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Consistency of child self-reports with parent proxy reports on the quality of life of children with attention-deficit/hyperactivity disorder in Riyadh, 2016

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Abstract:

BACKGROUND: The quality of life (QoL) of children with attention-deficit/hyperactivity disorder (ADHD) has not been addressed in Saudi Arabia despite the considerable attention it has on account of its prevalence, duration of illness, and sociopsychological effects. The aim of this study was to report on the QoL of children with ADHD and test the concord between children's and parents' reports.

MATERIALS AND METHODS: Using the generic PedsQL™ (version 4.0) from both children's and parents' perspectives, a cross-sectional study of 112 children was conducted on children aged 5–18 years with an established diagnosis of ADHD attending child psychiatry clinics of three referral hospitals in Riyadh between December 2015 and May 2016.

RESULTS: A total of 112 children with an established diagnosis of ADHD were recruited from the Child Psychiatry Clinic of Al Amal Mental Health Complex (41.1%), Prince Sultan Military Medical City (PSMMC), (33%), and King Khalid University Hospital (KKUH), (25.9%). The majority were boys (74.1%) and Saudi nationals (93.8%). The mean age of children with ADHD was 10.45 ± 3.06 years (Range 5 - 18 years). One-fourth of the mothers of children with ADHD had completed high school and 41.1% had a diploma, university, or postgraduate degree. One-third of the fathers of these children had completed high school (34%) and 38.4% had a diploma, university, or postgraduate degree. The intra-class correlation coefficients between the scores of children and parents were good for physical functioning, fair for social functioning, but moderate for school, emotional, and psychosocial functioning. Children rated themselves significantly better than their parents for emotional, social, school, and psychosocial functioning. The standardized response means indicated a small difference for social functioning and medium differences for the other three domains. The only significant discrepancy was observed in social functioning in relation to the child's age.

CONCLUSION: Parents mirrored adequately the observable physical component of the QoL of their children. The QoL report of children with ADHD with respect to communications and intellectual abilities should be taken into account whenever possible and their parents' report also should be sought to provide a more comprehensive view of the child's status.

Keywords:

Attention-deficit/hyperactivity disorder, parent's proxy, PedsQL, quality of life, Saudi Arabia

Introduction

Attention-deficit/hyperactivity disorder (ADHD), which is considered one of the most common neuropsychiatric disorders, predominantly affects children^[1] with a

worldwide pooled prevalence of 5.29% in populations below the age of 18 years.^[2] The systematic review of research published from 11 Arab countries between 1978 and 2014 yielded a prevalence ranging from 1.3% to 16% with a male-to-female ratio of

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1.6:1 and 5:2.^[3] In 2010, the prevalence of ADHD was 2.7% in children aged 7–9 years in the southern region of Saudi Arabia.^[4] In the eastern region of the kingdom, the prevalence was 3.5% in girls aged 6–15 years in 2012^[3] but 16.4% in boys aged 6–13 in 2008.^[5] ADHD represents 25.5% of the diagnoses in children attending a child psychiatry clinic in Riyadh,^[6] creating a significant economic burden because of the increased use of health, social, and education services.^[7]

ADHD is characterized by pervasive, persistent, and impairing symptoms of impulsivity, hyperactivity, and inattention that starts in childhood, with the possibility of extending into adult life.^[8] The co-existence of developmental, emotional, and behavioral disorders^[6,8,9] with ADHD is not uncommon. Children with ADHD often have low academic achievement,^[9] impaired social performance,^[9] and poor interpersonal relationship^[10] resulting in unemployment,^[11] low financial status,^[11] and difficulties in relationships^[11] in adult life. The chronic nature of ADHD and its consequences impact negatively on one or more components of the quality of life (QoL) of affected children.^[12-14]

QoL is a quantitative measurement of wellness^[15] and a relevant “patient-reported outcome” as it reflects the subjective perception of health.^[16,17] QoL is useful in assessing the effectiveness of interventions, where treatment evaluation should not be based merely on its therapeutic effect, but also on more favorable social, psychological, and physical consequences.^[18,19] Varni *et al.*^[20] reported that the assessment of QoL in pediatric clinical practice has the advantages of facilitating patient–physician communication, improving patient satisfaction, detecting hidden morbidities, and aiding clinical decision-making with the result of better patient outcome over time.^[20]

Although QoL is subjective, children were previously thought unable to report on their QoL.^[21] However, self-report is now mandatory for children as they become involved in the process of assessing and understanding their health and QoL depending on their capabilities and limitations.^[21] Owing to the skepticism with which the capacity of children to self-report is regarded, observer-based assessment by family or medical staff is considered an alternative or an adjunct to the child’s self-report. However, it is important that these last are handled independently and not taken as “proxy” since they may not necessarily reflect the patient’s perception.^[22,23] However, for both self-reports and observer-based reports, usually the parents’ are important for the understanding of the child’s perception as well as the family’s perception of their child’s QoL.^[23]

Although QoL is considered an important indicator of outcome, an assessment of the QoL of children with ADHD does not form part of the routine evaluation of care in Saudi Arabia. Moreover, it is not known the extent to which parents’ reports can adequately reflect the QoL of their children. The aim of this study was to report the QoL of children with ADHD and test how much the children’s reports accord with those of their parents.

Materials and Methods

A hospital-based cross-sectional study was conducted on children aged 5–18 years with an established diagnosis of ADHD in line with the DSM-IV-TR and DSM-5 criteria. These include symptoms of inattention and/or hyperactivity that persist for at least 6 months to a degree that is inconsistent with the developmental level of the child and which negatively impact directly on social and academic/occupational activities.^[8]

In view of the lack of data on Saudi children with ADHD, the estimated sample size was based on the self-report scores of Iranian children with ADHD on the Pediatric QoL Inventory PedsQL™ version 4.0 (Mapi Research Trust, Lyon, France) of 62.39 ± 17.20 .^[24] The minimum sample size (n) calculated on the assumption of a standard deviation (σ) of 17.20 and a degree of precision (d) of 3 on each side at the 95% level of confidence yielded 126 children. The primary sampling unit was children with ADHD and the unit of inquiry was children and their parents or guardians.

Cases of ADHD were recruited from child psychiatry outpatient clinics of three referral hospitals in Riyadh, namely King Khalid University Hospital (KKUH) affiliated to King Saud University (KSU), Al Amal Mental Health Complex affiliated to the Ministry of Health (MoH), and Prince Sultan Military Medical City (PSMMC). The former two hospitals provide care to the general population, while the latter provides care to children of military personnel.

Children with ADHD were identified and recruited from the appointment list of each hospital from December 2015 to May 2016 until no new eligible cases were found. All children with an established diagnosis of ADHD for at least 3 months were included in this study. Children with ADHD associated with any comorbid condition were included as they represented the status of the children. Children with intellectual disability (intelligent quotient <70) as well as those with hearing and speech impairment that precluded the self-report of QoL were excluded from the study. A total of 14 cases were excluded on account of being distracted or co-diagnosed with severe autistic spectrum disorder that interfered with communication. The resulting final sample size was 112 children.

Data were collected using an interview questionnaire, an Arabic version of the Pediatric QoL Inventory (PedsQL™ version 4.0) Generic Core Scales.^[25] The Arabic version had been validated and used in Jordan on Arabic-speaking children and their parents.^[26] The Parent's version of the PedsQL™ (23 statements) and the child's version of the PedsQL™ (23 statements) cover physical functioning (8 statements), emotional functioning (5 statements), social functioning (5 statements), and school functioning (5 statements). The child's version of the PedsQL™ consists of three forms that differ only in the phraseology of the statements and the responses which were tailored to the age: young children (5–7 years), children (8–12 years), and teens (13–18 years). For young children (5–7 years), there were three options to the responses: not at all (score 0), sometimes (score 2), and a lot (score 4). There were five options to the responses for children (8–12 years), teens (13–18 years), and the parent's version of the PedsQL™: not at all (score 0), almost never (score 1), sometimes (score 2), often (score 3), and a lot (score 4).

Parents of children with ADHD were interviewed for information on their children's characteristics, namely age, sex, and nationality as well as their own features including education, type of family, and family income. The medical records were scrutinized for data on the type of ADHD, age at the time of diagnosis, duration of the illness, and any co-existent psychiatric and physical morbidities. These variables were used to identify the factors affecting the similarity between the children's and parents' reports on the QoL.

The study was approved by the Institutional Review Board of KSU, MoH, and PSMHC. The purpose of the study was explained and written informed consent and assent were obtained from parents and children aged 12 years and above, who were assured that participation was voluntary, anonymous, and confidential. A written permission for the use of the PedsQL™ test was obtained from Dr. James W. Varni.

The Statistical Package for the Social Sciences, version 21 (SPSS Inc., Chicago, IL, USA), was used for data processing and analysis. The raw scores on the PedsQL™ were transformed into 0–100 scale scores by recoding the raw scores of the responses into 100 (never), 75 (almost never), 50 (sometimes), 25 (often), and 0 (almost always). The "Physical Health Summary Subscale" was generated by summing the scores of the statements of the physical functioning divided by 8, which is the number of statements of this subscale. The QoL score was generated for emotional functioning, social functioning, and school functioning components by summing the scores on the statements divided by the number of statements in each component. The scores of all the statements of these three components were

summed and divided by 15, which represented the number of statements that generate the "Psychosocial Health Summary Subscale."^[27] Higher scores on the QoL scale and subscales reflect better QoL.

The Cronbach's alpha reliability was used to test inter-item reliability of the two subscales. The alpha reliability for the "Physical Health Summary" was 0.823 for the parent's version and 0.508 for the child's version. The alpha reliability for the "Psychosocial Health Summary" was 0.779 for the parent's version and 0.761 for the child's version. The concord between the child's and the parent's reports was tested using the intraclass correlation coefficients (ICCs) and the strength of agreement was classified as poor to fair (≤ 0.4), moderate (0.4–0.6), good (>0.6 –0.8), and excellent (>0.8).^[28] The extent of the difference between child's and parent's rating of QoL was determined using the standardized response means (SRMs) expressed as the ratio of the mean difference to that of the standard deviation and classified into small (0.2), medium (0.5), and large (0.8) difference.^[29] The significance of the difference between child's and parent's scores on the domains of the QoL was tested using the one-sample *t*-test. The factors affecting the directional difference between children's scores and parents' scores on the domains of the QoL were evaluated using the Mann–Whitney U and Kruskal–Wallis tests. Significance of the obtained results was judged at the 5% level.

Results

A total of 112 children with an established diagnosis of ADHD were recruited from the Child Psychiatry Clinic of Al Amal Mental Health Complex (41.1%), PSMHC (33%), and KKHU (25.9%). The majority were boys (74.1%) and Saudi nationals (93.8%). The mean age of children with ADHD was 10.45 ± 3.06 years (min = 5 years, max = 18 years). One-fourth (25%) of the mothers of the children with ADHD had completed high school and 41.1% had a diploma, university, or postgraduate degree. One-third of the fathers of these children had completed high school (34%) and 38.4% had a diploma, university, or postgraduate degree. The families of 84% of children with ADHD were normal families, while 16.1% of children with ADHD came from broken homes as a result of divorce or separation of parents, jailed, or an absent father. The mean per capita family income for these children was 2497.56 ± 1816.31 (min = 42.86, max = 8666.67) [Table 1].

Most children with ADHD had a combined presentation: inattention and hyperactivity impulsivity (91.1%). These children were diagnosed at a mean age of 5.76 ± 2.28 years (min = 1.00 years, max = 13.00 years) with a mean duration of illness of 4.62 ± 3.40 years

Table 1: Characteristics of children with attention deficit disorder and their parents

Characteristics	N (%)
Child's age (years)	
5-7	18 (16.1)
8-12	65 (58.0)
13-18	29 (25.9)
Child's sex	
Boys	83 (74.1)
Girls	29 (25.9)
Child's nationality	
Saudi	105 (93.8)
Non-Saudi	7 (6.3)
Mothers' educational attainment	
Never been to school	5 (4.5)
Primary school (uncompleted)	5 (4.5)
Basic education	28 (25.0)
High school (completed)	28 (25.0)
Diploma, university, or postgraduate degree	46 (41.1)
Fathers' educational attainment	
Never been to school	4 (3.6)
Primary school (uncompleted)	4 (3.6)
Basic education	23 (20.5)
High school (completed)	38 (34.0)
Diploma, university, or postgraduate degree	43 (38.4)
Family status	
Intact family	94 (83.9)
Broken family	18 (16.1)
Per capita family income (Saudi Riyals)	
Lowest quartile	28 (25.0)
Second quartile	25 (22.3)
Third quartile	32 (28.6)
Upper quartile	27 (24.1)

Table 2: Medical profile of children with attention-deficit/hyperactivity disorder

Medical profile	N (%)
Type of ADHD	
Predominantly inattention	7 (6.3)
Predominantly hyperactivity	3 (2.7)
Combined type	102 (91.1)
Age at diagnosis (years)	
<5	35 (31.3)
5-<8	52 (46.4)
≥8	25 (22.3)
Duration of the illness (years)	
<3	37 (33.0)
3-<7	45 (40.2)
≥7	30 (26.8)
Psychiatric comorbidities	
Absent	71 (63.4)
Present	41 (36.6)
Physical comorbidities	
Absent	76 (67.9)
Present	36 (32.1)

ADHD=Attention-deficit/hyperactivity disorder

(min = 3 months, max = 14.00 years). More than one-third of these children had a psychiatric comorbidity (36.6%). Similarly, physical comorbidities were present in 32.1% of children with ADHD [Table 2].

The ICCs between the scores of children and parents in the five domains of QoL were significant statistically. The ICC was good for the physical functioning (ICC = 0.606), fair for the social functioning (ICC = 0.378), while moderate for school, emotional, and psychosocial functioning [Table 3].

The highest scores were observed on the physical component of QoL with no significant statistical difference between the scores of parents (91.71 ± 14.12) and those of their children (89.48 ± 12.06) with ADHD ($P = 0.092$). Children rated themselves significantly better than their parents in the emotional functioning ($P < 0.0001$), social functioning ($P = 0.009$), school functioning ($P < 0.0001$), and psychosocial functioning ($P < 0.0001$) domains. The SRM indicates a small difference of 0.25 for the social functioning domain and medium differences for the remaining three domains [Table 4].

Agreement between the scores of children and those of their parents in the emotional, social, school, and psychosocial functioning domains was examined in relation to the child's and family's characteristics as well as the medical profile of the child [Table 5]. The only significant discrepancy was observed in the social functioning domain in relation to the age of the child ($P = 0.037$). The discrepancy in this domain was significantly lower in children aged 8–12 years compared to those aged 5–7 years ($P = 0.049$) and 13–18 years ($P = 0.036$), while the discrepancy between the latter age groups was comparable ($P = 0.869$).

Discussion

ADHD is a neuropsychiatric disorder that affects children in a critical period of development, the treatment of which extends over years. The incorporation of the evaluation of the QoL of affected children during the course of the illness and its treatment aims at achieving a balance between physical and psychological well-being. Previous studies have shown that children with ADHD are able to report their own QoL,^[12,30,31] and that parent's proxy report presents an additional source of information.^[17] In this study, reports on the physical and psychosocial QoL of children with ADHD were obtained from the children themselves and their parents. As they are not equivalent, the child's and the parent's reports of QoL should be interpreted independently without

considering one or the other as the “gold standard.”^[17] Children with ADHD in this study and their parents rated the physical component of QoL better than the psychosocial component, which is consistent with earlier studies^[12,13,32] that reported more impairment in the psychosocial domain of QoL of children with ADHD since it is a mental disorder.

This study and previous ones^[12,24,33] pointed out the differences between parent’s report and child’s self-report of QoL. Discrepancies were observed between the reports of Iranian children with ADHD and those of their parents where the children rated their QoL significantly better than their parents in all domains except for the social functioning domain.^[24] There was a high correlation between the rating of QoL of treatment-naïve children with ADHD in Brazil and their parents except in school functioning where the perception of the children with ADHD was better than their parents’.^[12] Limbers *et al.*^[33] noted a poor-to-fair agreement between the self-report of the QoL of children with ADHD and comorbid psychiatric disorders and those of their parents, with the closest accord on school functioning, while the least was on the physical component of QoL. Children with ADHD in this study tended to rate their QoL better than their parents. This study showed concord between children’s and parents’ reports on the physical functioning domain and a variance in the psychosocial domain in all its three dimensions, namely emotional, social, and school functioning. This accord with the reports of Klassen *et al.*^[30] and Velö *et al.*^[34] which indicates that children tend to provide better ratings of their social and mental functioning. The systematic review on the relationship between parents’ and children’s ratings of children’s QoL emphasized the better accord for observable functioning, such as the physical component of QoL,

and less agreement in nonobservable functioning, such as emotional or social component of QoL.^[35]

In general, children with ADHD rate their own QoL less negatively than their parents,^[36] which could be the result of the overoptimistic perception of children with ADHD of their own capabilities and performance; the desire to conceal their behavioral problems either due to fear that their parents may expose their answers or in an attempt to cope; the nature of the disorder which urges children to rush in with a response; the changes in the children’s internal values caused by their adapting to their situation that leads to a change in their self-evaluation of QoL; or the exacerbation of children’s situation by their parents in an effort to secure health-care services.^[12,30,36]

The disagreement between a parent’s and a child’s reports of QoL has been found to be associated with younger children, the presence of a psychosocial stressor such as parental separation or divorce and conflict with siblings or peers, increased symptoms of ADHD, and the presence of psychiatric comorbidity, particularly oppositional defiant disorders and conduct disorders.^[30,37] However, in the current study, the difference between the child’s and parent’s reports was only significantly associated with the child’s age with regard to the social functioning domain.

Conclusion

This study provided an understanding of the differences and similarities between children with ADHD and their parents in the rating of their QoL. Parents mirrored adequately the observable physical component of the QoL of their children but not their psychosocial functioning. Given this disparity, the importance of evaluating the child’s QoL through both the parent’s and child’s eyes is emphasized to address this gap, dealing with each as a unique source of information. The child’s report should be taken into account whenever the child is capable of reporting through communication and intellectual ability, as reliance on parent’s proxy report provides an incomplete picture of the child’s QoL. However, the parental report of the QoL of children with ADHD is also necessary to achieve a comprehensive view of the child’s status.

Table 3: Intraclass correlation coefficients of the domains of PedsQL™ quality of life

QoL domain	ICC	95% CI	p-Value
Physical functioning	0.606	0.430, 0.729	<0.0001
Emotional functioning	0.542	0.281, 0.701	<0.0001
Social functioning	0.378	0.108, 0.569	0.005
School functioning	0.419	0.133, 0.608	<0.0001
Psychosocial functioning	0.504	0.195, 0.685	<0.0001

QoL=Quality of life, ICC=Intraclass correlation coefficient, CI=Confidence interval

Table 4: Mean scores of children and their parents on the domains of PedsQL™ quality of life

QoL domain	Child score x̄±s	Parent score x̄±s	Difference x̄±s (95% CI)	t-test	p-Value	SRM
Physical functioning	89.48±12.06	91.71±14.12	-2.23±13.90 (-4.84, 0.37)	1.70	0.092	0.16
Emotional functioning	76.34±23.83	63.99±22.52	12.35±24.92 (7.69, 17.02)	5.25	<0.0001	0.50
Social functioning	76.79±24.18	69.06±26.03	7.72±30.92 (1.93, 13.51)	2.64	0.009	0.25
School functioning	73.96±20.84	61.31±21.48	12.66±24.84 (7.99, 17.33)	5.37	<0.0001	0.51
Psychosocial functioning	75.63±16.74	64.68±17.79	10.96±18.89 (7.42, 14.49)	6.15	<0.0001	0.58

CI=Confidence interval, SRM=Standardized response mean, QoL=Quality of life

Table 5: Predictors of agreement between children's and parents' report on quality of life

Predictor	QoL domain			
	Emotional functioning $\bar{x}\pm SE$	Social functioning $\bar{x}\pm SE$	School functioning $\bar{x}\pm SE$	Psychosocial functioning $\bar{x}\pm SE$
Child's age (years)				
5-7	14.34±5.31	18.33±9.12	10.00±7.55	14.23±4.41
8-12	10.20±3.21	0.92±3.49	11.62±2.90	7.72±2.19
13-18	15.95±4.52	16.38±5.30	16.21±4.30	16.18±3.84
p-Value	0.593	0.037	0.680	0.153
Child's sex				
Boys	13.28±2.76	7.83±3.27	13.86±2.76	11.77±2.09
Girls	9.70±4.55	7.41±6.39	8.79±4.42	8.64±3.43
p-Value	0.549	0.963	0.462	0.673
Child's nationality				
Saudi	12.56±2.47	7.48±3.07	11.71±2.38	10.67±1.87
Non-Saudi	9.11±7.22	11.43±8.57	25.00±11.02	15.18±5.19
p-Value	0.857	0.588	0.137	0.348
Mothers' education attainment				
Never been to school/primary (uncompleted)	13.00±10.33	-11.50±4.41	17.32±4.54	3.58±5.85
Basic education	5.65±4.78	12.86±6.48	17.32±4.54	11.94±3.50
High school (completed)	15.68±3.96	10.00±5.39	11.39±4.40	12.36±3.55
Diploma, university, or postgraduate degree	13.97±3.82	6.84±4.73	11.71±3.98	10.84±2.76
p-Value	0.675	0.127	0.483	0.840
Fathers' education attainment				
Never been to school/primary (uncompleted)	26.80±8.86	17.50±17.24	11.25±9.67	19.66±6.95
Basic education	7.75±7.17	3.91±6.22	14.78±4.84	8.81±4.15
High school (completed)	13.11±3.56	10.95±4.84	12.74±4.29	12.27±3.08
Diploma, university, or postgraduate degree	11.29±3.12	4.49±4.31	11.28±3.59	9.02±2.71
p-Value	0.404	0.759	0.925	0.545
Family status				
Intact family	12.09±2.51	7.02±3.15	12.55±2.44	1.65±1.85
Broken family	13.72±6.67	11.39±7.89	12.50±7.19	12.54±5.61
p-Value	0.978	0.668	0.918	0.934
Per capita family income (Saudi Riyals)				
Lowest quartile	14.40±6.22	12.68±6.88	14.64±4.59	14.23±3.85
Second quartile	10.68±4.29	7.60±4.07	11.60±5.51	9.96±3.18
Third quartile	12.25±4.41	2.50±6.56	9.06±4.49	7.94±3.75
Upper quartile	11.90±3.60	8.89±4.77	15.37±4.34	12.05±3.30
p-Value	0.870	0.752	0.789	0.622
Type of ADHD				
Predominantly inattention	10.54±4.80	15.71±11.36	22.86±9.05	16.37±6.45
Predominantly hyperactivity	40.00±8.66	-8.33±18.56	6.67±14.24	12.78±4.55
Combined type	11.66±2.51	7.65±3.07	12.01±2.46	10.53±1.91
p-Value	0.109	0.701	0.446	0.556
Age at diagnosis (years)				
<5	16.38±3.78	9.86±5.69	10.86±4.34	12.63±3.28
5-<8	8.71±3.54	9.62±4.20	13.85±3.69	10.72±2.62
≥8	14.30±5.37	0.80±5.68	12.20±3.95	9.10±3.72
p-Value	0.547	0.233	0.676	0.718
Duration of the illness (years)				
<3	10.66±4.74	5.54±5.82	15.95±4.65	10.72±3.02
3-<7	10.69±3.62	3.33±3.97	10.11±3.33	8.05±2.83

Contd...

Table 5: Contd...

Predictor	QoL domain			
	Emotional functioning $\bar{x}\pm SE$	Social functioning $\bar{x}\pm SE$	School functioning $\bar{x}\pm SE$	Psychosocial functioning $\bar{x}\pm SE$
≥ 7	16.92 \pm 3.73	17.00 \pm 5.49	12.00 \pm 4.38	15.61 \pm 3.48
p -Value	0.500	0.110	0.418	0.188
Psychiatric comorbidities				
Absent	9.12 \pm 2.74	7.39 \pm 3.50	12.32 \pm 2.74	9.61 \pm 1.99
Present	17.96 \pm 4.24	8.29 \pm 5.25	12.93 \pm 4.34	13.28 \pm 3.45
p -Value	0.182	0.916	0.986	0.546
Physical comorbidities				
Absent	12.80 \pm 2.92	6.97 \pm 3.26	10.59 \pm 2.92	10.12 \pm 2.02
Present	11.41 \pm 4.02	9.31 \pm 6.00	16.67 \pm 3.83	12.72 \pm 3.58
p -Value	0.583	0.878	0.233	0.663

QoL=Quality of life, SE=Standard error, ADHD=Attention-deficit/hyperactivity disorder

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Conflicts of interest

There are no conflicts of interest.

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