Araştırma / *Original article*

An evaluation of the quality of life of children with ADHD and their families

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ABSTRACT

Objective: *This study evaluated the quality of life of children with attention-deficit/hyperactivity disorder (ADHD) and their families to identify the effects of the psychosocial distress associated with the disorder.* ***Methods:*** *Seventy-six children and adolescents aged 7 to 16 with ADHD who had been referred to the Ankara University School of Medicine Department of Child and Adolescent Psychiatry and 59 age and gender matched control children who had never been referred to a child psychiatric clinic were included in the study. The Pediatric Quality of Life Inventory (PedsQL), Short Form-36, Strengths and Difficulties Questionnaire, Turgay's Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV)-Based Child and Adolescent Behavior Disorders Screening and Rating Scale, and the McMaster Family Assessment Device (FAD) were administered.* ***Results:*** *The children with ADHD showed lower school achievements and had more school absences than the control group. In SF-36, parents of the children with ADHD showed statistically significant differences in their pain, general health, vital energy, and mental health subscale scores compared to the control group. The PedsQL-child scale psychosocial health subscale and total scale scores of the ADHD patients were significantly lower than the control group. The PedsQL-parent psychosocial health and total scale scores of the ADHD group were significantly lower than the control group. In the McMaster (FAD) results, there were significant differences in the problem-solving, communication, roles, affective responsiveness, and affective involvement subscale scores.* ***Conclusion:*** *The results of this study suggest that children with ADHD and their families have poorer quality of life in some domains. In child and adolescent psychiatric clinics, the psychosocial and clinical aspects of ADHD must be taken into account.* ***(Anatolian Journal of Psychiatry 2014; 15:265-271)***

Key words: *ADHD, child, life quality, PedsQL, SF-36*

DEHB'li çocuklar ve ailelerinde yaşam kalitesinin değerlendirilmesi

Amaç: *Bu çalışmada, dikkat eksikliği hiperaktivite bozukluğu (DEHB) olan çocuklarda ve bu çocukların ailelerinde yaşam kalitesinin değerlendirilmesi ve rahatsızlığın psikososyal boyutunun incelenmesi amaçlanmıştır.* ***Yöntem:*** *Ankara Üniversitesi Tıp Fakültesi Çocuk Ruh Sağlığı ve Hastalıkları Anabilim Dalı'na başvuran DEHB tanısı ilk kez konan veya bu tanıyla izlenen 7-16 yaşları arasındaki 76 çocukla, önceden klinik başvurusu olmayan bir örneklemden seçilmiş, yaş ve cinsiyet gibi özellikler bakımından hasta grubuyla eşleştirilmiş 59 kişiyi içeren kontrol grubu çalışmaya alınmıştır.* ***Bulgular:*** *DEHB'li çocukların okul başarıları daha kötü ve okula devamsızlık süresi daha fazla bulunmuştur. SF-36 verilerine göre DEHB'li grupta ağrı, genel sağlık, vitalite enerji, mental sağlık alt ölçek puanlarında kontrol grubuna göre anlamlı fark saptanmıştır. ÇİYKÖ çocuk ölçeğinde psikososyal sağlık puanı ve ölçek toplam puanı alt ölçeklerinde DEHB grubunda kontrol grubuna göre anlamlı düşüklük bulunmuştur. ÇİYKÖ-anababa psikososyal sağlık puanı ve ölçek toplam puanı DEHB'li grupta anlamlı düzeyde düşük bulunmuştur. ADÖ verilerine bakıldığında, problem çözme, iletişim, duygusal tepki verebilme, genel işlev-*

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ler, gereken ilgiyi gösterme ve roller alt ölçeklerinde iki grup arasında anlamlı fark olduğu saptanmıştır. ***Tartışma:*** *Bu çalışmada DEHB'li çocuklar ve ailelerinde yaşam kalitesinin değerlendirildiği bazı alanlarda kontrol grubuna oranla daha olumsuz bir durum sergiledikleri belirlenmiştir. Çocuk ruh sağlığı ve hastalıkları kliniklerinde DEHB'nin klinik yönü kadar psikososyal boyutu da gözardı edilmemelidir.* ***(Anadolu Psikiyatri Derg 2014; 15:265-271)***

Anahtar sözcükler*: ÇİYKÖ, çocuk, DEHB, SF-36, yaşam kalitesi*

INTRODUCTION

Attention-deficit/hyperactivity disorder (ADHD) is an early onset neuropsychiatric disorder, which is characterized by hyperactivity, impulsivity, and attention deficit (AD). It is a highly prevalent mental disorder of childhood, which affects 3-7% of school-age children. Boys are two to nine times more likely to be affected than girls.[1] Twin, adoption, and molecular genetic studies show ADHD to be highly heritable.[2] It continues during adolescence and adulthood and is associated with a loss of functioning throughout the entire lifespan.[3] ADHD symptoms are associated with impairments across a number of domains, including academic, social, and emotional functioning.[4] AD causes regulational difficulties and academic underachievement, and hyperactive/impulsive features and mood lability may result in poor peer relationships.[5]

In recent years, quality of life (QOL) has emerged as an important outcome measure in guiding health care. In ADHD, inadequacy in the academic, social, and emotional areas of a child's life may cause decreased self-esteem and unhappiness, and deterioration in interpersonal and family relationships results in a worsening of quality of life. For this reason, multi-dimensional monitoring of the clinical parameters of the disease as well as the psychosocial dimensions is becoming increasingly important.[6] In children with ADHD, health-related quality of life (HRQL) was also investigated, and lower HRQL scores were documented compared to normal children.[7,8] The relationships in families who have a child with ADHD are associated with more conflicts and are considerably more stressful than the relationships in families without a family member affected by ADHD.[9,10] There are few studies that have assessed the quality of life of parents who have a children with ADHD; however, interest in this subject has increased in recent years. There have been efforts to develop original scales for measuring the quality of life of families of children with ADHD.[6] In this study we aimed to evaluate the effects of ADHD not only on children but also their families with respect to the meaning of quality of life and family functioning.

METHODS

Subjects

The study was conducted between February and September 2008 in the outpatient clinic of the Ankara University Department of Child and Adolescent Psychiatry. The research sample consisted of a group of 150 children who had both been referred to the clinic for the first time and diagnosed with ADHD or were undergoing follow-ups as they had previously been diagnosed with ADHD. All patients had been diagnosed with ADHD by two child psychiatrists according to the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) diagnostic criteria. The study was conducted with 76 persons who were selected from the 150 ADHD sample and did not have any other medical and/or psychiatric disorders. The control group was created from 150 children who had attended a summer school and were matched with the ADHD group in terms of socio-demographic characteristics like age, gender, family income level, and family type. The Strength and Difficulties Questionnaire was completed by the parents to evaluate the children. According to these scales, participants who showed a high risk for any psychiatric disorder were excluded, and the control group finally consisted of 59 children.

Evaluation measures

Strength and Difficulties Questionnaire (SDQ): SDQ is a well-established and widely used screening instrument for psychopathology among children and adolescents. It consists of 25 statements relating to children's strengths and difficulties.[11] The 25 items are divided into five subscales: conduct problems, emotional problems, hyperactivity, peer problems, and prosocial behavior (each containing five items). Scores on the first four of these subscales are summed to provide a total difficulties score. The parent version of the SDQ was used in the present study, and it has been validated for use among Turkish children.[12]

DSM-IV-Based Behavior Disorders Screening and Rating Scale: This scale was developed by Turgay,[13] and the validity and reliability study was performed in Turkey in 2001.[14] The scale has three subscales to inquire about ADHD, oppositional defiant disorder (ODD), and conduct disorder (CD). These subscales have 41 items, which include nine inattention items, six hyperactivity items, three impulsivity items, eight items related to ODD, and 15 items related to CD.

Pediatric Quality of Life Inventory: Parent and Child Versions (PedsQL-P and -C): This scale was developed by Varni et al.[15] in order to evaluate HRQL in children. The reliability and validity study of the scale for 8-12 year-old and 13-18 year-old Turkish children was conducted by Memik et al.[16,17] It is a short and easy-to-apply instrument, which is scored on a five-point Likert-type scale. The scale has parent and child versions that investigate physical and psychosocial functioning.

Short Form-36 (SF-36): The SF-36 was developed by Ware and Sherbourne.[18] It is a short questionnaire with 36 items, which measure eight multi-item variables: physical functioning, social functioning role limitations due to physical problems, role limitations due to emotional problems, mental health, energy and vitality, pain, and general perception of health. There is a further un-scaled single item on changes in respondents' health over the past year. The reliability and validity study of the scale in the Turkish population was conducted by Koçyiğit et al.[19]

McMaster Family Assessment Device (FAD): The McMaster (FAD) was developed in the context of the Family Research Program at Brown University and Butler Hospital in the United States.[20] It aims to evaluate family functioning in a general manner and determine problematic areas. It includes 60 questions, which are divided into seven different areas. These are problem-solving, communication, roles, affective responsiveness, affective involvement, behavior control, and general functions. The scores for the scales range between 1.00 (healthy) and 4.00 (non-healthy). Generally, scores over 2.00 are accepted as a non-healthy tendency in family functioning, but reliability studies are continuing. Test-retest reliability was found as 0.62 and 0.90, and internal consistency was 0.38 and 0.86 in the Turkish version.[21]

Procedure

The study was approved by the Ankara University Ethical Committee. A detailed description of the study was given to all the children and parents. The parents of the children who agreed to participate in the study signed a written informed consent. Parents further completed the SDQ, FAD, SF-36, and PedsQL-P. All the children were interviewed and ADHD diagnoses were made according to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition, -Based Child and Adolescent Behavior Disorders Screening and Rating Scale (DSM-IV-TR), and the children also completed the PedQL.

Statistical analysis

The analysis of the data was performed using Statistical Package for the Social Sciences (SPSS) 11.5 statistical software. Continuous variables were analyzed by the student t-test and chi-squared test, which was used for categorical variables. The alpha value was accepted as statistically significant when it was less than 0.05.

RESULTS

There were 54 (71.1%) boys and 22 (28.9%) girls in the study group (n=76), and 37 (62.7%) boys and 22 (37.3%) girls in the control group (n=59). There were no significant differences between the groups for age (t=0.83, p=0.934), gender (χ^2=1.05, p=0.305), mothers' education level (t=1.47, p=0.144), fathers' education level (t=0.41, p=0.686), income (χ^2=1.05, p=0.305), and number of siblings (t=0.85, p=0.392). The results of the SF-36, FAD, PedsQL-C, and PedsQL-P scores are given in Table 1, 2, 3, respectively.

DISCUSSION

All the children in the study were in the range 7-16 years, undergoing age-appropriate education, and receiving no special education. The male/female ratio was 2.4 in the ADHD study group. This rate is compatible with other research where the disorder is 2-5 times more common in men.[22]

Since most psychiatric illnesses tend to persist,[23] improvement in the quality of everyday life should be an important treatment goal.[24] Behavioral problems in children with chronic diseases are treated more frequently than community samplings in the literature.[25] These problems may be seen as a result of the efforts

Table 1. The SF-36 mean and standard deviation values of the study and control groups' parents

	ADHD parents (n=76)	Control parents (n=59)	t	p
Physical functioning	83.22±17.75	83.89±18.10	-0.22	0.828
Role limitations due to physical problems	75.00±33.41	82.62±26.77	-1.43	0.154
Pain	65.72±24.14	74.62±20.88	-2.25	0.026
General perception of health	55.88±19.42	69.67±20.57	-3.99	0.000
Vitality and energy	57.96±23.62	66.10±19.71	-2.13	0.035
Social functioning	76.31±22.96	79.66±21.00	-0.87	0.385
Emotional problems	73.68±35.40	74.57±34.09	-0.15	0.883
Mental health	61.42±18.78	69.22±18.42	-2.41	0.017

Table 2. The FAD mean and standard deviation values of the study and control groups' parents

	ADHD parents (n=76)	Control parents (n=59)	t	p
Problem-solving	1.99±0.63	1.74±0.55	2.42	0.017
Communication	1.98±0.59	1.72±0.73	2.34	0.021
Roles	2.21±0.42	1.95±0.40	3.50	0.001
Affective responsiveness	1.78±0.64	1.55±0.44	2.28	0.024
Affective involvement	2.23±0.36	2.07±0.29	2.83	0.005
Behavior control	2.16±0.37	2.07±0.29	1.65	0.102
General functions	1.86±0.62	1.49±0.65	3.35	0.001

Table 3. The PedsQL-C and PedsQL-P mean and standard deviation values of the study and control groups

		ADHD parents (n=76)	Control parents (n=59)	t	p
Physical health subscale scores	Child	77.53±16.85	80.33±18.13	-0.93	0.356
	Parent	74.91±18.34	79.33±18.35	-1.39	0.167
Psychosocial subscale scores	Child	69.76±15.70	85.02±11.59	-6.23	<0.001
	Parent	65.75±15.06	83.81±12.11	-7.51	<0.001
Total scores	Child	72.13±15.02	83.35±13.10	-4.55	<0.001
	Parent	69.06±14.32	81.92±13.15	-5.38	<0.001

of compliance with the disease and/or the direct effects of the disease.[26]

According to SF-36, there wasn't a significant difference between the parents' physical functioning subscale scores in the ADHD and control groups. Klassen et al.[8] found that ADHD worsened the mental health of families but did not affect physical health. In one study, it was found that the parents of children with ADHD were more dissatisfied in terms of their parenting roles than those whose children did not have ADHD.[27] Some studies determined that there were increased rates of psychopathology in families of children with ADHD and reported that having a children with ADHD is a predictor of depression in mothers.[28] Pre-school children with ADHD respond less favorably to their parents' recommendations and behavioral needs than their peers, and this leads to increased parenting stress.[29] ADHD raises important issues in the areas of social communication. ADHD children can develop problematic relationships with families, and this pattern may continue into late adolescence.[30] This negative interaction has detrimental effects on children and their families' lives. Increased parenting stress, alcohol abuse, marital conflict, and depression are seen more frequently in the par-

ents of children with ADHD.[31]

Even though the ADHD group obtained low scores in the role limitations due to physical problems and role limitations due to emotional problems subscale scores, these differences were not statistically significant. The emotional problems subscale scores were close in the two groups. The mental health subscale scores were worse in the ADHD parents' group, and it can therefore be said that having an ADHD child has more demanding effects on mental health than physical health. On the other hand, the damage to parents' own mental health may hinder their ability to cope with the challenges of ADHD children, and as a result, the nature of the mutual interaction between parents and their children should not be forgotten.

According to PedsQL-C, the psychosocial subscale scores and total scores were significantly poorer in the ADHD group; however, there wasn't any significant difference in the physical health subscales scores. Matza et al.[31] found similar results, and psychosocial subscale scores improved with treatment. According to the literature, ADHD had a worse effect on psychosocial subscale scores.[8] One study ascertained that newly diagnosed ADHD patients experienced more problems in psychosocial areas than healthy subjects and asthma patients.[32] Sawyer et al.'s 2002 study confirmed that ADHD worsens quality of life in general.[33] Varni and Burwinkle[34] found that psychosocial subscale scores were lower than physical health scores, but this difference was not statistically significant. Another review similarly concluded that the disorder especially influenced psychosocial health.[8]

Study findings have indicated that the development of the self in adolescents with ADHD is negatively affected.[35] Adolescents with ADHD showed failure in educational and vocational areas, frequently changed jobs, and had substance abuse, a tendency to addiction, and conflict with authority.[36]

In the PedsQL-P results, the psychosocial subscale scores and total scores were significantly poor in the ADHD group although there wasn't a significant difference in the physical health subscale scores. The data received from the parents' forms aligned with the data from the children. A study by Bastiaansen et al.[37] showed similarities between the parents' and children's data. In Eiser and Morse's study,[38] the data of the parents and children was more compatible in the physical health subscale scores than the psychosocial subscale scores. Our study supported the finding that physical health scores were harmonious in the data from the two groups.

Considering that there are often mental disorders in the parents of children with psychiatric problems, the functioning in the families of these children is expected to be adversely affected. According to FAD, even the problem-solving, communication, affective responsiveness, and general functioning subscale scores were under 2 (over 2 is unhealthy) in both groups although the difference was statistically significant in the ADHD group. The affective involvement subscale scores were over 2 in both groups, but the ADHD group's scores were statistically significantly higher. The roles subscale scores were statistically different between the groups, but the behavioral control subscale scores were similar. Pekcanlar et al.[39] found that family functioning was generally normal in children with ADHD. But in the same study, control and communication problems were present in the families of children with CD in addition to ADHD. Özcan et al.[40] evaluated family functioning in ADHD children with and without ODD by using FAD. They found significantly higher results in the behavior control subscale in the families of ADHD children with the ODD comorbidity. These higher results mean unhealthy states. Similarly, Kılıç and Sener[41] found higher results in the roles and behavior control subscales of FAD in the families of ADHD children with ODD and/or CD comorbidities. To have a child who has a disruptive behavioral disorder may cause social difficulties and increase parental stress. In a study in which the psychosocial characteristics of families of ADHD children with ODD and/or CD comorbidities were evaluated, interpersonal relations were more conflicted and less organized. Moreover, the impairment of psychiatric health was more prominent in mothers of ADHD children with ODD and/or CD comorbidities.[42] Matza et al. found similar results that supported the notion that ADHD worsened family functioning.[31]

CONCLUSION

As a comprehensive result, we can see that ADHD affects either children or their families' health-related quality of life. Family functioning is worse in families that have a member with ADHD. In child and adolescent psychiatric clinics, the psychosocial aspects of ADHD must

be taken into account as well as its clinical aspects. A true diagnosis, comprehensive evaluation, and appropriate treatment will affect the whole family of a child with ADHD as well as the related community's quality of life.

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