Life quality problem of children and adolescents in selected neurological disorders

Problem jakości życia u dzieci i młodzieży w wybranych chorobach neurologicznych

Key words: neurological disorders, children, the quality of life

Słowa kluczowe: schorzenia neurologiczne, dzieci, jakość życia

Chronic disease can be defined as long-term health disorder, lasting three months or longer, which as a consequence of symptoms, need for treatment, limitations in activities at school and outside of school, violates the normal development of the child [1; 2]. Specialists - allergists, nephrologists, dialectologists, and neurologists observe the growing problem of chronic diseases in children and adolescents which directly affects their functioning in the immediate vicinity, and especially in the home and school.
Invariably, the diagnosis of chronic illness in a child results in significant changes in the lives of the whole family - for it is a kind of crisis situation, introduces permanent changes in a child's life, and often causes confusion, uncertainty, fear and anxiety. In addition to somatic disorders which necessarily accompany chronic diseases occur in children requiring extensive psychological effects, in addition to medical therapy, measures aimed at solving the problems of psychological and psychosocial. These problems are particularly evident in children after long-term outpatient care, hospitalization or stays in sanatoria return to a mainstream school.

The essence of monitoring and evaluating the health of children and adolescents, it is important not only from the point of view of the current state of health, but also plays a crucial parameter for the assessment of public health in the future [1; 3]. In this process, the most important role is played by preventive examinations. Many chronic diseases take their origins in early childhood or during adolescence, affecting the health condition in later stages of life, revealing the negative health effects of social and economic felt both now and in the future.

The percentage of children and adolescents with chronic diseases in school age in Poland ranges from 20% to 30%. Nationwide research results, made before 2009, shows that 28% of the children, suffer from at least one disease [4; 5].

Long-term illness is a stressor aggravating the body and the psyche, which puts the child in front of the new requirements and restrictions, increasing the risk of the child having emotional disorders and behavioural disorders. The risk of psychosocial failure in children and adolescents with chronic disease is 2-4 times higher than in their healthy peers group. The dependence of the impact of the disease on the overall development of the child according to age - the younger child, the impact is greater - was also observed. Researches of HBSC (Health Behaviour In School-Aged Children) made in Poland show that pupils with chronic illnesses much worse rate their life satisfaction and well-being than their healthy peers ([5]. The significant difficulties with emotions, concentration, and social behaviour were observed in such group of children. Moreover, chronic illness often interferes with the implementation of the developmental tasks typical of the period, providing a source of many unpleasant feelings such as fear, anger, sadness, helplessness, horror, despair, shame. Can lead to feelings of loneliness, guilt, lack of understanding, a sense of otherness, depression and loss of hope, loss affect self-esteem and even interfere with the formation of self-esteem and consequently hinder the relationship with peers (6). chronic sick child and especially with neurological disease, is often exposed to adverse situations resulting from the reduction of its independence, dependence on others, isolation from the social environment particularly difficult in contact with colleagues and classmates.

A sensitive measure of the effects of the applied therapy and expectations of patients in this regard, and indirectly also the effectiveness of the health care system is the quality of life.

The World Health Organization presents quality of life as a personal perception of the body of his station in life, in the context of cultural and value system in which
lives and in relation to given to determine the quality of life and standard of living (called Well-being or quality of life) is most commonly used two types of criteria: objective and subjective. In determining the first of them refer to the material conditions of life, role-social or position, and the ties that connect the unit to other people. They define the quality of life and standard, that does not guarantee basic needs. [6]

The second criterion is the subjective evaluation of the individual, on satisfaction with life in all its aspects. This dimension is very important because it plays a significant role in the perception and assessment of their own situation, often deviating from the objective parameters [7]. Quality of life in the most common meaning is a collective category, which includes: physical and mental well-being, material well-being and general living conditions, personal development, working conditions and recreation, subjectivity, the quality of relations with the immediate environment and the ability to implement plans. Depending on the composition of the above dimensions of the life of the individual, they constitute a chain from low quality, characterized by a lack of the most important needs to high quality of life, which is synonymous of “full life”, marked by the desired degree of prosperity [7].

The state of illness or disability brings additional variables to quality of life. On the basis of medical science uses the identification of health related quality of life (HRQL). HRQL is understood as a functional effect of the disease and its treatment experienced by the patient. Reference is made here to the four main spheres of human functioning: physical condition and mobility, mental state, somatic sensations and social situation, as well as economic conditions [8]. Separation of these dimensions allows for an overall assessment of quality of life and its dimensions involved.

In the assessment of global quality of life, the conditioned state of health, in addition to focusing on the symptoms or onerousness, treatment to be assessed also the patient’s attitude towards himself, his illness and how to cope with it. Assessing quality of life pays attention to the need to distinguish between the objective state of health and his subjective feeling. The objective assessment of quality of care, which is conditional on the state of health we analyse the type of disease, severity of symptoms and the resulting limits of life and social and economic consequences of the disease. This is especially useful when defining the ownership of health or loss, and various kinds of disability. Effect of subjective health assessment, carried out by the unit is to experience a sense of quality.

OBJECTIVE

The main objective of the study was to assess the quality of life of children and adolescents in selected neurological disorders such as cerebral palsy, mental retardation, epilepsy.

CEREBRAL PALSY AND MENTAL RETARDATION

Cerebral palsy (CP) is a group of permanent disorders of the development of motion and posture, causing limitation of activity, and is assigned to non-progressive brain damage occurring in the brain development of foetus or infant. In patients with
cerebral palsy outside the motoric consequences of damage, the disturbances of sensory, cognitive, communication, perception, behaviour or epilepsy, and often secondary musculoskeletal problems, are observed. Literature reports that the incidence of band ranges from 1.0 to 3.0 children for every 1,000 live births, acting first in the order of cause of physical disability and the second, the intellectual disability, the cause of permanent neurodevelopmental disorders in children.

Due to the complex nature of the illness, for different spheres of functioning and levels of organization of life of the patient and his family, the treatment requires a multi-evaluation conducted in order to program targeted therapy to achieve optimal independence at the level of motor, so emotional and social. In patients with CP, the optimization of therapeutic conduct is only possible in case of permanent cooperation of a group of specialists: neurologist, physiotherapist, nurse, teacher, psychologist, speech therapist, occupational therapist, orthopaedic surgeon, ophthalmologist and the use of indicators of the effectiveness of therapy in the form of a systematic clinical and functional evaluation. The concept of health related quality of life-HRQOL was introduced to modern clinical medicine by Schipper in 1990. The research is based on a subjective assessment of the three dimensions of life physical, mental and social well performed by the patient or in the case of children by the caregiver or parent. Movement limitations, pain level, range of activities carried out with daily life, the level of overall life energy, cognitive functioning and emotional range of role of family and social relationships with other people are subject to assessment. Cerebral palsy due to posture and movement disorders, as well as sensory disorders, cognitive, perceptual and communication restricts the activity of the patients and can lead to reduced quality of life [9].

The presence of a more disorders (disabilities), referred to in pedagogy as conjugate disability, results in the need of a specific teaching organization and distinct teaching and therapeutic methods.

The small therapeutic effects in children with moderate and severe disabilities Intellectual compared to children with normal development or a slight delay were observed. It is estimated that about 30% -50% of children with CP have an intellectual disability [10; 9]. Although the degree of cognitive deficits is not definitively correlated with the type of cerebral palsy, although heavier degree of deficits are more common in people with severe motoric dysfunctions, described a strong association between severe intellectual disability and the presence of epilepsy, abnormal EEG, and abnormal neuroimaging [11].

The results of research of Michalska et al, show a significant deficit in HRCOL children and adolescents with cerebral palsy, confirming that the quality of life of people with cerebral palsy is lower than healthy children [12]. The level can be compared to patients treated for cancer and rheumatic [13; 14] and in patients with myelomeningocele, what was earlier observed [15]. The results confirm the scale of the specific low level of functioning of children and young people in activities of daily living such as speech, eating and sleep [16]. Described in many works low score performed daily activities and school work, with a relatively high assessment of movement skills in children with cerebral palsy, should verify therapeutic targets.
According to the Yang at all., emphasis in therapy should be given to the appropriate tailored to the needs of the child's home environment and school and to develop these skills, which allow self-handling or assisting in the daily activities of self-service and the implementation of the educational program. For patients with cerebral palsy who use non-verbal and speech in a limited way, it is very important to use Augmentative and Alternative Communication, ACC, which contributes to the elimination of communication barriers, pain sensation significantly affects the quality of patients' lives [15]. The results of the Michalska et all study, indicate a negative correlation between age and children's developmental parameters. The results indicate that the growth of the patient's age corresponds to the lower assessment of the functioning of the physical, emotional and overall rating on a scale of generic and lower assessment of pain and fatigue. These tests were carried out on a large number of patients at levels IV and V GMFCS scales and a high proportion of individuals with severe forms of CP. Rapid progression of secondary disorders of the musculoskeletal system (deformities, contractures, muscle atrophy) is a characteristic of this group. This is due to potentially higher levels of pain and fatigue, which can affect the lower value of HRQOL in these domains [12].

**EPILEPSY**

Epilepsy is one of the most common diseases. Prevalence of epilepsy in the world is very diverse. The prevalence ratio per 1000 people varies from 1.5 (Japan) to 37 (Nigeria). In Poland this ratio oscillates about 7/1000 inhabitants. Section of the prevalence of active epilepsy is estimated to be generally about 0.4-1% ([17; 18] and the cumulative incidence over the life of 2-5% [19; 20]. In various reports, the incidence of epilepsy in the populations surveyed was 20-375/100,000, mostly 2072/100,000 [20; 21]. The higher frequency was reported in developing countries [21; 22; 23]. In approximately 75% of epilepsy cases begins during childhood and adolescence (to 17 years of age). At this age, the frequency of its occurrence is greater than in the general population and estimates about 2-6% [20]. The highest incidence of epilepsy is recorded in the first years of life and after the age of 75 years old [24].

The etiology of seizures varies depending on the age of patient [18; 25]. The most common reason of epilepsy in neonatal period, hypoxia, hypoglycaemia, disorders of ion deficiency of pyridoxine, intracranial bleeding, birth defects of the brain and metabolic diseases are considered [26]. The instability of Ion energy and economy, in new-borns, as well as neuroanatomical and neurophysiological brain properties, such as: the unfinished process of maturation of the between neuronal connections and myelinate the nerve pathways, advantage over the GABA receptors, immaturity substance of grey brain stem responsible for inhibition of abnormal discharge, foster increased excitability of neurons [27]. In general, clinical seizure incidents during this period are different from those observed in the later stages of the process [28]. This is probably due unfinished process of synaptic maturation and myelination. Another is a correlation between the neonatal EEG recording and morphology of the incident panic than later. Sometimes there is an attack, which is only
reflected in the record EEG, in other situations, incidents are not accompanied by paroxysmal typical EEG changes in the image. During infancy seizures are the most common cause of birth defects of the brain, metabolic diseases, intracranial infection [29; 30]. In the early years of life is dominated febrile seizures, and epileptic seizures Etiology varies depending on age [25; 18]. In the neonatal period the most common reason for their consideration: hypoxia, hypoglycaemia, abnormal ion, pyridoxine deficiency, intracranial bleeding, birth defects of the brain and metabolic diseases [26] inhibition of abnormal discharges, favour increased in infancy seizures are the most common cause of congenital brain disease metabolic intracranial infection [31; 29]. In the first years of life is dominated by febrile seizures, and seizures in the course of infection in the brain and birth defects. In older children and adolescents play a vital role genetic factors, whereas in adults, especially after 60 years cerebrovascular disease. Injuries and brain tumours can occur at any stage of life, but more often are the cause of epilepsy in adolescents and adults. In adults, also plays an important role drug withdrawal (e.g., chronically taking benzodiazepines), and/or alcohol. The majority of patients fail to clearly identify the causes of epilepsy. This is possible only in 25-45% of cases [32; 24]. Some authors believe that the influence of genetic factors on the occurrence of epilepsy reaches 70-88%, and 12% environmental. Epilepsy is one of the most common social diseases, so it is useful to analyse the quality of life in the unity of the disease. In the case of epilepsy a significant impact on the lives of patients is the number of attacks but also the side effects of drugs. For a long time, patients with epilepsy suffer from depression; complain of stigma, poorer quality of life. Depending on the course of disease and therapeutic effects in varying degrees, may impair such areas of human activity such as education, professional work, family life, activities of daily living, and even socialize pastime. In the young, it is in isolation in society, with negative emotions. The most severely youth lacks acceptance from peers, school problems and the possibility of obtaining the dream of education. With a view to improving the quality of life of patients with epilepsy, there are attempts to create an antiepileptic drug with the greatest efficacy and low risk of side effects. Effects of treatment of children with epilepsy depend on the specifics of epileptic syndromes, separation of drugs in different groups of epilepsy and the impact of disease and applied drugs on the quality of life in children, especially on cognitive processes. McEwan et al analysing research on the quality of life of the most noted in their findings published authors, emphasizing that epilepsy is delayed achievement of independence, hinders social functioning and relationships with peers, deteriorating self-esteem, mood and cognitive processes [33].

Most symptoms affecting the assessment of quality of life were observed in children and adolescents treated with poly-therapy, watching hyperactivity, drowsiness, weight gain and difficulty in learning. According to the Mula and Trimle polypharmacy and higher doses of anti-epileptic drugs have a negative impact on cognitive function.
CONCLUSIONS

Quality of life in children and adolescents in all studied aspects is lower than the quality of life of healthy peers. Daily and school activities and verbal communication were identified by their parents as the biggest problem in children. Age is a factor reducing the quality of life in terms of physical and emotional functioning, pain, and fatigue. In the group of patients with epilepsy showed a significant difference in the functioning of children and youth in the areas of depression, well-being, stigma, the overall quality of life, depending on the medication. In all chronic diseases, including epilepsy, the essence of treatment is not only the elimination of troublesome symptoms, but also to improve quality of life.

REFERENCES


Life quality problem of children and adolescents in selected neurological disorders


ABSTRACT

The results of actions taken, to improve the quality of life in children and adolescents with chronic diseases, in particular with neurological diseases are not fully satisfactory. This situation encourages us to in-depth analysis, based on self-assessment of health and well-being. The observed dominant fatigue, lack of strength and energy and even total exhaustion, as a negative phenomenon, accompanied by most of the neurological disorders in both children and adolescents, in the later stages of life. Difficulties in the process of healing and rehabilitation of the patient makes distinguishing between fatigue, weakness, drowsiness and, above all from depression, so often coexisting in neurological disorders in children. Quality of life related to health is one of the important, recommended by the World Health Organisation methods, enabling the detection of irregularities in the functioning of physical, mental and social identification of people at risk of health problems and take preventive measures.

STRESZCZENIE

Rezultaty podejmowanych działań, zmierzających do poprawy jakości życia u dzieci i młodzieży ze schorzeniami przewlekłymi, w tym w szczególności z chorobami neurologicznymi, nie są w pełni zadowalające. Zaistniała sytuacja zachęca nas do pogłębionej analizy, opartej na samoocenę zdrowia i dobrego samopoczucia. Obserwowane, dominujące zmęczenie, brak sił i energii a nawet całkowite wyczerpanie, jako negatywne zjawisko, towarzyszy większości schorzeń neurologicznych zarówno u dzieci jak i młodzieży, w późniejszych etapach życia. Trudności w procesie leczniczym i rehabilitacyjnym pacjenta sprawia odróżnianie od mękliwości, niedowładu, senności a przede wszystkim od depresji, tak często współistniejącej w
schorzeniach neurologicznych u dzieci. Ocena, jakości życia związanej ze zdrowiem, stanowi jedną z ważnych metod, rekomendowaną przez Światową Organizację Zdrowia, umożliwiającą wykrycie nieprawidłowości w funkcjonowaniu fizycznym, psychicznym oraz społecznym, identyfikację osób zagrożonych problemami zdrowotnymi oraz podjęcie działań prewencyjnych.

Artykuł zawiera 26092 znaki ze spacjami