient by the therapist in the different functional situations (6 categories).

Results. In 29.4% of patients there was found the improvement in functional status between the first and second examination. 29.4% of patients showed no change in functional status among particular studies, while functional deterioration was observed in 41.2% of patients.

Conclusion. The observational method OFC – paediatric version, performed on the basis of the assessment of the functional status is an individualized and sensitive form of gathering information about the functional status of children with cerebral palsy and profound intellectual disabilities. The paediatric version of the OFC

method is characterized by the diagnostic value in the rehabilitation process of rehabilitation as a method that determines the degree of loss and recovery of function daily life activities of children with cerebral palsy and profound intellectual disabilities.

Key words: Functional assessment, deep intellectual disability, OFC – paediatric version, cerebral palsy

Introduction

The satisfactory function is, next to the psychological adjustment and well-being, the most important exponent of health. It is defined as a set of features making possible the adaptation of individual organs and systems, and the whole human body to perform vital functions in terms of the environment. It is both the correct morphological structure of individual organs, as well as the appropriate interaction of the vital systems during physiological reactions in the body (Cywińska-Wasilewska 2004).

The World Health Organization (WHO) notes that in determining the state of health, it should be also taken into account the functional state of man. Precise determination of the functional status of the patient is the main factor determining the correct therapeutic decision-making and establishing an interdisciplinary plan of treatment (Dudziński and Józwiak 2006).

In 2001 WHO published The International Classification of Functioning, Disability and Health (ICF), the scheme of which includes 3 different perspectives on the functioning of the per-

son (Heerkens et al 2006): the perspective of the body (physiological and mental functions and characteristic of the anatomical properties), the prospect of purposeful daily life activities and a third perspective which includes the participation in social life.

The disable child, according to the WHO terminology, is characterized by long-term, total or substantial inability to participate in the group properly developed and healthy children. The chronic nature of most diseases in many cases leads to the loss of efficiency in the extent that it becomes necessary to put in place various kinds of forms of medical and social support enabling the child the proper functioning (Sowa 2004).

Cerebral palsy (CP) – this is, in accordance with the definition of Rosenbaum et al (Rosenbaum et al 2007) from 2007, who proposed the extension of the definition by Bax (Bax 1964) of 1964, the term that describes a group of permanent disorders in the development of movement and posture, causing the activity limitation ascribable to distortions appearing with the poorly accompanying brain development of the fetus or infant. Motility disorders in CP are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, epilepsy and the secondary musculoskeletal problems.

Polish studies, covering a population affected by CP with the disability in Poznan, reports 2.5 children per 1000 live births (Zgorzalewicz et al 2001). CP is the world's third most common cause of long-term disability in the paediatric population, which makes the CP seen not only on the basis of medical and psychosocial but also economical ground (Połatyńska and Kępczyński 2010).

Apart from the main symptoms of injuries in the central nervous system (CNS), which constitute the diagnostic criteria for CP, the most serious symptoms are associated with mental retardation and include the epilepsy as well. Although noticeable are large discrepancies between the different researchers, on the issue of co-occurrence of intellectual disability among children with CP, it is on average at 50%. The mental retardation occurring in the population of children with CP is caused by the limited contact with the child's physical environment. The process of skill acquisition in control of the head movement, visual fixation on objects, movement and grasp of objects and manipulate them in the course of development, leading to a reduction of knowledge about the environment and the properties and functions of utility facili-

ties is considered as to be difficult (Borkowska and Domańska 2006).

According to the record of the WHO since 1968, there is a four step classification of mental retardation: mild, moderate, severe and profound. The population of people with intellectual disabilities only at 1.5% have a diagnosis of mental retardation involving profound step (Sowa 2004).

People with the profound intellectual disabilities require the ongoing support for everyday life activities. They are characterized by a deep deficit making difficult to enable the development of performing the elementary activities. Physical deformities are common, as well as CNS pathologies and comorbidities. Patients exhibit limits in the ability to understand, executing commands and signaling needs. They require the permanent care, they are unable to live independently. They show emotional disorders, behavioural and psychotic disorders. They emit the inarticulate sounds; express simple emotions (satisfaction and dissatisfaction).

The study of the functional status of children with CP, along with the concomitant profound intellectual disability is a complex undertaking, both in terms of organizational and methodological fields. Particularly troublesome is an evaluation of the development of motor skills and motor capabilities and changes that may occur in the course of therapy and rehabilitation. Analysis of the available functional scales revealed a lack of adequate and appropriate in these group methods of assessment, meeting the expectations of therapists regarding the methodology, individualization of study and sensitivity measurements.

Aim

The aim of the study was to determine the diagnostic value of the Functional Assessment Methods Patients – OFC – the paediatric version during the rehabilitation process as a method of determining the degree of impairment, possibility of acquisition or recovery of the daily life activities in children with cerebral palsy and profound intellectual disabilities.

Material and methods

The material in this study was children with CP with the profound intellectual disabilities attending Special School No. 103 in Poznań (Poland).

The study involved 17 children (7 girls and 10 boys). At the start of the study patients ranged in age from 7 to 17 years (mean: 11 years 9 months).

The study used a paediatric version of the scale OFC available on the website www.ofc.pl. The research was carried out twice (in December), at an interval of 12 months between two tests. Tests were performed on an observation based on the same sheet. The children were improved during rehabilitation process applied 1 hour per week with the group therapy and the individual therapy lasting 2 hours a week.

Methods of testing using OFC paediatric version relied on observation of the patient by the therapist in different situations and on the functional sheet completion, which included six categories of observed features. The total number of functional tasks was 195. The "efficiency" category contained 60 questions and included functional tasks associated with such skills as raising the head in lying, sitting, standing up, balancing, self-standing, performing simple movements of the limbs and torso. The category of "moving" included such functional tasks as grabbing, independent walking, walking with the use of rehabilitation equipment, walking up the stairs, jumping, running – and contained 44 questions. In the category of "mobility" there were 35 questions covering a small motor skills – including grabbing, holding, repositioning, hitting, drawing, throwing and imitation of simple movements. The category of "food" consisted of 17 questions in the skills of eating, drinking and the use of devices in everyday life. In the category of "dressing" there were 20 questions covering the skills of individual items or dressing clothes. The last category of "washing/cleaning" contained 19 questions on the ability to perform personal hygiene – including wash up, brushing teeth and using the toilet.

The method OFC abandoned entirely of assigning point values for a given activity, introducing a binary model. The assessment consisted of performing a specific function independently without the undefined outside assistance, which always can have a different degree and nature. Answering "yes/no" allowed obtaining the actual picture of the evaluated parameters of the function (Dudziński and Józwiak 2002). For answering "yes" the child received 1 point, while answering "no" was scored at 0.

The results were entered into the system OFC – paediatric versions. The system automatically made a calculation of input data (performed summing up the points for the subsequent functional tasks) and applying them to all of the questions raised (100%),

thus yielding a percentage score for each patient. The system presented graphically and mathematically the current state of patient, both in the first study and in the second, so that it was possible to observe changes in the functional image over time in each test. The program calculated the percentage of positive answers to all the questions raised in the study, during both the first and in the second study. The result of the difference between these values testified improvement (when it was positive), deterioration (when it was negative) or the absence of changes in the functional status of the respondents at the time.

With these results it was possible to observe the usefulness of diagnostic method, which identified the three groups of patients with various functional state – with the improvement or deterioration, or the lack of changes in the functional state found between two tests.

The research methodology was approved by the Bioethical Committee of the K. Marcinkowski University of Medical Sciences in Poznan.

Results

Double-performance study of the functional status of all patients was designed to capture changes in the reporting of their functional status, especially when it was applied the therapy which aimed improving the mobility.

Analysis of the results in this study included evaluation of the individual results obtained by individual patients.

In the first study, children overall score ranged from 0% to 72% of positive responses (mean 22%). However, in the second study, the overall result of children ranged from 0% to 71% (mean 21%). It follows that no child presented the functional status of 100%. The results indicate low values describing the functional status of patients.

Figure 1 shows the distribution of difference values between the first and second test. It shows that the largest group (7 persons) consisted of patients whose functional status in the second study was deteriorated in comparison with the first survey in the range of -1% to -8% ("deterioration") – stakes with diagonal lines. In 5 children there were no changes in the functional status between the first and second study ("no change") – stakes with black colour. Also 5 children in the second study received a positive change in their functional status – ie, "improvement" in the range of 1% to 5% compared with the first survey (stakes with grey colour).

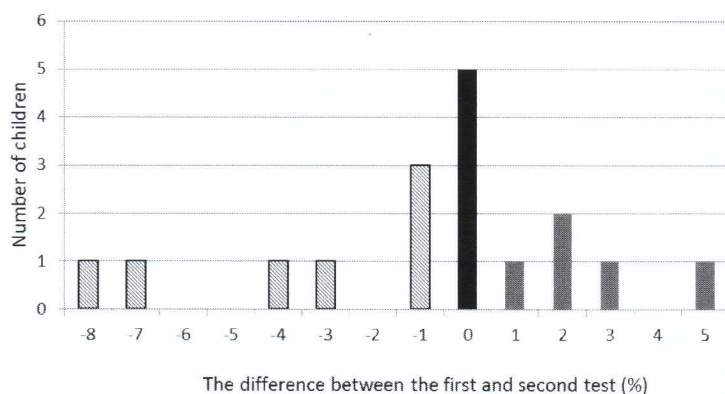


Figure 1. Distribution of the difference between the first and second test

Table I shows the percentage distribution of the results obtained in the “improvement”, “no change” and “deterioration” of the functional status of children with profound intellectual disabilities between the first and second examination.

Table I. Distribution between the first and second study in patients with profound intellectual disability.

Distribution of the results OFC – paediatric version	Number of children (%)
improvement	5 (29,4%)
no change	5 (29,4%)
deterioration	7 (41,2%)
Total	17 (100,0%)

These data suggest that in children with profound intellectual disabilities there cannot be seen the dynamics changes in functional status because of coupled disabilities, often observed in this group of patients, which are not without impact on achieving the positive changes in functional and often lead to deterioration (41.2%).

Discussion

Observed close relationships of the patient’s functional status and choosing the optimal form of treatment contribute to the development of functional tests. From the results obtained through the use of appropriate methods to assess the functional status of the patient, there depend the selection of appropriate surgical techniques, rehabilitation procedures, physiotherapy treatments and pharmacological treatment. The results of the assessment of the functional status impact the whole holistic approach to the patient (Ronikier and Rola 2010).

In the cases of CP patients with co-occurring profound intellectual disabilities only the scale of an

observation can be applied during the functional status test. Analyses show that this is the most appropriate form of collecting information about the child. Observation is a useful method – often basic in the diagnosis of little children and and severely retarded people who are uncooperative in the case study by standard methods. The method used in this study provided information on the achievements and child’s development deficits in all developmental aspects (Domagalska et al 2007).

Domagalska et al (2007) state, that the unpredictable effects of damage in the immature CNS and individual opportunities arising from the plasticity of the brain prejudice that psychomotor development of each child with CP who is individual and unique. This in turn consists to the idea of individual potential rehabilitation of each child with CP. OFC scale – paediatric version has been designed to individualization of the study and it was its top priority. So there is the possibility of configuration both the individual questions on the worksheet in OFC, as well as create the new categories depending on needs – all new set of questions and categories are added to the mathematical and graphical analysis computer program. The OFC scale- paediatric version, as a result, gives each user the possibility of copyright. In principle of OFC – no matter the paediatric version equates the results to results from other patients, the essence is to compare and analyse the changes in performance of the same particular patient at a time. It should be emphasized that the patient is characterized by individual needs, individual capabilities and potential, individual constraints, for whom the family determines the individual priorities of therapy and treatment. Functional tasks proposed by the OFC – paediatric version consist of 195 tasks; it is only the foundation on which the investigator can rely creating the new questions and categories.

The paediatric version of the OFC through its openness to new categories and questions becomes a friendly individual approach to the patient, respecting the uniqueness of each individual. The researcher has the ability to individually configure this research tool in accordance with the needs of the patient and an assumed functional assessment detail.

In researching the OFC scale – paediatric version, it has been observed that increasing number of functional tasks increases the chances of getting a positive response for the task properly done. The

greater the intellectual and physical disability of the child is, the more difficult it becomes for him to complete the task. Despite the very poor performance of children with profound intellectual disabilities during first study they had a chance to get positive results (in less sensitive scales the score would gain 0). A similar situation occurred in the second study, conducted after the year – in this case children also received points for the tasks performed. The most important is the fact that it was possible to observe the changes in functional status of these children by comparing the results obtained in the first and second study. In the case of less sensitive scales in both the first and second study, the result “0” would have no give or no relevant information about the functional state of children and changes found. In the case of a smaller number of questions about the functional status, the results would certainly be worse, and the used tool would not serve the description of functional status. Searching for appropriate methods to assess the functional status of patients it was observed that the scales with a small number of tasks to be performed could not be applied in work with children representing serious disorders such as profound intellectual disability and accompanying physical disabilities, or different types of comorbidities.

Stokes (2010) believes that one of the factors judging for the choice of the measuring tool should be its precise and sensitivity to changes. Under the concept of the sensitivity of the measurement, the tool must be understood with the ability to detect significant changes in the concept measured over time (Heerkens et al 2006). The concept was also analysed in category of the sensitivity scale by Ronikier and Rola (2010), who believe that the tests for assessing the functional abilities for assistance in planning of rehabilitation must diagnose the largest number of motor parameters and endurance. Too limited functional analysis may cause misdiagnosis and delay the healing process and rehabilitation.

Conclusions

1. Observational OFC method – paediatric version, performed on the basis of the assessment with the functional status sheet is individualized and sensitive form of gathering information about the health of children with cerebral palsy and profound intellectual disabilities.
2. The paediatric version of the OFC method is characterized by the diagnostic value in the

rehabilitation process as a method that determines the degree of loss, gaining or recovery of function within daily life activities of children with cerebral palsy and profound intellectual disabilities.

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