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AGREEMENT BETWEEN CHILD AND PARENT REPORTS ON QUALITY OF LIFE IN CHILDREN WITH CEREBRAL PALSY: ASSOCIATIONS WITH FUNCTIONAL DOMAINS, PSYCHOSOCIAL HEALTH, AND THE IMPACT OF SOCIODEMOGRAPHIC FACTORS

USKLAĐENOST PROCJENA KVALITETE ŽIVOTA DJECE S CEREBRALNOM PARALIZOM I NJIHOVIH MAJKI: POVEZANOST FUNKCIONALNIH DOMENA, PSIHOSOCIJALNOG ZDRAVLJA I UTJECAJ SOCIODEMOGRAFSKIH FAKTORA

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ABSTRACT

This study examines the agreement between health-related quality of life assessments in children with cerebral palsy and their mothers, analyzes the relationship between functional domains (daily activities, mobility, pain, fatigue, nutrition, communication) and psychosocial health of the child from the perspectives of both children and mothers, and investigates the impact of maternal education level and family socioeconomic status on the psychosocial health of children as assessed by their mothers.

The study involved 61 children with cerebral palsy, aged 5 to 18 years, along with their mothers who were the primary caregivers. Data were collected using validated instruments, including the PedsQL 4.0 and PedsQL 3.0 questionnaires, completed by both the children and their mothers. Socioeconomic status was determined using the Hollingshead index, and statistical analysis—descriptive statistics and non-parametric tests (Wilcoxon signed-rank test, Spearman's correlation)—was conducted using IBM SPSS Statistics 25.

The results showed significant differences in quality of life assessments between children and their mothers, particularly in the domains of daily activities, school activities, mobility, and balance. Daily activities, mobility, and nutrition were correlated with the psychosocial health of children according to the children's self-reports, while, according to mothers' assessments, the strongest correlations were observed for daily activities and nutrition.

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Socioeconomic status and maternal education level did not have a significant association with the psychosocial health of children in this sample. The findings highlight the importance of considering the child's perspective and focusing interventions on daily functioning.

Key words: cerebral palsy, quality of life, psychosocial health, daily activities, socioeconomic status.

SAŽETAK

Ova studija ispituje usklađenost procjena kvalitete života povezane sa zdravljem djece s cerebralnom paralizom i njihovih majki, analizira povezanost između funkcionalnih domena (dnevne aktivnosti, pokretljivost, bol, umor, prehrana, komunikacija) i psihosocijalnog zdravlja djeteta, iz perspektive djece i majki, te ispituje utjecaj obrazovnog nivoa majke i socioekonomskog statusa porodice na psihosocijalno zdravlje djece prema majčinoj procjeni. U studiji je sudjelovalo 61 dijete s cerebralnom paralizom, u dobi od 5 do 18 godina, zajedno s njihovim majkama koje su bile primarni skrbnici. Podaci su prikupljeni korištenjem validiranih instrumenata, uključujući upitnike PedsQL 4.0 i PedsQL 3.0, koje su ispunili i majke i djeca. Socioekonomski status određen je Hollingsheadovim indeksom, a statistička obrada — deskriptivna statistika i neparametrijski testovi (Wilcoxonov test za uparene uzorke, Spearmanova korelacija) — provedena je u IBM SPSS Statistics 25. Rezultati su pokazali značajne razlike u procjenama kvalitete života između djece i njihovih majki, osobito u domenama dnevnih aktivnosti, školskih aktivnosti, pokretljivosti i ravnoteže. Dnevne aktivnosti, pokretljivost i ishrana bili su u korelaciji s psihosocijalnim zdravljem djece prema samoprocjeni djece, dok prema procjeni majki najsnažnije povezanosti bile su zabilježene za dnevne aktivnosti i ishranu. Socioekonomski status i obrazovni nivo majki nisu imali značajnu povezanost s psihosocijalnim zdravljem djece u ovom uzorku. Nalazi ukazuju na važnost uvažavanja djetetove perspektive i usmjeravanja intervencija na svakodnevno funkcionisanje.

Ključne riječi: cerebralna paraliza, kvaliteta života, psihosocijalno zdravlje, dnevne aktivnosti, socioekonomski status.

INTRODUCTION

Cerebral palsy (CP) is a group of permanent, but changeable movement and body posture disorders, caused by non-progressive brain damage during early development, most often during pregnancy, childbirth, or shortly after birth (Bhattacharjee, 2020). According to the International Classification of Functioning, Disability and Health, CP is defined as a complex developmental disorder that, in addition to motor functions, significantly affects the sensory, communication, cognitive, and emotional domains of a child's functioning (WHO, 2001).

CP is the most common cause of physical disability in childhood, affecting approximately one in 500 newborns (Sadowska, Sarecka-Hujar & Kopyta, 2020). The diagnosis is most commonly made within the first two years of life, using a combination of medical history, neurological, and motor assessments (Bhattacharjee, 2020). Motor disorders are often

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accompanied by comorbidities such as epilepsy, intellectual disabilities, behavioral problems, emotional difficulties, sensory and perceptual disorders, as well as secondary musculoskeletal problems (Sadowska, Sarecka-Hujar & Kopyta, 2020; Blasco, García-Galant, Berenguer-González et al., 2023).

An interdisciplinary approach is essential for children with cerebral palsy, involving collaboration among various specialists such as physiotherapists, occupational therapists, speech therapists, special educators, ophthalmologists, orthopedists, and pediatricians. Therapeutic interventions cover motor, sensory, communication, and cognitive aspects of functioning, aiming to improve functional abilities, prevent secondary complications, and enhance the quality of life for the child and family. The greatest therapeutic effect is often achieved through a combined, multimodal approach, resulting in better functional outcomes for the child and increased family cohesion and support (Benić, 2021).

The World Health Organization defines quality of life as "an individual's perception of their position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns." Children with CP face significant limitations in daily activities such as feeding, dressing, bathing, and social participation, which often require long-term care and place additional psychological, time, and financial pressure on the family (Blasco, García-Galant, Berenguer-González, et al., 2023). Given that there is no known cure for CP, the assessment of the success of therapeutic and rehabilitation services is increasingly based on quality of life as a key outcome (Badia, Riquelme, Orgaz, et al., 2014). Previous studies have shown that children with cerebral palsy have compromised quality of life, with negative outcomes associated with various factors such as medication use, poor sleep quality, and other similar influences (Izzah, Irwanto, Andriati & Gunawan, 2021). The assessment of quality of life is important for identifying problematic areas in chronically ill children to ensure adequate support and interventions in more severe cases (Vles, Hendriksen, Hendriksen, et al., 2015).

However, although the quality of life of children with CP is increasingly the focus of research, relatively few studies simultaneously examine the agreement between children's and parents' assessments, particularly in the context of different functional domains and psychosocial health. Furthermore, the role of sociodemographic factors in shaping these assessments remains insufficiently explored. The objectives of this study were:

- To examine the alignment of quality of life assessments related to the health of children with cerebral palsy and their mothers;
- To analyze the relationship between functional domains (daily activities, mobility, pain, fatigue, nutrition, communication) and psychosocial health of the child, from the perspectives of both children and mothers;
- To examine the impact of family educational and socioeconomic status on children's psychosocial health according to maternal assessment.

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MATERIALS AND METHODS

Participants

This retrospective study included a total of 61 children with clinically confirmed diagnoses of cerebral palsy (CP), aged between 5 and 18 years, and 61 mothers who were the primary caregivers of the children. Participant inclusion was based on the availability of data from archived individual files, which were previously collected using validated instruments to assess quality of life – the Pediatric Quality of Life Inventory (PedsQL) version 4.0 and the PedsQL Cerebral Palsy Module version 3.0.

Inclusion criteria were: confirmed diagnosis of cerebral palsy, child's age between 5 and 18 years at the time of assessment, and availability of completed and correctly filled PedsQL 4.0 (generic module) and PedsQL 3.0 (CP-specific module) questionnaires, completed from the perspective of both the mother and the child. Only those cases were included in the analysis where mothers, as primary caregivers, completed the parent portion of the questionnaire, and where basic sociodemographic data relevant for analysis were available in the files.

Exclusion criteria included: incomplete questionnaires, lack of key data about the child or mother, and the presence of comorbid diagnoses that could significantly interfere with the interpretation of quality of life perceptions (e.g., severe intellectual disabilities and psychiatric conditions unrelated to cerebral palsy).

Study Design and Procedures

This study employs a retrospective design, based on the analysis of data previously collected regarding the quality of life of children with cerebral palsy. The data were initially gathered as part of a research project conducted at the University Clinical Center Tuzla. All data used in this study were collected with written and informed consent from the participants (children and mothers), with participants being informed in advance that their data would be used for scientific purposes. For the purposes of the retrospective analysis, only de-identified data were used, ensuring the privacy and confidentiality of the participants.

Measurement Instrument

Two validated questionnaires were used for the research: the Pediatric Quality of Life Inventory (PedsQL) 4.0 (generic) and the PedsQL Cerebral Palsy Module 3.0 (CP-specific). PedsQL 4.0 covers four domains: physical, emotional, social, and school functioning (Varni, Seid, & Kurtin, 2001). The PedsQL Cerebral Palsy Module 3.0 includes seven areas: daily activities, school activities, balance, pain, fatigue, nutrition, and communication (Varni, Burwinkle, Berrin et al., 2006). Responses are assessed using a Likert scale (0 – never a problem, 4 – almost always a problem), and then scores are reverse-scored and transformed onto a 0-100 scale, where higher scores indicate better quality of life. For children aged 5 to 8 years, an adapted PedsQL 4.0 questionnaire with visual aids was used to assist children in answering questions about their physical, emotional, and social functioning. A standard Likert scale was used for parents.

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To determine the socioeconomic status (SES) of the families, the educational level and current employment status of the parents were analyzed using the Hollingshead two-factor index of social position. This index assigns higher values to families with lower SES, while lower values indicate a higher socioeconomic status (Stepnowsky, Nelesen, DeJardin & Dimsdale, 2004).

Ethical Aspects

This retrospective study was conducted with prior approval from the Ethics Committee of the University Clinical Center Tuzla, Bosnia and Herzegovina. All analyzed data were collected from existing documentation while ensuring the anonymity and confidentiality of the participants, in accordance with the applicable ethical guidelines.

Statistical Analysis

All collected data were analyzed using descriptive and inferential statistics. Descriptive statistics included the calculation of frequencies, percentages, medians, and interquartile ranges (IQR) to describe the basic sociodemographic and clinical characteristics of the sample. The normality of the distribution of continuous variables was assessed using the Shapiro-Wilk test.

For comparing two related groups, the Wilcoxon signed-rank test for paired samples was used, given the nonparametric nature of the data. Correlation analysis was conducted using Spearman's rank correlation coefficient (ρ) to examine the direction and strength of the relationship between variables.

Statistical significance was set at $p<0.05$. All analyses were performed using the IBM SPSS Statistics software, version 25.0 (IBM Corp., Armonk, NY, USA).

RESULTS

The median age of children with cerebral palsy at the time of the study was 8.5 years (range: 5–16.7 years). Of the total of 61 children with cerebral palsy, 34 (55.7%) were boys, and 27 (44.3%) were girls. The median age of mothers at the time of the study was 36 years (range: 26–56 years).

Regarding the educational status of mothers, 26 (42.6%) mothers had completed primary education, 33 (54.1%) had completed secondary education, while only 2 mothers (3.3%) had higher education. The Hollingshead socioeconomic status (SES) index for this sample ranged from 6 to 53, with a median score of 24.5. The majority of families belonged to the low to middle socioeconomic status category.

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Table 1. Concordance of quality of life assessments between children with cerebral palsy and their mothers

PedQL™ 3.0 Cerebral Palsy Module	Number of question	Children with CP (n=61)	Mothers (n=61)	Wilcoxon test	
		Median (IQR)	Median (IQR)	Z	P
Daily activities	9	27.78 (15.28-73.61)	27.78 (8,33-59.72)	-3.568	0.000
School activities	4	75.00 (37.50-100.00)	56.25 (15.62-75.00)	-4.844	0.000
Mobility and balance	5	60.00 (35.00-80.00)	40.00 (25.00-62.50)	-4.408	0.000
Pain and pain occurrence	4	87.50 (81.25-100.00)	87.50 (75.00-100.00)	-1.847	0.065
Fatigue	4	68.75 (50.00-100.00)	50.00 (43.75-84.35)	-3.285	0.001
Nutrition	5	80.00 (60.00-100.00)	70.00 (50.00-90.00)	-3.505	0.000
Speech and communication	4	100.00 (75.00-100.00)	100 (71.87-100.00)	-1.552	0.121

Mothers significantly rated the quality of life of their children lower in the domains of daily activities, school activities, mobility and balance, fatigue, and nutrition ($p < 0.01$), while the difference in the domains of pain and pain occurrence, and speech and communication was not statistically significant ($p > 0.05$). The greatest discordance was observed in the domain of school activities ($Z = –4.844$; $p < 0.001$).

Table 2. Association between functional domains and psychosocial health of children with cerebral palsy according to self-assessment

PedQL™ 3.0 Cerebral Palsy Module PedQL™ 4.0 Pediatric Quality of Life Inventory		DA	MO	PA	FA	NU	CO
CPH	Spearman	0.402**	0.410**	-0.011	0.042	0.395**	0.257*
	p	0.001	0.001	0.933	0.748	0.002	0.045

CPH – child's psychosocial health; DA – daily activities; MO – mobility; PA – pain; FA – fatigue; NU – nutrition; CO – communication; *Statistical significance $p < 0.05$; ** statistical significance $p < 0.01$.

Spearman's correlation analysis revealed a strong positive association between psychosocial health and the domains of daily activities (Spearman's rho = 0.402, $p < 0.001$), mobility (Spearman's rho = 0.410, $p < 0.001$), and nutrition (Spearman's rho = 0.395, $p = 0.002$). The communication domain was also statistically significantly associated, but to a lesser degree (Spearman's rho = 0.257, $p = 0.045$). In contrast, the associations between psychosocial health

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and the domains of pain (Spearman's rho = –0.011, p = 0.933) and fatigue (Spearman's rho = 0.042, p = 0.748) were not statistically significant.

Table 3. Association between Functional Domains and Psychosocial Health According to Mothers' Assessments of Children with Cerebral Palsy

PedQL™ 3.0 Cerebral Palsy Module PedQL™ 4.0 Pediatric Quality of Life Inventory		DA	MO	PA	FA	NU	CO
CPH	Spearman	0.487**	0.332**	0.335**	0.327*	0.540**	0.479**
	p	0.000	0.009	0.008	0.010	0.000	0.000

CPH – child's psychosocial health; DA – daily activities; MO – mobility; PA – pain; FA – fatigue; NU – nutrition; CO – communication; *Statistical significance p < 0.05; ** statistical significance p < 0.01

Spearman's correlation analysis of mothers' assessments of psychosocial health in children and functional domains revealed the strongest association with the domains of nutrition (Spearman's rho = 0.540; p < 0.001) and daily activities (Spearman's rho = 0.487; p < 0.001). Moderate but statistically significant correlations were also found for the domains of communication (Spearman's rho = 0.479; p < 0.001), pain (Spearman's rho = 0.335; p = 0.008), fatigue (Spearman's rho = 0.327; p = 0.010), and mobility (Spearman's rho = 0.332; p = 0.009).

Table 4. Association between educational level and socioeconomic status of the family with psychosocial health of children with cerebral palsy: mothers' assessment

PedQL™ 4.0 Pediatric Quality of Life Inventory		Education	Socioeconomic status
Child's psychosocial health	Spearman	-0.077	0.091
	p	0.553	0.485

Spearman's analysis did not reveal a significant association between the mothers' educational level and their assessment of the child's psychosocial health (Spearman's rho = –0.077; p = 0.553), nor between the family's socioeconomic status and the same assessment (Spearman's rho = 0.091; p = 0.485), indicating that these factors did not influence the perceived psychosocial health of children with cerebral palsy in this sample.

DISCUSSION

The results of this study revealed statistically significant differences between self-assessments of quality of life in children with cerebral palsy and the assessments made by their mothers across several key functional domains. Mothers consistently rated their child's abilities lower in the domains of daily and school activities, mobility, nutrition, and fatigue (p < 0.01), with the most pronounced difference in the domain of school activities (Z = -4.844; p < 0.001). Similarly, in the study by Izzah, Irwanto, Andriati & Gunawan (2021), parents also reported lower quality of life ratings compared to the children's self-assessments, with only the domain

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of movement and balance showing a satisfactory average result. These findings suggest potential differences in the perception of functional status between children and their parents, which can be interpreted through the lens of the parental perspective, especially mothers who are daily involved in caregiving. The obtained results align with the findings of Aza, Riquelme, Gómez Vela & Badia (2024), who also found a tendency for mothers to rate their child's functional abilities and emotional state lower. A similar pattern was observed in the dimensions of emotional and social well-being, while the differences between children's and parents' ratings were more pronounced in the domains of pain and school activities, as confirmed by other authors (Lennon, Kalisperis, Church et al., 2024; Shields, Leonard, Munteanu et al., 2018). The research by Perez Sousa, Olivares Sánchez-Toledo & Gusi Fuerte (2017) suggests that mothers are more likely to perceive greater problems than the children themselves, with slightly greater agreement between mothers and children compared to fathers, which is associated with the greater involvement of mothers in the child's daily care. Furthermore, studies by Longo, Badia, Begoña Orgaz & Gómez-Vela (2017) and Rajmil, López, López-Aguilà & Alonso (2013) confirm the existence of disagreement between children's self-assessments and parental ratings, noting that the level of disagreement increases with the child's age. The differences in quality of life perception between children and parents can be explained by varying understandings of the concept of quality of life, as well as parental concerns, stress, and emotional pressures (Glinac, Matović & Delalić, 2016). Additionally, parents—particularly mothers—often perceive greater difficulties due to their own exposure to stress and responsibility for the child's future, while children, on the other hand, often show greater adaptation to their circumstances, which can result in higher self-assessments (Glinac, Tahirović & Delalić, 2013).

Spearman's correlation analysis conducted in this study showed a significant positive association between psychosocial health and functional domains, including daily activities (Spearman's rho = 0.402, $p < 0.001$), mobility (Spearman's rho = 0.410, $p < 0.001$), and nutrition (Spearman's rho = 0.395, $p = 0.002$) in children's self-assessments. The correlation with the communication domain was weaker (Spearman's rho = 0.257, $p = 0.045$). On the other hand, pain (Spearman's rho = -0.011, $p = 0.933$) and fatigue (Spearman's rho = 0.042, $p = 0.748$) did not show a significant association with psychosocial health. In the mothers' assessments, the strongest associations were with the nutrition domain (Spearman's rho = 0.540, $p < 0.001$) and daily activities (Spearman's rho = 0.487, $p < 0.001$), while correlations with communication (Spearman's rho = 0.479, $p < 0.001$), pain (Spearman's rho = 0.335, $p = 0.008$), fatigue (Spearman's rho = 0.327, $p = 0.010$), and mobility (Spearman's rho = 0.332, $p = 0.009$) were also statistically significant. These results are consistent with the research by Chen, Tseng, Shieh, Lu & Huang (2014), who found that functional abilities are stronger predictors of quality of life than symptoms like pain, which may be present but are not necessarily perceived as limiting. On the other hand, parents, particularly mothers, often focus on visible physical challenges and limitations, while children emphasize deeper concerns related to social inclusion and emotional well-being. These differences in perceiving functional domains further highlight the complex relationship between physical limitations and psychosocial health, as well as the importance of including both perspectives to gain a comprehensive understanding of the actual needs of children with cerebral palsy (Lindsay,

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2016).

The absence of statistically significant correlations between the parents' education level and the family's socioeconomic status with the psychosocial health of children with cerebral palsy, as assessed by mothers, suggests that these factors are likely not key determinants of parental perception of the child's psychosocial functioning in this sample. The obtained results are consistent with the research by Pérez-Ardanaz, Morales-Asencio, León-Campos et al. (2020), who found no significant association between parental education or occupation and the quality of life of children with cerebral palsy. On the other hand, data from the study by Saikia & Pradhan (2024) indicate a contrasting pattern, where a higher level of maternal education was associated with better assessments of the child's quality of life. These findings support the results of earlier studies suggesting that parental education, particularly that of mothers, may play a protective role through increased awareness, better access to healthcare and educational resources, and more effective management of daily challenges related to the child's disability (Das, Aggarwal, Roy & Kumar, 2017).

The limitations of the study include several factors. Although this is a retrospective analysis, validated and standardized instruments were used, and the data were collected in a systematic manner, improving their reliability. The group of children with cerebral palsy was formed at the Clinical Center, which provides continuous healthcare to most children with this condition within the canton, contributing to its representativeness. Given the prevalence of cerebral palsy and the population size in the region, the sample size (n = 61) can be considered methodologically acceptable. The study involved only mothers, while children with more severe intellectual disabilities were excluded from the self-assessment section due to limited verbal abilities that would prevent reliable assessment of subjective experience.

CONCLUSION

The study revealed significant discrepancies between the assessments of children with cerebral palsy and their mothers regarding quality of life, with the most pronounced difference in the domain of school activities. Psychosocial health of children, as assessed by mothers, was significantly associated with functional domains, particularly nutrition and daily activities. Maternal education and socioeconomic status did not show a significant impact. The findings highlight the importance of incorporating the child’s perspective in the assessment of quality of life and focusing on daily functioning when planning interventions.

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