

Does the quality of life in autism spectrum disorder differ from other chronic disorders and healthy children?

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ABSTRACT

Objective: Autism spectrum disorder (ASD) is characterized by deficits in social interaction, communication, restricted interests, and repetitive patterns of behavior. This study examined quality of life (QoL) and related clinical factors in children with ASD, compared to children with Attention Deficit Hyperactivity Disorder (ADHD), children with asthma, and healthy controls (HC). **Methods:** QoL was assessed by the Pediatric Quality of Life Inventory 4.0 (PedsQLTM 4.0). Additionally, parents of the children provided sociodemographic information and filled out an evaluation questionnaire, child behavior check list (CBCL), and Turgay DSM-IV Disruptive Behavior Disorders Rating Scale (T-DSM-IV-S). **Results:** The physical health, psychosocial health, social functioning, and scale total score of the ASD group were significantly lower than those of the three comparison groups. The school functioning score domain was lower in the ASD group than in the asthma and HC groups. In contrast, the emotional functioning domain assessments did not reveal statistically significant differences between the ASD group and the comparison groups. In the ASD group, the total problem score, inattention, and hyperactivity scores were significantly higher than both the asthma and HC groups, and the internalizing scores were higher than the healthy group. **Conclusion:** The poor QoL is most likely due to functional losses and problem behaviors related to ASD and may negatively affect not only children with ASD but also the whole life of the family. (*Anatolian Journal of Psychiatry* 2016; 17(5):419-426)

Keywords: autism spectrum disorders, autism, quality of life, chronic disorder

Otizm spektrum bozukluğunda yaşam kalitesi diğer kronik hastalıklardan veya sağlıklılarından farklı mıdır?

ÖZ

Amaç: Otistik spektrum bozukluğu (OSB) sosyal becerilerde ve iletişimde bozukluk, kısıtlı ilgiler ve yineleyici hareketlerle karakterize bir tablodur. Çalışmamızda 102 OSB olan çocuğun yaşam kalitesini (YK) dikkat eksikliği hiperaktivite bozukluğu (DEHB) olan, astımı olan çocuklarla ve sağlıklı çocuklarla karşılaştırmak ve ilişkili klinik etkenleri değerlendirmek amaçlanmıştır. **Yöntem:** Çalışmamızda YK değerlendirmesinde Çocuklar için Yaşam Kalitesi Ölçeği (ÇİYKÖ) kullanılmıştır. Anne-babalar çalışmamız için hazırlanan sosyodemografik bilgi formunu, Çocukların Davranışlarını Değerlendirme Ölçeği'ni ve Turgay DSM-IV'e Dayalı Yıkıcı Davranış Bozukluklarını Tarama ve Değerlendirme Ölçeği'ni doldürmüşlerdir. **Bulgular:** Analiz sonuçlarına göre, fiziksel sağlık, psikososyal sağlık, sosyal işlevsellik ve ölçek toplam puanı OSB grubunda hem sağlıklı çocuklardan, hem de DEHB ve astımlı çocuk

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*hastalardan daha düşük bulunmuştur. Okul işlevselliği OSB grubunda astım hastalarından ve sağlıklılardan düşük bulunurken, emosyonel işlevsellik puanı açısından gruplar arası anlamlı fark bulunamamıştır. Bunun yanında OSB grubunda toplam problem puanı, dikkat eksikliği ve hiperaktivite puanı astımlılardan ve sağlıklılardan; içe yönelim puanı ise sağlıklılardan anlamlı olarak yüksek bulunmuştur. **Sonuç:** OSB hastalarında belirlenen YK'deki olumsuz etkilenmenin, olasılıkla hastalardaki işlev kayıplarına ve hastalıkla ilişkili sorun davranışlara bağlı olabileceği düşünülmüştür. Ayrıca bu sorunun sadece çocukları değil, tüm aileyi etkilemesi olası bir sonuçtur. (Anadolu Psikiyatri Derg 2016; 17(5):419-426)*

Anahtar sözcükler: Otizm spektrum bozukluğu, otizm, yaşam kalitesi, kronik hastalık

INTRODUCTION

Autism spectrum disorder (ASD) is a chronic neurodevelopmental disorder, which begins in early childhood. The most prominent features are abnormalities in social and communication skills, repetitive behaviors and narrow interests.¹ Children with ASD can exhibit temper tantrums, atypical actions and aggressive behaviors. In addition, children with ASD show more depressive and anxiety symptoms versus typical developing children.² Furthermore, they have delayed development of motor functions, loss of skills, sleeping problems, gastrointestinal problems, and allergic symptoms.^{2,3} All of these problems can affect many aspects of life and lead to significant challenges related to physical, psychological, social, and emotional health.

The quality of life (QoL) has recently become an important topic in chronic disorders. The QoL is a multidimensional and subjective notion and includes social, physical and emotional domains. The assessment of QoL requires information about clinical status, physical functioning, life satisfaction, psychosocial well-being as well as patient social support.

There are few studies of QoL in children with ASD. Kuhlthau et al. compared the QoL scores of ASD children with a national norm for a healthy population as well as the norm for children with chronic conditions. They found worse QoL in children with ASD than both comparison groups except for school functions and physical health.⁴ Similarly, a heavier burden of care, more educational and social difficulties, more parental concerns and lower QoL scores were reported in children with autistic disorders (AD) than both ADHD and HC groups.⁵ In another study, Bastiansen et al. reported that psychosocial and emotional functioning of an ASD group was lower than groups with ADHD, disruptive behavior disorders, anxiety and affective disorders.⁶ Similar results have been reported for the families of ASD children. Mugno et al. reported that QoL in parents of children with ASD was worse than parents of children with mental retardation,

cerebral palsy and HC.⁷

The previous study conducted by our team investigated QoL and related clinical variables in children with ASD.⁸ Here, we compared the QoL of the same ASD children and the children diagnosed with ADHD as a chronic psychiatric disorder, children with asthma as a chronic physical disorders and healthy controls. We also evaluated clinical factors (e.g. problem behaviors and attention deficit hyperactivity symptoms) that might be related to the impairment of QoL in ASD. We considered that ASD affects QoL more negatively than other chronic disorders, and we hypothesized that lower QoL scores would be found in ASD children relative to three other groups of children.

METHODS

Participants and procedures

The ASD sample of the previous study, which was conducted by Sezen (2013) et al.⁸ to investigate the QoL and related clinical variables in children with ASD, formed the ASD sample of this study. The sample included 102 children with ASD diagnosis between the ages of 3 and 18 who were followed up in our outpatient unit and who were recruited at their routine visit. Forty-six were diagnosed with AD, 18 with Asperger's syndrome (AS), and 38 with pervasive developmental disorder-not otherwise specified (PDD- NOS). The diagnosis of ASD was given according to DSM-IV-TR¹ criteria by the researchers, who had at least five years of experience working with children and adolescents with ASD. In addition, the autistic symptoms of these children were assessed with Childhood Autism Rating Scale (CARS). Forty children with diagnosed ADHD and who were followed up in our outpatient unit were included in the study. The exclusion criterion for the ADHD group was the presence of a comorbid conduct disorder. Forty-four children with asthma between 3 to 18 years of age who were followed up in outpatient unit of pediatric respiratory allergy for at least six months were recruited into the study. The exclu-

sion criteria for asthmatic children were the presence of any psychiatric diagnosis. Thirty-nine HC subjects who did not have any psychiatric or chronic physical disease were recruited from the same population for the study. The HC subjects had no family history for ASD.

All the parents of participants were individually briefed on the aim of the study and signed an informed consent form in accordance with the Declaration of Helsinki. Furthermore, the children who possessed communication skills were briefed on the aim of the study and assent was received for the study. The local Ethics Committee of Ege University School of Medicine approved the study.

Instruments

Sociodemographic Information and Evaluation Questionnaire: This questionnaire was formed by the study authors with the aim to collect data about the child's age, gender, developmental history, education, medical history, therapeutic data and the parents' age, gender and educational year.

PedsQLTM 4.0: The scale is one of the measures that evaluates HRQoL in 2 to 18 years old children and adolescents and was developed by Varni et al. It is a 23 item questionnaire, includes four age appropriate versions (2 to 4 years old, 5 to 7 years old, 8 to 12 years old, and 13 to 18 years old). It examines four distinct areas of health-related functioning: physical functioning, emotional functioning, social functioning and school functioning. As a result, three main score is obtained, physical health total score (PHTS), psychosocial health total score (PSHTS), scale total score (STS). The higher the total PedsQLTM 4.0 score reflects the better the HRQoL.¹⁰ Numerous studies show that PedsQLTM 4.0 is a valid, reliable, and sensitive instrument.^{9,10} Turkish translation, reliability, and validity studies for 2-18 years of children have been carried out.^{11,12} Since the communication difficulties among children with ASD are common, we used parent-report version of the PedsQLTM 4.0 to assess child QoL.

CARS: The CARS is commonly used to determine the presence and degree of autism in the absence of more validated instruments developed by Schopler et al.¹³ Turkish translation, reliability, and validity studies have been carried out by Sucuoglu et al.¹⁴

CBCL: This is a parent rating scale developed to assess competence and problem behaviors in children by Achenbach and Edelbrock.¹⁵ The

adaptation of the scale to Turkish was done by Akçakin¹⁶ and Erol et al.¹⁷ collected the Turkish norms and reliability data for the scale. Scores obtained from the scale constitute the total problem score, and also internalizing and externalizing problems.

T-DSM-IV-S: This scale was developed by Turgay for screening the disruptive behavior disorders based on DSM-IV criteria¹⁸ and its Turkish reliability and validity study was conducted by Ercan et al.¹⁹ The scale evaluate problems related inattention, hyperactivity-impulsivity and oppositional defiant disorder (ODD).

Statistical analysis

SPSS for Windows (version 15.0) was used for the statistical analysis. The normality of the variables was evaluated with Shapiro-Wilks test. The comparison of groups was assessed by using one-way ANOVA test, Kruskal-Wallis test and Mann-Whitney U test. Chi-square analyses were used to compare categorical variables. Differences were considered significant if p values were <0.05.

RESULTS

Sociodemographic characteristics

We enrolled 225 children and adolescents from age 3 to 18 (mean age: 9.26±3.67). The ASD group consisted of 102 patients with a mean age of 8.23±3.68. While there was not a significant difference on the mean ages of ASD, ADHD and healthy control groups (p=0.08); the asthma group's mean age was significantly higher than the other three groups (p=0.001) (Table 1). As expected, there were more boys in the ASD group. In the ASD group, 36.4% of the patients participated in formal education-this was significantly lower than the other groups ($\chi^2=96.86$, p<0.001). There was no significant difference for age of the mothers (p=0.14). Sociodemographic characteristics of the groups are shown in Table 1.

The scores of PedsQLTM 4.0

PHTS, PSHTS and STS were significantly lower in the ASD groups than all the other groups (p<0.01). When we evaluated the psychosocial health scale subscores, social functioning scores were significantly lower in the ASD group than in the comparison groups (p<0.01). School functioning scores were lower in the ASD group than both the asthma and HC groups (p<0.01). In terms of emotional functioning scores, no statistically significant differences were found

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Table 1. Sociodemographic characteristics of participants

	ASD (n=102)	ADHD (n=40)	Asthma (n=44)	Healthy (n=39)
Age (mean±SD, year)*	8.2±3.7	9.4±2.1	11.3±3.2	9.4±4.3
Gender (female/male, n)**	18/84	14/26	16/28	23/16
Participate in formal education (n, %)	41, 36.4	36, 90.0	41, 95.3	28, 71.8
Mother's age (mean±SD, year)***	35.6±7.1	36.3±4.8	38.3±6.5	36.3±5.2
Mother's education (%)				
Primary	44.5	42.5	32.6	33.3
Secondary	32.7	42.5	39.5	35.9
University	21.8	15.0	27.9	30.8

* One way variance analysis (ANOVA), $p=0.001$; ** $\chi^2=23.35$, $p<0.001$; *** One way variance analysis, $p=0.14$

Table 2. The comparison of groups' scores

	The comparison of groups' quality of life scores								p	Multiple comparisons
	ASD (n=102)		ADHD (n=40)		Asthma (n=44)		Healthy (n=39)			
	Median	Min/Max	Median	Min/Max	Median	Min/Max	Median	Min/Max		
PHTS	65.6	18-100	87.5	59-100	81.2	40-100	87.5	62-100	<0.001*	1<2,3,4
PSHTS	53.3	23-98	67.4	33-96	77.4	21-100	78.3	55-100	<0.001*	1<2,3,4
Emotional functioning	65.0	25-95	75.0	20-100	75.0	25-100	75.0	40-100	0.06	
Social functioning	50.0	0-100	80.0	0-100	90.0	25-100	85.0	30-100	<0.001*	1<2,3,4
School functioning	50.0	0-100	62.5	0-95	75.0	5-100	85.0	15-100	<0.001*	1<3,4
STS	55.4	25-96	73.3	43-95	78.8	34-100	83.6	68-100	<0.001*	1<2,3,4
All four groups' DSM-IV based behavior disorders screening and rating scale scores										
	Median	Min/Max	Median	Min/Max	Median	Min/Max	Median	Min/Max		
Inattention	15	1-27	18	8-26	5	0-27	4	0-27	<0.001*	1>3,4
Hyperactivity	11	0-27	17	2-27	7	0-23	6	0-23	<0.001*	1>3,4
ODD	5	0-18	11	0-24	4	0-20	4	0-23	<0.001*	1<2
Child Behavior Checklist scores of all four groups										
	Mean±SD		Mean±SD		Mean±SD		Mean±SD			
Externalizing	52.8±10		61.7±9.8		51.6±11.5		51.9±9.8		<0.001 ^a	1<2
Internalizing	59.5±9.1		63.1±10.6		57.0±11.2		51.6±11.1		<0.001 ^a	1>4
Total problem	62.5±8.8		65.6±8.6		55.1±12.4		52.7±10.8		<0.001 ^a	1>3,4

PHTS: Physical health total score; PSHTS: Psychosocial health total score; STS: Scale total score; * Kruskal-Wallis test and Mann-Whitney U test; ^a One-way variance analysis (ANOVA); 1=SD, 2=DEHB, 3=Asthma, 4=Healthy

between the groups ($p=0.06$) (Table 2 and Figure 1).

CBCL scores

In the ASD group, the total problem score was significantly higher than both the asthma and HC groups internalizing scores were higher than the HC group. In terms of externalizing scores, the ADHD group scored significantly higher than the ASD group ($p<0.001$) (Table 2).

T-DSM-IV-S

Comparisons of T-DSM-IV-S showed that the ASD group's inattention and hyperactivity scores were significantly higher than both the asthma and HC groups ($p<0.001$). Oppositional defiant

scores in the ASD group were significantly lower than the ADHD group ($p<0.001$) (Table 2).

DISCUSSION

We compared the QoL of ASD children with other groups of children including those with ADHD, asthma and HC groups. The results suggest that the ASD group has a lower QoL than the other groups. Other QoL studies have shown that patients with ASD had a worse QoL versus healthy subjects^{4,20-22} or patients with chronic conditions.^{4,20,22}

Low physical health scores may be related and have variable factors. Motor developmental

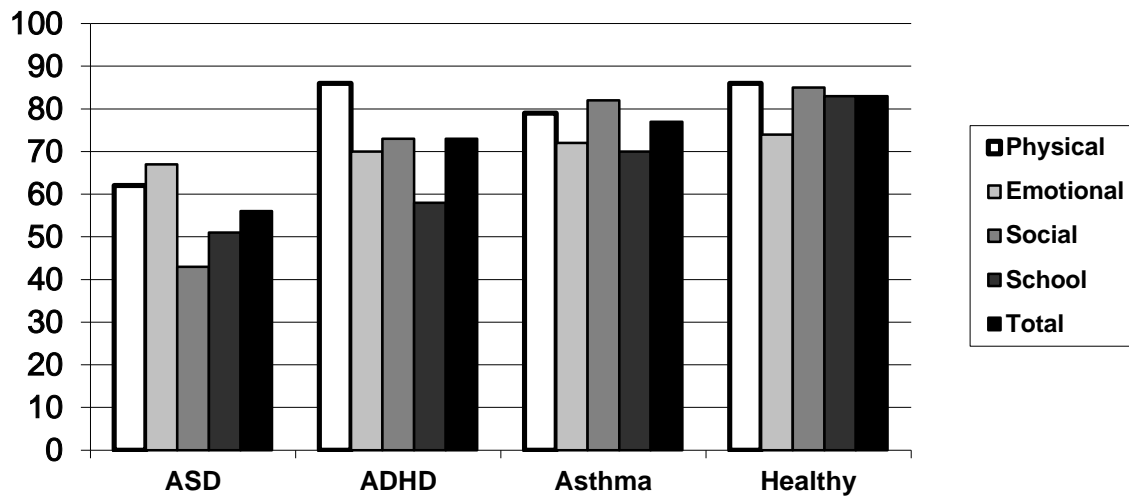


Figure 1. The comparison of groups' quality of life scores

delay in autistic children, motor clumsiness in AS, and significant motor coordination problems and soft neurological signs in PDD-NOS have been reported in previous studies.²³⁻²⁵ Moreover, much poorer physical health status, more sleeping problems, gastrointestinal and allergic problems were frequently reported in ASD patients.^{2,3,26} Beyond these findings, it has been shown that there are serious problems with self-care skills²⁷ and more dependency²⁸ in ASD patients. All these factors may lead to more dependency on their caregivers and low QoL scores in terms of physical health domain ASD children. In contrast to our findings, Kuhlthau (2010) et al. found similar physical health scores between the ASD group and the norm of children with chronic conditions.⁴ The contradictory findings may be to the characteristics of the selected chronic disorders.

In our study, the ASD group had lower PSHTS, social functioning scores and school functioning scores versus comparison subjects. This is consistent with the literature. Emotional functioning scores were also lower in the ASD group but the difference was not statistically significant.

We queried the emotional functioning, anxiety, depressive mood, aggression frequency and sleeping problems of the subjects. Studies have revealed that children with ASD have more symptoms of depression and anxiety versus healthy children.^{2,3} They also report more sleeping problems.³ Temper tantrums are common in ASD, and Bastiaansen et al. demonstrated that the emotional functioning scores were lower versus HC.⁶ Bachevalier and Loveland reported that patients with ASD were im-

paired in their understanding of others' mental states and self-regulation of social-emotional behavior.²⁹ In light of these data, lower emotional functioning scores were an expected result in ASD. Inconsistency between our findings and the literature may be due to the relatively insufficient sample size in our study.

The social functioning domain investigates peer relationships and social skills in children. As is well-known, problems with social interactions and difficulties in communication skills are characteristic features of ASD. Furthermore, mental retardation is often seen in autism. It disrupts social skills. These problems may lead to poor social skills and social isolation. Lee et al. Reported that autistic children had a heavier burden of care, more deprivation in social activities and poorer QoL versus ADHD and healthy children.⁵ Bastiaansen et al. reported that psychosocial and emotional functioning were significantly lower in the ASD group than some psychiatric disorders including ADHD and the other disruptive disorders, anxiety and mood disorders.⁶ Liss et al. and de Bildt et al. have shown weaker social skills and less adaptive capacity in patients with ASD versus HC.^{30,31} Our finding regarding the lower social functioning scores among the ASD group was consistent with the literature.

In the school functioning domain, ASD children performed worse and had higher levels of inattention, forgetfulness, and truancy. Inattention and hyperactivity, which frequently accompany ASD, lead to a loss of function in the field of education. Our study showed that inattention and hyperactivity subscores of T-DSM-IV-S was

significantly higher in the ASD group than the asthma patients' group and HC. Lee and Ousley reported that the ADHD prevalence in children with ASD is as high as 78%.²⁰ In the ASD group, the presence of inattention and hyperactivity increase the hospitalization rates, drug use, and need for psychotherapy in addition to medical treatment and morbidity.³² This leads to poor quality of life.³³ On the other hand, the mental retardation that often accompanies autistic disorders negatively impacts school functioning in autistic children. Studies related to this topic have shown that there are more learning difficulties and academic problems in this cohort.^{32,34,35} Lee et al. reported that children with autism had more school-related problems including school achievement. Their parents had more concerns related to learning difficulties versus children with ADHD and HC.⁵

In ASD, one of the major factors that can affect the QoL in various areas is problem behaviors. We found that the problems score of children with ASD evaluated with the CBCL was significantly higher than those of the comparison groups except ADHD group. In the literature, there are studies which reported a relationship between quality of life and internalizing and externalizing scores^{36,37} and this relation has been reported to be stronger in the externalizing domain.³⁸ In patients with ASD, the increase in problem behaviors may lead to disrupt the social

adaptation and increase in burden of care. Therefore our finding of higher CBCL scores in ASD group is concomitance with the literature helped us to explain the poorer QoL in ASD group.

The study has several limitations. First, it was a cross-sectional study. Second, the severity of the disorders of ADHD and asthma was not categorized. Third, the data were obtained by parent observations. Fourth, the study did not include any self-reporting data. Fifth, our study sample including ASD, ADHD and asthma and consisted of participants according to the study criteria who admitted to the outpatient clinic over a certain time interval. Therefore, age and gender matching was not performed. Finally, all of the patients with ADHD have already been diagnosed and followed up in our outpatient clinic. Therefore, we did not use any diagnostic structural interview for ADHD groups.

CONCLUSION

We found that ASD children have poorer QoL than children with ADHD or asthma as well as a HC group. The result is most likely due to functional losses and problem behaviors related to ASD. To improve the life quality of ASD children, effective health policies and treatment options should be considered.

Yazarların katkıları: Ö.Ö.: Planlama, literatür tarama, olgu toplama, araştırmanın yürütülmesi, istatistik, makaleyi yazma; S.E.: Konuyu bulma, planlama, olgu toplama, araştırmanın yürütülmesi, istatistik, makaleyi yazma; E.S.E.: Planlama, olgu toplama, araştırmanın yürütülmesi; F.G.: Planlama, olgu toplama, araştırmanın yürütülmesi; B.K.B.: Olgu toplama, makaleyi yazma; Ö.B.: Olgu toplama, istatistik; S.K.: İstatistik, makaleyi yazma; F.Ö.Ö.: Literatür tarama, makaleyi yazma; H.A.: İstatistik, makale yazma; C.A.: Konuyu bulma, planlama.

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