

Autistic children and parental stress

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Abstract

Introduction: Raising a child with autism is a major challenge both physically and emotionally, it is one of the most difficult things a parent has to do.

The purpose of the study is to analyze the impact of parental stress on children diagnosed with autism aged 2–12 years, based on the experiences, experiences and perspectives of parents.

Methodology: population were 143 parents from the Prishtina region, divided into two groups: parents with children with autism and with children with no autism.

Results: there were 83 parents with autistic children and 60 parents who did not have autistic children. Children are divided into two age groups: 2 - 6 years (119 or 83.2%), and 7 - 12 years (24 or 16.8%). 78 (54.5%) parents resulted in moderate stress, 49 (34.2%) in high stress and 3 (2.1%) in very high stress.

Conclusions: parents of children with autism experience higher levels of stress, so more services should be provided to parents, because services are mainly focused on children and not parents. Organizing regular meetings with parents, as well as their training by professionals in the field.

Keywords: autism, children, parents, stress, care, professionals.

1. Introduction

Raising a child with autism is a big challenge both physically and emotionally, it is one of the most difficult things parents have to do. Several studies have reported a range of growing psychological distress in parents who have children with autism such as: anxiety, depression, stress and its components, also reducing family cohesion and increasing somatic complaints (Higgins et al , 2005).

Parents of children with autism spectrum disorders are known to experience more stress than parents who have children in normal condition. A study conducted by Rivard (2014) on the presence of stress in the parents of 118 children with autism has found that at the beginning of the intervention higher levels of stress were encountered in fathers than mothers. Correlations showed that stress levels in both parents were related to the child's age, IQ, severity of autism symptoms, and adaptive behaviors. The stress from the father was not the same as the stress the mother was experiencing, he was influenced by the severity of the symptoms and the gender of the child.

Another study conducted in Denmark, based on the records of the Psychiatric Research Center, from January 1995 to the end of December 2006, found that children born to older parents were more likely to develop autism than those born to young

parents 25-29 years old. Children, who's father was of an older age were particularly more predisposed to autism than those who had an older mother (John J. McGrath et al 2014)

Dardas & Ahmad (2013) in their study on the quality of life of parents with children with autism, based on interviews of 184 parents found that there were no differences between the two parents in terms of their physical, psychological, social and environmental condition but both parents have shown that they have problems with coping strategies and poor quality of life.

McStay and colleagues (2013) studied the difference between general stress, with the perception that they fail to perform their parental role as well as the role they play in influencing child variables such as age, gender, depth of symptoms, and problems in behavior. This study has found that the behavioral symptoms of the child have a major impact on the demands on parents as well as on their stress level.

A study in the U.S. A researched the relationships between child characteristics, diagnostic severity and problematic behaviors, parental stress, relationship quality, and depressive symptoms in 70 mothers of young children with autism.

The study hypothesized that relationship quality and parental stress should be associated with maternal depression beyond the contributions of child characteristics. Multiple regression analysis revealed a major stress effect in parents who have children with problematic behaviors and autism severity. An important interaction emerged, between the quality of relationships with depressed parental stress. The results suggest that the link between child problematic behaviors and maternal depression should be considered along with other measures around marriage and family stress. The quality of the relationship with the child and stress are important factors that should be explicitly considered, the intervention should be immediate in young children with autism disorders.

2. Literature review

The term 'autism' was first used in 1913 by psychiatrist Eugen Bleuler, to describe an aspect of schizophrenia when an individual loses contact with the reality and environment that surrounds them (Sicile-Kira, 2004; Trevarthen et al., 1996).

Autism is a disorder that is manifested in early childhood, usually around the age of 3 years. The first cases of autistic children were described about 200 years ago by Jean Marc Gaspard Itard and John Haslam. The description they gave to Victor, the child found in the forest "wild child" coincides with the characteristics of Autism syndrome that is diagnosed today. However autism was discussed as a distinct psychopathological form only in the 1940s by Leo Kanner (1943) and Hans Asperger (1944).

In 1943, it was Leo Kanner, a psychiatrist, who through a study described the cases of eleven children with characteristics that today we know by the term autism. Kanner described these cases of children as having difficulty in communication and social interactions, unusual behaviors, and developing special interests (Chawarska et al., 2008; Fein & Dunn, 2007; Feinstein, 2010; Jordan, 1999; Ozonof, Dawson & McPartland, 2002; Sicile-Kira, 2003; Trevarthen et al., 1996).

Statistics provide data that show an alarming increase in the number of children affected by autism disorders. According to statistics, WHO and autism rates in 2022 it results that: approximately 1 in 100 children worldwide has autism; in most cases, the symptoms of autism become apparent before the age of 5 and persist into adulthood; approximately 1.8% of children in America have a diagnosis of autism, a rate that has more than doubled in the last two decades; autism is a common developmental condition, affecting approximately 1 in 44 children in the United States; Boys are more likely to be diagnosed with autism than girls (3.7% of boys versus 9% of girls); most diagnoses are made after age 4, although a diagnosis of Autism Spectrum Disorder (SAD) can be made reliably by age 2; parents who have a child diagnosed with autism have a 2% - 18% chance of having a second child with autism; children born to older parents have a higher risk of autism; autism has been reported to occur in all races, ethnicities, and socioeconomic groups; medical expenses for an individual with autism are on average 4.1 to 6.2 times higher than for an individual without autism; while there is no cure for autism, early intervention services can help significantly reduce lifelong health care costs. It is estimated that the living expenses for an autistic person can go up to 2 million \$.

People with autism are at a much higher risk of being: approximately 1/3 of people with autism spectrum disorder are nonverbal; almost 2/3 of children with ASD between the ages of 6 and 15 are bullied by their peers; about 28% of 8-year-olds with autism exhibit self-injurious behaviors, such as hitting their head on hard surfaces, biting their arms, or scratching their skin; the leading cause of death in children with autism is suffocation; over 30% of people with ASD also have a common intellectual disability; approximately 30% - 60% of children with ASD are also diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), over 50% of children with ASD experience a chronic sleep disorder; about 7% of children and 26% of adults with autism experience depression; up to 1/3 of people with ASD also have epilepsy; between 4% and 35% of adults with autism are also diagnosed with schizophrenia, compared to just over 1% of the regular population; among children 2 to 5 years old with autism, 32% are overweight and 16% are obese.

According to Siegel (2003), the reformulation of diagnostic criteria has made them more rigorous. Another factor is thought to be the increase of expertise of professionals who deal with the diagnosis of autism. The influential factor is also thought to be the greater awareness of parents and society as a whole about this problem (Beytien, 2011).

According to the Diagnostic Manual for Mental Illness (DSM), there are several criteria that a child must meet to be diagnosed with autism: A) Persistent deficits in communication and social interaction in different contexts (Deficit in social-emotional reciprocity; Deficiency in non-verbal communicative behaviors to use in social interactions; Developmental deficits, in understanding relationships with others.) and B) Repetitive, rigid behavior (motor movements, words or use of objects repeatedly, insistence on doing things) alike, rituals, abnormal connections to different objects, increased sensitivity to temperature, textile materials, noise or touch of different objects).

The causes of autism are said to be unknown to this day. According to researchers

(Chawarska et al., 2008; Fein & Dunn, 2007; Siegel, 2003; Wiseman, 2009) it is thought that some of the main causes of autism may be genetic, neurological, pregnancy development, environmental, vaccination, psychological.

At present, autism is incurable but treatable and children can make progress in their independence and their lives (Chawarska et al., 2008). Early treatment is very important for the future and life of children with autism and their families (Kika, 2013). Individuals with autism can benefit from different varieties and types of interventions (Cotugno, 2009; Volkmar & Wiesner 2009). Therapies can be successful for children with autism in learning skills, and a number of these children may change over time (Richman, 2001).

Many studies have shown that parents of children with autism report more stress, anxiety and depressive symptoms compared to parents who have children not diagnosed with autism (Dyson, 2000; Fisman & Boyd). High stress experiences in parents with children of autism have major consequences for their health, their well-being, their interaction with the child, and family life. It has been demonstrated that parents of these children have poorer health and lower psychological well-being, than parents of children with other disorders (e.g. Abbeduto et al., 2004).

It is important to note that increasing levels of parental stress can have a significant negative impact on parenting skills and children's outcomes (Anthony Et al., 2005; Bonds, Gondoli, Sturge - Apple, & Salem, 2002; Hastings & Beck, 2004). Due to high levels of parental stress and its potential impact on child outcome (Anthony et al., 2005; Bonds, Gondoli, Sturge-Apple & Salem, 2002; Hastings & Beck, 2004), clinicians should identify ways with which they can help reduce stress. Previous research shows that social support can help reduce parental stress (Benson, 2006; Boyd, 2002; Siman Tov & Kaniel, 2011), although the differentiated influence of different forms of social support is unclear.

Many study results show that parents with children with autism use more strategies that involve distancing themselves from parents with children who are not diagnosed with autism and they are less likely to choose strategies that include self-control, social support, and problem solving (Sivberg et al., 2002).

In terms of problematic behaviors, fathers are less affected, while mothers are more affected (Davis & Carter, 2008). According to various findings, it is mothers who receive the most criticism or remarks from other people, unlike fathers (Gray, 2002b). In addition to the studies conducted on this relationship, there are very few differences between mothers and fathers with children with autism, based on their stressful experiences. Research shows that mothers generally experience more stress and anxiety, having these mental states more persistent, compared to fathers.

According to Largo (2000) children's illnesses can cause great concern to parents. The same can be said for the diagnosis of autism. According to researchers, the experiences of parents from diagnosing a child with autism are difficult (Ariel & Naseef, 2006; Chawarska et al., 2008; Fein & Dunn, 2007; Powers, 2000; Siegel, 1996).

Whatever the news formulated, it usually brings a devastating shock to parents who have struggled for months against anxiety and bad foreboding. For many parents this is such a stabbing pain that even in the years that follow, the memory automatically causes tears. Indeed, very few things are more bitter than receiving the news that

a child has autism (Powers, 2000). According to Siegel (1996) the stages of pain that parents go through after diagnosing a child with autism are the same as those experienced with the death of a loved one family member.

1. Purpose

The aim of the study is to analyze the impact of parental stress on children diagnosed with autism aged 2 - 12 years, based on the experiences and perspectives of parents. The study analyzes the link between functional disorder of autism and the stress that this condition creates in parents of this category of children. The general objectives are: to analyze the link between the functional disorder of autism and the stress that this condition creates in the parents of this category of children; identifying and exploring the experiences and attitudes of parents who have children with autism: identifying: exploring and analyzing the services provided to the family and its members and their needs, based on the experiences and perspectives of the parents.

2. Methodology

The population of this study was 150 parents, but for subjective reasons 7 of these parents did not participate, which means a total of 143 parents participated in the study, mainly from the Prishtina region. Parents represented two groups: Gr.1 - Parents with children with autism and Gr.2 - Parents with children without any problems.

The demographic data questionnaire, questionnaire 'Parenting Stress Index' ('PSI-SF' Parenting Stress Index - Short Form) as well as the questionnaire 'Parenting Sense of Competence' ['PSCO' 'Parenting Sense of Competence' (Johnston & Mash, 1989)], were used to conduct the study who were completed and self-reported by parents in both groups.

For the realization of the research, we informed and received the consent to cooperate with the Association of Parents of Children with Autism in Prishtina as well as with parents who have children with autism in the attached classes in the primary school "Ismail Qemali" in Prishtina and in the special school "Përparimi" in Prishtina. The realization took place during the period November 2021 - May 2022.

The complete data were collected from all questionnaires, initially analyzed through descriptive analysis, through which the basic statistical parameters were presented and the normal distribution of the obtained data was reflected.

3. Results

This study included 143 parents who had a child with autism $N = 83$ (58%) and a group of parents from the community who did not have a sick child $N = 60$ (42%). The average age of the parents taken in this study was $M = 41.1$ years ($DS = 8.2$). Parents from both groups had no differences in age distribution.

Table No.1 - Descriptive statistics for parent age

Parent group	N	Minimum	Maximum	Average	DS
1.00 With the autistic child	83	25.0	55.0	40.3	7.5
2.00 From the community	60	26.0	60.0	41.9	9.2

The average age of children taken in this research was $M = 4.3$ years, $DS = 3.0$. The group of children with autism ($M = 4.3$ years old, $DS = 2.7$) while the group from the community ($M = 5.6$ years old, $DS = 3.3$). For the purpose of data analysis, children were grouped into two groups: Gr. 1 - children from 2 to 6 years (119 or 83.2%), and Gr. 2 - children from 7 to 12 years old (24 or 16.8%).

Table 2 shows that there were significant differences in the cross-tabulation of age with gender.

The children presented in table no.2 are: 79 (55.2%) male and 64 (44.8%) female. But when the distribution of gender within the two groups is analyzed, we see that children with autism are re-introduced in $N = 49$ (59%) of males and $N = 34$ (41%) of females. While the group from the community had $N = 30$ (50%) of males and $N = 30$ (50%) of females. There were no significant differences in the distribution of groups by gender. This study has tried to include an equal number of children in relation to gender in the group of children with autism, but it is known that male children are more predisposed to have autism.

Table no.2 - Age of the child by gender

		Male	Female	Total
Categorized age	2-6 years old	61	58	119
	7-12 years old	18	6	24
Total: Fisher exact test ($\chi^2(1) = 4.5$ p = .043).		79	64	143

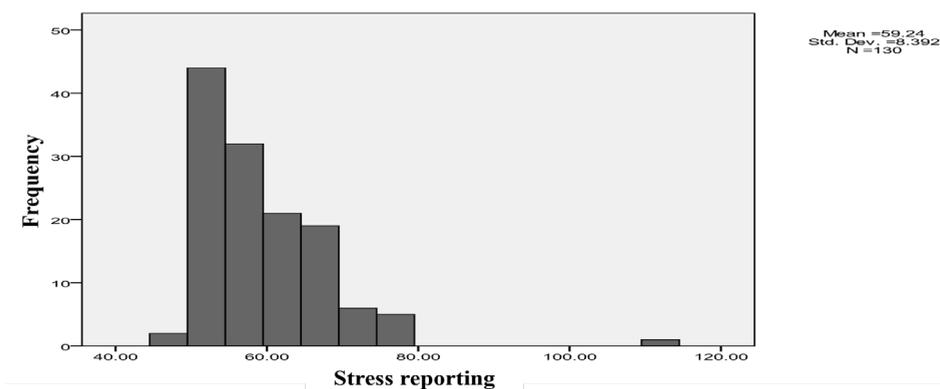
When it comes to socio-economic status, participants were asked about their perception in relation to income, how they categorize their economic situation. Most of the participants as seen in table no.3, come from families with average economic status $N = 121$ (84.6%), followed by those with poor economic status $N = 17$ (11.9%). Only 5 (3.5%) parents reported very good economic situation. When the economic status data were cross-tabulated with the groups involved we found that 17 children who come from a bad economic situation were represented by the group of children suffering from autism. This study has found that children who are in the most difficult economic situation are those who are represented by children suffering from autism. The difficult economic situation can be explained not only in income, but at the same time this disorder, being quite costly in treatment, deepens the economic problems even more. Parents who have children with autism not only have problems in the emotional realm, but also have the inability to afford the cost of effective treatment

for their child. A problem identified during their interview has been the use of speculators who promote new ways of treatment which are very costly. This has had a tremendous impact on increasing anxiety and at the same time increasing the sense of guilt that they are unable to do what a parent is expected to do for their child

Table no.3 - Cross-tabulation of income with groups involved

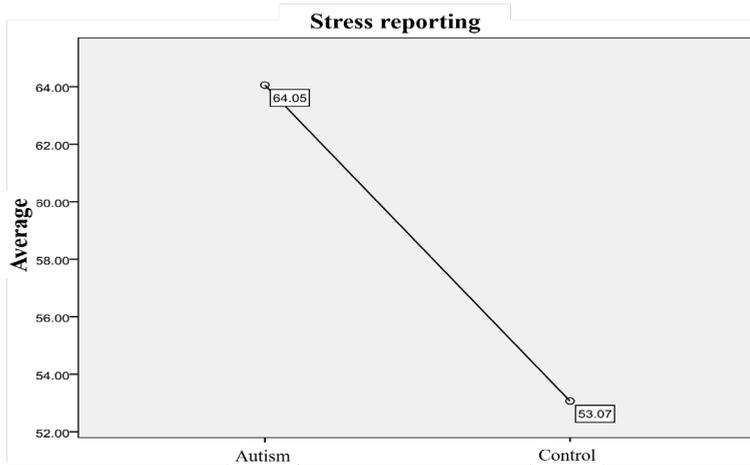
		Group				Total	
		Children with autism		Community			
		N	%	N	%	N	%
Economic situation	Very good	5	3.5	0	0	5	3.5
	Average	61	42.6	60	42	121	84.6
	Bad	17	11.9	0	0	17	11.9

In this study was measured the level of stress reported by parents with children with autism, as well as by parents with children without autism



Graph no.1 - Stress reporting

Graph no.1 shows the stress distribution of the parents involved in the research (M = 59.4, DS = 8.3). There was no parent from either group who did not report stress on the child’s growth. The highest percentage is occupied by parents with moderate stress with 54.5% or 78 of the respondents, followed by 34.2% or 49 of the parents who reported high stress. Only 3 (2.1%) parents reported very high stress.



Graph No. 2 - Stress Reporting (Autism vs. Control)

T test analysis shows that there are significant differences between the two groups included in this study ($t(1) = 9.7, p = .001$). Parents of children with autism reported higher average of stress ($M = 64.1, DS = 8.1$) compared to parents in the control group ($M = 53.0, DS = 2.8$)

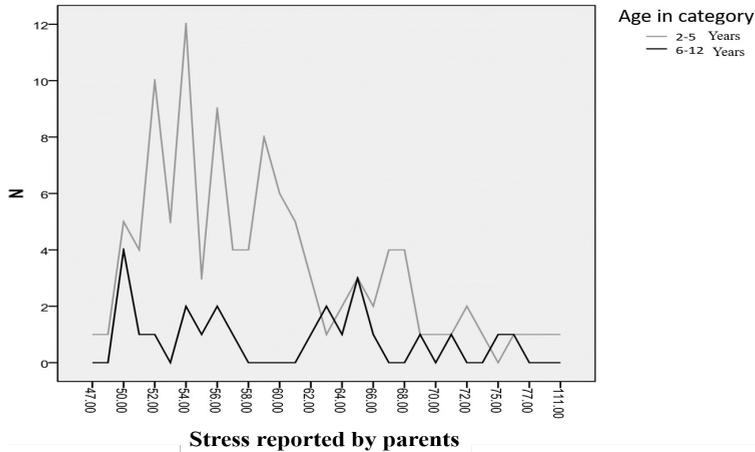
In table no.4 and graph no.3 we see that the parents of the control group reported having moderate stress in 98.2% or 56 of them, while only 1 parent reported high stress. While the parents of the group of children with autism reported high stress in 65.8% or 48 of them, and 3 parents reported very high stress or 4.1%. Parents in this group reported 30.1% or 22 having moderate stress.

Children with autism present increased demands on the family due to the disorder they have, in particular these children have inappropriate social behaviors by reacting aggressively to themselves and others (American Psychiatric Association, 1994). It has been found that parents of children with autism experience more stress than parents of children with intellectual disabilities or Down Syndrome because children with autism cannot express their wants and needs in a way that others can understand. Behavioral problems that accompany autism can be a major challenge for parents. Frustration leads children to aggression and harmful behavior of themselves and often others, becoming a preoccupation for the safety of the child but also of the parents (Holroyd & McArthur 1976).

Table no.4 - Cross-tabulated stress with groups

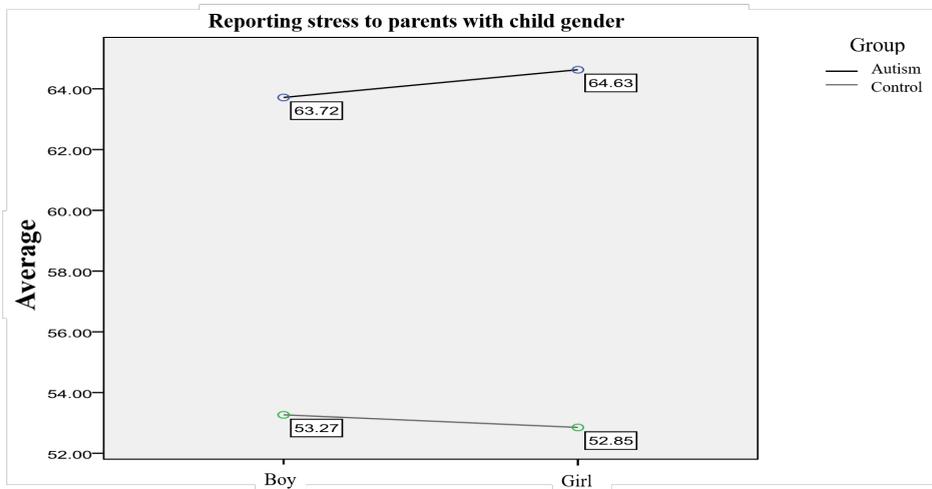
		Groups		Total
		Autism	Control	
Stress	Average	22 (30.1%)	56 (98.2%)	78 (60.0%)
	High	48 (65.8%)	1 (1.8%)	49 (37.7%)
	Very high	3 (4.1%)	0 (0%)	3 (2.3%)
Total		73 (30.1%)	57 (30.1%)	130 (100%)

According to the ANOVA multivariate analysis, the age of the child was found to have an impact on the onset of stress. Parents of children aged 2-6 years reported higher levels of stress than parents who had older children $F(12)=1.97, p=.032$.

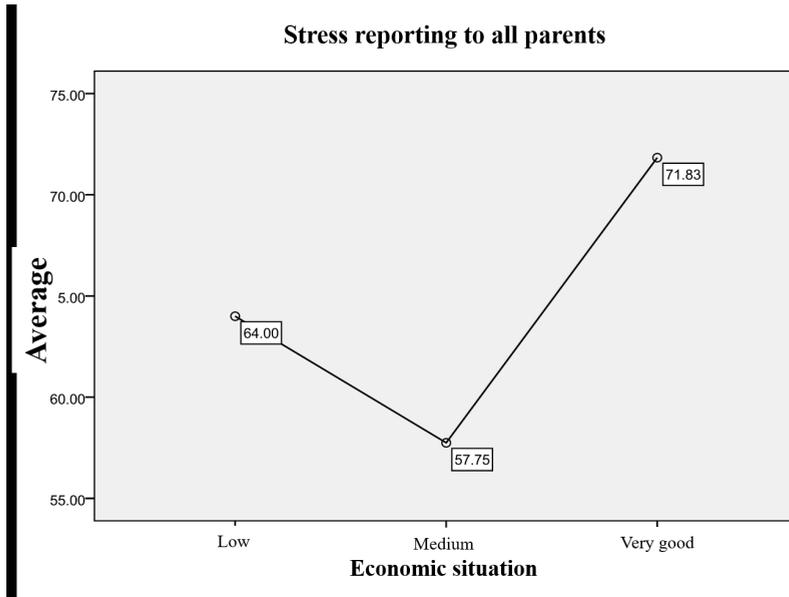


Graph no.3 – Stress reported by parents

The gender of the child was not found to have any influence on the occurrence of stress in the parents. The T Test was performed to compare the reporting of the parental stress level in relation to the gender of the child. T-test data are reported in graphs no.4 and no.5. Given that the significant value (p) in our example of 0.571., is above 0.05, we can say that there is no significant difference in the mean of stress reporting in relation to the gender of the child within the two groups.



Graph no.4 – Reportong stress to parents with child gender



Graph no.5 – Stress reporting to all participants

To compare the means of these three groups, the Kruskal-Wallis test was used (test not pre-metric) and significant differences were found between the groups ($\chi^2(2) = 22.4$ $p = .001$), the group of parents with incomes lower than average have reported higher averages than those with median incomes.

Graph no.6 - Stress reporting by parental age

Graph no.6 reported stress related to the categorized age of the parents in both groups included in the research. As can be seen, the age of the parent was not found as an important variable for reporting stress, as the distribution of the average of stress in the parents of the control group 25-30 years ($M = 53.3$, $DS = 1.6$) did not differ significantly from that. of parents 31 - 60 years old ($M = 53.1$, $DS = 3.1$). The same trend is seen for the distribution of the average of stress in the parents of the group of children with autism 25-30 years ($M = 64.8$, $DS = 8.7$) versus the age group 31 - 60 years ($M = 64.1$, $DS = 8.1$).

Table no.5 - Stress reporting by parental age

	Reported stress
Pearson coefficients	
(r)	-.070
P	.428
N	130

Meanwhile the age of the parent as a constant variable is correlated with stress reporting, and we found a negative correlation, meaning that the older the parent experiences the less stress, the younger the parent the more stress they experience. This correlation has not reached significance.

4. Conclusions

Given that this study is built on the basis of two hypotheses: Hypothesis 1: There are differences in the level of stress experienced by parents who have children diagnosed with autism disorder and parents of children with typical development; and Hypothesis 2: *Parents who have children diagnosed with autism disorder do not differ from each other in the level of stress experienced*; from the data analysis it results that the first hypothesis was proved, while the second hypothesis was not proved. Based on the findings, analysis of the results and the above discussion, we conclude that: parents of children with autism experience a moderate and high level of stress, unlike parents of children who are not attacked; the comparison of the two groups shows that parents of children with autism experience higher levels of stress than parents of children with normal development; parent's age as a constant variable is correlated with stress reporting, and we found a negative correlation, meaning that the older the parent experiences the less stress, the younger the parent experiences more stress. Finally, based on the results and conclusions of the study, it is proposed: to provide more services to parents, because services are mainly focused on children and not on parents and families; greater support and assistance from various professionals in information and counseling; involvement in treatment sessions not only of children with autism, but also of parents; providing services not only in institutions, but also with families; arranging regular meetings with parents, as well as their training by professionals in the field; creating appropriate environments to enable recreational and fun activities for parents and their children; to present / offer a combined help, firstly to alleviate the symptoms of stress and secondly training to improve behavioral skills.

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