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Quality of Life in Attention Deficit Hyperactivity Disorder: Children's Self-Report in Detail

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Abstract

ADHD is a health problem with implications in academic, psychological, social and motor performance. The perspective of the child's quality of life is currently considered reliable and should be further explored to guide intervention planning. This study aimed to analyze each item of a quality of life questionnaire, comparing Attention Deficit and Hyperactivity Disorder (ADHD) and typically developing children, and verify which specific situations may contribute to their difficulties. Eighty-five children were included, distributed into two groups: 42 children with ADHD and 43 typically developing children. Pediatric Quality of Life Inventory TM 4.0 assessed quality of life. Differences between groups were found on to do chores around the house (p=0.032), to feel afraid or scared (p=0.033), and angry (p=0.040), to get along with other kids (p=0.023), to pay attention in class and to forget things (p=0.000), to keep up schoolwork (p=0.001). In addition, children with ADHD perceived that other kids do not want to be their friends (p=0.038), other kids tease them (p=0.026), they cannot do things that other kids the same age can do (p=0.032). The current study was mild and different from those of other pediatric reports that have included in children with ADHD. Our results reinforce the findings of worse quality of life in this population and add the understanding that this impact reflect a self-perceived of greater difficulty in social relationship with peers, emotional control related to anger and fear, and difficulty in school attendance.

Keywords: Attention Deficit and Hyperactivity Disorder (ADHD); Quality of life; Children; Social impairment

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Introduction

Attention Deficit and Hyperactivity Disorder (ADHD) is a health problem, which implications that range from difficulties in academic performance to psychological, social and motor problems [1,2]. It has a characteristically persistent pattern of inattention, hyperactivity and/or impulsivity, more frequent and severe than typically observed in individuals with equivalent level of development [3].

According to Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), ADHD is considered a neurodevelopmental disorder, manifested generally before starting school [3]. Children with ADHD usually are not able to consciously select the task or the priority object of their action and do not have control of their own body, showing a lack of harmony between feeling, thinking

and acting [4,5]. These difficulties lead to losses in many areas of life, including relationships with adults and peers, academic performance, higher rates of school failure, suspensions and expulsions from school [6,7].

The disorder has a chronic course and is associated with a number of complications in childhood, adolescence and adulthood [8,9]. Several authors emphasize that 60 to 70% of these children become symptomatic adults [10,11]. The persistence of this disorder and its remission rates are not yet clear, however, there is current evidence regarding the association between symptoms continuation and severity in childhood [10].

The main goal treatment of ADHD (as well as in most mental health problems in children) is a reduction of symptoms, improvement of functionality, children's well-being and in contact with their families and peers [12]. However, measuring treatment response often becomes difficult, even why would it be considered effective if does not positively affect the individuals' quality of life? Therefore, it is important to use instruments that can assess and monitor the effects of treatment [13,14].

The multi-dimensional constructions of quality of life instruments have been increasingly applied in research with children with ADHD to better understand daily experiences of these children in relation to their health and well-being [15]. The World Health Organization defines quality of life as "an individual's perception of their position in life in context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [16].

In this definition, six main areas are included: physical health, psychological state, independence level, social relationships, environmental characteristics and spiritual standard [16]. In addition to the great influence of these conditions in quality of life, there is also direct interference of proximal (family and friends) and distal forces (socioeconomic and cultural factors). Besides the effects of physical disease on quality of life, there is now substantial evidence that neurodevelopmental disorders have greater impact [13,16].

The child's perspective of their quality of life has currently been considered valid and reliable, except in cases where the child is too young, has intellectual disability, is too ill or fatigued to complete the assessments. In these cases, only the parent's opinion is considered. It is important to emphasize that the agreement between parents and child regarding the child's quality of life is higher when related to physical domains, such as walking and running, and lesser in terms of emotional and social functioning, such as internalizing symptoms [17]. Regarding children with ADHD, studies have reported that they have awareness and insight of their difficulties [18].

For a better understanding of which situations are crucial to the quality of life of these children, we consider important to evaluate the child's self-report in detail. Therefore, we believe it is possible to understand in which moments ADHD child feels more difficulties, and this detailing could help to generate appropriate intervention, aiming to provide and measure the extent of these disorder in child well-being. In this scenario, this study aimed to analyze each item of a quality of life questionnaire, comparing children with ADHD with typically developing children.

Research Methodology

Participants

Eighty-five children, aged between 8 and 12 years (M=9.10, SD=1.21), were distributed into two groups: 42 children clinically diagnosed with ADHD (ADHD group) combined presentation (inattention, hyperactivity and impulsivity symptoms), and 43 typically developing children (TD group). Sociodemographic characteristics were described in **Table 1.**

Exclusion criteria for both groups were the presence of visual and/or hearing disturbances, heart disease, rheumatologic or orthopedic disorders and comorbidities such as other neurological and/or neuropsychiatric disorders according to DSM-5, except the Oppositional Defiant Disorder (ODD), due to its high comorbidity rate with ADHD, occurring in up to 60% of the cases [19]. Children who had undergone previous treatment for ADHD, with drugs introduction or cognitive behavioral therapy were also excluded because these therapeutic strategies could improve the scores of quality of life [20].

All parents and/or guardians that agreed to participate signed a free informed consent form before answering the questionnaire.

Assessment instruments

SNAP-IV Questionnaire: The SNAP-IV is a public domain instrument, translated for Brazilian population in 2006 by [20], with the aim of assessing symptoms of ADHD in children and adolescents. In this study, we used a shortened version with 18 items that evaluate symptoms of ADHD, which was answered by parents or teachers [21].

PedsQL™-Pediatric Quality of Life Inventory™ 4.0: Some aspects related to quality of life were assessed by PedsQL™

Table 1: Comparison between groups.

Variables	ADHD	TD	*p-value*
Mean Age	9.79	9.16	0.03*
Female	10	8	0.67
Male	33	35	
Family Income			
≤ 03 MW	53.66	58.14	0.67
>04 MW	46.34	41.86	
Marital Status			
Married	53.66	72.09	0.06
Single/Divorced	46.34	27.91	
Father's Education			
>08 years	56.1	72.09	0.25
05-08 years	14.63	4.65	
≤ 04 years	29.27	23.25	
Mother's Education			
>08 years	73.17	72.09	0.87
05-08 years	9.76	9.3	
≤ 04 years	17.07	18.6	

*d square test / mw = Minimum wages

scale. The generic module of the scale was chosen for this study due to present validation in Brazil and was considered suitable for our pediatric population [22]. It was designed to measure core dimensions of health, as outlined by the World Health Organization concerning physical, social, emotional and school functioning [23].

This instrument consists of 23 items (Physical Functioning: 8 items; Social Functioning: 5 items; Emotional Functioning: 5 items; School Functioning: 5 items). The questions refer to how each item was a problem during the last month, and the respondents use a scale of five levels (0=never a problem; 1=almost never a problem; 2=sometimes a problem; 3=often a problem; 4=almost always a problem). The results can be interpreted by the total score or grouped according to the areas: Physical Health and Psychosocial Health. In both cases, the score ranges from zero to 100 and the higher the score the better quality of life [22].

Procedure

The Local Research Ethics Committee (Protocol no. 0572/08) approved the study. For the ADHD group formation, a neurologist assessed children with disorder symptoms in the Ambulatory of Learning Disorders at Child Institute (University of São Paulo Medical School).

For the TD group formation, it was necessary a screening in public schools in the city of São Paulo, with SNAP-IV implementation for parents and teachers to the exclusion of ADHD symptoms and other possible diagnosis in these participants. After inclusion in ADHD and TD groups, parents or caregivers have filled an identification sheet with the following information: personal data of the child, family income, parent's educational level and marital status.

After this process, the presentation and management of PedsQL™ scale was held. The questionnaire was applied in children, only once, following a specific assessment for the age of eight to 12 years. All items were read to the children by the researcher.

Statistical analysis

Initially, Shapiro-Wilk test was employed to determine the framework of numeric variables in the model of Gaussian distribution. Then, values of mean (M), standard deviations (SD) and confidence intervals (95% CIs) were presented as descriptive statistics.

The Mann-Whitney U-test established the comparison between values. Statistical Package SPSS 20 was used for all calculations and level of significance was set at $p<0.05$.

Results and Discussion

Tables 2, 3, 4 and 5 presents descriptive data and comparison between groups respectively in Physical, Emotional, Social and School Functioning domains.

This study aimed at a better understanding of the situations that ADHD children experience and consider as harder to deal with by their self-perception, compared to typically developing children, and their direct influence in what is considered better or worse quality of life. For this, we analyzed each item of the PedsQLTM questionnaire in the following domains: Physical, Emotional, Social and School Functioning.

Physical functioning

In Physical Functioning domain there was a statistically significant difference only in the question "It is hard to me to do chores

Table 2: Comparison between ADHD and TD in the physical functioning domain-PedsQL™.

ADHD			TD			
About My Health and Activities (problems with...)	M	CI 95%	M	CI 95%	U Mann-Whitney	*p-value*
It is hard for me to walk more than one block	74.40 ± 5.35	63.59-85.22	79.07 ± 3.98	71.03-87.11	896.50	0.78
It is hard for me to run	81.55 ± 5.39	70.66-92.44	86.05 ± 3.65	78.67-93.42	912.50	0.89
It is hard for me to do sports activity or exercise	79.76 ± 4.68	70.30-89.22	89.53 ± 2.78	83.91-95.16	815.00	0.24
It is hard for me to lift something heavy	75.60 ± 5.35	64.78-86.41	66.86 ± 4.83	57.11-76.61	746.00	0.09
It is hard for me to take a bath or shower by myself	94.05 ± 3.16	87.65-100.44	96.51 ± 2.57	91.31 -101.71	862.00	0.25
It is hard for me to do chores around the house	68.45 ± 5.52	57.29-79.61	85.47 ± 3.45	78.50 -92.43	703.00	0.03*
I hurt or ache	79.17 ± 4.33	70.41-87.93	72.09 ± 4.49	63.02-81.17	787.50	0.19
I have low energy	69.05 ± 5.44	58.09-80.04	75.58 ± 4.03	67.44-83.72	879.00	0.67

*p<0.0/m=mean/CI=Confidence interval.

Table 3: Analysis of ADHD and TD groups in the emotional aspect domain-PedsQL™.

ADHD			TD			
About My Feelings (Problems with...)	M	CI 95%	M	CI 95%	U Mann-Whitney	*p-value*
I feel afraid or Scared	63.10 ± 4.36	54.28-71.91	76.74 ± 4.35	67.96-85.53	690.50	0.03*
I feel sad or blue	64.88 ± 4.43	55.93-73.83	78.49 ± 3.77	70.87-86.11	691.00	0.32
I feel angry	44.05 ± 5.50	32.92-55.17	60.47 ± 5.14	50.05-70.85	693.00	0.04*
I have trouble sleeping	82.74 ± 4.21	74.22-91.25	81.98± 4.26	73.36-90.59	896.50	0.77
I worry about what will happen to me	62.50 ± 5.13	52.14-72.86	63.95± 5.41	53.03-74.87	892.50	0.77

*p<0.05/m=mean/CI=Confidence interval.

Table 4: Comparison of the social functioning domain-PedsQL™.

ADHD			TD			
How I get along with others (problems with...)	M	CI 95%	M	CI 95%	U Mann-Whitney	*p-value*
I have trouble getting along with other kids	70.83 ± 5.58	59.56-82.11	88.37 ± 3.15	82.01-94.73	694.5	0.02*
Other kids do not want to be my friends	64.88 ± 5.99	53.59-76.17	82.56 ± 3.77	74.95-90.17	703.5	0.03*
Other kids tease me	57.74 ± 5.29	47.06-68.41	75.00 ± 3.72	67.49-82.51	679	0.02*
I cannot do things that other kids my age can do	59.52 ± 5.45	48.51-70.53	76.16 ± 4.48	67.13-85.20	688.5	0.03*
It is hard to keep up when I play with other kids	72.02 ± 6.10	59.71-84.34	84.30 ± 3.43	77.38-91.23	865.5	0.56

*p>0,05/m=mean/CI=Confidence interval.

Table 5: Analysis of groups ADHD and TD responses in the school activity domain-PedsQL TM.

ADHD			TD			
About School (problems with...)	M	CI 95%	M	CI 95%	U Mann-Whitney	*p-value*
It is hard to pay attention in class	55.95 ± 4.57	46.72-65.19	86.63 ± 3.25	80.05-93.21	400	0.00**
I forget things	41.07 ± 4.15	32.67-49.47	75.00 ± 3.72	67.49-82.51	327.5	0.00**
I have trouble keeping up with my schoolwork	63.69 ± 6.27	51.02-73.36	90.12 ± 3.44	83.17-97.07	594.5	0.00**
I miss school because of not feeling well	80.95 ± 4.32	72.21-89.69	83.72 ± 3.51	76.62-90.82	919.5	0.96
I miss school to go to the doctor or hospital	76.19 ± 4.89	66.31-86.07	88.95 ± 3.84	81.20-96.70	771.5	0.14

**p>0,001/m =mean/CI=Confidence interval.

around the house". This reflects the difficulty these children present in situations where it is necessary to organize, plan and establish routines. Usually in these moments, there is a tendency to not accomplish determined task or not finish what is expected. This behavior can bring losses in the relationship with parents/family, and difficulties in maintaining affective relationships in adulthood, difficulty in staying in a job for a long time or worse professional life related status [24,25].

Indirectly what is considered better or worse quality of life, and yet, in the other items of this domain the ADHD presented an approximation to the TD group score. These results suggest that aspects of physical functioning are similar between the groups, being a favorable point for the quality of life of these children. These results contradict studies that found poor motor performance in children with ADHD compared to typically developing children [26]. In this sense, we believe that these children demonstrate significantly incomes in specific tests that verified global motor coordination, fine motor coordination, and balance. However, functionally these difficulties are not self-perceived when questions are raised that encompasses these motor aspects in form of daily life activity. Corroborating a previous study [14], the results indicated that children with ADHD and their parents do not consider the domain of physical function as a negative impact factor in their lives. With this, activities that use physical skills stimulating resources can facilitate the integration of these children with their peers, as the difficulties they present will not be exposed, stimulating the creation of bonds with other children.

Another research [26] also used the PedsQL™ generic module for evaluation of children with ADHD diagnosis, however with other psychiatric disorders besides ODD (as was done in this study) as mood, anxiety and behavior disorders, etc. They found that children presented worse scores in all domains of the instrument, including Physical Functioning, which may had occurred due to comorbid disorders that affected aspects of children's quality of life in a more intense way.

Emotional functioning

Our results showed that children with ADHD presented a greater sensation of fear, suggesting that they feel more insecure, what may be associated with fear of failure, difficulties in autonomy and low self-esteem, and reflect over their lives [27,28]. These findings are in line with a previous study that evaluated ADHD children and their behavior through child's self-perception and parents' report. In addition, parents' perception of their child relationship was also assessed. In this research, it was observed that, as the interaction between parent and child becomes more difficult, which occurs more frequently due to difficulty of self-regulation that the child with ADHD presents, insecurity and anxiety feelings of ADHD child worsen [27]. We emphasize that children with anxiety disorder were excluded in the current study in the neurological evaluation, according to DSM-5 criteria.

In the item "I feel angry", there was also statistical significance between ADHD and TD groups, indicating a higher intensity of this feeling through individuals who have ADHD. This difference between groups reflects a frequent and harmful feeling for these children. Anger is a state of arousal resulting from social conditions that involve threat or frustration and which generates an unpleasant sensation to angry person or to those who are involved [29]. The results of this feeling are not limited to physical aggression alone, but impairments in interpersonal relationships, school problems, anxiety, depression and even substance abuse.

Several studies report a more intense presence of anger in these individuals and the difficulty of controlling this feeling, presenting emotional impulsivity and being able to engage in conflicts more frequently than children with typical development [30-32].

It is important to emphasize that this interferes in a negative way in quality of life of these children and may also reflect in relationships with their relatives and peers. It is important to emphasize those patients with depression, bipolar disorder; severe mood dysregulation and anxiety were excluded from the analysis according to DSM-5 criteria.

Regarding the item "I have trouble sleeping", participants in this study did not observe difficulties, which differs from several studies that relate sleep problems as one of the factors that may even worsen ADHD symptoms and directly influence the quality of life of these individuals [33,34]. Possibly in this study, the child's perception of sleep problems may be influenced by the difficulty of understanding what is a sleep problem, since other studies indicate that approximately 50% of children with ADHD, according to reports of parents, have difficulty initiating sleep and/or maintaining sleep [34]. Early identification of these risks is important so that appropriate interventions can be performed to improve these emotional compromises suffered by these children, avoiding or minimizing the effect throughout their lives.

Social functioning

It was observed that according to the child's perception, there was statistical significance in all the administered questions, except at keeping up when playing with other children, indicating that this is one of the domains of great loss to these children. Corroborating with the literature that reports impairment in social behavior and adjustment problems, directly influencing the quality of life of these patients [35,36].

In our study, children with ADHD reported greater difficulty in living with other children, feeling more provoked by others and excluded from the social group in which they live. These findings reinforce previous results [35] indicating that boys with ADHD have a positive relationship in being the bully and the girls in being victims of this behavior. Suggesting as a hypothesis that bullying, both in practicing it and in being a victim of it, is related to ADHD symptoms and the greater difficulty that they present to mediate their school difficulties besides the rejection by their peers.

It is also important to analyse items which there was no statistical difference, because if the child with ADHD notices difficulty in doing things that their peers do, he/she feels provoked by his/her colleagues and also that others do not want to be his/her friends, how will they keep up with the play? At what point will real integration with other children happen? For the accompaniment of ludic activities, it is necessary integration, to feel as part of the whole, and we observe from the other items answered that this fact does not occur in the proper way. The behavior in preschool children with ADHD was observed and compared to children without the disorder in free play activities, and children with ADHD have greater difficulty in getting involved in games because of attention difficulties, consequently they played less than their peers, besides a greater exchange between games due to difficulty in maintaining the same task for longer [37]. According to these findings, it is important to think about the maturational process of these children, as in the current study, they do not consider to present difficulties in keeping up with playing. Some studies [38] suggested that children with ADHD tend to overestimate their social and academic abilities, when compared to the perception of parents and teachers, what may be a self-protective mechanism due to negative feedback that they receive from adults who live with them. Another factor that may influence this result is the delay in cortical maturation presented by these children [39].

School functioning

When analyzing items of School Functioning domain, results obtained statistical significance in the items “It is hard to pay attention in class”, “I forget things” and “I have trouble keeping up with my schoolwork”. Individuals with ADHD have deficits in executive functions, such as worse inhibitory response, vigilance, cognitive flexibility, operational memory and planning [40,41]. These difficulties do not determine the diagnosis of ADHD; however, they are identified as frequent signs in patients [42,43] and may be related to the questions present in SNAP-IV about inattentive symptoms [21]. It is important to relate deficit in executive functions to the worst performance in academic world. A study with children who presented difficulties in mathematics, without ADHD diagnosis, worse performance was observed in tasks related to operational memory [41]. In the current study, children with ADHD reported greater difficulty in items in the domain related to situations that favor learning and that need attention, memory and self-control. Precisely situations that demand greater cognitive control and those individuals with ADHD present a greater delay for acquisition [44,45].

The results of this study corroborate others, reaffirming the fact that poor academic performance is a limiting factor and the need for specialized intervention for a more adequate professional and social growth [46-48]. The early investment in diagnosis and interventions is decisive, considering the need to create special support groups, avoiding or reducing personal and family suffering, as well as negative influence in adult life [49]. Academic performance of hyperactive adolescents is considerably lower than their peers without the disorder [11]. Individuals with ADHD have high rates of school failure (three times greater than typical subjects), suspensions or expulsions. Patients with ADHD had 2.5 years of study less than controls, and 23% did not complete their studies, when compared to 2% of the control group [50]. Educational and occupational outcome of hyperactive boys grown up. Studies suggest that adults with ADHD have poorer professional status, poorer job performance, and lower job stability [51].

The present study presented some limitations that should be considered in future research. For example, the sample number is small when compared to the large presence of this disorder in the pediatric population, although we included only treatment-naive patients for ADHD and excluded children with other comorbidities, with the exception of ODD. The impossibility of cluster by disorder presentation could not differentiate the impact

on quality of life according to different ADHD presentations. Another limitation was the use of the PedsQL™ generic scale of quality of life. It may reflect difficulties that children with the disorder may present, however, the possibility of a more specific instrument for neurodevelopmental disorders could bring better detailing of the difficulties presented by this population, but a specific instrument for mental disorders in school age has not yet been translated and validated in Brazil.

We believe that more national studies should be carried out to evaluate issues related to quality of life, well-being, self-esteem and psychosocial functioning, since they are still scarce in the Brazilian population. We also consider it important that other instruments would be developed for the specific assessment of children with the mental disorders and peculiarities that this population has. We emphasize the importance of investing in interventions that can act directly on the issues raised in this study, with the evaluation of the quality of life of these children before and after the chosen treatment. We highlight the importance of this issue in daily life of ADHD patients, in preschool, school, adolescence and adult life, so that strategies interfere positively in these individuals quality of life, since negative impact it can have on their lives and the lives of their family members has been demonstrated in several other studies.

Conclusion

The current study was mild and different from those of other pediatric reports that have included in children with ADHD. Our results reinforce the findings of worse quality of life in this population and add the understanding that this impact reflect a self-perceived of greater difficulty in social relationship with peers, emotional control related to anger and fear, and difficulty in school attendance.

Conflict of Interest

The authors declare that they have no conflict of interest.

Informed Consent

Informed consent was obtained from all parents by participants included in the study.

Ethical Approval

All procedures performed in studies involving human participants were 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.

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