

ASSESSING REHABILITATION OF CONVALESCENT CHILDREN AFTER INFECTIOUS DISEASES

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The fact that the disease sequelae can limit the development of the growing child's activity is the feature of pediatric medical rehabilitation, that is why there is a need for repeated courses of rehabilitation or habilitation, where each subsequent course is a continuation of the previous one. The specialist's mission is to determine indications for rehabilitation. The paper reports phenomenology and methods to diagnose abnormal activity and participation in convalescent children after infectious diseases in order to set the rehabilitation goals in the International Classification of Functioning, Disability and Health domains (categories). The use of method to estimate activity and participation from the point of view of both child and parent or caregiver is considered. The paper provides information useful for specialists dealing with the issues of rehabilitation of children after infectious diseases.

Keywords: children, rehabilitation, infectious diseases, ICF method, activity and participation

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ОЦЕНКА РЕАБИЛИТАЦИИ ДЕТЕЙ-РЕКОНВАЛЕСЦЕНТОВ ПОСЛЕ ИНФЕКЦИОННЫХ ЗАБОЛЕВАНИЙ

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Особенность медицинской реабилитации детей состоит в том, что последствия заболевания могут ограничивать развитие активностей растущего ребенка, поэтому необходимы повторные курсы реабилитации или абилитации, где каждый последующий курс — это продолжение предыдущего. Задача специалиста — выявить показания к реабилитации. В статье представлены феноменология и способы диагностики нарушений активности и участия у детей-реконвалесцентов после перенесенных инфекционных заболеваний для постановки целей реабилитации в доменах (категориях) Международной классификации функционирования, ограничений жизнедеятельности и здоровья. Рассмотрено применение метода оценки активности и участия как со стороны ребенка, так и со стороны родителя или опекуна. Статья содержит информацию, полезную для специалистов, занимающихся вопросами реабилитации детей после инфекционных заболеваний.

Ключевые слова: дети, реабилитация, инфекционные заболевания, МКФ, активность и участие

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The combination of the child's growth and development with the development of activities and skills on the one hand and disabling condition on the other hand is the feature of pediatric medical rehabilitation. Productive communication with the child and his/her parents is also important for pediatric rehabilitation, since family and closest relatives, physical surroundings, are essential for the child's development.

Modern medical rehabilitation has changed significantly and is developing dynamically. Now, as never before, it is important

to understand and master the tactical rehabilitation techniques, including in the field of pediatric infectology [1, 2].

ICF value and capabilities

International Classification of Functioning, Disability and Health (ICF) describes functional health as interaction between the individual's physical and mental states (the level of body's structures and functions) and his/her ability to manage daily

activities (activity level), as well as his/her involvement in real-life situations (participation level). It is believed that the individual's functioning and disability, including his/her participation, result from interaction between health and the factors of context, or environmental factors (such as air quality, environment accessibility, relationships with peers, availability of services, etc.), and personal factors (such as age, gender, virtues, lifestyle, etc.) [3]. Thus, the disease course and functioning are considered as interactive and evolving processes that can be affected at each of these levels via understanding and modification of human behavior. A clear and functioning-related rehabilitation goal increases motivation and leads to a significantly better outcome. Today, collaborative goal setting as part of a family-oriented approach is widely promoted in pediatric rehabilitation, and the focus is shifted from the level of body's structures and functions to expansion of children's activity and participation in daily activities [4].

According to ICF, human health is influenced by personal and environmental factors extending beyond anatomy and physiology. Alphanumeric characters are used to designate the ICF domains and further divide each domain into categories, thereby ensuring a comprehensive list of disabilities and providing a standard conceptual basis for classification of the components of health and disability [5]. However, such ICF completeness and extensive encoding structure (ICF can describe any deviation in health status) to some extent limited its use in daily clinical practice [6].

In terms of ICF, participation means involvement in real-life situations and activities [7]. Participation takes place in the environment, where a person lives, works and plays. It is important to remember that it is participation in various life situations that is considered as an end-product of rehabilitation of disabled people of any age. Based on definition of participation provided in ICF, it is necessary to use the complex assessment instruments that can be tailored to the community culture and used to estimate children's participation in various real-life situations.

Advanced instruments for assessment of children's participation

The modern instruments measuring children's participation in meaningful activities are as follows: Children's Assessment of Participation and Enjoyment (CAPE) [8], Pediatric Activity Card Sort (PACS) [9], Children Participation Questionnaire (CPQ) [10], and Life-Habit [11]. The listed above instruments do not cover all spheres of activity. For example, the frequently used CAPE scale provides good psychometric characteristics for disabled and non-disabled children, estimates participation in important events in the field of leisure and play. This scale does not allow one to estimate participation in such fields, as daily activities, instrumental activities, daily life and rest/sleep. Thus, there are two options for assessment of children's participation in meaningful activities: using the combination of several scales/instruments (CAPE, PACS, etc.), or using an instrument providing comprehensive assessment of participation in various real-life situations [12].

Participation is a multidimensional construct that is influenced by multiple factors (such as gender, age, performance skills), as well as by environmental factors (such as accessibility, social and economic status). Given the definition of participation provided in ICF and the fact that participation is considered to be the end-product of rehabilitation of disabled people [13], it is important to thoroughly and adequately assess participation in various life aspects using inclusive and complex

instruments for goal setting, realization of treatment programs and intervention efficiency estimation [14].

Value of contact with parents for pediatric rehabilitation

In pediatric rehabilitation, a full contact with parents and their involvement in rehabilitation activities, specifically in rehabilitation goal setting, provide the basis for successful work. However, the literature data suggest that physicians, who make an effort to determine the goals of the patient and the family, often set the goals that do not reflect the patient's or caregiver's preferences. Patients often consider goal setting as a kind of implicit agreement between the physician and the patients. Sometimes the family and the patient are not aware of rehabilitation goals [14], while collaborative goal setting allows the patient and his/her family to define their interests and help develop the rehabilitation plan [15]. Collaborative setting of goals and objectives in adults is associated with the increased patient's motivation and better treatment outcomes. As for pediatric population, improving the competence of caregivers during collaborative goal setting turned out to be the resource [4].

The experience of physical medicine and rehabilitation (PM&R) physicians shows that parents often feel uncomfortable when setting goals for children of early age due to the lack of knowledge about the condition and the rehabilitation interventions available [16]. In such cases parents can rely on the physician's expertise to set achievable and meaningful goals. Frankly speaking, this limits the depth of cooperation between patient and the family. In other cases PM&R physicians can feel more comfortable when using simplified goal-setting methods not involving the patient and the caregiver. Practitioners sometimes cast doubt on the ability of patient and the family to set realistic goals [17]. However, according to the literature data, understanding of rehabilitation goals by caregivers is improved when the patient, his/her family and physician set the goals together [18]. Moreover, the data show that caregivers and physicians often have different views on improvement during rehabilitation, which emphasizes the importance of the goal-setting model focused on ICF that guarantees that the goals would remain significant for patient and his/her family [6].

Determining the rehabilitation goal in pediatric practice

Rehabilitation goal is usually determined before the beginning of rehabilitation course. During the meeting rehabilitation specialists ask the patient and his/her family the following questions: "What matters most to you?", "What would you like us to help you achieve?" Among identified ICF domains, 3–5 most important ones are selected. The SMART (Specific, Measurable, Achievable, Relevant, and Time-Bound) goal is set based on these domains.

Limitations of rehabilitation goal setting in the "activity and participation" domains in children over the age of five years can be overcome by using the CASP questionnaire.

The Child and Adolescent Scale of Participation (CASP) measures the children's participation in activities at home, at school and in society relative to children of the same age [19, 20]. The scale was developed as part of the program "Child and Family Follow-up Survey" to monitor the results and needs of children with traumatic and other acquired brain injuries. The content and methods used in CASP that are based on ICF [7] have made possible the studies aimed at assessing participation of children/young adults with various chronic disorders, including disabling ones, as well as the studies

aimed at assessing environmental factors, phactors of physical and social surroundings that support or impede functioning.

Capabilities of CASP scale

Regardless of some limitations, CASP remains a brief and relatively simple to complete instrument offering a good coverage at the level of the “activity and participation” domains. Due to its brevity and simplicity it is useful in clinical practice, as well as for assessment of programs and population studies.

At the same time, CASP is one of very few measures of activity and participation at home, at school and in society for children and young adults with chronic disorders/disability, which can be used for both parents and children.

CASP consists of 20 ordinal-scaled items and four subsections: 1) Home Participation (6 points), 2) Community Participation (4 points), 3) School Participation (5 points), and 4) Home and Community Living Activities (5 points). The 20 items are rated on a four-point scale: “Age Expected” (Full Participation in the subscale), “Somewhat Restricted”, “Very Restricted”, “Unable” (“Unable” in the subscale). The “Not Applicable” response is selected in cases, when the item describes activity, in which the child must not participate due to age (for example, work).

Most of the items are applicable to children of five years and older, that is why it was suggested to use CASP for children starting from senior preschool age.

Each CASP item considers a broad aspect of activity or real-life situation. The item, subsection and total score can be used in research and practice. Higher scores reflect more active participation in community life in accordance with the age-related expectations. CASP also contains open-ended questions about effective strategies and supports, as well as about the obstacles affecting participation (for CASP protocol see Appendix).

CASP can be used for planning of distinct interventions, estimation of rehabilitation efficiency, and research. CASP does not include demographic data, that is why supplementary demographic information is required (for example, age, gender, disability type, organization, geographic location, time since diagnosis).

CASP has been translated into different languages. About 10 min is required to apply CASP. The specialists using CASP for their purposes must be aware of the content and estimation scales of CASP, the key terms subject to assessment (specifically “participation” and “environmental factors”) as defined in ICF [7, 21]. Self-completion of the questionnaire (in person or via email) by both child having an appropriate skill and parent is possible, like interviewing by specialist in person or by telephone.

The analysis of original sources suggests that the CASP version for children’s self-reports is promising from the perspective of assessing activity and participation of the child having a history of acute disorder or having a chronic disease/disability. The questionnaire is likely to almost evenly rank activity and participation to justify the use of questioning the child only, when the main interest of rehabilitation goal setting is focused on working with patient, or the use of parent’s report, when no child’s report is available (for example, due to the adolescent’s cognitive limitations), or the parallel use, when it is important to understand the nuances of differences between the parents’ and children’s points of view [22].

Despite the fact that children know best about their role in activities and participation at home, at school and in society, the differences between the reports provided by parents and

children are not likely to show, whether the study has been conducted correctly or incorrectly. These are more likely to reflect each person’s ideas about health, functioning, and child’s well-being. It is obvious that the points of view of both child and parent are important for selection of rehabilitation intervention or organizational measures. CASP is an interesting and promising specific instrument for estimation of activity and participation of children with various disorders due to the earlier reported by researchers [21, 22] correlations of impairments identified based on the data from the parents’ reports with certain disorders. A more thorough investigation of these correlation involving larger samples for each disorder/disability (for example, for the most prevalent infectious diseases constituting up to 90% of the causes of morbidity of children under the age of 14) can be useful for future research [23].

Features of rehabilitation of children with infectious diseases

It is well-known that up to 50% of all disability cases in children are associated with infectious diseases, and infectious diseases account for about 70% of the death rate of children in their first year of life [24–26]. The Russian experts more than once and in great detail raised the issue of arranging medical rehabilitation for children with communicable diseases due to the possibility of developing persistent severe residual effects [27–29].

The global data suggest that the ICF-oriented approaches to arranging and conducting rehabilitation treatment of children with infectious diseases are used. The results show significant heterogeneity of rehabilitation goals and emphasize that the goals should be assessed individually for each child, regardless of health status and such factors, as age or functional independence [4]. Furthermore, the studies that are of some organizational and practical value are based on the use of both rehabilitation diagnosis in terms of ICF domains and supplementary questionnaires.

Thus, the study focused on rehabilitation of children, who survived bacterial meningitis (BM), showed that children often suffered from the quality of life reduction due to disabling sequelae. The authors wanted to assess the health-related quality of life (HRQOL) and the impact of neurological and auditory sequelae in children, who had a history of BM, using the Pediatric Quality of Life Inventory (PedsQL) instrument to reveal the differences in HRQOL between patients and the control group. The findings showed that survivors had significantly lower scores than controls based on the parent-proxy PedsQL reports, which was indicative of lower quality of life (physical health: 82.5 vs. 100, $p = 0.001$; psychosocial health: 80 vs. 90, $p = 0.005$; total score: 82.61 vs. 93, $p = 0.004$), while the children’s PedsQL self-reports showed no differences between cases and control. In all classes of the Glasgow Outcome Scale cases were quite different from the control groups in terms of the parent-proxy PedsQL reports with the total score of 84.21 (mild/no disability), 43.54 (moderate disability) and 55.56 (severe disability), while the score of the control group was 91.3 ($p = 0.04$, $p = 0.02$ and $p < 0.001$, respectively). The parents believed that the BM survivors’ quality of life decreased regardless of the presence or absence of disability. Follow-up and timely rehabilitation (if necessary) had to be provided to all BM survivors [30].

The study aimed at exploring the patients’ beliefs and perceptions with regard to the needs of their children with congenital Zika virus infection using the ICF criteria is extremely interesting [31]. The findings have shown that, despite the fact that parents actually focused on the issues related to motor

ability of their children, their attention was generally focused on the environmental factors. These factors included services, system and policy for prevention and treatment of children and the factors, that could ensure healthy lifestyle, promote physical and psychological well-being, and contribute to the children's social status. Furthermore, given the children's early age, rehabilitation goals had to be adjusted later, when the children would be able to express their opinion [32].

The next study is focused on the importance of systemic approach to determination of all factors affecting the effects of rehabilitation, as well as on the impact of time on the natural course of recovery from acute encephalitis [33]. The study involved the use of five functional outcome measures for patients with neurological impairment or disability, including the Functional Independence Measure for Children (WeeFIM), Glasgow Outcome Scale-Extended (GOS-E), Modified Rankin Scale, International Classification of Functioning (ICF), and Liverpool assessment scale. The WeeFIM components obtained during patient assessment included estimates of assistance needed for moving, daily activities, bladder and gut control, need for transportation means, communicative and cognitive abilities. The clinically significant ICF domains included the degree of difficulty in moving body in space, maintaining sitting position, amount of sleep, maintaining sleep, adequacy of sleep, muscle tone of the whole body, involuntary jerking of muscles, and generalized pain.

ICF core sets for pediatric rehabilitation

It is well-known that ICF includes 1685 categories, which makes reliable goal selection during clinical work very difficult. The ICF core sets (i.e. the short list of ICF categories

considered to be the most suitable for an individual with certain health condition) mitigated this problem to some extent. The core sets are developed during the research process involving researchers, physicians, caregivers or patients from all over the world. Currently, there are only three ICF core sets for children and young adults with childhood-onset disability. The core sets have been developed for cerebral palsy (CP) [34]; autism spectrum disorder (ASD) [35]; and attention deficit hyperactivity disorder (ADHD) [36]. The common short datasets represent an international minimum standard for assessment and description of functioning at any age using the lowest possible number of categories [37]. Despite the fact the the core sets have reduced the number of ICF categories per diagnosis, problems with clinical realization persist. For example, the ICF core set for ADHD includes 111 categories, while a common short set for ADHD uses 73–81 categories depending on the age range [36].

CONCLUSION

Using the data of the CASP questionnaire to assess the child's activity and participation (child and parent version) will make it possible to considerably simplify establishing the rehabilitation diagnosis based on ICF, as well as the processes of goal setting and rehabilitation intervention efficiency assessment. Extensive use of ICF-based universal information by multidisciplinary rehabilitation teams, involvement of family members and children with infectious diseases into goal setting, development and realization of rehabilitation plan will contribute to achieving the optimal level of participation in the home, school and social life. In this case the CASP questionnaire is a novel, rather simple and effective instrument to meet these challenges.

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