



Quality of life in attention-deficit hyperactivity disorder: perception of parents and children

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Date of online publication:
22-marzo-2020

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Abstract

Introduction: health-related quality of life (HRQoL) is a relevant dimension in the evaluation of attention-deficit hyperactivity disorder (ADHD) and the effectiveness of its treatment. The aim of our study was to analyse discrepancies between parents and children in the perception of HRQoL in children with ADHD receiving pharmacological treatment, children with untreated ADHD and controls.

Material and methods: the sample included 228 children aged 8 to 14 years (114 controls, 57 cases of ADHD-Tx and 57 cases of ADHD-UT). We recruited patients with ADHD based on the DSM-IV criteria (ADHD Rating Scales IV) by consecutive sampling with random sampling of controls matched for sex and age. We assessed HRQoL through the 10 dimensions of the KIDSCREEN-52 in the child self-report and parent proxy report.

Results: we found significant differences between the parent and child reports in 3 out of 10 dimensions of the KIDSCREEN-52 in the control group (self-reliance, self-perception and financial resources), in 4 dimensions in the ADHD-Tx group (psychological well-being, self-perception, school environment and financial resources), and in 6 dimensions in the ADHD-UT group (psychological well-being, physical well-being, mood, self-perception, school environment and financial resources). In every dimension in which we found significant discrepancies, children perceived their HRQoL more positively than their parents, with the exception of financial resources, which children perceived more negatively. We did not find significant discrepancies between parent and child reports in the control, ADHD-UT or ADHD-Tx groups in the social acceptance, parent relations and peers dimensions.

Conclusion: the perspectives of both parents and children regarding HRQoL should be taken into account in the evaluation preceding any form of clinical intervention.

Palabras clave:

- Attention-deficit hyperactivity disorder
- Methylphenidate
- Quality of life

Resumen

Calidad de vida en el trastorno por déficit de atención con hiperactividad: percepción de padres e hijos

Introducción: la calidad de vida relacionada con la salud (CVRS) es una dimensión relevante en la evaluación y consideración de los efectos de un tratamiento en el trastorno por déficit de atención con hiperactividad (TDAH). El objetivo del estudio es analizar las diferencias entre la percepción de padres e hijos en la CVRS en casos TDAH tratados farmacológicamente (TDAH-T), casos no tratados (TDAH-N) y controles.

Material y métodos: muestra de 228 participantes entre 8 y 14 años (114 controles, 57 TDAH-T y 57 TDAH-N). Muestreo consecutivo de TDAH según DSM-IV (ADHD RS-IV) y muestreo aleatorio de controles emparejados por sexo y edad. Evaluación de CVRS mediante las diez dimensiones del KIDSCREEN-52 versión padres y versión hijos.

How to cite this article: López Villalobos JA, Rodríguez Molinero L, Sacristán Martín AM, López Sánchez MV, Garrido Redondo M, Andrés de Llano JM, et al. Calidad de vida en el trastorno por déficit de atención con hiperactividad: percepción de padres e hijos. Rev Pediatr Aten Primaria. 2021;23:e1-e9.

Palabras clave:

- Calidad de vida
- Metilfenidato
- Trastorno por déficit de atención con hiperactividad

Resultados: en los controles existen diferencias significativas entre padres e hijos en tres de las diez dimensiones del KIDSCREEN-52 (autonomía, auto percepción y recursos económicos), en cuatro dimensiones en TDAH-T (bienestar psicológico, auto percepción, entorno escolar y recursos económicos) y en seis dimensiones en TDAH-N (bienestar psicológico y físico, estado de ánimo, auto percepción, entorno escolar y recursos económicos). En todas las dimensiones donde existen diferencias significativas los hijos perciben mejor CVRS que la atribuida por los padres, excepto en la dimensión económica que sucede a la inversa. No existen diferencias significativas entre padres e hijos en controles, TDAH-N o TDAH-T en las dimensiones de aceptación social, relación con padres y amigos.

Conclusiones: es necesario que en la evaluación que precede a cualquier intervención clínica se deban tener en cuenta las perspectivas de padres e hijos sobre la CVRS.

INTRODUCTION

Attention-deficit hyperactivity disorder (ADHD) is characterised by a pattern of inattention or hyperactivity-impulsivity that interferes with functioning or development and is included in the neurodevelopmental disorders class of the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5).¹

The systematic reviews in the literature suggest that the prevalence of ADHD in the general population worldwide ranges from 2% to 7%, with an average of 5%,² while in Spain, the reported prevalence is of 6.6%, with figures that remain stable through childhood (6.9%), preadolescence (6.2%) and adolescence (6.9%).³

At present, ADHD is a clinical diagnosis based on the criteria of the DSM-5 or the International Classification of Diseases, 10th revision (ICD-10) and there must be evidence of clinically significant impairment in social interactions or the school or work setting, which indicates the impact of its symptoms on the quality of life of the affected individual.⁴

The results of studies analysing health-related quality of life (HRQoL) in ADHD are heterogeneous. Systematic reviews have found greater impairment in different dimensions of HRQoL in children with ADHD compared to controls,⁵ indicating a poorer HRQoL in psychological and psychosocial functioning and the school environment, with a lesser impact on physical dimensions.^{4,6-7} When the reporting individual is the child or adolescent, ADHD cases tend to exhibit a poorer HRQoL com-

pared to controls,^{7,8} although in some instances there are no differences between these groups⁹ and differences are frequently not detected in every dimension.¹⁰

In Spain, recent studies that used the same measuring tool we used in our study found a significant and moderate correlation between the severity of ADHD symptoms and the deterioration of HRQoL, whether the questionnaire was completed by the child¹⁰ or a parent.⁴ Cases of ADHD that were not managed with pharmacotherapy had poorer results in psychological well-being, mood, school environment and social acceptance, whether the questionnaire was completed by the parent or the child.^{4,10} When the test is completed by the parents, there is also evidence of poorer relations with parents and peers.^{4,10} In these studies, ADHD cases treated pharmacologically have significantly better results than untreated ADHD cases the school dimension of HRQoL, but there are no significant differences in other dimensions.^{4,10} This highlights the need to provide evidence-based complementary therapies to address the different dimensions of HRQoL that are impacted in children with ADHD.¹¹

Previous systematic reviews suggest that proxy parent reports of HRQoL tend to be more positive compared to the HRQoL perceived by children in the general population, while the opposite trend is observed when it comes to children with health problems such as ADHD.^{5,12}

A systematic review focused on children and adolescents with ADHD concluded that in most studies, children with ADHD reported a more positive

perception of their HRQoL compared to the parent proxy report, but a more negative perception compared to controls, with stronger agreement when it came to physical health compared to psychosocial dimensions of HRQoL.¹³

Another recent systematic review on HRQoL that used the Pediatric Quality of Life Inventory found that parents rated their children's HRQoL less favourably compared to children with ADHD and healthy controls.¹⁴ A more recent study in children and adolescents with ADHD also found more positive ratings in the self-reports of children compared to parent proxy reports in emotional, social, school and psychosocial functioning, but not in physical functioning.¹⁵

Lastly, there are also studies that have found that ADHD affects children's quality of life in all areas negatively compared to controls, and that the perceptions of quality of life of parents and children in this respect were consistent with each other.¹⁶

To date, no studies have been conducted in Spain considering the discrepancies between parents and children in the perception of HRQoL while comparing healthy children or children with ADHD receiving pharmacological treatment or no treatment. We also have not found studies analysing a wide range of dimensions of HRQoL that would allow more accurate assessments in dimensions in which theoretically there is disagreement and to analyse whether there is greater agreement in observable/external dimensions versus internal dimensions.¹⁷

Our study addresses these gaps in the evidence by analysing the discrepancies between parents and children in the perception of HRQoL assessed by means of the KIDSCREEN-52¹⁸ in cases of ADHD managed with pharmacotherapy, cases of untreated ADHD and controls.

MATERIAL AND METHODS

Design

We recruited a sample of children aged 8 to 14 years, including children with a diagnosis of ADHD

undergoing pharmacological treatment with methylphenidate (ADHD-Tx), children with untreated ADHD (ADHD-UT) and controls matched for sex, age and sociodemographic area. We assessed HRQoL in the 3 groups of children by means of the KIDSCREEN-52¹⁸ in both the self-report and the parent-proxy version, which children and their parents completed independently, and analysed the differences observed in the different dimensions of the instrument.

We recruited patients for the ADHD-UT group (who had not received treatment of any kind) through consecutive sampling offering participation in the initial visit in the primary care paediatrics clinic and/or mental health clinic. Based on this initial sample, we selected ADHD-Tx cases in the same context consecutively enrolling patients matched to ADHD-UT cases for sex, age and sociodemographic area. We selected controls from the primary care caseload through stratified random sampling matching ADHD cases for sex, age and sociodemographic area.

We performed a sample size calculation to compare means in related samples for an alpha level of 0.05 and a beta level of 0.2 in two-tailed tests, according to which 35 participants were required per group to detect a difference of 5 or more units assuming a standard deviation of 10 (anticipating losses of 10%).

The main inclusion criterion for the ADHD group was meeting the diagnostic criteria of the DSM-IV, which was determined by means of the Attention Deficit Hyperactivity Disorder Rating Scale IV (ADHD RS-IV)¹⁹ and a supplemental clinical interview used to verify a persistent pattern in the symptoms and their presence in 2 or more settings before age 7 years with a clinically significant deterioration in social relationships or academic performance. The other inclusion criteria were absence of chronic disease that could affect quality of life, ability to complete the KIDSCREEN-52 and assent to participation in the study. Inclusion in the ADHD-UT required absence of any form of treatment and inclusion in the ADHD-Tx group required current pharmacological treatment

(methylphenidate) initiated at least 3 months prior and not being in treatment with structured psychotherapy at the time of the assessment.

The inclusion criteria for controls were absence of ADHD assessed by means of the ADHD RS-IV¹⁹ and a clinical interview based on the DSM-IV criteria, absence of chronic disease, ability to complete the KIDSCREEN-52 and assent to participation.

Participants

The sample included 228 parents and 228 children, of which 114 were controls and 114 cases of ADHD. Of the children with ADHD, 57 were receiving pharmacological treatment and 57 were not.

Variables and instruments

The KIDSCREEN-52¹⁸ is an instrument used to measure quality of life in children and adolescents aged 8 to 18 years available in parent report and child report versions that include the same dimensions and items. The difference between the two versions is that the child report is completed by the child or adolescent and the parent report is a proxy measure in which parents report the quality of life they perceive in their children.

In the process of adapting the instrument to the Spanish language, the new version exhibited an adequate reliability and criterion validity, with moderate to strong correlations to other HRQoL questionnaires and more than adequate levels of convergent and divergent construct validity.^{20,21} The confirmatory factor analysis and structural equation models demonstrated that the KIDSCREEN-52 is structured into 10 dimensions. These dimensions are physical well-being, psychological well-being, moods and emotion, self-perception, self-reliance, parent relations and home life, peers and social support, school environment, social acceptance (bullying) and financial resources. The scores for each dimension are transformed to *t*-scores, with higher scores reflecting a better quality of life. In our study, we used the KIDSCREEN-52 because it assesses more dimensions compared to other HRQoL questionnaires and its Spanish version has

been found to have adequate psychometric properties.

ADHD RS-IV¹⁹: the items in this questionnaire measures symptoms of ADHD according to the DSM-IV diagnostic criteria. Parents respond to this item considering the frequency of the symptom in the past 6 months. Each item is rated on a 4-point Likert scale with the possible answer choices *never or rarely, sometimes, often or very often* corresponding to scores of 0 to 3. The questionnaire has been found to offer an adequate reliability and criterion validity for assessment of ADHD.¹⁹

We obtained the parental signed informed consent for each of the paediatric participants of the study, and the study was approved by the research ethics committee of the university hospital.

RESULTS

The sex distribution of the paediatric sample in our study was 78.5% male and 21.5% female, with a similar distribution in cases and controls. The mean age was 10.05 for male participants and 10.46 for female participants, and the difference was not statistically significant ($t = 1.351$; $p = 0.178$). In our study, we also found no significant differences in the sex or the age distribution between participants in the different groups.

Differences between parents and children in the perceived quality of life

The relevant data for this section is summarised in **Table 1**, reflecting the differences between parent and child reports in each of the dimensions of the KIDSCREEN-52 in the ADHD-Tx, ADHD-UT and control groups. The table shows the mean score in each dimension given by parents and children, along with the 95% confidence interval (CI) to assess the precision of the result, the *t* values corresponding to the testing of the differences in the means of parent and child reports with the corresponding level of significance and the *d* values used to assess the magnitude of these differences, or effect size.

Table 1. Differences between parent and child reports in the KIDSCREEN-52.

| Dimension | Group | Controls | | ADHD-UT | | ADHD-Tx | |
|------------------------|----------|-----------------------|------------|-----------------------|-----------|-----------------------|------------|
| | | Results M (95% CI) | t/d | Results M (95% CI) | t/d | Results M (95% CI) | t/d |
| PHYSWB ^a | Parents | 50.40 ± 1.72 | t: 1.15 | 47.53 ± 2.40 | t: 2.38* | 50.38 ± 2.58 | t: 0.75 |
| | Children | 51.31 ± 1.71 | d: -0.08 | 51.30 ± 2.33 | d: -0.38 | 51.49 ± 2.53 | d: -0.12 |
| PSYCHWB ^b | Parents | 54.43 ± 1.66 | t: 1.63 | 46.18 ± 2.90 | t: 3.08** | 49.48 ± 2.33 | t: 2.96** |
| | Children | 55.98 ± 1.65 | d: -0.17 | 51.10 ± 2.33 | d: -0.51 | 52.86 ± 2.34 | d: -0.38 |
| MOOD/EM ^c | Parents | 53.69 ± 2.08 | t: 1.71 | 42.81 ± 3.29 | t: 2.59* | 46.16 ± 3.25 | t: 0.94 |
| | Children | 55.71 ± 1.90 | d: -0.18 | 47.48 ± 2.68 | d: -0.41 | 47.86 ± 2.69 | d: -0.15 |
| SELFPERC ^d | Parents | 52.00 ± 1.67 | t: 5.53*** | 49.54 ± 2.72 | t: 2.97** | 49.59 ± 2.47 | t: 3.95*** |
| | Children | 57.08 ± 1.82 | d: -0.53 | 53.84 ± 2.58 | d: -0.44 | 55.46 ± 2.58 | d: -0.62 |
| SELFREL ^e | Parents | 52.10 ± 1.58 | t: 2.12* | 49.21 ± 2.46 | t: 0.04 | 48.19 ± 2.16 | t: 1.65 |
| | Children | 54.07 ± 1.76 | d: -0.22 | 49.29 ± 2.40 | d: -0.01 | 50.18 ± 2.39 | d: -0.22 |
| RELARENTS ^f | Parents | 55.42 ± 1.51 | t: 1.88 | 49.50 ± 2.39 | t: 0.83 | 51.39 ± 2.37 | t: 0.54 |
| | Children | 53.95 ± 1.59 | d: 0.18 | 50.77 ± 2.26 | d: -0.14 | 50.78 ± 2.25 | d: 0.07 |
| PEERS ^g | Parents | 56.68 ± 1.61 | t: 0.31 | 51.87 ± 3.07 | t: 1.09 | 51.83 ± 2.24 | t: 0.96 |
| | Children | 56.33 ± 1.97 | d: 0.04 | 53.63 ± 2.79 | d: -0.18 | 53.25 ± 2.79 | d: -0.15 |
| SCHOOL ^h | Parents | 56.72 ± 1.80 | t: 1.30 | 41.44 ± 2.44 | t: 3.61** | 49.24 ± 2.15 | t: 3.35** |
| | Children | 56.72 ± 2.11 | d: 0.00 | 46.88 ± 2.98 | d: -0.47 | 53.84 ± 2.99 | d: -0.45 |
| SOCIAL ⁱ | Parents | 48.34 ± 2.00 | t: 1.63 | 41.50 ± 3.48 | t: 1.07 | 42.92 ± 3.38 | t: 0.23 |
| | Children | 50.30 ± 2.15 | d: -0.19 | 43.74 ± 3.02 | d: -0.17 | 43.37 ± 3.04 | d: -0.03 |
| FINANCIAL ^j | Parents | 54.31 ± 1.40 | t: 4.02** | 51.48 ± 2.48 | t: 2.52* | 49.50 ± 2.63 | t: 2.25* |
| | Children | 51.81 ± 1.94 | d: 0.28 | 47.80 ± 2.75 | d: 0.37 | 46.16 ± 2.74 | d: 0.31 |

^aPhysical well-being.

^bPsychological well-being.

^cMoods and emotions.

^dSelf-perception.

^eSelf-reliance.

^fParent relations and home life.

^gPeers and social support.

^hSchool environment.

ⁱSocial acceptance.

^jFinancial resources.

*p < 0.05.

**p < 0.01.

***p < 0.001.

ADHD-UT: ADHD without pharmacological treatment; ADHD-Tx: ADHD with pharmacological treatment; CI: confidence interval; d: Cohen d to measure effect size; M: mean; t: Student t.

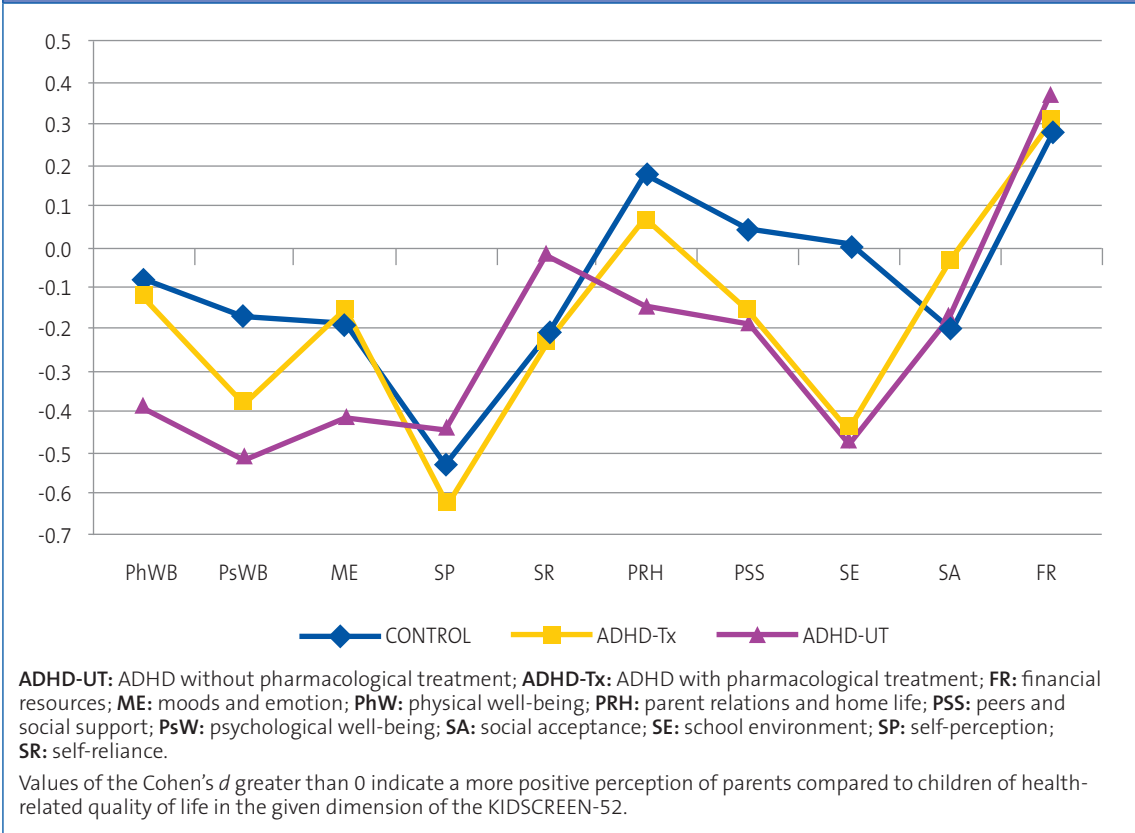
In the control group, children gave significantly higher ratings than their parents (more positive perception of HRQoL) to items in the self-perception and self-reliance dimensions of the KIDSCREEN-52, while the reverse occurred in the financial resources dimension of HRQoL, which was perceived more positively by parents. We did not find significant differences in any of the other 7 dimensions of the del KIDSCREEN-52 (Table 1).

In the ADHD-Tx and ADHD-UT groups, we found that children had a significantly more positive perception of their HRQoL compared to their parents in the psychological well-being, self-perception and school environment dimensions, and conver-

sely had a more negative perception of financial resources. We also found significantly more positive reports of children in the ADHD-UT group compared to their parents in the physical well-being and moods and emotion dimensions (Table 1).

Figure 1 offers a graphic representation of the effect size (d) of the differences between parent and child reports in the different dimensions of the del KIDSCREEN-52 for the control, ADHD-Tx and ADHD-UT groups. In this figure, negative Cohen d values indicate a more positive perception of HRQoL by parents compared to children. We considered that Cohen d values of 0.2 to 0.3 corresponded to a small effect size, values from 0.5 an interme-

Figure 1. Effect size (Cohen *d*) of the differences in the KIDSCREEN-52 dimensions between parent and child reports in the control, ADHD-Tx and ADHD-UT groups



mediate effect size and values above 0.8 a large effect size. Considering values of *d* greater than 0.5 as intermediate, we found that children gave a lower rating to their HRQoL in the dimension of self-perception in every group, in the school environment dimension in the ADHD-UT and ADHD-Tx groups and in the mood and psychological well-being dimensions in the ADHD-UT group.

DISCUSSION

At present, ADHD is essentially a clinical diagnosis that requires fulfilment of criteria reflecting impairment in social functioning or in the school or work environment and indicative of its negative impact on HRQoL.⁴ The study presented here with the use of a multidimensional instrument and its particular design is the first of its kind, so any com-

parisons with previous research are inevitably indirect (we are comparing dimensions with similar names, but not strictly equivalent).

In our discussion, we will reflect on the discrepancies found between the parent and child reports in each of the dimensions of the KIDSCREEN-52.

When it came to the physical well-being dimension, our study did not find significant differences between the parent and child reports in the perceived HRQoL in the control and ADHD-Tx group, whereas in the ADHD-UT group children reported greater physical well-being compared to parents. A recent systematic review also found a significant difference, with children perceiving physical health dimensions more positively compared to their parents.¹⁴

As for psychological well-being (positive feelings and satisfaction with life), our study did not find

significant differences in perceived HRQoL between parents and children in the control group, while in the ADHD group children reported significantly greater well-being compared to the well-being attributed by their parents. This result was consistent with the findings of a recent systematic review that evinced significant differences in the assessment of emotional functioning dimensions by children with ADHD compared to their parents that were not observed in controls.¹⁴

Our study did not find significant differences between parent and child reports in the mood dimension of HRQoL in the control and ADHD-Tx groups, while in the ADHD-UT group children rated their mood better compared to the perception of their parents. The aforementioned systematic review had found significant differences between parents and children in the perceived emotional HRQoL in cases of ADHD but not in controls.¹⁴ Previous studies using the KIDSCREEN-52 have found poorer results in the moods and emotions dimension in children with either ADHD-UT or ADHD-Tx compared to healthy controls.^{4,10}

In the analysis of the self-perception dimension in our study, children with ADHD and health controls perceived their own satisfaction with their body image more positively than their parents believed. This discrepancy between parents and children was unexpected taking into account that body image issues are common in adolescence.

As regards self-reliance, our study did not find significant differences in the ADHD groups, whereas in the control group, children perceived more self-reliance and autonomy compared to the level attributed by the parents.

In the dimensions pertaining the relationships with parents and peers and social acceptance, we found no significant discrepancies between the perception of parents versus children in any of the groups of participants. Systematic reviews that used a different instrument than the one used in our study have found discrepancies between parent and child reports, with a tendency of children to perceive social dimensions more positively than their parents.^{13-15,22} One possible explanation is

that the KIDSCREEN-52 is more sensitive to the different social dimensions because it has more items to assess them.

When it came to the school environment, our study did not find significant differences between the parent and child report in the control group, whereas children with ADHD perceived their experience in the school setting more positively compared to their parents. A recent systematic review found that children with ADHD and controls rated their functioning in school environment dimensions more positively compared to their parents.¹⁴ Other studies that focused exclusively in children with ADHD had similar findings.^{15,22}

In the financial resources dimension, parents perceived more satisfaction compared to children both in the ADHD groups and the control group.

In short, our multidimensional analysis allowed us to define the discrepancies in the perception of HRQoL between parents and children with greater precision compared to studies that analysed fewer dimensions. We found significant discrepancies between parent and child reports in 3 of the 10 dimensions in the control group (autonomy, self-perception and financial resources), in 4 dimensions in the ADHD-Tx group (psychological well-being, self-perception, school environment and financial resources) and in 6 dimensions in the ADHD-UT group (psychological and physical well-being, moods, self-perception, school environment and financial resources). It appeared that the greater the psychological well-being of the children, the lesser the parent-child discrepancies were in the assessment of HRQoL.

We close this discussion with some theoretical reflections. Children with ADHD have a more positive perception of their HRQoL compared to the HRQoL attributed by their parents as regards psychological well-being, mood, self-perception and the school environment, despite the high frequency of mood and behavioural comorbidities and problems in school.^{23,24} Some authors suggest that this can be explained by the phenomenon known as positive illusory bias, by which children with ADHD would report higher levels of

competence compared to their actual performance.^{13,25} A complementary or alternative explanation would be that parents experiencing significant stress in relation to rearing children with ADHD²⁶ or multiple psychiatric comorbidities²⁷ may perceive their children's HRQoL more negatively than they do.

In conclusion, based on our observation of the discrepancies between parents and children in the assessment of different dimensions of HRQoL, it seems important to include both their perspectives in the evaluation preceding initiation of any clinical intervention, as suggested by other authors.²⁸

CONFLICTS OF INTEREST

The study was funded by the Fundación Ernesto Sánchez Villares of the Sociedad de Pediatría de Asturias, Cantabria, Castilla y León (file no. 05/2014).

The authors have no conflicts of interest to declare in relation to the preparation and publication of this article.

ABBREVIATIONS

ADHD: attention-deficit hyperactivity disorder • **ADHD RS-IV:** Attention Deficit Hyperactivity Disorder Rating Scale-IV • **ADHD-Tx:** ADHD cases managed with pharmacotherapy • **ADHD-UT:** untreated ADHD cases • **d:** effect size • **DSM-5:** Diagnostic and Statistical Manual of Mental Disorders • **HRQoL:** health-related quality of life.

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