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# Family Quality of Life in Autism Spectrum Disorders (ASD)

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Additional information is available at the end of the chapter

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## Abstract

In latest years the concept of quality of life (QoL) has been acknowledged as an important outcome in psychiatric pathology fields. Most researchers consider that social indicators and the perception of personal wellbeing also, should be considered when measuring the quality of life. Our purpose was to investigate the QoL of the families of children with autism spectrum disorders (ASD) and to determine whether in this population, the potential mediators (irrational cognitions, negative automatic thoughts, coping strategies) relate significantly with the emotional distress reported. We also aimed to assess the parents' irrational cognitions and negative automatic thoughts as mediators in the relationship between the overall assessment of family QoL and their emotional distress. We found significant correlations between the emotional distress reported by the parents and their automatic negative thoughts, irrational cognitions, and different coping strategies. The relationship between the overall assessment of family QoL and the parents' emotional distress was partially explained by their negative automatic thoughts and irrational cognitions. In this view, the specialised services should include also interventions for the parents of children with developmental disorders (ASD, ADHD) in order to improve their overall assessment of family QoL.

**Keywords:** family quality of life, autism spectrum disorders, emotion regulation, coping mechanisms

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## 1. Introduction

Quality of life (QoL) is a measure of individual well-being, which includes multiple areas of functioning and is increasingly recognized as a necessary construct in developmental disorder studies. The QoL concept is not new. Happiness and well-being have been discussed by Plato and Aristotle in their writings. QoL has been defined in various ways, from "general

conditions for happiness" [2] to "positive life experiences" [3]. Most researchers consider that social indicators, but also the perception of personal well-being should be considered when measuring QoL and that the objective and subjective indicators are two complementary facets that have to be measured separately [1, 4].

QoL is a construct that has been used for a wide range of health problems (drug abuse, mental disorders, oncology, geriatrics, cardiovascular disease, etc.), but lacks a coherent theoretical-derived model or a definition generally accepted [5, 6]. Although there is a general consensus on the main characteristics of the construct [7–9], there are still some issues to be clarified for the development of appropriate QoL measurement instruments: the principles that should guide the measurement process and how should be carried the assessment [10, 11].

The concept of family QoL has been studied systematically only in the recent years. Parents' experience was considered to be a part of the family life and was initially explored as part of the QoL concept. In the late 1990s, there were initiated two large projects on the families' QoL, one at Kansas University and the other led by a team of researchers from Australia, Canada, and Israel. The main rationale for these studies was the tendency of governments and other funding sources to assign to the families the care of children and adults with disabilities. This trend was especially important for the families who had a member with intellectual disability that required constant care and supervision. Even though most families are willing to assume this role, many difficulties arise and affect their quality of life [12, 13].

The concept of family QoL emerged as a viable alternative to the use of multiple measurements, which most often caused difficulties in design studies and results reporting because these measurements, developed individually, are rarely suitable to produce a global profile of family status. Given the increasing interest in health status or economic well-being of families and community, these issues were included in the instruments that measure family QoL. Although some researchers have conceptualized and measured some aspects of the family QoL in terms of services available for the child or the family [14], most of them developed a multidimensional construct, with a number of domains representing different areas of the family life, the sum of their ratings indicating the overall family quality of life. That view was shared by many researchers, each of them describing a framework for the domains of the family quality of life. The International Family Quality of Life Project [13, 15, 16] developed an instrument that organizes family QoL in nine domains. Another research team [17] proposed an instrument with six areas. The third research team [18, 19] conceptualized, developed, and tested an instrument that evaluates five domains: family relationships, parenting style, emotional well-being, physical and material wellbeing, and disability support.

A way to assess families' perceptions and needs is to investigate the areas in which they function. One of the problems that arise from using these questionnaires is the difficulty to convince other family members than mothers to answer to them. However, overall satisfaction with the family quality of life can be high, even if there are problems in some areas. Satisfaction varies significantly in each assessed area of the family life. This variation may be associated with the intensity of child's behavioral problems or family experience. It is also important to note that family members are different in terms of resilience and coping

strategies and that they may report high levels in satisfaction, even if they have many difficulties and need support [20]. The concept of family quality of life is a multidimensional construct, involving a variety of physical, economic, and emotional dimensions, which cannot be properly measured by focusing only on the perspective of the mother. In a systematic review on the conceptualization and assessment of the effects on families who have children with disabilities, among the 20 studies evaluated, 14 used assessments focused on family welfare, family adjustment, and functioning. Among these studies, 55% were focused on the maternal perspective, 35% included both parents, and only one study included the siblings of children with disabilities [21].

The use of variables such as stress and depression to study the effect of disability on families has been criticized because these variables do not take an objective view on the families' experience and do not consider the possibility that many families experience positive effects and adapt well to raising a child with disabilities [22].

Stress level was studied in relation to parents' mental health QoL in several studies [23–25]. Lee et al. found stress to be a significant predictor of mental health QoL, after controlling for five demographic variables (e.g., age, education, income, number of children in family, and severity of child with disability). Stress was negatively correlated with all aspects of QoL including physical, psychological, social, and environmental HRQOL [26].

In another study on parents of children with autism spectrum disorders (ASD), Johnson et al. evaluated the relationships between parents' stress, family functioning, and QoL. They found that parents' stress had a negative impact on mental health outcomes [27]. These results are supported by other studies and confirm the negative impact of stress on psychological outcomes among parents of children with ASD (e.g., depression, anxiety, and adjustment) [28, 29].

Smith et al. evaluated the depressive symptoms of the mother of children and adolescents with ASD. A third of them had clinically significant depressive symptoms [30]. Wallace et al. suggested that parents' depression is associated with the intensity of child repetitive behaviors and their anxiety with child social communication problems [31]. Family history of depression or shyness had the greatest influence on children socialization scores. Parents of children with autism were more likely to be hospitalized for a mental disorder than those in the control group, and depression and personality disorders were more common in mothers than fathers [32].

Social support, family functioning, and parents' coping mechanisms are factors that mediate the quality of life of parents of children with ASD [33]. High social support is associated with low levels of anxiety, depression, and stress. The high degree of cohesion and adaptability of the family was shown to be protective against the potential negative effects of raising a child with ASD.

Another factors found to be associated with parental QoL are child's symptom severity and behavioral problems [25, 26, 34]. Benson et al. studied the impact of child ASD symptoms severity on parents' depression, the results suggesting that both child symptoms severity and

parental stress predicted depression and that the effect of child symptom severity on parental depression was partially mediated by stress [23].

In a study that investigated the QoL of the main caregiver of children with ASD, the results suggested that the most important predictors for caregiver' physical health were the intensity of children behavioral problems and social support and for their mental health, the level of child functional impairment, social support, use of maladaptive coping strategies, and perceived difficulty. The impact on mental health was more important than that on physical health, which was only slightly below the norms for general population [35].

Coping refers to the cognitive and behavioral effort of an individual to adapt to a stressful situation [36]. Studies in autism reported that the frequent use of emotion-oriented coping is associated with parents' low quality of life [37]. In contrast to these findings, Lee et al. found no association between coping strategies and QoL [26].

Family emotional environment, including the expression of different types of emotions, help children to develop emotional competence. A chronically poor emotional expression of parents and high levels of negative emotions have significant implications for children emotion regulation skill development (failure in understanding emotions, poor management of stressful emotional situations, and incorrect social use of emotions). Chronic suppression of emotional experiences is associated with higher subjective distress and on a long term with emotional regulation deficits.

There are some data suggesting that parental capacity to assure their children health and adaptability may be affected by their emotional state and well-being. Parental stress can influence parents' and children's coping resources and affect their ability to perform [38, 39].

A study that investigated the quality of life of 286 children with ASD, compared with the norms for general population and the population with chronic somatic disorders, reported that the children with ASD had lower scores for the psychosocial, emotional, and social functioning, but comparative to the population with chronic somatic disorders for physical and school functioning. QoL did not significantly correlate with the diagnosis of ASD or the intellectual abilities, but was significantly associated with the internalizing/externalizing problems measured by child Behavior checklist (CBCL), with the repetitive behaviors, social responsiveness, and adaptive behaviors. Given the fact that the socialization difficulties that characterize ASD are not specific to chronic somatic disorders, such as asthma or diabetes, it is not surprising that children with ASD had lower scores on the psychosocial functioning domain [39]. Storch et al. found a stronger correlation between the CBCL scores and quality of life for the internalizing problems [40]. This stronger association with the internalizing problems is not necessarily surprising for children with ASD, given that withdrawal is an important clinical feature in ASD and also a significant part of internalization scores measured by CBCL.

Studies on QoL of the caregivers of children with ASD reported different results. Allik et al. found the behavioral problems and not the autism severity as predictors for the mental health of mothers of children with ASD. This study included parents of children with Asperger syndrome and high-functioning autism, which could influence the results related to autism severity, these forms of ASD associating a lower symptoms severity [41].

Stuart and McGrew reported a protective effect for social support and a negative one for the use of maladaptive coping strategies, on the subjective difficulty reported by the parents of children with autism. The problems in family functioning also contributed to the level of difficulties reported [42]. These results are similar to those described by Altieri and von Kluge, who found a more frequent use of the adaptive coping mechanisms and social support for the parents of children with autism who had better family relationships than for those with family problems or separated [43].

For children with autism, it was demonstrated a strong correlation between their behavioral problems, the autism symptoms severity and parental stress. Osborne and Reed reported that the parental stress levels have a negative influence on the child outcomes after receiving different educational interventions. The negative effects were observed in both cognitive and adaptive behavior acquisitions [44]. The reason why high levels of parental stress have a negative impact on child's behavioral problems and are predictive for poor outcomes in therapy has not been elucidated yet. The most plausible explanation is that the parental stress produces changes in the parent's ability to adjust and respond to child's behavioral problems.

The aim of this study was to assess the mediating role of parents' irrational beliefs and automatic negative thoughts in the relationship between the children's emotional/behavioral problems and the parents' emotional distress. Our goal was also to investigate whether in this population (families of the children with ASD or attention deficit hyperactivity disorder (ADHD)), the potential mediators (irrational cognitions, negative automatic thoughts, and coping strategies) relate significantly with the emotional distress reported and to assess the parents irrational cognitions and negative automatic thoughts as mediators in the relationship between the assessment of the overall family quality of life and their emotional distress [1]. Few studies have been reported on this topic, especially, much less in families of the children with ASD or ADHD.

The results from previous studies [45, 46] showed no differences between the two diagnosis categories regarding the parents' levels of emotional distress and the overall assessment of family QoL, so analyses were performed on all studied clinical sample.

## 2. Method

### 2.1. Participants

The data were collected from 114 children aged 2–14 years, diagnosed with ASD or ADHD, according to international diagnosis criteria DSM IV-TR and ICD-10 and from their parents (65 children with ASD and 49 children with ADHD).

Children and adolescents included in the study were recruited between January 2011 and November 2011. They were patients in the Child and Adolescent Psychiatry Clinic from Cluj-Napoca, Romania or included in a therapy program in various specialized centers from Romania (ClujNapoca, Sibiu, Oradea, Arad, and Tg. Jiu). Children diagnosed and treated in this clinic come from all parts of the country and are diverse in terms of socioeconomic status.

We included in the study: boys or girls with ages between 2 and 14 years, with diagnosis of autistic spectrum disorder (ASD) or attention deficit hyperactivity disorder (ADHD), according to DSM IV-TR international criteria; sign consent of parents to be included in the study. We excluded from the study: the children with a known medical condition (heart or lung and chronic disorders); children who suffered accidents or had major stress or in the last 6 months, which may significantly affect the family quality of life; the children placed in foster care [1].

## 2.2. Instruments

Child Behavior Checklist (CBCL) was used to assess the internalizing/externalizing problems. There are two versions of the instrument, depending on the age of the child: the preschool checklist (CBCL/1½-5) and the school-age version (CBCL/6-18). The CBCL is to be filled in by the parent/caretaker who spends the most time with the child and assesses various problems and child functioning over the past 2 months. It has been one of the most widely used standardized measures for evaluating maladaptive behaviors and emotional problems in children and adolescents. CBCL assesses internalizing (i.e., anxious, depressive, and overcontrolled) and externalizing (i.e., aggressive, hyperactive, noncompliant, and under controlled) behaviors, as well as scores on DSM-IV-related scales (emotional problems, anxiety disorders, ADHD, opposition defiant disorder, and pervasive developmental disorders/somatic problems) [47].

To assess parents' emotions and emotional regulation strategies, we used the following instruments: profile of affective distress (PAD)—rating scale with 39 items that assesses subjective dimensions of positive and negative emotions (functional and dysfunctional) [47]; white bear suppression inventory (WBSI)—rating scale with 15 items that assesses the use of suppression as a cognitive and emotional coping strategy; self-efficacy scale (SES)—rating scale with 10 items that assesses the perceived self-efficacy; automatic thoughts questionnaire (ATQ)—rating scale with 30 items that measures the negative automatic thoughts frequency; attitudes and beliefs scale—short form (ABSs)—is a global measure of irrationality into adulthood; it has eight items that assess four types of irrational evaluative beliefs (absolutist claims, catastrophic interpretation, low frustration tolerance and negative overall assessment); cognitive-emotional regulation questionnaire (CERQ)—has 36 items and assesses nine cognitive coping strategies that a person uses when experiencing negative events or situations (self-blame; other-blame; rumination; catastrophizing; putting into perspective; positive refocusing; positive reappraisal; acceptance; refocus on planning) [48, 49].

Family quality of life survey (FQOL) was used to assess the family quality of life, instrument designed to assess the quality of life of the families that have one or more members with intellectual or developmental disability. The family quality of life can be approached from different perspectives.

The FQOL has several sections: first section includes the description of the family members; the following nine assess specific areas of family life (health, financial status, family interactions, support from others, and support from services, values influence, career, leisure activities, and integration in community life). Each of these areas has two sections: Section A

contains questions of a more general nature and Section B contains questions related to six key concepts for the theoretical construction of the instrument: importance, opportunities, initiative, achievement/current status, stability, and satisfaction. The final section is shorter and is designed to collect the overall impressions regarding the family QoL [50].

The demographics and other data of interest were obtained through a questionnaire containing questions about the patient (age, sex, age at diagnosis, school activities, and treatment) and his family (mother and father's age, marital status, education level, and occupation).

### 2.3. Design

The study is cross-sectional. Parents and children who agreed to participate to the study received additional information and signed the informed consent. Psychiatric and somatic evaluations were performed for the patients who met the study inclusion and exclusion criteria in order to confirm the diagnosis and detect possible comorbidities. Each child was psychologically evaluated in order to determine the developmental level and symptoms severity. After the clinical interview, the parents/caregivers filled in the CBCL for the assessment of child internalizing/externalizing problems, the emotional assessment rating scales (PAD, WBI, SES, ATQ, ABSs, and CERQ) and the family quality of life questionnaire (FQOL) [1]. Data were supplemented with information from the patients' charts and other medical documents. For all the children included in the study, we required and obtained the consent to use medical data, ensuring the privacy and subject's identity protection. The questionnaires were filled in by the mothers for all children included in the study.

### 2.4. Data analysis

Data were collected into a SPSS database (version 17). Analyses were performed to assess the mediating role of parents' automatic thoughts and irrational beliefs as mediators of the relationship between children's problems (affective, anxiety, behavioral) and parents' emotional distress. The same procedure was used to assess the role of parents' irrational beliefs and automatic thoughts as mediators of the relationship between the global assessment of family QoL and their emotional distress.

The mediation analysis was used following the next steps: first, the mediation criteria were tested according to the following procedure. We tested if the independent variable is a significant predictor of the dependent variable (criterion). In this way, the total effect was identified. Then we tested whether the independent variable is a significant predictor of the mediating variable and if the latter is a significant predictor of the dependent variable. After that, it was tested whether the independent variable predictive value is reduced when it is placed next to the mediating variable in the multiple linear regression equation on the dependent variable. The difference between the total effect and the independent variable predictive value on controlled mediator represents the mediation effect.

Its difference from 0 value was tested using the Sobel test, at a probability of the null hypothesis (mediation effect is null)  $p < 0.05$ . For the situations where the mediation effect proved to be statistically significant, in the last phase of the analysis, the mediation effect size was calculated. An effect size indicator was used. It represents the proportion of the



total effect explained by the mediating variable. This indicator was calculated as: the difference between the total effect and the mediation effect divided by the total effect and multiplied by 100.

## 2.5. Ethical aspects

The study was conducted in compliance with the international ethical standards set out in the Helsinki Declaration of Human Rights updated. We obtain the approval of the University of Medicine and Pharmacy Cluj-Napoca Ethics Committee to conduct the study. All the parents and children included in the study signed the informed consent and received additional information. Data were used ensuring the privacy and subject's identity protection.

## 3. Results

### 3.1. Sample description

One hundred and fourteen subjects were enrolled in the study, with ages ranging between 2 and 14 years ( $M = 6.95$  years,  $SD = 2.67$ ) (see **Table 1**). In terms of gender distribution, the sample included 84 boys (73.7%) and 30 girls (26.3%), with a clear predominance of male subjects. Sixty-five children (57%) were diagnosed with ASD and 49 with ADHD (43%). After psychological evaluations, 54 (47.37%) children had a proper developmental level, 51 (44.74%) had developmental delay in all areas (cognitive, language, independence, communication), and 9 children had language delay (7.89%). Most children were under psychological or pharmacological therapy.

Out of the 114 participants in the study, 32 (28.07%) were from rural and 82 (71.93%) from urban environment. In both diagnosis groups, most parents were married, with secondary education and employed [1].

The results of our previous studies on the comparison of satisfaction for the nine areas of family quality of life (QoL) among families of children with ASD and ADHD highlighted the lack of statistically significant differences between the two categories of diagnosis in all the domains assessed by FQOL. We also found no statistically significant differences between the two diagnosis groups regarding parents' emotional distress, meaning that the diagnostic category does not moderate the intensity and/or direction of the relationship between parental emotional distress and the overall assessment of family QoL, so analyses were performed on the whole clinical sample [45, 46].

### 3.2. Analysis of parents automatic thoughts and irrational cognitions as mediators in the relationship between children problems (affective, anxiety, behavioral) and parents' emotional distress

Previous analysis on the relationship between the child affective, anxiety, and behavioral problems and the overall assessment of the family QoL revealed no significant relationship for both category of diagnosis, TSA and ADHD.

	ASD (N = 65)	ADHD (N = 49)
<b>Child characteristics</b>		
Age mean (SD)	6.46 (2.17)	7.61 (3.13)
Gender (% male)	58.3	41.7
Developmental level	N (%)	N (%)
Normal	15 (23.07)	39 (79.59)
Developmental delay	44 (67.69)	7 (14.28)
Language delay	6 (9.23)	3 (6.12)
Pharmacological therapy N (%)	43 (66.2)	27 (55.1)
Psychotherapy N (%)	60 (92.3)	24 (48.97)
<b>Family characteristics</b>		
Mothers age mean (SD)	33.21 (5.58)	35.46 (6.37)
Fathers age mean (SD)	36.79 (5.54)	37.78 (6.50)
Marital status N married (%)	55 (84.6)	40 (81.6)
Level of education	N (%)	N (%)
Less than 12th grade	4 (6.2)	8 (16.3)
Bachelor's degree	37 (56.9)	28 (57.1)
Graduate degree	24 (36.9)	13 (26.6)
<b>Employment status</b>		
N employed (%)	58 (89.2)	38 (77.6)

**Table 1.** Sample demographic description.

The parents included in the study showed high emotional distress mean scores compared with the general population norms ( $M = 56.21$ ,  $SD = 19.64$ ). Analyses performed separately for the two diagnosis categories revealed no statistically significant differences ( $t(112) = -1.08$ ,  $p > 0.05$ ) on the level of distress reported.

The scores for negative dysfunctional emotions were average to high when compared with the general population norms ( $M = 25.1$ ,  $SD = 10.9$ ), 40% of the parents reporting high and very high levels of negative dysfunctional emotions. Analyses performed separately for the two diagnosis categories revealed no statistically significant differences ( $t(112) = -1.29$ ,  $p > 0.05$ ), suggesting that for the studied sample, increased levels of negative dysfunctional emotions and emotional distress, may be due to child developmental problems, but they are not specific to diagnosis.

### 3.2.1. Study on the relationship between the intensity of children affective problems and parents' emotional distress

Analysis of variance (ANOVA) revealed no statistically significant differences between the three groups (non-clinical, sub-clinical, and clinical) for any aspect of parents' emotional distress measured in the study: emotional distress total score ( $F = 0.40$ ,  $p > 0.05$ ), negative

dysfunctional emotion total score ( $F = 0.16, p > 0.05$ ), worry/anxiety dysfunctional emotion score ( $F = 0.14, p > 0.05$ ), respectively, sadness/depression dysfunctional emotion score ( $F = 0.16, p > 0.05$ ) (see **Table 2**).

### 3.2.2. Study on the relationship between the intensity of children anxiety problems and parents' emotional distress

Comparative analysis of the parents' emotional distress scores in the three groups (nonclinical, subclinical, and clinical), highlighted a lack of statistically significant differences, as follows: emotional distress total score ( $F = 0.37, p > 0.05$ ), negative dysfunctional emotion total score ( $F = 0.39, p > 0.05$ ), worry/anxiety dysfunctional emotion score ( $F = 0.03, p > 0.05$ ), and sadness/depression dysfunctional emotion score ( $F = 1.05, p > 0.05$ ) (see **Table 3**).

### 3.2.3. Study on the relationship between the intensity of children behavioral problems and parents' emotional distress

Comparative analysis of parents' emotional distress scores in the three groups (nonclinical, subclinical, and clinical) showed a lack of statistically significant differences for the level of emotional distress total score ( $F = 0.44, p > 0.05$ ), negative dysfunctional emotion total score

Variable	Lot	N	Mean (M)	Standard deviation (SD)
Emotional distress total score	Nonclinic	67	55.22	19.86
	Subclinic	25	55.92	18.82
	Clinic	22	59.59	20.41
	Total	114	56.21	19.64
Negative dysfunctional emotion total score	Nonclinic	67	24.80	11.31
	Subclinic	25	24.84	10.66
	Clinic	22	26.31	10.70
	Total	114	25.10	10.98
Worry/anxiety dysfunctional emotion score	Nonclinic	67	11.44	6.54
	Subclinic	25	11.24	4.53
	Clinic	22	12.09	4.17
	Total	114	11.52	5.71
Sadness/depression dysfunctional emotion score	Nonclinic	67	13.35	5.56
	Subclinic	25	13.60	6.55
	Clinic	22	14.22	7.26
	Total	114	13.57	6.09

**Table 2.** Central tendency and dispersion indicators of parents' emotional distress in relation with the intensity of children affective problems.

Variable	Lot	N	Mean (M)	Standard deviation (SD)
Emotional distress total score	Nonclinic	58	54.68	17.75
	Subclinic	30	57.30	20.16
	Clinic	26	58.38	23.28
	Total	114	56.21	19.64
Negative dysfunctional emotion total score	Nonclinic	58	24.20	10.33
	Subclinic	30	25.86	10.62
	Clinic	26	26.23	12.90
	Total	114	25.10	10.98
Worry/anxiety dysfunctional emotion score	Nonclinic	58	11.41	6.47
	Subclinic	30	11.76	4.84
	Clinic	26	11.50	4.98
	Total	114	11.52	5.71
Sadness/depression dysfunctional emotion score	Nonclinic	58	12.79	4.78
	Subclinic	30	14.10	6.05
	Clinic	26	14.73	8.35
	Total	114	13.57	6.09

**Table 3.** Central tendency and dispersion indicators of parents' emotional distress in relation with the intensity of children anxiety problems.

( $F = 0.28, p > 0.05$ ), worry/anxiety dysfunctional emotion score ( $F = 0.23, p > 0.05$ ), and sadness/depression dysfunctional emotion score ( $F = 0.48, p > 0.05$ ) (see **Table 4**) [1].

### 3.3. Automatic thoughts, irrational beliefs and coping strategies

Assuming that the high levels of parental emotional distress is generated among other factors, by the child developmental disorder, we investigated whether in this population (parents of children diagnosed with ASD or ADHD), the potential mediators (irrational beliefs, negative automatic thoughts, coping strategies) relate statistically significant to the reported emotional distress.

Parents of children included in the study registered high levels of negative automatic thoughts ( $M = 30.15, SD = 10.39$ ) (more than 69.1% of the general population). For the irrational beliefs measured by ABSs, the mean scores were also very high ( $M = 11.29, SD = 3.54$ ). Low to medium levels of self-efficacy were reported ( $M = 30.22, SD = 4.61$ ) (>6.7 of the general population).

**Table 5** shows the correlations of parents' automatic thoughts, irrational beliefs, perceived self-efficacy, and suppression coping strategy with their emotional distress scores.

Variable	Lot	N	Mean (M)	Standard deviation (SD)
Emotional distress total score	Nonclinic	61	55.80	21.05
	Subclinic	22	53.77	16.89
	Clinic	31	58.77	18.86
	Total	114	56.21	19.64
Negative dysfunctional emotion total score	Nonclinic	61	25.04	12.16
	Subclinic	22	23.81	8.53
	Clinic	31	26.12	10.23
	Total	114	25.10	10.98
Worry/anxiety dysfunctional emotion score	Nonclinic	61	11.73	6.90
	Subclinic	22	10.77	3.89
	Clinic	31	11.64	4.07
	Total	114	11.52	5.71
Sadness/depression dysfunctional emotion score	Nonclinic	61	13.31	6.11
	Subclinic	22	13.04	5.07
	Clinic	31	14.48	6.76
	Total	114	13.57	6.09

**Table 4.** Central tendency and dispersion indicators of parents' emotional distress in relation with the intensity of children behavioral problems.

	Automatic negative thoughts (ATQ)	Irrational beliefs (ABSs)	Self-efficacy (SES)	Suppression coping strategy (WBSI)
Emotional distress total score	0.48**	0.41**	-0.40**	0.38**
Negative dysfunctional emotion total score	0.49**	0.39**	-0.37**	0.36**
Worry/anxiety dysfunctional emotion score	0.37**	0.30**	-0.28**	0.31**
Sadness/depression dysfunctional emotion score	0.53**	0.43**	-0.41**	0.36**

\*\*Correlation significant at  $p < 0.01$ .

**Table 5.** The correlation of parents' emotional distress scores with their automatic thoughts, irrational beliefs, perceived self-efficacy and use of suppression coping strategy.

Both automatic negative thoughts and irrational beliefs correlate positively and statistically significant with all emotional distress scores, the intensity varying from medium to high. The relationship is positive, meaning that when the intensity of the negative automatic thoughts increases, the emotional distress increases also. In terms of explanatory value, negative automatic thoughts explain between 13% ( $R^2 = 0.13$  for worry/anxiety dysfunctional emotion score) and 28% ( $R^2 = 0.28$  for sadness/depression dysfunctional emotion score) of the emotional distress variance.

For the irrational beliefs, the relationship is also positive, meaning that when the level of irrationality increases, the emotional distress increases also. The determination coefficients obtained from the square of the correlation coefficients indicate that irrationality explains between 9% ( $R^2 = 0.09$  for worry/anxiety dysfunctional emotion scores) and 18% ( $R^2 = 0.18$  for sadness/depression dysfunctional emotion score) of the emotional distress variance.

The perceived self-efficacy correlated with all emotional distress scores with values between  $-0.28$  and  $-0.41$ . The negative relationship means that, if the self-efficacy reported by parents is higher, the emotional distress will be lower. In terms of explanatory value, the perceived self-efficacy explains between 7.8% ( $R^2 = 0.078$  for worry/anxiety dysfunctional emotion score) and 16.8% ( $R^2 = 0.168$  for sadness/depression dysfunctional emotion score) of the emotional distress variance.

The suppression coping strategy measured by WBSI correlated with all emotional distress scores with values between  $r = 0.31$  and  $r = 0.38$ , statistically significant at  $p < 0.01$ . The mean scores ( $M = 48.51$ ,  $SD = 11.79$ ) did not exceed the critical cut-off ( $M > 60$ ). The use of suppression coping strategy (WBSI) explains between 9% ( $R^2 = 0.09$  for worry/anxiety dysfunctional emotion score) and 14% ( $R^2 = 0.14$  for the emotional distress total score) of the emotional distress variance.

Regarding the cognitive coping strategies used, the scores reported by the parents showed above average use for catastrophizing ( $M = 9.64$ ,  $SD = 3.82$ ), average use for self-blame ( $M = 9.66$ ,  $SD = 3.06$ ), acceptance ( $M = 13.51$ ,  $SD = 3.49$ ), rumination ( $M = 12.24$ ,  $SD = 3.52$ ), refocus on planning ( $M = 15.9$ ,  $SD = 3.25$ ), positive reappraisal ( $M = 14.37$ ,  $SD = 3.82$ ), putting into perspective ( $M = 14.19$ ,  $SD = 3.76$ ), and below average for positive refocusing ( $M = 10.89$ ,  $SD = 3.91$ ) and blame others ( $M = 7.05$ ,  $SD = 2.90$ ).

As seen in **Table 6**, the reported emotional distress correlated statistically significant with the strategies: self-blame ( $r = 0.32$ ), rumination ( $r = 0.20$ ), positive refocusing ( $r = -0.22$ ), positive reappraisal ( $r = -0.23$ ), catastrophizing ( $r = 0.37$ ), and blame others ( $r = 0.19$ ). The only coping strategies that correlated with all scores of emotional distress measured were self-blame and catastrophizing strategies. Both registered positive relationships meaning that their frequent use associated with higher emotional distress scores. For the self-blame strategy the intensity was mild. The most intense correlation was obtained for the catastrophizing strategy ( $r = 0.37$ ). The positive refocusing, positive reappraisal, refocus on planning registered negative relationships with different scores of emotional distress, meaning that their frequent use associated with lower emotional distress scores [1].

### **3.4. The parents' irrational cognitions and negative automatic thoughts as mediators in the relationship between the assessment of the overall family quality of life and their emotional distress**

#### *3.4.1. Model 1*

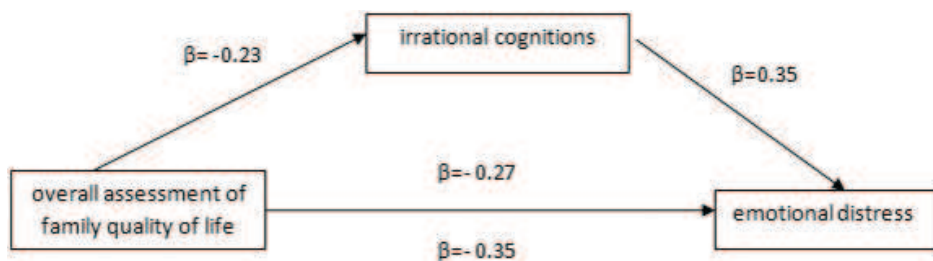
This mediation model includes the following variables: overall assessment of family quality of life ( $M = 3.57$ ,  $SD = 0.65$ )—predictor variable, emotional distress—criterion variable and irrational cognitions—the mediator variable (**Figure 1**).

CERQ coping strategy	Emotional distress total score	Negative dysfunctional emotion total score	Worry/anxiety dysfunctional emotion score	Sadness/depression dysfunctional emotion score
Self-blame	0.32**	0.32**	0.30**	0.29**
Acceptance	0.07	0.05	0.06	0.03
Rumination	0.20*	0.15	0.13	0.15
Positive refocusing	-0.22*	-0.18*	-0.07	-0.26**
Refocus on planning	-0.10	-0.14	-0.02	-0.23*
Positive reappraisal	-0.23*	-0.25**	-0.13	-0.34**
Putting into perspective	-0.06	-0.09	-0.03	-0.14
Catastrophizing	0.37**	0.38**	0.32**	0.38**
Blame others	0.19*	0.14	0.10	0.15
CERQ coping strategy	Emotional distress total score	Negative dysfunctional emotion total score	Worry/anxiety dysfunctional emotion score	Sadness/depression dysfunctional emotion score

\*\*Correlation significant at  $p < 0.01$ .

\*Correlations significant at  $p < 0.05$ .

**Table 6.** Correlation of parents’ emotional distress with their coping strategies (CERQ).



**Figure 1.** Mediation model 1 diagram.

Mediation model 1 testing included the following steps:

Step 1. Testing the relationship between the overall assessment of family quality of life and parents reported emotional distress. Simple linear regression analysis proved overall assessment of family quality of life to be a significant predictor for the emotional distress ( $B = -0.97$ ,  $\beta = -0.35$ ,  $SE = 2.27$ ,  $p < 0.05$ ). This represents the total effect of the overall assessment of family quality of life on the parents’ emotional distress.

Step 2. Testing the relationship between the overall assessment of family quality of life and parents irrational beliefs. Simple linear regression analysis showed the overall assessment of family quality of life as significant predictor for parents’ irrational cognitions ( $B = -1.07$ ,  $\beta = -0.23$ ,  $SE = 0.42$ ,  $p < 0.05$ ).

Step 3. Testing the simultaneous predictive value of the overall assessment of family quality of life and irrational beliefs on parents’ emotional distress. The multiple linear regression

analysis showed the predictive value of parents irrational cognitions on their emotional distress, when controlling for the overall assessment of family quality of life ( $B = 1.93$ ,  $\beta = 0.35$ ,  $SE = 0.47$ ,  $p < 0.05$ ). It showed also a reduction in the predictive value of the overall assessment of family quality of life on the parents emotional distress, when controlling for their irrational cognitions ( $B = -6.98$ ,  $\beta = -0.27$ ,  $SE = 2.18$ ,  $p < 0.05$ ). The mediation effect (the difference in predictive value),  $\Delta B = -9.07 - (-6.98)$ , was tested for statistical significance using the Sobel test. The mediating effect was statistically significant,  $Z = -2.16$ ,  $p = 0.03$ . Next, the mediation effect size was calculated as follows: the ratio between the mediation effect and the total effect, multiplied by the value  $\{[-9.07 - (-6.98)] / -9.07\} \times 100$ . This indicator shows the proportion of relationship between the overall assessments of family quality and parents' emotional distress explained by irrational cognitions. The mediation size effect was  $ES = 23\%$ , which expresses a partial mediation effect [1].

### 3.4.2. Model 2

The second mediation model includes three variables: family quality of life— predictor variable, parents' emotional distress—criterion variable and parents' automatic negative thoughts—the mediator variable (**Figure 2**).

Mediation model 2 testing included, as in the previous case, the following steps:

Step 1. Testing the relationship between the overall assessment of family quality of life and parents reported emotional distress. Simple linear regression analysis showed overall assessment of family quality of life as significant predictor for the emotional distress ( $B = -0.97$ ,  $\beta = -0.35$ ,  $SE = 2.27$ ,  $p < 0.05$ ).

Step 2. Testing the relationship between the overall assessment of family quality of life and parents automatic negative thoughts. Simple linear regression analysis showed the overall assessment of family quality of life as significant predictor of parents automatic negative thoughts ( $B = -4.50$ ,  $\beta = -0.33$ ,  $SE = 1.21$ ,  $p < 0.05$ ).

Step 3. Testing the simultaneous predictive value of the overall assessment of family quality of life and automatic negative thoughts on parents' emotional distress. The multiple linear regression analysis showed the predictive value of parents negative automatic thoughts on their emotional distress, when controlling for the overall assessment of family quality of life ( $B = 0.78$ ,  $\beta = 0.41$ ,  $SE = 0.16$ ,  $p < 0.05$ ). It showed also a reduction of the predictive value

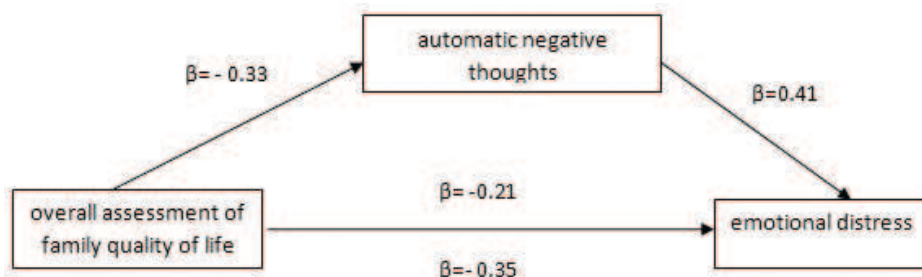


Figure 2. Mediation model 2 diagram.



of the overall assessment of family quality of life on the parents emotional distress, when controlling for their automatic negative thoughts ( $B = -5.54$ ,  $\beta = -0.21$ ,  $SE = 2.19$ ,  $p < 0.05$ ). The mediation effect, delta  $B = -9.07 - (-5.54)$ , was tested with the Sobel test. The mediating effect was statistically significant,  $Z = -2.95$ ,  $p = 0.003$ . ES = effect size was 38.9%, which represents a partial mediator effect. From the total effect of the overall assessment of family quality of life on parents' emotional distress, 38.9% is explained by their automatic negative thoughts [1].

## 4. Discussion

### 4.1. Main findings

The impact of an autism spectrum disorder (ASD) diagnosis on families is devastating, particularly because there is no curative pharmacological or psychological treatment.

It has been already proven that having a child with special needs involves child-care-related stress, and less time for parents to fulfill their own needs. Compared to typical children's parents, parents of children with autism have reported higher family difficulties and are at greater risk for developing physical or psychological problems. Lee et al. investigated the main predictors of mental health for the parents of children with high-functioning autism and reported that physical health, financial status, and low stress are the most critical. The study underlined the need for more research on the potential stress of these parents and stated the need for services targeting the parents' mental health, in addition to the therapies addressed to the child problems [26].

Some studies have reported that parents' emotional problems correlated positively with child's behavioral problem severity and low ability to communicate functionally. Also, a strong correlation between child behavioral problems, autism symptom severity and parental stress was demonstrated. Khanna et al. found a correlation between the physical QoL dimension and child's behavioral problems [35]. Tung et al. and McStay et al. reported lower QoL among parents of children with higher levels of externalizing problems [24, 25]. Lower scores on prosocial behaviors and higher scores of hyperactivity and conduct problems indicated lower maternal mental health [51, 52]. Only half of the studies that assessed the impact of child emotional problems on parents QoL indicated a significant correlation between the child's emotional problems and maternal mental health [52, 53].

Although recent studies have suggested that there is a link between the level of parents' emotional distress and the intensity of child internalizing/externalizing problems, the results of this study showed no statistically significant differences between the levels of emotional distress, negative dysfunctional emotions, worry/anxiety dysfunctional emotions, sadness/depression dysfunctional emotions in relation to the intensity of children's affective, anxiety and behavioral problems, measured by CBCL. In this view, we believe that child's developmental disorders may increase parents' emotional distress, but it does not differ significantly depending on the diagnosis or child-associated internalizing/externalizing problems.

Parental stress levels were found to be more pronounced in the parents of children with ASD compared to the parents of children with disabilities or other health problems [54]. Hastings and Johnson reported that increased severity levels of autistic symptoms are associated with higher levels of parental stress [55]. Elevated levels of stress can have a negative impact on parents and can lead to depression, anger, anxiety, and family conflicts [56]. Most studies considered the child with autism the source of stress and the well-being of the other family members as the result, but this relationship is bidirectional, meaning that the family members can influence the children with ASD (e.g., maternal marital stress and depression can influence child behavior) [37]. Another study reported that the most important stressors for the parents of children with ASD are: the permanence of the disorder, lack of acceptance of ASD-associated behaviors by the family members and society and low levels of support available. Among the stressors identified were also included: the financial difficulties due to raising a child with ASD, parents concern about the child's future, behavioral problems and parents' psychological characteristics (perceived self-efficacy, locus of control and coping styles) [57].

Parents of children included in the study showed higher mean scores for emotional distress and average for the negative dysfunctional emotions, compared with the norms for general population. These results can be explained by the impact of raising a child with a developmental disorder, considering that some children did not received any form of psychological intervention to help parents manage the disorder-associated problems. The increased levels of negative dysfunctional emotions and emotional distress may be due to the child developmental problems, but it was not specific to the diagnosis.

Several studies assessed the levels of stress, anxiety, and depression in parents of children with ASD [30, 32]. Stress, coping style, and parental self-efficacy emerged as important factors associated with QoL. The results of a recently published review [58] suggested that parental stress was negatively associated with QoL and also that parents of children with ASD are more likely to experience high levels of stress [59].

Emotional or behavioral problems are probably based on the maladaptive and irrational beliefs about selves, world, and life. The results of an unpublished study showed that people with high levels of distress presented more maladaptive cognitions, irrational beliefs, and dysfunctional attitudes, while having a diminished unconditional acceptance of self, when compared to people with low-distress levels [60].

The frequency of negative automatic thoughts on self is theoretically associated with depression. Parents' mean scores indicated a high level of negative automatic thoughts. For the irrational beliefs measured by ABSs, the mean scores were very high, high level of irrationality being usually associated with emotional distress, anxiety, depression, and various cognitive distortions. Both automatic thoughts and irrational beliefs correlate positively and statistically significant with all measured scores of emotional distress. Self-efficacy represents a person belief that their actions can be/are responsible for the success of a particular activity. Parents reported low to medium levels of self-efficacy. High levels of self-efficacy are positively correlated with unconditional acceptance, optimism, and self-esteem. Studies have shown a negative relation between the levels of anxiety and self-

efficacy. It was demonstrated that self-efficacy improved parental well-being [61], but very few studies addressed its impact on parental QoL. Parental self-efficacy in managing their children's problems and dealing with other family problems was found to be an important factor associated with QoL [53, 58].

Coping refers to a person cognitive and behavioral effort to adapt to a stressful situation. Generally, two types of coping strategies are used: problem-oriented (adaptive coping) and emotion-centered (maladaptive coping). Problem-oriented coping strategies address directly the problem causing the stress, while emotion-centered coping involves strategies to reduce the stress created by the problem. Although more studies emphasized the role of coping in parental adjustment, results were conflicting on the specific coping strategies that were associated with QoL due to the variation in the measurements used and in the theoretical conceptualization of coping. Hastings et al. identified four key coping dimensions: active avoidance coping, problem-focused coping, positive coping, and religious/denial coping [62]. Other studies reported that the use of emotion-oriented coping is associated with parents' low quality of life [30, 63]. A chronic and general trend of using suppression as coping strategy may result in increased frequency of the thoughts that the person tries to avoid, and may be a precursor or a maintenance factor to certain psychopathological conditions. Suppression measured by WBSI correlated to all scores of emotional distress. Further research on the relationship between coping dimensions and QoL is necessary to establish which coping styles are helpful when raising a child with ASD. Future studies should aim at distinguishing between ASD and other conditions when examining parental coping and QoL.

The scores reported by the parents on the cognitive coping strategies measured by CERQ showed above average use for catastrophizing, average use for self-blame, acceptance, rumination, refocus on planning, positive reappraisal, putting into perspective, and below average for positive refocusing and blame others. Parents' emotional distress correlated significantly with self-blame, rumination, positive refocusing, catastrophizing, and blame others strategies. For the strategies self-blame, rumination, catastrophizing, and blame others, the positive correlation indicates that their frequent use associated with higher emotional distress levels. The positive refocusing, positive reappraisal, refocus on planning strategies registered negative relationships with different scores of emotional distress, meaning that their frequent use associated with lower emotional distress levels.

The study on parents' irrational beliefs and negative automatic thoughts as mediators of the relationship between the overall assessment of family quality of life and parents' emotional distress showed that of the total effect of the overall assessment of family quality of life on the parents' emotional distress, 38.9% is explained by their negative automatic thoughts and 23% by their irrational cognitions. Therefore, correct identification of parents' irrational cognitions and negative automatic thoughts and their relationship with quality of life (that became the main therapeutic outcome) are essential for adequate family support and therapy efficiency. These results suggest that the development of support services for parents in order to reduce negative automatic thoughts and irrational beliefs could have a beneficial effect on the families' quality of life and level of distress experienced due to raising a child with developmental disorders.

## 4.2. Study limits

The study is cross-sectional and the results do not allow a causal relationship deduction. Also, the clinical sample size was relatively small. The instruments were filled in by a parent (mother) and the answers reflect its perception on the family quality of life. The parents were asked to answer the questions considering different periods of time (ranging from 2 weeks to the last 2 months) and the reporting accuracy could be reduced. The tested variables were analyzed in relation to the overall assessment of family quality of life. They may have an impact on certain areas or domains included in the family quality of life assessment (e.g., health, financial well-being, etc.), but not change the overall perceived family quality of life. The mediation analyses were also calculated using the overall assessment of family quality of life scores. The psychometric instruments used do not fully identify the emotional regulation mechanisms and some cognitive or noncognitive strategies may be excluded or not considered. Also, emotions and regulation strategies are difficult to separate, but the instruments used were standardized, validated, and proved to be optimal in previous studies. The results will reflect the experience of families of children with ASD and ADHD who receive specialized services in the Child and Adolescent Psychiatry Clinic from Cluj-Napoca and other specialized centers in the country, and that exclude some families with children diagnosed with ASD or ADHD who do not have health insurance, live in rural areas or the financial status does not allow them access to specialized services.

## 5. Conclusion

There were no statistically significant differences between the levels of emotional distress, negative dysfunctional emotions, worry/anxiety dysfunctional emotions, sadness/depression dysfunctional emotions reported by parents, in relation to the intensity of children's affective, anxiety and behavioral problems. Increased levels of emotional distress may be due to child developmental problems, but it is not specific to the diagnosis. We found significant correlations between the emotional distress reported by the parents and their automatic negative thoughts and irrational cognitions, the relation intensities varying from medium to high [1]. Significant correlations were obtained also for the relationship between parents' emotional distress and the coping strategies: self-blame, rumination, positive refocusing, positive reappraisal, blame others, and catastrophizing. The level of parents' emotional distress proved also to be linked with the use of suppression strategy and self-perceived efficacy. Part of the relationship between the overall assessments of family quality of life with parents' emotional distress was explained by their irrational beliefs and negative automatic thoughts, the mediating effect being partial. In this view, the specialized services should include also interventions for the parents of children with developmental disorders (ASD, ADHD) [1]. Adaptive coping mechanisms, low levels of perceived distress, irrational cognitions, and negative dysfunctional emotions may become relevant outcomes for parents' psychological interventions due to their impact on the assessment of the overall family quality of life.

Future studies should investigate more links between the emotional distress, cognitive strategies used, irrational cognitions, self-efficacy, negative automatic thoughts, and the satisfaction

with QoL. These studies should be longitudinal, with large clinical samples and involving different pathologies. Thus, the reported quality of life could be more accurately assessed in the processes of establishing and monitoring the therapeutic outcomes.

### **Conflict of interests**

The authors declare that they have no conflict of interest.

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