UDK 316.728-053.9:159.922.63 **Review Paper**
Doi: 10.7251/SANUS2604103A

THE IMPORTANCE OF HEALTH CARE FOR PEOPLE WITH DISABILITIES, THROUGH EDUCATION, IMPLEMENTATION OF EARLY INTERVENTION PROGRAMS AND THE ACTIVE PARTICIPATION OF NURSES

***Slađana Arsić*[1], *Andrijana Petrović*[1] *Dragana Kljajić*[2]**
[1]The Academy of Applied Preschool Teaching and Health Studies, Department of medical studies Ćuprija, Republic of Serbia
[2] Academy of Applied Studies Belgrade, The College of Health Sciences, Republic of Serbia

Abstract. *Cerebral palsy is one of the most common causes of physical disability in children and is characterized by permanent disorders of movement and posture caused by damage to the developing brain in the early stages of life. The aim of this paper is to present the importance of the education of nurses and their participation in the health care of people with disabilities, specifically in working with patients with cerebral palsy. The paper is based on a review of relevant scientific and professional literature obtained from medical databases Medline; Google Scholar; PubMed. Special attention is focused on the most common nursing problems in these patients, such as reduced mobility, oral motor disorders, feeding and swallowing difficulties, pain, and problems in performing daily activities. Nurses play a significant role in assessing the patient's condition, planning and implementing nursing interventions, preventing possible complications, and educating the family. A multidisciplinary approach, including cooperation with physicians, physiotherapists, speech therapists, psychologists, and other health professionals, is essential for achieving optimal treatment and rehabilitation outcomes. Family support and continuous education of parents represent an important component of successful care for children with cerebral palsy. Improving health and social support systems can significantly contribute to a better quality of life for people with disabilities.*

Keywords: *persons with disabilities, cerebral palsy, nursing care, rehabilitation, education*

Introduction

Cerebral palsy is one of the most common causes of physical disability in children. It is a set of permanent movement and posture disorders that occur as a result of damage or abnormal development of the brain early in life, most often before, during, or immediately after birth. Although specific epidemiological data on the incidence of cerebral palsy in Republic of Serbia are not available in the form of a relative rate per live birth, global and European trends indicate a prevalence of 2–3.5 cases per 1,000 live births. According to the Cerebral and Infantile Palsy Association of Republic of Serbia, there are approximately 6,000 people living with cerebral palsy in the country

[1]. These data indicate a significant number of those affected, but not the need for more detailed research on the incidence, in order to enable more precise planning of health and social support.

The risk is higher in premature infants (5–8% weighing less than 1,500 grams). The prevalence increases dramatically with decreasing gestational age: the incidence in infants born at less than 28 weeks gestation is 100/100 live births [2].

The pathology of cerebral palsy is defined as a group of non-progressive disorders of movement and posture, and is the most common cause of severe neurodisability in children. Understanding its physiopathology is crucial for the development of some protective strategies. Fetal oxygen deprivation or brain asphyxia has been classically considered the main causal factor explaining later cerebral palsy. Congenital malformations are rarely identified [3].

The etiology of cerebral palsy is determined by structural disorders of the CNS that can occur prenatally, perinatally and postnatally due to vascular insufficiency, infections and toxic effects. Prenatal factors are the most common (70-80% of children). Risk factors are related to maternal and/or fetal diseases, developmental anomalies of the brain, vascular occlusions, metabolic and genetic syndromes, infections, premature birth, intrauterine growth retardation, multiple pregnancy [2,4,5]. Perinatal factors are found in about 10%. The most common are premature birth, chorioamnionitis, pathological presentation at birth and asphyxia [2,4,5]. Postnatal factors (10%) include CNS infections, kernicterus, hypoglycemia, intracranial hemorrhage (premature birth, vascular anomalies, trauma), hypoxia/ischemia (meconium aspiration, persistent fetal circulation, or persistent pulmonary hypertension of the newborn). About 2% of children have a genetic cause [2,4,5].

Cerebral palsy profoundly affects the lives and daily functioning of both patients and their families. Nurses play a significant role in the assessment, prevention and management of a range of symptoms and difficulties faced by people with cerebral palsy and their families. Education and encouragement of people with cerebral palsy, their parents and families are essential in the care process, as well as discussions during hospitalization, decision-making and procedures. Parents and family are considered primary caregivers because they spend most of their time with the person with cerebral palsy, and educational interventions are considered key to improving the quality of life of those with cerebral palsy. The most common health care problems are related to oral motor impairment, pain, reduced mobility, impaired social functioning, SMBS syndrome - syndrome of reduced ability to care for oneself (feeding, elimination, personal hygiene, dressing/undressing), sleep disorders, and ineffective coping and adherence to health instructions/education [6,7].

The healthcare process for people with cerebral palsy is primarily focused on addressing movement and posture difficulties, which cause activity limitations. Brain damage is static and unchanging, but symptoms are variable and change over the

years, which increases the health care needs of those with cerebral palsy [8]. In addition to movement and posture difficulties, people with cerebral palsy may also have a number of associated difficulties, including intellectual disabilities, hearing and vision impairments, problems with nutrition, feeding, swallowing, respiratory difficulties (infections, difficulty breathing, difficulty with oxygen depletion, difficulties related to respiratory diseases such as pneumonia due to bedridden patients), and epilepsy [7,8].

Work Methodology

The aim of the paper was to demonstrate the importance of healthcare implementation and the role of the nurse in patients with cerebral palsy.

The basic methodological principle of this work is based on a literature review and a presentation of the implementation of health care in patients with cerebral palsy. By reviewing the relevant literature using appropriate keywords, the medical databases MedLine; Google Scholar; PubMed were searched; Existing data from these databases were used and all medical activities applied to people with cerebral palsy were analyzed.

Theoretical basis

Cerebral palsy is defined as a group of non-progressive movement and posture disorders and is the most common cause of severe neurodisability in children. Traditional classification schemes for cerebral palsy have focused mainly on the distribution of paralysis affecting the extremities (e.g., hemiplegia, diplegia) and the description of the predominant type of muscle tone abnormality (e.g., spasticity, dyskinesia), [4].

The characteristics of cerebral palsy can vary as the affected person grows up, so the influence of age on changes in clinical phenomenology, and therefore on classification, is important. Also, in young children, it is sometimes difficult to determine the type of motor disorder, which calls into question the reliability of the classification. In addition to age, other factors can influence the classification, such as anamnestic data, especially for the period of pregnancy, then associated disorders, which include cognitive deficits, epileptic seizures, visual and hearing impairment and behavioral disorders, as well as the results of neuroradiological and genetic-metabolic testing [1,7].

A characteristic of all types is a disorder of muscle tone, posture, reflexes, motor development and coordination of movements. Symptoms include spasticity, involuntary movements, gait and balance disorders.

Cerebral palsy can be divided into spastic cerebral palsy, hemiplegic cerebral palsy, spastic quadriplegic cerebral palsy, spastic diplegic cerebral palsy, ataxic cerebral

palsy, dyskinetic - choreo/athetoid/extrapyramidal cerebral palsy, and mixed cerebral palsy [1,3,5].

Spastic cerebral palsy occurs in 80% of children. Corticospinal tract damage results in hypertonia, hyperreflexia, clonus, preservation of primitive reflexes and extensor Babinski response, increased tone of the adductors of the thighs, with the feet in the equinus position. In the supine position, tone may be normal, less pronounced or even reduced, while it is greatly increased when standing [6,7].

The characteristics of hemiplegic cerebral palsy are upper motor neuron deficits that are stronger on one side, the hand is usually affected. The first symptoms are observed between the 4th and 12th months, the handful is clenched, the hand is semiflexed, the forearm is pronated, the grip is asymmetrical. The gait is later on the fingertips with circumduction. There is often oromotor dysfunction, learning disabilities, unilateral sensory disturbances in the visual field and strabismus are also possible, as well as the appearance of convulsions [6,7]. Spastic quadriplegic cerebral palsy affects all four limbs, with hypertonia of the whole body or truncal hypotonia and hypertonia of the limbs. Head control is poor, the arms are flexed in pronation, the hands are clenched, and the trunk and legs are extended. Oromotor dysfunction, microcephaly, mental retardation, and epilepsy are present. Spastic diplegic cerebral palsy shows greater involvement of the legs than the arms, with a scissor gait, but cognitive impairment and seizures are less common than in spastic hemiplegia [6,7].

Ataxia in the context of cerebral palsy is a form where the cerebellum – the part of the brain responsible for coordination of movement, balance and fine control of movement – is most severely damaged. This is the rarest form of cerebral palsy and it is estimated that between 5 – 10% of all cases of cerebral palsy are of the ataxic type. Damage to the cerebellum can be congenital (present at birth) or acquired in early childhood. Possible causes include: infection during pregnancy, hypoxia before, during or after birth, prenatal or birth brain injury, complications such as premature birth, low birth weight, multiple pregnancies (twins), genetic variations/mutations in some cases. Some of the characteristic symptoms are: coordination problems (difficulty reaching or grasping objects); balance disorders (unsteady gait, often feet are widely spaced to reduce the risk of falling); tremor (especially when attempting precise or voluntary movement); hypotonia – low muscle tone (partially improves with growth but does not reach normal levels); difficulty with fast and precise movements (writing, using cutlery); speech disorder (slurred speech, separated syllables, pauses in speech, irregularity of speech); cognitive disorders, speech, hearing disorders, but intelligence can be preserved in many [6,8].

Dyskinetic – choreo/athetoid/extrapyramidal cerebral palsy accounts for 40%. The main characteristics are extrapyramidal pathological movements, pathological regulation of tone, postural tone disorder and movement coordination deficit. Tone is variable, hypotonia is present first, and involuntary movements are observed at the age of 1 – 3 years (chorea, athetosis, dystonia). The arms are more affected than the legs, it is difficult to hold the body in an upright position, with truncal instability.

Tendon reflexes are normal or slightly increased. The damage occurs in the extrapyramidal system - most often in the basal ganglia that control involuntary movements. The most common causes: hypoxia during childbirth; hyperbilirubinemia; intracranial hemorrhage, infections or toxic brain damage in the perinatal period. Clinical picture: involuntary movements (whirring – athetous, rapid – choreatic or twisted – dystonic); variable muscle tone; movements worsen with excitement, exertion or attempts to control the movements; movements calm down during sleep; facial expressions (frequent grimaces, twitching of the lips, tongue or eyes); speech may be slurred, often accompanied by involuntary facial movements; dysphagia; epileptic seizures, which are less common than in spastic forms; vision and/or hearing impairment may occur [3,6,8]. The mixed form of cerebral palsy is manifested by spastic and extrapyramidal symptoms. It occurs with extensive lesions of the cortex, basal ganglia, and subcortical connections.

The most important are the history and neuropediatric examination. Examinations are carried out individually. There are no specific laboratory tests to confirm the diagnosis. Certain tests rule out the following diseases: assessment of thyroid function, lactate and pyruvate (mitochondrial cytopathies), ammonia (liver dysfunction or urea cycle defect), organic and amino acids (hereditary metabolic diseases), genetic testing (suspected genetic syndromes due to dysmorphic appearance, organomegaly, skin changes, eye changes), [3].

Neuroradiological examinations reveal structural brain damage. A normal radiological finding does not exclude the diagnosis of cerebral palsy. Ultrasonography is of great use in the neonatal and infantile periods. It reliably confirms structural abnormalities, hemorrhage, and hypoxic-ischemic damage. CT of the head detects congenital malformations, intracranial hemorrhage, and periventricular leukomalacia with greater certainty. MRI of the head is most useful after 2–3 weeks of life, and is the method of choice for older children because it better defines cortical and white matter structures than all other examinations. MRI/CT of the head can indicate the time and type of brain damage or detect conditions that require specific therapy (hydrocephalus, subdural hematoma, AV malformations). EEG is useful in the evaluation of hypoxic-ischemic encephalopathy and seizure disorders. EMNG and nerve conduction velocity are indicated in suspected hereditary sensory-motor neuropathies [1,3].

Early diagnosis of cerebral palsy is often difficult in the newborn and infant period. Clinical signs that indicate cerebral palsy include muscle tone variability, slow motor development, altered postural tone, persistence of primitive reflexes, asymmetric hand function, difficulties with feeding, bathing and dressing, hypersalivation, and inadequate contact with the environment. In infancy, motor development disorder is diagnosed as a central coordination disorder. The diagnosis in the first three months of life is made when brain lesions are diffuse and the neurological findings are markedly altered [1,3,6]. Associated neurological disorders include mental retardation (50-75%), speech disorder (25%), epilepsy (40%), blindness and visual

impairment (30%), hearing impairment (20%), joint contracture, scoliosis, and hip subluxation.
Differential diagnosis includes: hereditary metabolic diseases, metabolic myopathies, metabolic neuropathies, movement disorders in children with developmental problems, traumatic lesions of peripheral nerves, tumors of the conus and cauda equina, vascular malformations of the spinal cord [3].

Discussion

The role of health care in patients with cerebral palasy

The healthcare process for patients with cerebral palsy is primarily focused on addressing movement and posture difficulties, which cause activity limitations. Brain damage is static and unchanging, but symptoms are variable and change over the years, which increases the healthcare needs of those affected. In addition to movement and posture difficulties, people with cerebral palsy may have a number of associated difficulties, including intellectual disabilities, hearing and vision impairments, problems with nutrition, feeding, swallowing, respiratory difficulties (infections, difficulty breathing, difficulty with oxygen depletion, difficulties related to respiratory system diseases such as pneumonia due to bedridden patients), and epilepsy [7,9].

Cerebral palsy profoundly impacts the lives and daily functioning of both patients and their families. Nurses play a significant role in assessing, preventing, and managing the range of symptoms and difficulties faced by people with cerebral palsy and their families. In the care process, education and encouragement of the person with cerebral palsy, their parents and family are of great importance, as well as discussion during hospitalization, when making decisions and implementing procedures. Parents and family are considered primary caregivers because they spend most of their time with the affected person, so educational interventions are considered crucial in improving the quality of life of those affected. The most common health care problems are related to oral motor impairment, pain, reduced mobility, impaired social functioning, SMBS syndrome - syndrome of reduced ability to care for oneself (feeding, elimination, personal hygiene, dressing/undressing), sleep disorders, and ineffective coping and adherence to health instructions/education [9].

Application of healthcare in cases of mobility impairment

Damage to the area of the brain responsible for controlling motor functions can cause stiffness or spasticity in the muscles. Lesions lead to impaired movement and reduced mobility, and ultimately lead to muscle atrophy and chronic contractures. People with cerebral palsy experience stiffness of the extremities, weak and slow muscle twitches, loss of motor skills, and loss of postural stability. The role of a nurse in patients with reduced mobility includes the assessment of auditory, visual, motor, intellectual and cognitive deficits, which facilitates the implementation of interventions and planning of healthcare.

It is important to assess the patient's level of independence when sitting, standing and walking, so that the assessment can be used to plan the implementation of health care and improve the patient's condition. It is necessary to do motor exercises with the patient every 4 hours during the day, because in people with cerebral palsy, mobility is reduced due to spasticity. This is how we prevent the formation of contractures. It is also necessary to educate the family about exercises and how to perform them properly. If the degree of cerebral palsy is more severe, it is necessary to change the patient's position in bed and monitor the patient's condition, as well as train the family in changing positions and correct positions both during the day and during sleep, as well as during feeding, as well as in some conditions such as pneumonia [7,9].

Application of health care in cases of oral motor impairment

Specific problems associated with oral motor skills and swallowing problems include poor salivary control, difficulty chewing, difficulty swallowing, and a high risk of aspiration. Poor control of salivary secretion results in poor oral hygiene. The impact of oral motor impairment on feeding and swallowing is associated with reduced food intake, leading to impaired nutritional status and the need for placement and feeding via nasogastric tube or PEG (percutaneous endoscopic gastrostomy), [7].

Impaired oral motor skills and swallowing problems also contribute to the development of pulmonary complications, i.e. the development of pneumonia, which increases the need for hospitalization. Impaired motor skills also affect the muscles of swallowing and chewing, leading to chewing disorders and feeding difficulties, which are particularly pronounced in people with severe forms of motor impairment. These difficulties can lead to choking, vomiting, and aspiration of food [7]. People with cerebral palsy often need full assistance with feeding, because in addition to impaired oral motor skills, these patients have impaired hand coordination and a reduced ability to sit upright. These difficulties often lead to malnutrition, poor general condition, and an increased risk of developing infections [7,9].

The role of the nurse is to assist in feeding the patient, educate the family about feeding the patient, educate the family about feeding a patient with a nasogastric tube in place, educate the family about feeding a patient with a percutaneous endoscopic gastrostomy in place, educate on food preparation, gradual feeding to prevent food aspiration, choking, and vomiting of food. Therefore, it is necessary for the nurse to assess the independence of the child and family, assess the condition of the oral cavity, and assess the extent of oral motor impairment. Therefore, people who have problems chewing and swallowing need to have smaller but more frequent meals and monitor between bites to prevent aspiration or choking on food. Also, after finishing feeding, the patient must be in an elevated position for at least 20-30 minutes to prevent aspiration or choking on food [9].

The nurse's role is to provide education, assistance, and support to both the patient (if possible) and their family. The education plan should include ways to perform personal hygiene, feeding, dressing/undressing, and elimination to enable the patient

to be as independent as possible. When performing self-care activities, the patient should be educated about the level of fatigue and the risk of falls and injuries [6,9,10].

Application of health care when elimination is not possible

In patients with cerebral palsy, elimination is often impossible, so nurses need to monitor the patient's elimination of substances and train the family in monitoring elimination. If elimination has not occurred for a long time, the patient should be given rectal suppositories, and if that does not help, the patient should be given an enema. After giving suppositories or performing an enema intervention, it is necessary to monitor the patient's condition, as well as the frequency or further inability to eliminate the patient, as well as the amount of food consumed. It is also important to monitor the stool [9,10].

Application of healthcare in the presence of pain

People with cerebral palsy often experience pain for several reasons, including movement disorders, comorbidities, musculoskeletal problems, diagnostic and therapeutic procedures, and surgical procedures. Pain has a significant negative impact on the daily life of the patient and family, and it affects the patient's sleep [11].

The presence of pain in people with spastic-dyskinetic cerebral palsy is particularly emphasized. Pain can also be associated with nutritional status. Pain can also occur due to some complications such as improper placement and adjustment of a nasogastric tube, percutaneous endoscopic gastrostomy, due to improperly performed diagnostic and therapeutic procedures, due to improperly performed surgical procedures, due to improper patient positioning, improperly performed exercises, skipping therapy, during vomiting, choking, aspiration of food or some content, some infections or related diseases (for example, GERD - gastroesophageal reflux disease, epilepsy, pneumonia...).The nurse's role is to assess the patient's pain and collect data. Pain assessment determines the intensity of pain using a pain assessment scale, localization, mode of spread, duration and quality of pain. It is necessary to determine and monitor the impact of pain on daily activities, sleep disorders, eating disorders, and changes in the patient's mood. When patients are in pain, mood changes, depression, irritability, restlessness, anorexia, and reduced social activity are visible. The nurse's role in pain management is focused on reducing the intensity of pain and educating patients and families about identifying factors that influence the increase and decrease in pain intensity, the use of pharmacological (medication) and non-pharmacological methods [10,11].

Nurse interventions: monitoring vital signs; selecting pain relief methods according to the patient and family; removing factors that increase pain intensity; encouraging the patient; informing the patient and family about position changes that can relieve pain; naming positions; placing the patient in a comfortable position and explaining the importance of avoiding pressure on predilection points and painful areas; educating the patient on the implementation of relaxation techniques, distraction, cold

and warm compresses; allowing the patient time to rest; administering medications and implementing other methods of pain relief; conducting continuous assessment before and after therapy and monitoring the effect of therapy; encouraging the patient in daily activities; recording pain, therapy and achieved outcomes [10].

The establishment of specialized care units and the involvement of the primary care physician are essential for providing adequate care. The care team should include pediatricians with specific training in chronic and complex diseases, who are familiar with the most common comorbidities and have experience in treating with medications commonly used in this population. Therefore, most clinical manifestations in these patients could be treated in a single location, coordinating and integrating care from other specialists [9,10].

The need to care for a patient takes time away not only from career development, but also from activities related to self-care, leisure time or caring for other family members. For this reason, increasing resources are being invested in supporting caregivers, which is collectively called palliative care. Some foundations offer medical staff who travel to the home and care for the children for a few hours so that the family can spend time doing other things. These resources are still being developed for the pediatric population, despite previous studies showing that the best way to improve the quality of life of pediatric patients with chronic or terminal illness and their families is to develop a family-centered palliative and hospice care network – Spain. This study aims to clarify how cerebral palsy in children affects the burden of childcare and identify social supports that can effectively reduce this burden [12].

This is a cross-sectional study in which mothers of children with cerebral palsy completed questionnaires and provided information about their child's condition, family support, use of social support, satisfaction with support, and the burden of caring for them. We analyzed the responses of 1,190 mothers. The use of support, special home care, home rehabilitation, and mobility support was higher in the groups with more severe impairment. Mothers whose children had intellectual disabilities and exercised more than once a day in addition to tube feeding or intravenous nutrition felt the burden especially. The most effective measure in reducing the burden on mothers was short stays. The Japan Obstetric Compensation System for Cerebral Palsy (JOCSC) provides financial compensation to parents of children born during and after January 2009 who are diagnosed with cerebral palsy after assessment by the organization's management. The criteria for compensation are a birth weight of 1,400g or more and a gestational age of 32 weeks or more [13].

Types of social support:

- Home care 1: home medical and nursing services (for example, ventilator support, home oxygen treatment, gastric fistula, tube feeding, intravenous infusion, injections, blood sampling)
- Home care 2: care provided in the home (home help, support with household chores)

- Rehabilitation in home care: home physiotherapy, occupational therapy or other rehabilitation at home
- Treatment and training: support, such as training for adaptation to shared living, rehabilitation or treatment in day hospitals
- Short-stay: a service where a child is admitted to a short-term facility where they stay while receiving care, nurturing, and assistance with daily living.
- Mobility support: public transport services for children going to kindergartens, primary schools, hospitals and other places.

Rehabilitation of patients with cerebral palsy in Germany is a long and complicated process. The goal is to adapt children to interact with the outside world, work on motor skills and reach the maximum in motor development, correct speech and other skills. During rehabilitation, a child should learn the following: walk on a flat surface; climb stairs; take a shower; eat; move an object or feel and recognize it; use the toilet; dress; make decisions; talk; interact with other people/children.Some of the advantages of rehabilitation in Germany: high efficiency of rehabilitation measures; good technological equipment of hospitals; experienced staff; living conditions in medical centers that are comfortable for parents and children [14].

For example, the Bavarian Rehabilitation Clinic in Cechwitz works on an individual approach with patients, using the most effective methods that guarantee optimal success. Rehabilitation measures take place in modern rooms equipped with all the necessary equipment, for example, physiotherapy gyms, gyms with swimming pools, rooms for speech and language therapy, music therapy, and so on. In addition, the healthcare facility provides a full range of diagnostic examinations, such as electroencephalography, evoked potential recording and transcranial magnetic stimulation, electromyography, ergometry, pulmonary function tests, ultrasound scanning, classic X-ray diagnostics, scanner, magnetic resonance imaging, laboratory tests and so on (Rehabilitation Clinic Bavaria Zscheckwitz Kreischa).

According to sources, in Japan, care for people with cerebral palsy is more focused on caring for the entire family and helping the family in everyday life, as well as the patient, educating the family about the care and needs of the patient. While in Germany, the system is focused on socialization, social protection, influencing rehabilitation, and preserving and improving children's motor and cognitive skills [15].

In Japan, the Ryouiku model is used – it is family-centered and focused on function, while in Germany the Pflegegrad model is used – assistance that comes to the family and helps the family and the child, provides financial compensation, institutional assistance and access to aids. So in Germany, unlike Japan, the emphasis is more on institutional – formal and financial support than on family orientation [14,15].

In Republic of Serbia, child care is provided through healthcare institutions (special hospitals such as the Special Hospital for Cerebral Palsy and Developmental Neurology in Belgrade) and with the support of associations and federations.

Rehabilitation includes physical therapy, occupational therapy and speech therapy, while spa rehabilitation is often used as an additional option. Compared to Germany and Japan, there are differences in the availability and equity of services: families face the costs of private therapies, regional differences (the availability of services is greater in urban centers) and limited implementation of a family-centered approach in practice (Special Hospital for Cerebral Palsy and Developmental Neurology Belgrade).

Research in Republic of Serbia shows that children with cerebral palsy have a significantly lower level of participation in home and social activities compared to their peers without disabilities, which indicates the need for greater integration of social and rehabilitation services. Although there are professional staff and a tradition of rehabilitation, systemic financial and institutional support is less developed than in Germany. Republic of Serbia is located between the models of institutional and family care but without a single standardized system [7].

Proposal for measures to improve the care of children with cerebral palsy in Republic of Serbia:

- Standardization of care needs – By introducing a national system for assessing the needs of a child with cerebral palsy that would enable equal access to rights and financial support regardless of region.
- Development of home care services – Organizing the services of a nurse, physiotherapist and caregiver who comes to the child's home, which would relieve the family and reduce difficulties in everyday life.
- Increase day care centers and rehabilitation services in the local community – Increase accessibility to day care centers for people from rural areas, so that children can receive adequate therapy and socialization closer to their place of residence.
- Financial support for families – Introducing a larger number of subsidies for orthopedic devices, speech therapy and physical therapy, as well as spa rehabilitation.
- Education and psychological support for parents – Organizing lectures for parents and educating them (training in care, feeding, positioning of the child, etc.).
- Multidisciplinary teams – Inclusion of a nurse, physiotherapist, occupational therapist, speech therapist, psychologist and social worker in the care plan, with regular checks and revision of therapy programs.
- Early intervention – Introduction of a national program for early detection and intervention in children at risk of cerebral palsy (in the first months of life).
- Inclusion and education in society – Provide greater availability of inclusive schools and preschools with adapted teaching, assistants and accessible spaces. Encourage sports and cultural events adapted for people with disabilities.

- Research and data monitoring – Establish a national registry of children with cerebral palsy to monitor prevalence, needs, and treatment outcomes. This would help in resource and policy planning.

Conclusion

Cerebral palsy is a chronic neurological disorder that requires long-term, comprehensive and multidisciplinary support. The role of the nurse in the care of these children is crucial because it is not limited to the implementation of medical procedures, but also includes educational, advisory and psychosocial functions. Nursing interventions are aimed at maintaining and improving mobility, preventing complications (contractures, pressure ulcers, respiratory infections), as well as supporting daily activities such as nutrition, hygiene and communication.

The nurse plays a key role in educating parents and family members to gain skills and confidence in caring for the child at home. In addition, the nurse acts as a mediator between the family and other members of the multidisciplinary team – doctors, physiotherapists, speech therapists and social workers – ensuring coordination and continuity of care.

Experiences from other countries show the importance of systemic support for families and the involvement of nursing staff throughout all phases of care. In Republic of Serbia, it is necessary to improve the organization of nursing practice through better education, the development of home care services, and more active participation of nurses in early intervention and inclusion programs. Of particular importance is a holistic approach to nursing care, which includes not only physical care, but also recognition of the emotional and social needs of the child and family.

Continuing education of nurses and development of specialized care programs would enable Republic of Serbia to achieve a higher standard of care for children with cerebral palsy. In this way, nursing practice would become an even stronger support for families, contributing to the prevention of complications, improvement of quality of life and more active social integration of children with cerebral palsy.

References

[1] Milena Milićević. Funkcionalni profil i pridruženi poremećaji kod dece sa dečijom cerebralnom paralizom u Srbiji, Zdravstvena zaštita. Septrmbar 2025, 54(3):28-49. DOI: https://www.doi.org/10.5937/zdravzast54-60883

[2] Christine Cans Javier De-la-Cruz Marie-Ange Mermet. Epidemiology of cerebral palsy. Paediatr Child Health. September,2008;18(9):393–398. DOI: 10.1016/j.paed.2008.05.015

[3] Joshua A Vova. Cerebral Palsy: An Overview of Etiology, Types and Comorbidities. OBM Neurobiol. April, 2022; 6(2):1–1. DOI: 10.21926/obm.neurobiol.2202120

[4] Dan B, Rosenbaum P, Carr L, Gough M, Coughlan J, Nweke N. Proposed updated description of cerebral palsy. Develop Med Child Neuro. April, 2025;67(6):700–709. DOI: 10.1111/dmcn.16274

[5] Paulson A, Vargus-Adams J. Overview of Four Functional Classification Systems Commonly Used in Cerebral Palsy. Children. April, 2017;4(4):30. DOI: 10.3390/children4040030
[6] Dar H, Stewart K, McIntyre S, Paget S. Multiple motor disorders in cerebral palsy. Develop Med Child Neuro. August,2024;66(3):317–25. DOI: 10.1111/dmcn.15730
[7] Milena Milićević. Cerebralna paraliza – šta nam literatura govori o složenosti ovog stanja? Belgrade School of Special Education and Rehabilitation Vol. 22, No. 3 (2016), str. 53-71
[8] Fluss J, Lidzba K. Cognitive and academic profiles in children with cerebral palsy: A narrative review. Ann Phys Rehabil Med. 2020;63(5):447–56. DOI: 10.1016/j.rehab.2020.01.005
[9 Panteliadis C, Hagel C, Karch D, Heinemann K. Cerebral palsy: A lifelong challenge asks for early intervention. The Open Neurology Journal, 2015; 9(1):45-52 DOI: 10.2174/1874205X01509010045
[10] Marija Knežić; Health care of people with cerebral palsy; SG/NJ 2015; 20:250-3. DOI: 10.11608/sgnj.2015.20.049
[11] Laura K Vogtle. Pain in adults with cerebral palsy: Impact and solutions. Developmental Medicine & Child Neurology, October 2009,51 Suppl 4(s4):113-21 DOI: 10.1111/j.1469-8749.2009.03423.x
[12] Dorleta López de Suso Martínez de Aguirre, Ricardo Martino-Alba.The challenge of comperhensive care for patients with cerebral palsy; Anales de Pediatria; May, 2021;94(5):275-277. doi: 10.1016/j.anpedi.2021.02.002.
[13] Mutsuko Moriwaki, Hitomi Yuasa, Masayuki Kakehashi, Hidea Suzuki, Yasuki Kobayashi; Impact of social support for mothers as caregivers of cerebral palsy children in Japan; J Pediatr Nurs. Mar-Apr2022: 63: e64-e71. DOI: 10.1016/j.pedn.2021.10.010
[14] P. Rosenbaum, A. – C. Eliasson, M.J.C. Hidecker; R.J. Palisano. Classification in childhood disability; focusing on function in the 21st century; Journal of Child Neurology, May,2014; 29(8) DOI: 10.1177/0883073814533008
[15] Nobuaki Himuro. Family – centered Care for Children with Disabilities in Japan the Origin and Future of the „Ryouiku“ Physical Therapy Research, April, 2024. 27(1):1-5DOI: 10.1298/ptr.R0029

ZNAČAJ ZDRAVSTVENE NEGE KOD OSOBA SA INVALIDITETOM, KROZ EDUKACIJU, SPROVOĐENJE PROGRAMA RANE INTERVENCIJE I AKTIVNO UČEŠĆE MEDICINSKIH SESTARA

***Slađana Arsić*[1], *Andrijana Petrović*[1], *Dragana Kljajić*[2]**
[1] Akademija vaspitačko medicinskih strukovnih studija Kruševac, Odsek madicinskih studija Ćuprija, Republika Srbija
[2]Akademija strukovnih studija Beograd, Odsek Visoka zdravstvena škola, Republika Srbija

Sažetak. *Cerebralna paraliza je jedan od najčešćih uzroka fizičkog invaliditeta kod dece i karakterišu je trajni poremećaji pokreta i držanja tela uzrokovani oštećenjem mozga u razvoju u ranim fazama života. Cilj ovog rada je da predstavi značaj edukacije medicinskih sestara i njihovo učešće u zdravstvenoj nezi osoba sa invaliditetom, konkretno u radu sa pacijentima sa cerebralnom paralizom. Rad se zasniva na pregledu relevantne naučne i stručne literature dobijene iz medicinskih baza podataka MedLine; Google Scholar; PubMed. Posebna pažnja je usmerena na najčešće probleme u primeni zdravstvene nege kod ovih pacijenata, kao što su smanjena pokretljivost, oralno-motorni poremećaji, teškoće sa hranjenjem i gutanjem, bol i problemi u obavljanju svakodnevnih aktivnosti. Medicinske sestre igraju značajnu ulogu u proceni stanja ovih pacijenata, planiraju i spovode sestrinske intervencije, sprečavaju moguće komplikacije i edukuju članove porodica. Multidisciplinarni pristup, koji uključuje saradnju sa lekarima, fizioterapeutima, logopedima, psiholozima i drugim zdravstvenim radnicima, neophodan je za postizanje optimalnih ishoda lečenja i rehabilitacije. Podrška porodice i kontinuirana edukacija roditelja predstavljaju važnu komponentu uspešne nege dece sa cerebralnom paralizom. Unapređenje zdravstvenih i socijalnih sistema podrške može značajno doprineti boljem kvalitetu života osobama sa invaliditetom.*

Ključne reči: *osobe sa invaliditetom, cerebralna paraliza, medicinska nega, rehabilitacija, edukacija*