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THE EFFECT OF STRESS ON THE QUALITY OF THE PARENTAL ROLE OF CHILDREN WITH AUTISM

UTICAJ STRESA NA KVALITET RODITELJSKE ULOGE DECE SA AUTIZMOM

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ABSTRACT

Parents finding out that their child has been diagnosed with autism is a great stress, which changes family dynamics and patterns of family life. That is, great concern and the need to provide everything necessary for the adequate development and functioning of these children in everyday conditions. All these changes directly affect the quality of life of these families. The aim of the research was to examine the impact of stress on the quality of the parental role of children with autism, i.e. the difficulties and importance of these families compared to parents of children from the typical population. 90 families participated in this study, 45 families with a child with autism and 45 families with children from the typical population. The age of children of both sexes is from seven to 10 years. Two measuring instruments were used to assess the quality of life. The research results showed that parents of children with autism face a high level of stress, lower satisfaction with the parental role (38.87±49.78), a higher level of parenting burden (40.38±45.33) and the lower importance of the parental role (2.53±52.31) compared to parents of children in the typical population.

Key words: autism, family, stress, quality of life.

SAŽETAK

Saznanje roditelja da je kod deteta dijagnostikovan autizam predstavlja veliki stres, koji menja porodičnu dinamiku i obrazce porodičnog života. Odnosno, velika briga i potreba da se obezbedi sve što je neophodno za adekvatan razvoj i funkcionisanje ove dece u svakodnevnim uslovima. Sve ove promene utiču dirktno na kvalitet života ovih porodica.

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Cilj istraživanja bio je ispitati uticaj stresa na kvalitet roditeljske uloge dece sa autizmom, odnosno, poteškoće i značaj ovih porodica u odnosu na roditelje dece tipične populacije. U ovoj studiji učestvovalo je 90 porodica, 45 porodica koje imaju dete sa autizmom i 45 porodica koje imaju decu tipične populacije. Uzrast dece oba pola je od sedme do 10 godine. Za procenu kvaliteta života korišćene su dva merna instrumenta. Rezultati istraživanja pokazali su da se roditelji dece sa autizmom suočavaju sa visokim nivoom stresa, nižim zadovoljstvom roditeljskom ulogom (38,87±49,78), višem nivou tereta roditeljstva (opterećenja roditeljstvom) (40,38±45,33) i nižem značaju roditeljske uloge (62,53±52,31) u donosu na roditelje dece tipične populacije.

Ključne reči: autizam, porodica, stres, kvalitet života.

INTRODUCTION

Autism is a general term used to describe complex developmental brain disorders known as Pervasive Developmental Disorders (PDD). It is a biological developmental disorder of the brain that is very complex in nature and manifestation, characterized by a triad of disorders: social interactions, communication and the presence of stereotyped patterns of behavior (APA 2013; Bunievac and Čauševac 2020). The prevalence of autism ranges from two to four per 10,000 or 15 to 20 per 20,000 population. It occurs more often in boys than in girls. It is considered that this increase is not apparent, but the frequency is actually increasing, and the reason is the change in diagnostic criteria and more precise diagnosis (Glumbić, 2009). Autism is a multietiological syndrome, that is, a group of related disorders with many different factors. It represents a combination of genetic disorders and a strong influence of external factors (Bunijevac and Čauševac 2020). Today, the prevailing opinion is that it is a polygenetic hereditary disease. In families where there is already a child with autism, the probability that other offspring will also have this disorder is 50% higher than in the typical population (Bolton et al. 1994). Although the heritability in autism is estimated to be high, the challenges in understanding the etiology of autism lie in the fact that genetic factors are heterogeneous, complex, and that the interaction between genes and the environment is still unclear. The clinical picture in children with autism is different, it depends on the symptoms, age and intellectual capacity, that is, it can vary during growing up (Bujas-Petković and Škrinjar 2010). These children lack social or emotional reciprocity. Due to the impairment of communication, there is a failure in developing peer relationships, a lack of spontaneous sharing of common enjoyment, interests or achievements (Firth and Dryer 2013). Communicative abnormality manifests itself in a variety of ways: delays in speech development, complete absence of speech, difficulty initiating or maintaining a conversation, difficulty understanding oral information, presence of echolalia, or stereotypical, repetitive or idiosyncratic language (Goldstein et al. 2012). About 40% of people with autism have some sensory impairment. Reactions to sensory stimuli can range from hypersensitivity to hyposensitivity. Sleep, eating disorders, anxiety, aggressive and autoaggressive behavior are common (Rawdon, 2012).

Family is a social phenomenon, a group of individuals connected by intimate ties within which interactions between members take place. Family relationships are based on closeness, cooperation and exchange, which can be motivated by different interests (Golden-Vukov, 1994; Tomanić, 2019). A healthy, functional family is one that can grow despite the difficulties it encounters. A healthy family has flexible boundaries, internal (between family members) and external (between family and society). Also, in healthy families, each member has his freedom to modify his decisions and value based on his life experience, development and family heritage. Contrary to the concept of functionality, we also distinguish the concept of dysfunctionality. The family can develop dysfunctionality at the level of the structure and at the level of the emotional process (Milojković et al. 1997). The parents' knowledge that they have a child with autism is a stressor that puts the whole family under special burdens or challenges for a long period of time (Milačić-Vidojković, 2008). Various studies have shown that many parents use the word "stressful" when describing life with their child who has autism (Uhlenberg and Mueller 2003; Pettit and Arsiwalla 2008). The stress experienced by parents of children with disabilities varies in intensity and affects the entire family negatively (Sullivan and Knutson 2000). Parents experience a great deal of psychological stress and disappointment because the child has not fulfilled their hopes and expectations, which are aimed at obtaining healthy offspring (Barnett et al. 2003). The concept of quality of life can be explained in several ways. It is most often defined as an individual experience of satisfaction with all aspects of life, physical, social and psychological well-being (Waters et al. 2005; Gojčeta et al. 2008; Araújo de Melo et al. 2012). Some researchers believe that this concept cannot be precisely defined, so authors from different fields approach the concept of quality of life from the perspective of their interests and research goals (Keith 2001; Stewart et al. 2001; Jarvholm et al. 2009). Not only is there disagreement among researchers about what quality of life is, but also what contributes to quality of life and what its outcomes are. That is, there is a tendency of some researchers to combine quality of life with other concepts. The most common example of this approach of combining different concepts is expressed through the tendency of researchers to sometimes combine or equate the concepts of happiness, well-being, health and living conditions with the concept of quality of life. However, in practice it is not easy to distinguish between these concepts. Taillefer et al. (2003) recognize three models of quality of life: conceptual model, conceptual framework and theoretical framework. The conceptual model determines the dimension and properties of the quality of life, the conceptual framework is a model that describes, explains and predicts the nature of the relationship between the elements or dimensions of the quality of life, while the theoretical model represents the most sophisticated type that includes the structure of the elements and explains their relationship within that theory. Quality of life can be defined as "harmony within man", but also "harmony between man and his world". This definition is one of the most notable, because it emphasizes not only well-being and satisfaction (harmony in the person himself), but also the relationship of the individual to the environment, which refers to the functional status and conditions of the environment (Rančić et al. 2009). The goal of the research was to examine the impact of stress on the quality of the parental role of children with autism, i.e. the importance and difficulties of these families in relation to parents of children of the typical population, which can be significant for educational work with the child and the implementation of expert recommendations.

MATERIALS AND METHODS

Sample of respondents

90 parents participated in the study, 45 parents of children with typical development and 45 parents of children with autism (Table 1). The age of the children whose parents participated in the research was from the first to the fourth grade of primary school, that is, from the seventh to the tenth year. Children with autism attended a regular school with an inclusive program.

Table 1. Structure of the sample according to gender

Variables	Mother		Father	
	N	%	N	%
Children with typical development	38	84.4%	7	15.6%
Children with autism	42	93.3%	3	6.7%

Before conducting the research, all respondents - parents were informed about the purpose of the research, that the obtained data will be used exclusively for research purposes and that the identity of the children and parents will be protected. After the meeting, the parents gave their written consent to participate in the research.

Research instruments

In this research, a subjective assessment of the quality of life of families of children with autism was carried out using Likert-type scales: the Parental Stress Scale (Berry, Jones 1995) and the Parent Satisfaction Scale (Martin et al. 1991). The Parental Stress Scale consists of 18 questions - five Likert-type choices (1-5), where respondents had the task of choosing the offered answer for each given question. In this way, they expressed their current opinion about the presence or absence of parental stress. That is, the obtained results indicated the amount of parental stress arising from the parent-child relationship and stress resulting from the child's behavior, not stress arising from other life roles and events. The Parent Satisfaction Scale includes three aspects: satisfaction with the parental role, the burden/difficulty of parenting and the importance of parenting. Each subscale contains 10 questions, (1-7), where respondents also had the opportunity to choose the offered answer. A higher score indicates a better level of parental satisfaction and a lower score indicates a worse level of parental satisfaction. Basic data on the respondents were obtained through a questionnaire.

Data processing methods

Descriptive statistics measures were used in the paper (measures of central tendency - arithmetic mean, median and dispersion measures - standard deviation, assessment of normality of distribution), non-parametric group comparison techniques were used - Mann-

Whitney test for independent samples, and correlation analysis - Spearman's coefficient correlations. The data are presented in tabular form. The software package SPSS ver. was used for statistical data processing. 20 (Statistical Package for the Social Sciences).

RESULTS AND DISCUSSION

In Table 2, by reviewing the results, there is a statistically significant difference in the level of parental stress, that is, parents of children with autism have a significantly higher level of stress compared to parents of children with typical development.

Table 2. Differences in parenting stress between parents of children with autism and parents of typically developing children

Group	M	SD	Mdn	average rang	Sum of ranks	Z	p
Parents of typically developing children	25.78	2.22	26.00	23.00	1035.0	-8.19	**.000**
Parents of children with autism	46.55	7.18	46.00	68.00	3060.0		

M- arithmetic mean; SD- standard deviation; Mdn- the median; Z - Zed-Z test; p- statistical significance.

A large number of studies indicate that parents of children with autism spectrum disorder face a high level of stress and emotional burnout compared to parents of typically developing children, children with other disabilities, and children with chronic diseases. The most common sources of stress are uncertainty regarding the outcome of the child's health condition, unusual demands for care associated with the specifics of developmental disabilities, unpredictability in children's needs, finances, frequent visits to doctors, negative attitudes of other people towards these children, difficulties in forming the parenting style, as well as poor cooperation with institutions that provide support (Baker et al. 2003; Howe 2006; Mihić et al. 2016).

A large number of parents are burdened by their child's diagnosis, which increases the level of stress, guilt, and concern for their future (Papadopoulos 2021). High stress in parents of children with autism has been shown to be a significant predictor of reduced quality of life compared to parents of typically developing children (Wiley, Renk 2007; López et al. 2008; Hoffman et al. 2009; Varghese, Venkatesen 2013).

Examining parental satisfaction between parents of children with typical development and parents of children with autism, it was observed that there is a statistically significant difference in all three investigated subscales of parental satisfaction (Table 3). Parents of children with autism report significantly lower satisfaction with the parental role (8.87±49.78), higher level of parental role burden (40.38±45.33) and lower importance of the parental role compared to parents of children with typical development (62.53±52.31). There is also a statistically significant difference in the total score of parental satisfaction.

Table 3. Differences in parental satisfaction between parents of typically developing children and parents of children with autism

	Group	M	SD	Mdn	Average rang	Sum of ranks	Z	p
Parental satisfaction	Parents of children with typical development	49.78	.420	50	65.89	2965.0	-7.64	.000
	Parents of children with autism	38.87	7.399	39	25.11	1130.0		
The burden of parenthood	Parents of children with typial development	40.38	.834	40	28.44	1280.0	-6.31	.000
	Parents of children with autism	45.87	4.507	45	62.56	2815.0		
The meaning of parenthood	Parents of children with typical development	62.53	.7568	63	66.96	3013.0	-7.97	.000
	Parents of children with autism	52.31	7.960	55	24.04	1082.0		
Total	Parents of children with typical development	161.35	1.147	162	60.03	2701.5	-5.30	.000
	Parents of children with autism	147.09	14.962	149	30.97	1393.5		

M-arithmetic mean; SD- standard deviation; Mdn- the median;; Z - Zed-Z test; p- statistical significance.

By assessing parental satisfaction, we determined that parents of children with autism have much lower satisfaction than parents of children from the typical population. The obtained results can be described as the impossibility of fulfilling all the desired achievements that the parental role brings, due to the disorders that the child has. Parents often experience failure in their wishes and goals, which is why the burden of the parental role becomes greater, which is in line with the results of other research (Delale 2011). The level of parental satisfaction may be related to the structure, manner and level of information communicated. Parents of children with autism face numerous obstacles and difficulties when raising and raising children, they have a greater burden of the parental role than the satisfactions and importance of it. Many studies have found high levels of parenting stress in families of children with disabilities (Baker et al. 2003; Howe 2006). Parents of children without developmental disabilities do not feel the burden of parenthood, are satisfied with the parental role and attach much more importance to it than parents who have a child with autism, which has been confirmed in other studies (Baker et al. 2003; Howe 2006; Markie-Dadds, Sanders 2006; Mihić et al. 2016; Gogou and Kolios 2017).

Correlation analysis examined the relationship between parental stress and parental satisfaction in the experimental and control groups (Table 4). The results show that there is a statistically significant negative relationship between the importance of the parental role and parental stress, that is, parents of children with autism who perceive the parental role as more important report lower levels of parental stress. However, no statistically significant correlation was obtained between parental stress and the total score on the parental satisfaction scale, as well as on its subscales - satisfaction with parenthood and the burden of the parental role.

Table 4. Correlation between parental satisfaction and parental stress

Parental pleasure	Parental stress	
	Spirman's coefficient– rank of correlation	p
Parental satisfaction	-.095	.533
The burden of parenthood	-,.39	.362
The importance of parenthood	-.481	.001
A pleasure -total	-.146	.339

The results of our research point to a greater need for the development of intervention programs that would reduce parental stress and increase satisfaction with the parental role among parents of children with autism. By changing the experience of parenting, the behavior of the parents towards the child changes, which improves the quality of the parent-child relationship, and can positively affect the child's further development. Support for the development of parenting skills, while respecting the specific functioning of children with autism, certainly goes along with this, and the result of such support gives the best results when it is provided on time, within the framework of early intervention programs for children. Professional support affects the quality of family life through the adequacy of service services and partnership with the family (Bunijevac and Čauševac 2020).

CONCLUSION

Autism is a topic of interest for many scientists from various scientific fields, which will hopefully result in some standard procedures to help these children and their parents in the near future. Research that has recently begun to deal with this topic increasingly points to support for these families. Timely, comprehensive and integrated cooperation of experts of various profiles is necessary who would guide and educate parents, provide support, guidelines and knowledge in mastering everything needed on the path of raising a child with autism, which would make the role of parents much easier. With adequate education, parents should feel fulfilled, that they are active participants in the development of their child's abilities and potential, which, due to the diagnosis being in the foreground, can fall into the shadows and remain unused.

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