



ORIGINAL ARTICLE

Impact of ADHD symptoms on family functioning, family burden and parents' quality of life in a hospital area in Spain

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Abstract

Background and objectives: The aim of this study was to evaluate whether ADHD symptom severity and ADHD subtype are associated with family functioning, family burden and quality of life, in a sample of parents of children diagnosed with ADHD.

Methods: Seventy-four parents of children diagnosed with ADHD were recruited at an Outpatient Child & Adolescent Mental Health Clinic in Madrid (Spain) and afterwards completed four electronic self-administered scales to determine their perceived family functioning, family burden and quality of life, as well as the severity and subtype of ADHD symptoms in their children.

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Results: Severity of children's ADHD symptoms negatively affected parents' quality of life, family functioning and family burden. Higher scores in inattention and combined subtypes were correlated with lower results in those domains. In adjusted correlations, the SWAN hyperactivity/impulsivity subscale significantly correlated with the four scales.

Conclusions: These results suggest that severity of the ADHD symptoms has a negative impact on parent's quality of life and family functioning in inattention and combined subtypes. Family therapy and other interventions targeted towards improving family relationships and caregivers' wellbeing should be considered when managing ADHD in the clinical practice. Electronic measurement tools are a promising method of evaluation in mental health research.

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Introduction

Attention-deficit/hyperactivity disorder (ADHD) is the most common mental illness in children. Worldwide prevalence of ADHD is about 5.9%–7.1%.¹ In Spain, prevalence of ADHD is estimated at 6.8%.² According to the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5), ADHD is a neuro-developmental disorder characterized by inattentive and/or hyperactivity-impulsive behavior.^{3,4} ADHD has three different types of presentation: inattentive type, hyperactive/impulsive type, and combined type.³

ADHD has an impact on the family unit, increasing family burden and decreasing family functioning and quality of life (QoL) of both the children and their parents.^{5–7}

Studies show that ADHD places a significant burden on caregivers, economically as well as socially and emotionally.^{8–10} Regarding family functioning, observational studies of children with ADHD and their parents have shown conflicted parent-child interaction patterns and dysfunctional parenting styles.^{11,12} In families with children with ADHD, simple daily home activities such as doing homework or going to bed can be a challenge.^{13,14} Moreover, parents of children diagnosed with ADHD are more likely to present with marital problems.¹⁵

Additionally, the quality of life of caregivers can be affected by the disease. Thus, parents of children with ADHD are more likely to develop psychological, social, and physical problems than parents of asymptomatic children.^{11,16,17} Parents of children with ADHD have increased levels of distress, decreased parenting esteem and feelings of parental incompetence.^{12,18–21}

Previous research has shown that symptom severity may increase the impact of ADHD on the family unit,^{22,23} and that evidence-based treatments may improve family outcomes.^{24,25}

In spite of the body of research describing the impact of ADHD on family burden, family functioning, and QoL, the evidence about the distinct influence of each ADHD subtype is scarce. The aim of this study was to evaluate whether ADHD symptom severity and ADHD subtype are associated with family functioning, family burden and QoL, in a sample of parents of children with ADHD. We hypothesize that ADHD symptom severity and ADHD subtype will be associated with these variables.

Methods

Setting and design

This is a cross-sectional study carried out at the University Hospital Fundación Jiménez Díaz (Madrid, Spain). This hospital has a catchment area of over 100,000 people. Parents of children diagnosed with ADHD (one parent per child) were recruited from our Child and Adolescent Psychiatry Unit, where their children were treated at.

Sample

We performed a sample size calculation and found that we needed at least 70 participants in order to detect a correlation of 0.65 with a power ($1-\beta$) of 0.8 at a 95% confidence interval (CI).

Inclusion criteria were:

- Being the parent of a child diagnosed of ADHD in accordance with the Diagnostic and Statistical Manual of Mental Disorders — 5th edition (DSM-5) criteria.³
- Speaking Spanish fluently.
- Owning a personal computer with internet connection to be able to complete at-home computerized assessments (MEmind platform).
- Being able to provide written informed consent.

Exclusion criteria were:

- Being the parent of a child with a major psychiatric disorder different from ADHD, such as schizophrenia, autism-spectrum disorders, depressive disorders, or addictions.
- Not being able to provide written informed consent.

Parents were offered participation during their children's regular visits. After describing the study, written informed consent was obtained from Spanish-speaking parents (or legally authorized representatives) and patients who agreed to participate, respectively. Participation was voluntary. Participants did not receive any compensation for their participation.

Measures

Psychometric instruments were self-administered to parents using the electronic platform MEmind. This is a computer-based platform that allows to fill the electronic versions of the scales and automatically calculate scores. The parents of each child completed this self-assessment at their homes, directly on the computer. The computerized Spanish versions of the following scales were used:

- To measure general mental health problems, we used the General Health Questionnaire-12 (GHQ-12): a questionnaire consisting on 12 items assessing the presence and severity of mental health problems. Each item is scored 0–3 and global score is scored 0–36.^{26,27}
- To measure family burden, we used the Zarit Burden Interview: a 22-item self-report inventory that examines the burden associated with functional/behavioral impairments and the home care situation. The items are worded subjectively, focusing on the affective response of the caregiver. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale, ranging from “never” to “nearly always”.^{28,29}
- To measure family functioning we used the Family APGAR: the scale assesses the family member’s perception of family functioning by reported satisfaction with the five dimensions of family functioning: adaptability, partnership, growth, affection, and resolve. The response options were designed to describe the frequency with which individuals feel satisfied with each parameter, measuring these aspects according to a 3-point scale ranging from 0 (hardly ever) to 2 (almost always).^{30,31}
- To measure quality of life we used a Visual Analog Scale (VAS) created ad hoc by the Department of Translational Psychiatry of the Fundación Jiménez Díaz and included as one of the electronic questionnaires administered by the MEmind digital tool. Parents were asked to rate their own level of satisfaction in different life areas: themselves, family, friends, work, and leisure activities. Parents rated these aspects on a scale of 0–10, with greater numbers indicating more satisfaction.
- To measure ADHD-related symptoms we used the Strengths and Weaknesses of ADHD symptoms and Normal behavior rating scale (SWAN): composed of 18 items based on the DSM-5 criteria for ADHD diagnosis, measuring positive attention and impulse-regulation behaviors in the normal population. The scale consists of 3 factors. The first factor is related to inattention and comprises the first 9 items. The second factor, which includes 6 items, measures hyperactivity. The last factor, which comprises the last 3 items, characterizes impulsivity. In the standard form, each item is scored from –3 to +3, where 0 is “normal” and based on the population average.^{32,33} In order to adapt it to the electronic tool MEmind, the score of each item was transformed into a scale from 0 to 100.^{34,35}

Statistical analysis

Statistical analyses were performed using SPSS 25.0 (SPSS, Chicago, IL, USA). Descriptive analyses—percentage, mean,

Table 1 Baseline characteristics of the sample.

Parents (n = 74)		
	n (%)	Mean (SD)
Sex		
Male	19 (25.7%)	
Female	55 (74.3%)	
Age		46.32 (6.78)
Educational level		
University degree	39%	
High school diploma	36%	
Basic Education	25%	
Children/Adolescents (n = 74)		
Sex		
Male	56 (75.7%)	
Female	18 (24.3%)	
Age		12.45 (2.58)
ADHD subtype		
Combined	44 (59.5%)	
Inattentive	28 (37.8%)	
Hyperactivity/impulsivity	2 (2.7%)	
Receiving psychopharmacological medication	67 (90.5%)	

and standard deviation (SD)—were conducted for demographics and clinical variables. We calculated the mean, median, and SD of each measurement instrument. We tested the normality of each scale using the Kolmogorov–Smirnov test. Finally, Pearson analysis were calculated to explore the correlation between the ADHD symptom severity and ADHD subtype and family functioning, family burden and QoL. All tests were 2-tailed. Significance was established at the 0.05 level, with 95% CIs.

Ethical considerations

This study has been approved by the Institutional Review Board of Fundación Jiménez Díaz Hospital. All procedures were conducted in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.³⁶

Results

Baseline characteristics of the sample

Our sample consists of 74 parents (55 mothers, 19 fathers) of 74 children (18 girls, 56 boys. All participants were Caucasian. The mean age of the children/adolescents diagnosed with ADHD was 12.45 and the majority were male (75.7%). Combined subtype was the most common diagnosis (59.5%). 90.5% of patients were undergoing pharmacological treatment at the time of the evaluation. Two of the children included in the sample presented anxiety as a comorbidity. There were no other comorbid conditions among children. Table 1 shows the full sociodemographic characteristics of

the children/adolescents diagnosed with ADHD and their parents.

Results of the correlation analyses

All participants completed the self-administered questionnaires. The mean, median, and SD for each score are shown in Table 2. High scores on each of the scales positively correlated with high scores on the rest of the scales. The GHQ-12, Family APGAR, and VAS scales showed a significant correlation with the SWAN inattention score. GHQ-12 score was correlated with SWAN complete score. Moreover, we found a statistically significant negative correlation between SWAN inattention score and Zarit, indicating that in children with lower scores on the SWAN scale there was a negative influence on their parents' burden. Finally, none of the four scales showed a significant correlation with SWAN hyperactivity/impulsivity score. Table 3 shows the correlation between ADHD symptom severity and subtype and the different variables.

Adjusted correlations showed similar results with regards to correlations between scores of the inattention and complete subscales of SWAN and GHQ-12 and VAS scales. In adjusted correlations, the SWAN hyperactivity/impulsivity subscale did not correlate significantly with any of the four scales.

Discussion

This study examined family burden, family functioning, and QoL of parents of children diagnosed with ADHD, and the relationship between these factors and ADHD symptom severity and ADHD subtypes.

ADHD symptom severity

Our findings suggest that the severity of the ADHD symptoms—especially for the inattention and combined subtypes—may influence parents' well-being. Increased severity in the SWAN scale for the inattention and combined subtypes was associated with worse scores on the GHQ-12 scale, indicating higher levels of psychological distress. This is consistent with previous studies, which have found increased stress levels among caregivers of people with ADHD.³⁷ Taking care of a family member with ADHD has been related to worse caregiver health³⁸ and higher family stress.³⁹

Our results also indicate that higher severity of ADHD symptoms is associated with an increased family burden and decreased family functioning. Previous studies show that ADHD produces an increasing burden on families. Some of the mediators of such increased burden are poor academic performance,⁴⁰ impaired social interaction,⁴⁰ behavioural problems,⁴¹ and increased financial costs, both direct and indirect.⁴² Furthermore, families of children diagnosed with ADHD may have feelings of stigmatization, shame, guilt, and social rejection.⁴³ Parenting styles are also affected by ADHD: previous studies that parents of children diagnosed with ADHD tend to use negative reactive and less positive parenting strategies than control parents.⁴⁴ In return, the

way they deal with their children may have an influence on behavior difficulties experienced by the children.⁴⁵

Given the cross-sectional nature of our study, no firm conclusions can be drawn regarding the direction of the association between the severity of ADHD symptomatology and parental distress. While ADHD and its daily challenges can deteriorate the family's well-being, studies also show that dysfunctional parenting styles are a risk factor for the development of ADHD.⁴⁶

ADHD subtypes

Unexpectedly, we found that the inattentive subtype was the one with a higher impact on family burden. Research on inattention symptoms are limited, though the impairments involved appear to be partially distinct from hyperactive-impulsive and combined subtypes.⁴⁷ A previous study showed that the hyperactive/impulsive and the combined subtypes may have greater impact on caregiver's stress and QoL.⁴⁸ However, another study has described attention problems as the most important in determining the burden on parents or caregivers.⁴⁹ Children diagnosed with the inattention subtype tend to be assessed and treated later than children with hyperactivity/impulsivity.⁵⁰ The delay in the treatment of those children may be related to the burden, worse family functioning, and to their parents' psychological distress. In addition, our results suggest that correlations become stronger when adjusted for age, suggesting that age of children diagnosed with ADHD is an important factor to consider when studying the impact of ADHD in the family unit. Thus, the way in which each of the subtypes of ADHD is related to greater or lesser family impact may change according to the age of the child, since previous studies have shown that age can have a great influence on both the underlying mechanisms and the expression of ADHD.^{51,52}

The potential of electronic health (eHealth)

The possibility of completing the self-assessment at home using the computer increases the validity of results, since the usual environment of the participants is respected.⁵³ In addition, several studies show that patients may be more comfortable discussing their symptoms and problems with computerized assessments than with face-to-face interviews, both in psychiatry and in other areas.^{54–56} EHealth tools have been previously studied in the evaluation of differential patterns of emotion dysregulation, emotional impulsivity, and behavioral difficulties among children with ADHD.^{57,58} These tools may also be useful to assess emotional disturbances in parents of children diagnosed with ADHD. We consider that these results provide promising evidence in favor of using electronic methodologies as a primary evaluation method instead of the paper/standard evaluation, at least in the population analyzed. However, these findings are preliminary, and more are necessary to obtain a consensus opinion. Further studies might improve our ability to understand, assess, and provide services to aid parents affected by this disorder.

Table 2 Mean and median scores for each assessment tool among parents with children diagnosed with ADHD.

	SWAN	GHQ-12	Zarit	Family APGAR	VAS
Mean	767.15	9.42	51.91	7.77	34.88
Median	758.50	11.00	50.50	8.00	35.80
SD	298.12	3.30	15.07	2.16	7.26

GHQ-12: General Health Questionnaire-12; SD: standard deviation; SWAN: Strengths and Weaknesses of ADHD symptoms and Normal behavior rating scale; VAS: visual analog scale.

Table 3 Pearson's correlation matrix between SWAN scores and the rest of the assessment tools scores among parents with children diagnosed with ADHD.

	GHQ-12	Zarit	Family APGAR	VAS
SWAN complete	0.325 ^a	-0.221	0.226	0.252 ^a
SWAN inattention	0.394 ^a	-0.273 ^a	0.247 ^a	0.409 ^a
SWAN hyperactivity/impulsivity	0.208	-0.137	0.167	0.072

GHQ-12: General Health Questionnaire-12; SWAN: Strengths and Weaknesses of ADHD symptoms and Normal behavior rating scale; VAS: visual analog scale.

^a Correlation is significant at the 0.05 level (2-tailed).

Limitations

Although these results may be considered as a starting point for future studies focused on parents of children with ADHD, the present study has some limitations. First, a cross-sectional electronic tool was used in this preliminary study, whereas better assessment of QoL and burden of parents and caregivers should be assessed using a longitudinal measure. Second, all children were identified as Caucasians and most were males. In order to explore the relationship between gender and race, future studies should include substantial number of girls and add different races. Third, most of the parents were mothers, and future studies should include a higher proportion of fathers to study the different results depending on the gender of the parent. Fourth, two children presented with comorbid anxiety, which may introduce some bias. Finally, this was a hospital-based study, which may preclude generalizing our findings to the community level.

Conclusion

This study supports the notion that ADHD has a significant impact on the parents' QoL, family burden, and daily functioning of the family. This impact also seems to be related to ADHD symptom severity. Additionally, and contrary to expected, inattention and combined subtypes seem to have a greater impact on the family unit than hyperactive subtype. Although these findings shed some light on the impact of ADHD on the family unit and on the caregivers, further investigation needs to be done to expand our knowledge in this area.

Conflict of interest

The authors have no conflict of interest to declare.

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