

# The Evaluation of Family Quality of Life of Children with Autism Spectrum Disorder and Attention Deficit Hyperactive Disorder

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## Abstract

The Quality of Life (QoL) represents a dimension of the overall status and of the wellbeing that might be influenced by various factors. Researchers suggest that the parents of children with disabilities may be more vulnerable in developing physical or mental issues and that these families have a lower quality of life. Primary objective of the study was to evaluate the QoL of families with Autism Spectrum Disorder (ASD) children as compared with that of families with Attention Deficit Hyperactive Disorder (ADHD) children. The data were collected from 65 children with age ranging between 2 and 14 years, diagnosed with ASD and 49 children diagnosed with ADHD. The Family Quality of Life Survey (FQoL) was used to evaluate the family QoL. The multidimensional model of quality of life explains 48% of the variance of the global evaluation of the family's quality of life, proportion statistically significant ( $F(9, 103) = 12.71$   $p < 0.01$ ). Under statistical control of other factors the most important predictors remain family ( $\beta = 0.43$ ,  $p < 0.001$ ), support from others ( $\beta = -0.26$ ,  $p < 0.001$ ), career ( $\beta = 0.23$ ,  $p < 0.001$ ) and financial status ( $\beta = 0.15$ ,  $p = 0.04$ ). Parents of children from the ADHD sample believe that family relationships are less important for the family quality of life, have fewer opportunities to improve these relations, a lower initiative which can derive also from the reduced importance they place on this domain.

**Keywords:** Autism; Attention Deficit Hyperactive Disorder (ADHD); Family; Quality of Life (QoL).

## Introduction

The Quality of Life (QoL) represents a dimension of the overall status and wellbeing that might be influenced by various factors. It is a measure that includes multiple functional domains and it is increasingly recognized as a construct that is required in developmental disorders studies. Researchers suggest that the parents of children with disabilities may be more vulnerable in developing physical or mental issues [1,2] and that these families have a lower QoL. Although it is well known that a child with disabilities has a significant impact on his family, a low number of

studies on families with children diagnosed with ASD have been conducted [3,4]. The majority of studies that investigated the QoL of children with autism and their families enrolled a small number of patients, but suggested that these families have a high level of family distress and much more problems than the families with children with other cognitive or medical disorders. Although both ASD and ADHD are developmental neuropsychiatric disorders and are diagnosed in childhood, a lot of studies evaluated the QoL and concerns of the parents of ADHD children, but very few studied ASD or compared the two disorders.

In a 2008 study, Lee et al. evaluated the QoL and concerns of parents with ASD children using as a control group children with ADHD and a subgroup of children with typical development [5]. The study used the data from a national poll (National Survey of Children's Health – NSCH, sponsored by Maternal and Child Health Bureau, US Health Resources and Services Administration and Centers for Disease Control and Prevention's National Center for Health Statistics). The evaluated domains were: social interactions, family activities, the level of experienced difficulties, school performance, the independence and concerns of the parents regarding the child QoL. The study enrolled 483 children with autism, 6319 with ADHD and 58953 children without developmental disorders. The families of children with autism reported significant higher difficulties as compared with those of children with ADHD or healthy children, a smaller rate of participation in religious services, and a higher risk of one parent giving up work for child care. The parents of children with autism declared that they have serious concerns regarding the wellbeing of their children, especially regarding learning disabilities and collectivity acceptance. The parents of children with ADHD had similar concerns, but at a lower rate [5].

The aim of this study was to assess quality of life of the families of the children diagnosed with ASD, compared with families of the children diagnosed with ADHD and to identify the domains that primarily affect it.

## Material and Method

We conducted a clinical, analytic, observational, cross-sectional study.

### *Selection and Description of Participants*

The data were collected from 65 children with age ranging between 2 and 14 years, diagnosed with ASD and 49 children diagnosed with ADHD, children being diagnosed according to DSM IV-TR and ICD-10 international diagnosis criteria. For all the children enrolled in the study, we obtained from the family the agreement of using the medical data, also respecting the confidentiality of the subjects. The exclusion criteria were: child with a known medical condition (cardiac or pulmonary); accident or major distress in the last 6 months that can significantly affect the family QoL; and children in foster care.

### *Instruments*

Family Quality of Life Survey (FQoL) was used to evaluate the family QoL. FQoL is a specially designed instrument to evaluate the QoL of the families that include one or more members with intellectual or developmental disability. The FQoL has more sections: first section includes the description of the family members and the following nine observe specific domains of family life (health care, financial welfare, family interactions, others support, assistance from organizations providing services, influence of values, career, free time and recreational activities, integration in community life). The final section is designed for overall impressions regarding the family QoL.

### *Statistics*

The data were introduced in a SPSS v. 17 databases and analyzed with adequate statistical methods. The satisfaction regarding the QoL of families with ASD children was analyzed as compared to that of ADHD children, on the nine domains of FQoL. A univariate statistical analysis was used for the description of the studied population and the FQoL collected data. A

bivariate statistical analysis (Pearson correlation, t test for independent samples) was used to identify the significant associations between the groups. A linear multiple regression analysis was used to analyze the independent contribution of each factor of FQoL to overall satisfaction regarding the QoL. A two-tailed statistical significance level was set at  $p < 0.05$  for all analyses.

## **Results**

### *Sample Description*

114 subjects were enrolled in the study, with age ranging between 2 and 14 years, with a mean of 6.95 years and a standard deviation 2.67 years (95% CI: 6.45-7.45). For the ASD children group the mean age was 6.46 years, with a standard deviation of 2.17 years, and for the ADHD group the mean of 7.61 years, with a standard deviation of 3.13 years. Regarding the gender distribution, the sample included 84 boys (73.7%) and 30 girls (26.3%), with 95% CI: 1.18-1.35. Among these, 65 children (57%) were diagnosed with ASD and 49 with ADHD (43%), with 95% CI: 1.34-1.52. Regarding the integration in collectivity, 43 children were enrolled in kinder garden (37.7%), 11 in special kinder gardens (9.6%), 40 in school (35.1%), 6 (5.3%) in special schools, while 14 children (12.3%) were not enrolled in any form of collectivity (95% CI: 2.19-2.70).

After psychological evaluations, from the total of 114 children, 54 had a proper developmental level (15 with ASD and 39 with ADHD), 44 children with ASD and 5 with ADHD had delay in acquisitions on all aspects (cognitive, language, independence, communication), 2 children from the ADHD sample had cognitive retardation and 9 children presented only delay in language acquisition (6 with ASD and 3 with ADHD). The majority of ASD children benefit from a form of psychotherapy: behavioral psychotherapy – 57 patients, behavioral-cognitive psychotherapy – 3; without therapy – 5 patients, and considering the mean age of this sample, most of them benefit from behavioral psychotherapy. Regarding the ADHD children group, only half of them benefit from a form of psychotherapy: behavioral psychotherapy – 19 patients, behavioral-cognitive psychotherapy – 3; other therapies – 2, without psychotherapy – 25 patients). Out of the 114 participants in the study, 32 (28%) were from a rural environment and 82 (72%) from an urban environment (95% CI: 2.30-2.74), 31 coming from major urban centers. In both groups a higher number of parents had only medium education level (57%). In the ASD group – 55 parents were married, 9 divorced and 1 separated, and in ADHD group – 40 parents were married, 3 divorced and 6 separated. The family functionality is defined in general by the relationships and interactions among family members. A high level of cohesion and adaptability of the family has been demonstrated to be protective against potential negative impact of caring for an ASD child. Regarding professional status of the parents, 96 were employed, 1 unemployed and 17 home makers. In the ASD group 58 were employed, 1 unemployed and 6 home maker and in the ADHD group – 38 parents were employed and 11 home makers.

### *Comparison of Satisfaction Regarding the Quality of Family Life between the ASD and ADHD*

To compare the QoL of the families with children diagnosed with ASD versus those with children diagnosed with ADHD, we used the t test for independent samples. The statistical analysis showed the lack of a statistically significant difference ( $p > 0.05$ ) in the following aspects of family QoL: health satisfaction, financial satisfaction, satisfaction regarding the support from others, satisfaction with the support from services, satisfaction related to values, satisfaction related to career, satisfaction of leisure, and satisfaction related to the community.

The satisfaction related to family ( $t(112)=1.94$   $p=0.054$ ) was the only measure of FQoL where a difference close to the level of statistical significance was observed. Similar results were obtained for the global evaluation of family quality of life ( $t(112)=1.96$   $p=0.052$ ). No statistically significant difference was observed between the two groups with respect to global satisfaction with the family quality of life ( $t(112)=-0.01$   $p>0.05$ ). When comparing the two diagnostic categories and the six basic concepts for the theoretical construction of the instrument, statistically significant differences were observed for: the domain of family relations for the categories importance ( $t(72.22)=2.41$

p=0.018), opportunities (t(94.34)=2.22 p=0.028), initiative (t(112)=3.47 p=0.001), accomplishments (t(112)=3.30 p=0.001) and for the support from services domain, regarding the category importance (t(70.82)=2.61 p=0.011) and initiative (t(112)=2.16 p=0.032). For the values influence domain, a statistically significant difference between the two categories of diagnosis was observed for the degree in which the religious/cultural community is helping them to cope and to accept the child's disability (t(112)=2.11 p=0.036).

In the next step, we analyzed the relationship between each of the FQoL dimensions with the global satisfaction regarding the family quality of life. For this analysis we used the Pearson correlation coefficient (Table 1).

**Table 1.** Correlations of each FQoL dimension with the global evaluation of the family quality of life

Dimensions	FQoL – global score	Global satisfaction with FQoL
Health	0.40**	0.43**
Financial status	0.35**	0.34**
Family	0.53**	0.43**
Support from others	-0.01	0.07
Support from services	0.23*	0.32**
Values	0.28**	0.22*
Career	0.40**	0.44**
Leasure	0.36**	0.29**
Community	0.33**	0.36**

\*\*significant correlation at p<0.01; \* significant correlation at p<0.05; N=114

To analyze the independent contribution of each FQoL factor to the global satisfaction with the family quality of life, we used a multiple linear regression analysis, in which the dimensions of FQoL were entered as predictors, and the global evaluation of the family quality of life was the response variable (Table 2).

**Table 2.** The dimensions of FQoL as predictors of the global family quality of life

Model	Coeff. UnStd. B	Standard Error	Coeff. Std. Beta	t	p
(Constant)	-0.26	0.40		-0.65	0.51
Health	0.12	0.07	0.13	1.70	0.09
Financial status	0.13	0.06	0.15	2.05	0.04
Family	0.40	0.07	0.43	5.71	0.00
Support from others	-0.26	0.07	-0.26	-3.65	0.00
Support from services	0.08	0.06	0.09	1.20	0.23
Values	-0.00	0.08	-0.00	-0.06	0.94
Career	0.19	0.06	0.23	3.02	0.00
Leasure	0.12	0.08	0.12	1.52	0.13
Community	0.04	0.07	0.04	0.51	0.61

F (9, 103) =12.71 p<0.01; R<sup>2</sup> adjusted =0.4

A similar kind of analysis was used to determine the predictors of general satisfaction regarding the family quality of life. The results of the multiple linear regression, where the FQoL dimensions are treated as predictors and the general satisfaction regarding the family quality of life is the response variable, are presented in Table 3.

**Table 3.** The FQoL dimensions as predictors of the general satisfaction regarding the family quality of life

Model	Coef. NeStd. B	Eroarea standard	Coef. Std. Beta	t	p
(Constant)	0.84	0.37		2.25	0.02
Health	0.10	0.07	0.13	1.53	0.12
Financial status	0.08	0.05	0.12	1.50	0.13
Family	0.24	0.06	0.31	3.82	0.00
Support from others	-0.01	0.06	-0.02	-0.25	0.80
Support from services	0.14	0.06	0.19	2.38	0.01
Values	-0.05	0.07	-0.05	-0.70	0.48
Career	0.21	0.05	0.30	3.61	0.00
Leasure	-0.01	0.07	-0.02	-0.24	0.80
Community	0.06	0.07	0.08	0.93	0.35

F (9, 103)=9.16 p<0.01; R<sup>2</sup> adjusted = 0.44

## Discussion

In both groups, male gender is significantly predominant. According to literature, the prevalence of ASD in boys is 4 times higher than for girls, who are more severely affected [6].

Approximately 70% of the enrolled children were from urban environment. This fact can be relevant for the family quality of life, considering the access to specialized medical and therapeutic services. In Romania there are only a small number of professionals specialized in child and adolescent therapy, and they are concentrated mainly in the major cities.

In both groups there are a higher number of children with parents that have only medium education level. Parents' education level can influence the access to medical information sources and the availability of careful supervision for the child development. In general, parents with medium/higher education notice quicker the child developmental abnormalities and solicit medical opinion. The education level offers also the possibility of a better understanding of the disorder and therapeutic options, which may influence the family quality of life and the child recovery.

The differences obtained for the FQoL family relations domain can be explained by the fact that the parents of children with ADHD consider them less important for the family quality of life, have fewer opportunities to improve these relations, a lower initiative which can derive also from the reduced importance they place on this domain and as a result, a reduced level of accomplishments. Regarding the domain support from services, the parents of children with ADHD ranked this as less important for the family quality of life, than the parents of children with ASD, fact reflected in their initiative to access such services. The statistical analysis performed for the domain values influence, regarding the degree in which the religious/cultural community helps the family to accept and cope with the child disability, showed statistically significant differences between the two groups. The results are not surprising, taking into account that in Romania, religion is used most frequently as a support factor in adapting to unpleasant situations and events.

The domains with the lowest results with respect to FQoL were financial status, support from others and career. For the other domains evaluated by the FQoL, the results were average. Regarding opportunities, the lowest values were also for the financial status and support from others domains.

As it can be observed from Table 1, the only dimension of FQoL that is not significantly correlated with the global family QoL evaluation score is the satisfaction regarding the support from others ( $r=-0.01$ ,  $r=0.07$ , NS). All the other measured aspects show significant correlations, varying from  $r=0.22$  (satisfaction regarding values) to  $r=0.53$  (satisfaction regarding family).

From the Table 2, it can be observed that the multidimensional model of FQoL explains 48% of

the variance of the global evaluation of the family quality of life, proportion statistically significant,  $F(9, 103)=12.71$   $p<0.01$ . It can also be observed that, when controlling for the effect of the other factors, the most important predictors remain the family ( $\beta=0.43$ ,  $p=0.00$ ), support from others ( $\beta=-0.26$ ,  $p=0.00$ ), career ( $\beta=0.23$ ,  $p=0.00$ ), financial status ( $\beta=0.15$ ,  $p=0.04$ ), respectively.

The results presented in Table 3 show that the FQoL dimensions explain 44% of the variance of the general satisfaction regarding the family QoL, proportion statistically significant,  $F(9, 103)=9.16$   $p<0.01$ . When controlling for the effect of the other factors, the most important predictors remain, in the order of the predictive value, the family ( $\beta=0.31$ ,  $p<0.001$ ), career ( $\beta=0.30$ ,  $p<0.001$ ), support from services ( $\beta=0.19$ ,  $p<0.001$ ) respectively.

The International Family Quality of Life Project (IFQoLP) [7-9] developed an instrument that organized the FQoL in nine domains. In our study we used the original instrument developed by the research team for IFQoLP because the instrument was translated in Romanian by the authors, is free, doesn't need the authors agreement for usage and offered the possibility to compare the results with those obtained in other cultures.

One of the issues that appear after using these questionnaires is the difficulty to convince other family members than the mothers, to respond. It is also the case with our study, in which participated only the mothers of ASD and ADHD children.

The results of statistical analysis for the comparison of satisfaction with the nine domains of FQoL between the families with ASD and ADHD children, showed lack of statistically significant difference between the two diagnostic categories, considering the following FQoL dimensions: satisfaction regarding health, financial status, support from others, support from services; values, career, leisure and community related satisfaction. The only dimension of FQoL that showed a difference very close to statistical significance was the family related satisfaction.

The International Family Quality of Life Project studied the family quality of life using FQoL Survey. The study was conducted in 8 countries (Australia, Belgium, Canada, Israel, Japan, Nigeria, Slovenia and USA) and included families with at least one member with intellectual disabilities. The results were analyzed comparing the level of accomplishments and satisfaction. Regarding the accomplishments, the higher scores were obtained for the family domain, and the lower scores for the support from others, with similar results for the 8 countries. The domain of values influence had a high score for Nigeria, suggesting that religion is of a very importance for these families. The scores for overall assessment of the family quality of life were relatively close for most countries.

For our study, the higher scores regarding achievements were obtained for family domain, and lowest scores for support from other and financial status domains. In the overall assessment of the family quality of life, Japan had the lowest scores (Mean  $M=2.75$ ), the highest ones were in Belgium and Australia ( $M=3.52$ , and  $M=3.45$  respectively). For our study, results were similar to those from Japan ( $M=2.77$ ). For overall satisfaction with FQoL, results were similar for the 8 countries, averages ranging from 3.2 for Japan and 3.9 for Austria and Belgium. For our study, the average global satisfaction with FQoL was 3.57, close to the result obtained for Slovenia and the U.S. ( $M=3.6$ ).

The findings published by Brown in 2008, was that there is a similarity between caregivers assessments in the 8 countries for the level of achievement and satisfaction in some areas of family quality of life and there is a difference between the scoring mode for the nine domains assessed and overall satisfaction with FQoL, a situation which is also found in our study [10].

## Conclusions

The only dimension of the family quality of life that had very close difference to statistical significance between the two analyzed diagnosis categories was family satisfaction; families with ADHD children reported lower levels of satisfaction on family relationships. Parents of children with ADHD consider family relationships less important for the family quality of life, have fewer opportunities to improve these relations, a lower initiative and therefore a lower level of achievements.

Parents of children with ADHD believe support from the services to be less important for the

family quality of life than those of children with ASD, situation reflected in their initiative to access these services.

Families with ASD children benefit more from religious/cultural community support.

In general, areas with the lowest results in terms of satisfaction with the family quality of life domains were obtained for financial status, support from others (social) and career. As for opportunities, they also recorded the lowest values for the fields of financial status and support from others (social).

The most important predictors for the overall assessment of family quality of life are family, support from others, career and financial status domains.

The significant predictors for the overall satisfaction regarding the family quality of life are family, career and support from services domains.

### **Study Limits**

The limits and restrictions of this study are related to the fact that the FQoL Survey was completed by caregivers, which might be a loss in reporting accuracy, and can lead to data biases. Also, the questionnaire was completed only by one parent (mother), mainly reflecting its perception on the family quality of life. The results reflect the experience of families with ASD children receiving specialized services in Cluj-Napoca Pediatric Psychiatry Clinic and other specialized centers in the country. The analyzed sample excludes some families with ASD children with no health insurance, which are not enrolled in a family doctor practice, live in rural areas and have financial status that restricts access to specialized services. This study reflects the family quality of life for ASD and ADHD children at some point, so future longitudinal studies are needed to observe changes that occur depending on developmental stage (small child, childhood, adolescence).

### **Conflict of Interest**

The authors declare that they have no conflict of interest.

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