

QUALITY OF LIFE OF CHILDREN AND ADOLESCENTS WITH CEREBRAL PALSY - A REVIEW

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Abstract. *Cerebral palsy (CP) as a heterogeneous condition with different clinical presentations is accompanied by numerous physical impairments and disorders that interfere with the functioning of these individuals in the social environment. The environment, attitudes and barriers represent additional factors that limit the functioning of individuals with cerebral palsy and lead them to the level of temporary or permanent social incapacity. The aim of the paper is to review the available literature and present recent research on children with cerebral palsy, with a special focus on quality of life. By searching the Pub Med and Google Scholar databases, papers that examined the quality of life of children and adolescents with CP in Europe, North America, Bosnia and Herzegovina and the Republic of Serbia were analyzed. For the purposes of this research, the aspects of quality of life that were evaluated in children and adolescents with CP were in the areas of daily activities, mobility, health, nutrition, pain, frequency and duration of hospital stay, and exclusion from social groups.*

Key words: *quality of life, children and youth with cerebral palsy*

Introduction

Cerebral palsy is a heterogeneous condition with various clinical presentations and potential impairments, representing the most common cause of severe motor disabilities in children and is considered as physical impairment that affects motor development. CP is a chronic and non-progressive condition caused by brain damage in early development, manifesting as motor function impairment. Frequently, other associated disorders occur, including visual, hearing, intellectual, speech, or behavioral impairments.

CP often leads to multiple disabilities affecting functioning across all domains of daily life. It is the most common motor disorder in childhood [1] and one of the leading etiological factors for motor behavior disturbances. CP limits the development of functional abilities and negatively affects motor, cognitive, emotional, intellectual, and social functioning of the child. Therefore, CP requires continuous and intensive physiotherapeutic support [2]. Life with CP carries a high risk for secondary conditions that compromise functional abilities, daily activities, and social participation, negatively affecting quality of life [3]. Lower quality of life and health-related quality of life indicate that CP negatively impacts multiple dimensions of life.

Quality of life is defined in various ways. It is a multidimensional concept including an individual's perception of different life aspects, encompassing both objective and subjective indicators. Factors considered in assessing quality of life include emotions, social interactions, cognition, activities, schooling, family, independence, pain, future prospects, body image, and self-perception.

The aim of this review is to present recent research on children with CP, with a special focus on quality of life.

Methodology

There has been significant global interest in the concept of quality of life, particularly over the past 30 years. For this review, studies in English and Serbian were included. Only studies focusing on the quality of life in children and adolescents over the last 20 years were analyzed. Relevant databases, including PubMed and Google Scholar, were searched using the keywords: "cerebral palsy," "quality of life," "children," and "adolescents." Studies using validated instruments for assessing QoL (e.g., KIDSCREEN, PedsQL, CHK) were included. Potential limitations include the small number of studies in certain regions (Bosnia, Serbia), the variability of quality of life assessment tools that make cross-study comparisons difficult, and the lack of longitudinal studies that track changes over time.

Table 1. Comparative analysis of studies on quality of life in children with CP

Study/Author	Country/Region	Sample	Instruments	Main Findings
SPARCLE 1, 2, Europe 93 (2004–2020)	countries)	818 children (8–12 y), adolescents (13–17 y) (22–27y)	KIDSCREEN	Children self-reported good QoL; parents rated lower; pain and severity of impairment affected QoL and participation
NAGCPP (Liptak et al., 2001)	USA	235 children (2–18 y), 59% male 41% female	Global QoL + GMFCS	Poorer nutritional status and mental health in children with severe impairment; significant family impact
Glinac et al. (2015)	Bosnia & Herzegovina	76 children + 76 parents	PedsQL CP Module	Lowest QoL in daily activities and balance; parents rated QoL lower than children; gender and age effects
Slavković et al. (2017)	Serbia	50 children (25 CP, 25 typical)	Child Engagement in Daily Life	Lower participation in family and recreational activities in children with CP
Milićević (2014)	Serbia (14 cities)	112 parents (47 CP, 65 typical)	KIDSCREEN-10	Lower QoL in children with CP; older children had poorer QoL; parents reported high stress levels

Quality of Life in Children and Adolescents with CP in Europe

The most comprehensive study on QoL and participation of children with CP in Europe is SPARCLE (Study of Participation of Children with Cerebral Palsy Living in Europe). SPARCLE 1 was conducted in 2004/2005 and SPARCLE 2 in 2009. The study included 818 children aged 8–12 years and their parents from nine European countries. In SPARCLE 2, the same cohort was followed in adolescence (13–17 years), using the generic KIDSCREEN questionnaire. SPARCLE 3 is a longitudinal study focusing on young adults with cerebral palsy (CP) aged 22 to 27 years who previously participated in SPARCLE 1 and 2. The aim is to assess quality of life (QoL) and participation in various life domains, such as education, employment, health and social life.

According to SPARCLE 1, children able to self-report QoL generally rated it similarly to their peers in the general population, while parents reported lower QoL for their children with CP. Pain was associated with lower QoL and decreased participation. Participation was significantly lower compared to peers, especially in children with severe motor impairment. Children with CP exhibited more psychological problems compared to the general population. Children with milder physical impairment often experienced learning difficulties [4].

SPARCLE 2 found that severity of disability was significantly associated ($p < 0.01$) with lower QoL in adolescents with CP, particularly in mood/emotions, autonomy, and social support domains. Physical impairment directly impacted lower QoL. Differences in QoL compared to the general population became more pronounced during adolescence, especially in social participation and emotional health [5].

The SPARCLE 3 study recorded a significant decline in participation rates, especially among individuals whose parents did not complete secondary school. This factor doubled the risk of exclusion from the study. Young adults with CP showed lower quality of life and less participation in daily activities compared to the general population of the same age. These results indicate the need for additional support during the transition to adulthood. Factors such as pain, level of motor impairment, and social support in childhood had a long-term impact on quality of life and participation in youth. There were significant differences in quality of life and participation among different European countries, suggesting that factors such as access to services, educational opportunities, and social policies play a key role [6].

The findings of the SPARCLE study are of great importance for the creation of health and social systems. They must focus on improving participation through inclusive systems, providing adequate pain therapy, and developing support programs that are tailored to the needs of children and adolescents with CP. This study highlighted the importance of differences between health systems in Europe and their impact on quality of life.

Quality of Life in Children and Adolescents with CP in North America

The North American Growth in Cerebral Palsy Project (NAGCPP) was established in 1996 as a multicenter research program to address the need for scientific data on

children with CP. Data were collected from multiple centers in the USA and Canada to include children with varying severity and types of CP.

The study aimed to assess physical health, functional abilities, and QoL using global QoL measures. The coordinating center was the University of Virginia, with data collected from five regional sites. The sample included 235 children aged 2–18 years with moderate to severe impairment, categorized using the Gross Motor Function Classification System (GMFCS). The mean age was 9.7 years; 137 (59%) were male, 98 (41%) female. Children with severe motor impairment had poorer nutritional status, with 25% using feeding tubes. Parents reported lower QoL in all domains compared to the general population. Chronic pain was prevalent and negatively affected daily life. Children with severe impairments had poorer mental health and emotional well-being. Respiratory complications were the main reason for hospitalization. The family impact was significant, especially for children with severe CP, requiring parents to balance medical needs and family responsibilities.

Quality of Life in Children and Adolescents with CP in Bosnia and Herzegovina

Glinac et al. [7] examined the impact of age, gender, and socio-economic status on health-related QoL in children with CP, based on both child and parent reports. The cross-sectional study included 76 children (40 boys, 36 girls, median age 8.85 years) and 76 parents.

QoL was assessed using the PedsQL™ Cerebral Palsy Module, version 3.0. Children reported the lowest QoL in daily activities (dressing, grooming, toileting, bathing), mobility, balance, and school activities (writing, using scissors, keyboard/mouse).

According to the mentioned research, children of all age groups rated the quality of life as the weakest in the area of daily activities (dressing, putting on shoes, undressing, brushing, brushing teeth and going to the toilet, getting in and out of the bathtub), mobility and balance (moving legs, arms and other parts of the body, maintaining balance while sitting and standing) and school activities (writing, using scissors, keyboard and mouse on the computer). In relation to the socio-economic status of the family, children from the group with medium socio-economic status of the family had a statistically significantly lower quality of life ($p = 0.011$) in the area of nutrition compared to the group with low socio-economic status. This may be due to different parental expectations or less availability of support for the specific needs of children in middle-income families. Parents often reported a lower quality of life for their children than children reported for themselves. Older children reported a lower quality of life compared to younger children, especially in the domain of physical activity and social participation.

The results of research in Bosnia and Herzegovina confirm findings from European and North American studies, that mobility and participation are key factors in the life of children with CP. However, the specific impact of socio-economic status and weaker support for families indicates the need for locally adapted strategies.

Quality of Life in Children and Adolescents with CP in Serbia

Active participation of children with cerebral palsy (CP) in daily activities is a key predictor of overall social participation and significantly affects their quality of life. The research conducted by Slavković et al. [8] aimed to examine the participation of children with CP in everyday activities. The sample consisted of 50 children aged 7 to 11, divided into two groups: an experimental group of 25 children with CP and a control group of 25 children from the typical population.

The "Child Engagement in Daily Life" questionnaire was used to assess participation, focusing on three domains: self-care, family activities and recreational activities. The results show that children of the typical population have a statistically significantly higher degree of participation in all domains compared to children with CP ($p = .001$). Children with more pronounced motor disabilities participate less often in family and recreational activities, as well as in self-care activities. Also, a higher degree of participation in daily activities correlates with a higher quality of life of children with CP, while reduced participation negatively affects the child's social integration and emotional well-being. Factors such as physical limitations, accessibility of the environment and family support significantly influence the level of participation.

Similar results in terms of quality of life were shown by the research of Milićević [9], which was conducted on the territory of 14 cities of the Republic of Serbia. The sample included 112 parents or trustees of children aged 8–18, divided into two groups: 47 parents of children with CP and 65 parents of children with typical development. Quality of life was assessed using the KIDSCREEN-10 questionnaire. The results showed that parents of children with CP rate their children's quality of life as lower (Mdn = 47.71) compared to parents of children with typical development (Mdn = 52.65). Older subjects, both with CP and in the typical population group, had lower quality of life scores, and parents of children with CP often reported high levels of stress and worry about health and social challenges. Also, the lower socio-economic status of the family negatively affects the quality of life of children with CP, and families with lower incomes face greater challenges in providing adequate care and support for their children. These studies provide an important insight into the daily challenges faced by families of children with cerebral palsy in Serbia, emphasizing the need to improve social services and support for this population.

Conclusion

Children and adolescents with cerebral palsy (CP) face a number of challenges that affect their functional ability, social participation and quality of life. A review of the available studies shows that the quality of life in children with CP varies significantly depending on the severity of motor impairment, the presence of pain, social participation and other associated impairments. While the children themselves often report a quality of life similar to their peers from the general population, parents' assessments indicate a lower quality of life, especially in the domains of emotional well-being, social participation and physical activity.

The socio-economic status of the family, accessibility of the environment and parental support have a significant impact on the quality of life of children with CP. Greater

participation in daily activities, including self-care, family and recreational activities, correlates with higher quality of life. Pain and physical limitations are key factors that limit participation and therefore reduce quality of life.

Studies conducted in Europe (SPARCLE), North America (NAGCPP), Bosnia and Herzegovina and Serbia consistently confirm the importance of inclusive and supportive social and health systems, as well as the importance of locally adapted interventions that enable children with CP to actively participate in everyday life.

The results of the research indicate the need for the development of inclusive programs that enable greater participation of children with cerebral palsy in educational, recreational and social activities, adapted to the severity of the motor impairment and the individual needs of the child. Families with lower socio-economic status or limited support need targeted social and psychological assistance to reduce additional challenges in child care. Quality of life monitoring should include children's self-assessment, as parental assessments often do not reflect the child's subjective experiences. Preventive and rehabilitation programs that reduce pain, improve mobility, and support independence in daily activities can contribute to increased participation and improved quality of life. Finally, support strategies must be adapted to the local context, taking into account the availability of resources, socio-economic conditions and cultural specificities in Serbia and Bosnia and Herzegovina. These recommendations can serve as guidelines for planning health and social policies, developing educational and therapeutic programs, as well as supporting families of children with CP. Future research should focus on longitudinal follow-up of children and adolescents with cerebral palsy to monitor the long-term courses of quality of life and participation, as well as the factors that shape them during development. Special emphasis should be placed on the influence of socio-economic status, availability of health and educational services, as well as the environment on the functionality and social inclusion of children. It is necessary to evaluate the effectiveness of various therapeutic interventions, sports and recreational programs, as well as the role of assistive technology in improving everyday life. The development and validation of locally adapted instruments for the assessment of quality of life and participation would enable a more precise and culturally relevant evaluation. Also, research should examine the impact of parental stress and family support on the child's quality of life, as well as participation in the community and barriers that limit children with CP in everyday activities. The collection of representative data and the establishment of national registers of children with cerebral palsy in Serbia and Bosnia and Herzegovina would enable the monitoring of prevalence, planning of services and creation of effective health and social policies.

Literature

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KVALITET ŽIVOTA DECE I ADOLESCENATA SA CEREBRALNOM PARALIZOM – PREGLEDNI RAD

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Sažetak. *Cerebralna paraliza (CP) kao heterogeno stanje sa različitim kliničkim prezentacijama praćena je brojnim fizičkim oštećenjima i poremećajima koji ometaju funkcionisanje ovih osoba u društvenom okruženju. Okruženje, stavovi i barijere predstavljaju dodatne faktore koji ograničavaju funkcionisanje osoba sa cerebralnom paralizom i dovode ih do nivoa privremene ili trajne socijalne nesposobnosti. Cilj rada je da se pregledom dostupne literature predstave novija istraživanja o deci sa cerebralnom paralizom, sa posebnim fokusom na kvalitet života. Pretraživanjem baza podataka Pub Med i Google Scholar, analizirani su radovi koji su ispitivali kvalitet života dece i adolescenata sa CP u Evropi, Severnoj Americi, Bosni i Hercegovini i Republici Srbiji. Za potrebe ovog istraživanja, aspekti kvaliteta života koji su procenjivani kod dece i adolescenata sa CP bili su u oblastima svakodnevnih aktivnosti, mobilnosti, zdravlja, ishrane, bola, učestalosti i trajanja hospitalizacije i isključenosti iz društvenih grupa.*

Ključne reči: *Kvalitet života, deca i omladina sa cerebralnom paralizom*

