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PSYCHOLOGICAL CHARACTERISTICS AND QUALITY OF LIFE OF PARENTS OF CHILDREN WITH DISABILITIES

PSIHOLOŠKE KARAKTERISTIKE I KVALITETA ŽIVOTA KOD RODITELJA DJECE S INVALIDITETOM

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ABSTRACT

The aim of this research was to determine differences in the levels of anxiety, depression, perceived stress, and quality of life among parents of children with different developmental difficulties (intellectual disabilities, autism spectrum disorder, and cerebral palsy). The sample consisted of 104 parents, the majority of whom were female (85.6%). Most parents reported that their child had an autism spectrum disorder (45.2%), while the rest reported Down syndrome (29.8%) and cerebral palsy (25.0%). The following instruments were used for the purposes of the research: Demographic Data Questionnaire, Perceived Stress Scale (PSS), Family Quality of Life Scale (FQoL), Generalized Anxiety Disorder Scale (GAD-7), and the Patient Health Questionnaire (PHQ-9). Statistical data analysis was conducted using univariate analysis of variance (ANOVA). The results showed that parents of children with cerebral palsy exhibit statistically significantly higher levels of anxiety, depression, and perceived stress compared to parents of children with autism and Down syndrome. These findings confirm previous research on the impact of the complexity of motor impairments on the psychological state of parents and highlight the need for targeted psychosocial support for this population. On the other hand, the study did not show statistically significant differences in the perception of overall quality of life among parents, regardless of the type of their child's difficulty. This result implies that factors such as family support, adopted coping mechanisms, and the degree of acceptance of the situation may play a key role in maintaining the subjective sense of life homeostasis.

Key words: parents, developmental difficulties, anxiety, depression, quality of life.

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SAŽETAK

Cilj istraživanja bio je utvrditi razlike u nivou anksioznosti, depresivnosti, percipiranog stresa i kvaliteti života među roditeljima djece različitih teškoća u razvoju (intelektualne teškoće, autistični spektar poremećaja i cerebralna paraliza). Uzorak je obuhvatio 104 roditelja, od kojih je većina bila ženskog spola (85,6%). Najveći broj roditelja naveo je da njihovo dijete ima poremećaj iz autističnog spektra poremećaja (45,2%), dok su ostali naveli Down sindrom (29,8%) i cerebralnu paralizu (25,0%). Za potrebe istraživanja korišteni su sljedeći instrumenti: Upitnik o demografskim podacima, Percipirana skala stresa (PSS), Skala porodične kvalitete života (FQoL), Ljestvica generaliziranog anksioznog poremećaja (GAD-7) i Upitnik o zdravstvenom stanju pacijenta (PHQ-9). Statistička obrada podataka provedena je primjenom univarijatne analize varijanse (ANOVA). Rezultati su pokazali da roditelji djece s cerebralnom paralizom pokazuju statistički značajno više nivoe anksioznosti, depresivnosti i percipiranog stresa u poređenju s roditeljima djece s autizmom i Down sindromom. Ovi rezultati potvrđuju prethodna istraživanja o uticaju složenosti motoričkih teškoća na psihološko stanje roditelja, te upućuju na potrebu za ciljanom psihosocijalnom podrškom ovoj populaciji. S druge strane, istraživanje nije pokazalo statistički značajne razlike u percepciji ukupne kvalitete života među roditeljima, bez obzira na vrstu djetetove teškoće. Ovaj rezultat implicira da faktori poput porodične podrške, usvojenih koping mehanizama i stepena prihvatanja situacije mogu igrati ključnu ulogu u očuvanju subjektivnog osjećaja životne homeostaze.

Ključne riječi: roditelji, teškoće u razvoju, anksioznost, depresivnost, kvalitet života.

INTRODUCTION

A human being is a biopsychosocial but also a spiritual being, and therefore quality of life can be discussed in biological, psychological, social, and spiritual terms, as well as in terms of the interdependent interconnectedness of these structures. Thus, for example, using the language of biology, it is important to what extent physiological changes (nervous system, immunity, heart) in the human organism affect quality of life. From the psychological perspective, it is important to consider how trauma, stress, tension, fear as an emotional state, as well as, how relationships with family, friends, colleagues, and society in general influence quality of life. All this actually suggests that, in assessing quality of life, we must adopt a multidimensional approach, because, as Prstačić (2006) states, cited in Mehmedinović (2019), "the psychosomatic unity of man is inseparable from his spiritual and psychosocial structure," and therefore we can conclude that separating any structure of quality of life "disrupts" its objective measurability. Quality of life can be defined as a multidimensional structure of human satisfaction, "the degree of what makes life good," and overall general well-being (Mahmutagić, Prstačić et al., 2006, cited in Mehmedinović, Šarić, Bratovčić, 2019).

Parental expectations change after discovering that their child has a disability, which can become a powerful source of stress for the entire family. "The birth of a child at developmental risk and/or the realization that the child has a developmental difficulty is a traumatic event for parents, requiring resources for trauma recovery and coping with

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numerous challenges related to the care of a child with an atypical developmental trajectory" (Slišković et al., 2022). Parents, and often siblings, face numerous responsibilities related to meeting the basic life needs of the child with a disability, as well as carrying out specific medical interventions necessary to improve their health and development (Ljubičić, 2021). Children with more severe forms of disability require more intensive care, which can result in parents experiencing higher levels of stress (Leung, Li-Tsang, 2003, cited in Ljubičić, 2021). Although the perception of stressors and stressful events is individually conditioned and differs among individuals, it can lead to increased neurotransmitter, hormonal, and electrophysiological sensitivity of the central nervous system, thereby triggering a series of pathophysiological mechanisms with potentially negative health consequences (Ljubičić, 2021). Due to constant concern and focus on the needs of the child, parents often neglect their own symptoms—initially psychological and later also physical—which adversely affects their mental and physical health (Ljubičić, 2021). For example, anxiety and depression can imperceptibly cross the boundary of ordinary emotional reactivity and develop into pathological forms. Although anxiety and depression have different causes, their mutual connection is strong due to the presence of negative affect (Vuliš-Prtoriš & Macuka, 2004).
Developmental difficulties such as Down syndrome (DS), autism spectrum disorder (ASD), and cerebral palsy (CP) are among the most common chronic conditions in childhood (World Health Organization, 2012). Research shows that parents of children with ASD are exposed to chronic psychological stress, which negatively affects their quality of life, in comparison to parents of children with typical development (TD) and those without chronic conditions (Mazzone et al., 2018; Padden et al., 2018; Musetti et al., 2021, cited in Ljubičić et al., 2022), but also in relation to parents of children with Down syndrome (Pastor-Cerezuela, 2020).
Therefore, in accordance with the above, the aim of this research is to determine whether there are differences in the levels of anxiety, depression, and quality of life among parents of children with developmental difficulties (intellectual disabilities, autism spectrum disorder, cerebral palsy), based on the health condition of their children.

MATERIALS AND METHODS

Sample of participants

The research included a total sample of 104 parents of children with developmental difficulties. According to the sample structure, a larger percentage of participants were female (85.6%), while 14.4% were male. This distribution was expected, considering that mothers often assume the primary role in caring for a child with a disability and participate more actively in such research. Regarding the type of disability in children, the majority of parents stated that their child has an autism spectrum disorder (45.2%). This was followed by children with Down syndrome (29.8%) and children with cerebral palsy (25.0%). This distribution indicates a balanced sample in terms of types of developmental difficulties, with a slight predominance of autism as the most diagnosed difficulty in this study. In terms of educational attainment, the largest number of respondents completed secondary school (47.1%). Thirty-six respondents (34.6%) had a university degree, while eleven (10.6%) completed a college-

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level program. A smaller number of respondents held a master's or doctoral degree—seven in total (6.7%), and only one respondent had completed only primary school.

Measuring instruments

To examine the research objective, the following instruments were used: Demographic Data Questionnaire, Perceived Stress Scale (Cohen et al., 1983), Beach Center Family Quality of Life Scale (Hoffman, 2006), Generalised Anxiety Disorder Questionnaire (Spitzer, 2006), and Patient Health Questionnaire (Kroenke, 2001).

The Perceived Stress Scale is used to assess the subjective perception of stressful situations during the previous month, focusing on how the individual evaluates the demands of life circumstances and their own ability to cope with them. The Family Quality of Life Scale is intended to assess the perception of quality of life within families with a child with developmental difficulties or chronic illness, encompassing various aspects of family functioning and satisfaction. The Generalised Anxiety Disorder Questionnaire is used to identify symptoms of anxiety, irritability, and difficulty relaxing over the past two weeks. The Patient Health Questionnaire was used to assess the presence and intensity of depressive symptoms in the same time frame, providing insight into the level of depression among respondents.

The use of these validated instruments enables a comprehensive analysis of the psychological state of parents, as well as the quality of their family life in the context of challenges associated with raising a child with developmental difficulties.

Data processing methods

The research data were processed using parametric and non-parametric statistical methods. As part of descriptive statistics, basic statistical parameters were calculated—measures of central tendency and dispersion, frequencies, and percentages—and the results were presented in tables. To test the research hypothesis, a univariate analysis of variance (ANOVA) was applied, examining the existence of statistically significant differences between the observed respondent groups. The data were processed and analyzed using the statistical software package SPSS 25. for Windows.

RESULTS AND DISCUSSION

Table 1 presents the results for the four main constructs: level of anxiety, level of depression, perceived stress, and quality of life depending on the type of child's difficulty (autism, Down syndrome, cerebral palsy). The lowest average level of anxiety was recorded among parents of children with autism (M = 10.26; SD = 3.89), with a similar result observed among parents of children with Down syndrome (M = 10.48; SD = 3.55). The highest level of anxiety was observed among parents of children with cerebral palsy (M = 13.65; SD = 5.75), indicating potentially greater psychological burden in this group of parents. Parents of children with cerebral palsy also showed the highest level of depression (M = 19.04; SD = 8.92), while parents of children with Down syndrome (M = 15.52; SD = 4.81) and autism (M = 14.47; SD = 5.61) had slightly lower values.

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These results indicate more pronounced depressive symptoms among parents whose children have cerebral palsy. The highest level of perceived stress was also recorded among parents of children with cerebral palsy (M = 32.62; SD = 10.12), while parents of children with autism (M = 28.70; SD = 6.05) and Down syndrome (M = 28.42; SD = 3.91) showed approximately similar and slightly lower values. The highest average quality of life score was achieved by parents of children with cerebral palsy (M = 100.85; SD = 15.61), while parents of children with autism (M = 97.53; SD = 12.91) and Down syndrome (M = 97.03; SD = 22.99) showed slightly lower but similar average values. Interestingly, although parents of children with cerebral palsy exhibit higher levels of stress, anxiety, and depression, their perception of quality of life is higher, which may indicate a complex relationship between emotional state and perception of life quality.

Table 1. Results of descriptive statistics

Variables		N	M	SD	SE	MIN	MAX
Level of Anxiety	Autism spectrum	47	10.26	3.89	0.57	6.00	22.00
	Down syndrome	31	10.48	3.55	0.64	6.00	18.00
	Cerebral palsy	26	13.65	5.75	1.13	0.00	24.00
	Total	104	11.17	4.53	0.44	0.00	24.00
Level of Depression	Autism spectrum	47	14.47	5.61	0.82	9.00	34.00
	Down syndrome	31	15.52	4.81	0.86	9.00	27.00
	Cerebral palsy	26	19.04	8.92	1.75	0.00	35.00
	Total	104	15.92	6.60	0.65	0.00	35.00
Level of Perceived Stress	Autism spectrum	47	28.70	6.05	0.88	10.00	50.00
	Down syndrome	31	28.42	3.91	0.70	18.00	37.00
	Cerebral palsy	26	32.62	10.12	1.98	10.00	50.00
	Total	104	29.60	6.98	0.68	10.00	50.00
Quality of Life	Autism spectrum	47	97.53	12.91	1.88	59.00	123.00
	Down syndrome	31	97.03	22.99	4.13	0.00	125.00
	Cerebral palsy	26	100.85	15.61	3.06	54.00	123.00
	Total	104	98.21	17.03	1.67	0.00	125.00

Table 2 presents the results of the Univariate Analysis of Variance (ANOVA), which indicate the existence of statistically significant differences in the levels of anxiety, depression, and perceived stress among parents of children with different types of developmental difficulties (autism, Down syndrome, cerebral palsy). For the level of anxiety, a significant difference between groups was found ($p = 0.005$), indicating that the type of the child's difficulty affects the intensity of anxiety symptoms in parents. Similarly, a significant effect was observed in the case of depression levels ($p = 0.015$), suggesting that parents of children with different diagnoses differ statistically significantly in the intensity of depressive symptoms. Likewise, the level of perceived stress varies depending on the diagnosis, with a significant difference established between the groups ($p = 0.037$). The analysis of quality of life did not show a statistically significant difference among parents of children with autism, Down syndrome, and cerebral palsy ($p = 0.659$).

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These results indicate that although differences in psychological burden among parents exist, their overall perception of quality of life remains relatively stable regardless of the type of the child's developmental difficulty.

Table 2. ANOVA results

Variables		Sum of Squares	df	Mean Square	F	p
Level of Anxiety	Between Groups	214.32	2	107.16	5.68	**.005**
	Within Groups	1902.56	101	18.83		
	Total	2116.88	103			
Level of Depression	Between Groups	356.97	2	178.49	4.36	**.015**
	Within Groups	4128.40	101	40.87		
	Total	4485.38	103			
Level of Perceived Stress	Between Groups	317.50	2	158.75	3.40	**.037**
	Within Groups	4703.53	101	46.57		
	Total	5021.03	103			
Quality of Life	Between Groups	245.29	2	122.64	.41	.659
	Within Groups	29620.05	101	293.26		
	Total	29865.34	103			

The results of the post hoc Scheffe analysis (Table 3) explain the observed differences among parents of children with different developmental difficulties. Regarding the level of anxiety, statistically significant differences were found between parents of children with cerebral palsy and those whose children have autism ($p = 0.008$), as well as Down syndrome ($p = 0.026$). In both cases, parents of children with cerebral palsy showed significantly higher levels of anxiety, which confirms the earlier findings of the ANOVA analysis and indicates the specific emotional vulnerability of this group.

Similar results are evident in the level of depression, where a statistically significant difference was found between parents of children with cerebral palsy and parents of children with autism ($p = 0.016$). Parents of children with cerebral palsy exhibit higher levels of depressive symptoms. Although the difference between parents of children with cerebral palsy and Down syndrome was not statistically significant ($p = 0.122$), the result shows a trend in the same direction.

When considering perceived stress, although the ANOVA test indicates a statistically significant difference among the groups, the Scheffe analysis did not confirm significant differences at the $p \leq 0.05$ level. However, the differences between parents of children with cerebral palsy and parents of children with autism ($p = 0.069$), as well as parents of children with Down syndrome ($p = 0.074$), are on the borderline of significance, suggesting a potentially higher level of stress among parents of children with cerebral palsy, which could likely be confirmed in a larger sample.

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For the variable quality of life, no statistically significant differences were found among the groups of parents (all p-values > 0.70), which is consistent with the previous ANOVA findings. This result suggests that, despite differences in psychological burden, parents of children with different developmental difficulties do not perceive a significantly different overall quality of life. It is possible that factors such as family support, acceptance of the situation, and adopted coping strategies have a buffering effect on the perception of life quality.

Table 3. Multiple Comparisons (Scheffe test)

Dependent Variable			MD	SE	p
Level of Anxiety	Autism spectrum	Down syndrome	-0.23	1.00	.974
		Cerebral palsy	-3.39*	1.06	**.008**
	Down syndrome	Autism spectrum	0.23	1.00	.974
		Cerebral palsy	-3.16*	1.15	**.026**
	Cerebral palsy	Autism spectrum	3.39*	1.06	**.008**
		Down syndrome	3.16*	1.15	**.026**
Level of Depression	Autism spectrum	Down syndrome	-1.05	1.48	.779
		Cerebral palsy	-4.57*	1.56	**.016**
	Down syndrome	Autism spectrum	1.05	1.48	.779
		Cerebral palsy	-3.52	1.70	.122
	Cerebral palsy	Autism spectrum	4.57*	1.56	**.016**
		Down syndrome	3.52	1.70	.122
Level of Perceived Stress	Autism spectrum	Down syndrome	0.28	1.58	.984
		Cerebral palsy	-3.91	1.67	.069
	Down syndrome	Autism spectrum	-0.28	1.58	.984
		Cerebral palsy	-4.20	1.81	.074
	Cerebral palsy	Autism spectrum	3.91	1.67	.069
		Down syndrome	4.20	1.81	.074
Quality of Life	Autism spectrum	Down syndrome	0.50	3.96	.992
		Cerebral palsy	-3.31	4.19	.732
	Down syndrome	Autism spectrum	-0.50	3.96	.992
		Cerebral palsy	-3.81	4.55	.705
	Cerebral palsy	Autism spectrum	3.31	4.19	.732
		Down syndrome	3.81	4.55	.705

Overall, the results of this study revealed statistically significant differences in the levels of anxiety, depression, and perceived stress among parents of children with different developmental difficulties – autism, Down syndrome, and cerebral palsy.

Parents of children with cerebral palsy consistently reported higher levels of anxiety, depression, and stress, which aligns with previous findings indicating that the complexity of physical and health-related needs of these children may pose an additional psychological burden for parents (Raina et al., 2005; Brehaut et al., 2009).

Compared to parents of children with autism and Down syndrome, parents of children with cerebral palsy had the highest average level of depression (M = 19.04), confirming the findings of studies showing that parents of children with motor impairments are at increased risk of depression (Ketelaar et al., 2008). Moreover, although parents of children with autism

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have traditionally been considered a group under considerable stress (Hayes & Watson, 2013), in this study it was the parents of children with cerebral palsy who showed a higher level of psychological burden.

In terms of perceived stress, the highest result was again recorded among parents of children with cerebral palsy, which may be explained by the prolonged caregiving, medical interventions, and the need for constant supervision of the child. These findings are consistent with the study by Whittingham et al. (2013), which indicates that parents of children with complex physical needs are often exposed to chronic stress due to the lack of systemic support and exhausting daily routines.

Interestingly, however, this study did not identify a statistically significant difference in quality of life among parents, regardless of the type of difficulty the child had. This deviates from some previous findings which, for instance, showed that parents of children with autism often experience a lower quality of life compared to parents of children with Down syndrome (Lee et al., 2009). One possible explanation for this result is that parents, despite pronounced emotional difficulties, develop coping strategies that enable them to maintain a positive perception of their family life, especially when there is functional family support and acceptance of the situation (Dardas & Ahmad, 2014). Additionally, some authors, such as Hastings & Taunt (2002), have emphasized the importance of "positive perceptions of parenting," the idea that parents, despite challenges, can find meaning and satisfaction in caring for a child with difficulties, which could explain the relatively stable quality of life assessments in this sample.

CONCLUSION

The results of this study confirmed significant psychological differences among parents of children with different types of developmental difficulties. Statistically significantly higher levels of anxiety, depression, and perceived stress were identified in parents of children with cerebral palsy compared to parents of children with autism and Down syndrome. These findings confirm earlier knowledge that the complexity of caring for a child with motor impairments can have a strong impact on the mental health of parents. On the other hand, the study did not find statistically significant differences in the perception of overall quality of life among parents, regardless of the type of child's difficulty. This result implies that factors such as family support, adopted coping mechanisms, and the degree of acceptance of the situation may play a key role in preserving the subjective sense of life homeostasis. Based on the results obtained, the establishment of comprehensive support systems for parents of children with developmental difficulties is recommended, with a special focus on the early detection and treatment of symptoms of anxiety and depression. Psychological support should be tailored to the specific needs of each family, including both parents in the support programs. In addition to psychological assistance, it is essential to provide functional social and institutional support in order to reduce the overall burden of parental responsibilities. Further research in this area could shed additional light on risk factors and effective intervention approaches, thereby contributing to the improvement of quality of life and mental health among parents of children with disabilities.

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