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Current functioning of young adults diagnosed with autism spectrum disorder in childhood and depression and burnout among their parents in Türkiye

Meryem Özlem Kütük · Ali Evren Tufan · Fethiye Kılıçaslan · Burçin Şeyda Buran · Neslihan Taştepe · Nagihan Cevher Binici · Fatma Sibel Durak · Yadigar Düğüncü Terlemez · Ayşe Kutlu · Canem Kavurma · Enes Şamdan · Mehrişah Usta · Aylin Yılmaz · Oğuzhan Koyuncu · Alperen Bıkmazer · Aynur Görmez · Vahdet Görmez · Rabia Can · Müjdat Erarkadaş · Burcu Kardaş · Ömer Kardaş · İrem Damla Çimen · Özlem Yıldız Gündoğdu · Caner Mutlu · Ferhat Yaylacı · Barış Güller · Pınar Vural · Gonca Özyurt · Perihan Çam Ray · Burak Kamış · Rezan Karabulut Kılıç · Gonca Gül Çelik · Ayşegül Yolga Tahiroğlu · Fevziye Toros · Gülen Güler Aksu · Şafak Eray Çamlı · Serkan Turan · Bahtım Kütük · Sevay Alşen Güney · Neslihan İnal · Yasemin İmrek · Zeynep Vatansever Pınar · Şeyma İlhan · Hasan Kandemir · Sibelnur Avcil · Günay Budagova · Çisem Erdaş · Esra Demirci · Sevgi Özmen · Leyla Seviçin · Tuba Mutluer · Eren Yavuz Açıkalın · Leyla Bozatlı · Hasan Cem Aykutlu · Işık Görker · Tilbe Erten Almak · Esen Yıldırım Demirdöğen · Abdullah Bozkurt · Mehmet Akif Akıncı · Tuğba Nur Saylan Yavuz · Onur Burak Dursun · Esra Hoşoğlu · Bahadır Turan · Onur Tuğçe Poyraz Fındık · Bedia Sultan Önal · Cansu Çobanoğlu Osmanlı · Gülsüm Yitik Tonkaz · Berkan Şahin · Öznur Adıgüzel Akman · Hatice Altun · Funda Özyay Eroğlu · Fadime Hande Özer · Esma Nur Pamuk · Şeyma Çelikcan Yeşilmeşe · Şermin Yalın Sapmaz · Veysel Özdağ · Ceylan Carık · Bahaddin Çolak · Adem Türk · Ömer Akça · Ahmet Büber · Elif Abanoz · Ayla Uzun Çiçek · Cansu Mercan Işık · Öznur Bilaç · Rahime Mutlu Yaprakçı · Çağla Çelikkol Sadıç · Yekta Özkan · Aziz Kara · Masum Öztürk · Fatma Subaşı Turgut · Cem Gökçen · Mehmet Karadağ · Zehra Hangül · Yasemin Hoşgören Alıcı · Hande Ayraler Taner · Yüksel Sümeyra Naralan · Hüseyin Altuğ Yenice · Mehmet Hamid Boztaş · Çilem Bilginer · Nilfer Şahin · Enes Sarıgedik · Mustafa Tolga Tunagür · Pınar Algedik · Özlem Kahraman · Halil Kara · Bürge Kabukçu Başay · Ömer Başay · Özlem Çiçek Zekey · Fatih Hilmi Çetin · Halit Necmi Uçar · Serhat Türkoğlu · Alperen Aşanbuğa · Tuğba Eseroğlu Söylemez ·

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Meryem Özlem Kütük and Ali Evren Tufan contributed equally to this work.



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Abstract

We aimed to evaluate the current functioning of young Turkish adults with autism spectrum disorder (ASD) diagnosed in childhood and determine parental depression and burnout levels. Factors associated with current functioning and parental depression were also evaluated. This study was conducted at the Child and Adolescent Psychiatry Department of 61 cities in Turkey. Young adults with ASD and their parents were enrolled. 1500 participants (81.5%, $n=1222$ males) with a median age of 21.0 (IQR = 4.0) years were included in the present study. Most participants were high school graduates, and only 1 in 10 was able to work for some time at a job. 8.3%could travel alone between cities, 3.7% had experience of romantic relationships, and only sixty-one of them were able to obtain a driving license and use motor vehicles. The mean depression and overall burnout scores of mothers were significantly higher than those of fathers. Young adults with ASD and their parents may experience elevated stress during the transition to adult services. Therefore, there is an urgent need for further studies to identify these needs.

Keywords Adult ASD · Autism · Depression · Burnout · Parents

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder with a multifactorial and complex etiology presenting with impairments in communication and social interaction, restrictive interests, repetitive behaviors, insistence on sameness and sensory regulation problems[1,2]. Currently, the global prevalence of ASD is 0.7%, with a male-to-female ratio of 4.3[2–4]. ASD and its associated symptoms continue to affect individuals in adulthood, leading to functional impairment[5,6].

Advancing through developmental stages may be challenging and stressful, even for neurotypical peers[7]. For children with ASD, transitions may be even more challenging due to their aversion to change[8]. Among the developmental challenges, the transition into adulthood may be especially important because of uncertainties and the loss of entitlement to services available within the school and health systems[8–10]. Maladaptive behaviors, internalizing symptoms, and conflict with parents may increase among youth with ASD leaving high school, whereas their functional improvement may decelerate. These problems may be more pronounced among youth without comorbid intellectual disability and families with lower income and education levels[8]. Parental anxiety and stress levels also increase during the transition to adulthood[10,11].

The diagnosis of ASD in children is associated with elevated levels of parenting stress, caregiver burden, and symptoms of depression and anxiety among parents. Moreover, parental quality of life and family functioning may be impaired[12–15]. Parenting stress, caregiver burden, parental psychopathology, and quality of life may also display bidirectional associations with behavioral problems in children with ASD[16,17]. The process of psychological stress includes a causal event (i.e., a stressor), its cognitive appraisal, coping mechanisms, and stress reactions[18,19]. Studies up to now suggest that parenting stress among parents of children with ASD may be related with severity of autism symptoms, comorbid internalizing/externalizing disorders, repetitive/restrictive and aggressive behaviors, higher dysfunction, limited social supports available to parents along with a reduced perception of self-efficacy, lower parental education and income[8,9,13–17,20–22]. Previous studies conducted in Turkey also support elevated levels of burnout and depression among parents of children with ASD, which may persist into the early adulthood of their offspring[23,24].

Adult psychosocial outcomes reported in children diagnosed with ASD have generally been poor, although there has been a trend toward elevated rates of improvement among recent cohorts[8]. In earlier studies using fewer objective criteria less than 15.0% of adults diagnosed with ASD in their childhood were reported to display "very good"/"good" outcome[8]. In recent studies the rate of "very good"/"good" outcomes in adulthood varied between 3.0 and 62.0% while that of "very poor"/"poor" outcome varied between 3.0–78.0%[8,25–29]. Recent studies on adult outcome of children with ASD used more quantifiable criteria (i.e., "Howlin-Rutter criteria")[26]. The outcome in this method was based on a five-point composite rating of overall social and independent living functioning derived by summing individual scores for work status, friendships and, independence. In a meta-analysis of 18 studies Mason et al.[25] found that 20.0% of participants had a "very good"/"good" outcome (95% Confidence Interval = 10.9–30.1%) with the sole predictor being IQ levels. Recent studies reported elevated levels of "very good"/"good" outcomes (that is, 32.6–49.0%)[30,31], and stressed the importance of childhood IQ, severity of ASD symptoms, and adaptive functioning as the most important predictors of good outcomes. In a previous study we found the rate of "very good"/"good" outcome among Turkish young adults diagnosed with ASD as 5.4% with lack of comorbid intellectual disability (ID) in childhood and maternal participation in paid workforce as important predictors[24]. There is a dearth of outcome studies on the adult outcomes of childhood ASD in non-Western countries. In particular, no large-scale study from Türkiye has characterised the adult functioning of this population, and the few available reports—like much of the international literature—have relied on the Howlin-Rutter criteria without concurrent standardized assessments of intellectual ability, adaptive functioning, or ASD symptom severity. This reliance on composite clinical ratings rather than objective instruments limits comparability across studies and constitutes the principal gap that the present multicenter study seeks to address. As Turkish children initially diagnosed with ASD in the 1990s and the 2000 s became older and emerged into adulthood,

there is an urgent need to evaluate their outcomes and the mental health of their parents, along with the barriers to their effective care and management. Therefore, the goals of this study are as follows:

a. to evaluate the adult functioning of Turkish children diagnosed with autism and determine depression and burnout levels among their parents.
b. to identify factors associated with "very good"/"good" adult outcome in the current sample as per Howlin-Rutter criteria.
c. to determine associations with clinically significant depressive symptoms among parents.

Methods

Study centers

This study was performed in Child and Adolescent Psychiatry (CAP) departments located in 61 county centers out of 81 (75.3%) from all seven geographical regions in Turkey. Most study centers that were unable to participate in the current study were in the Eastern Anatolia ($n=8$) and Black Sea ($n=6$) regions. The reasons for the lack of participation were the effects of the 2023 Turkey- Earthquakes ($n=10$), refusal of medical directorates of the study centers ($n=5$), and lack of CAPs at the county centers ($n=5$). The proportion of samples from study centers compared to the total population aged < 18 years living in the counties as of December 2022[32] varied between 1:10.000–28:100.000. The comorbid diagnoses of the included patients at the time of the study were ascertained through clinical interviews by psychiatrists following them at the time, as per the DSM-5[1].

Sampling

The inclusion criterion for the ASD group was a diagnosis of simplex ASD without known genetic syndromes (i.e., Fragile X syndrome, Down Syndrome, Rett syndrome, or variants) during childhood (i.e., ≤ 12 years old). The patients in this study involved those who were diagnosed with "infantile autism" or "atypical pervasive developmental disorder" as per DSM-III, "autistic disorder" and "pervasive developmental disorder- not otherwise specified" (PDD-NOS) as per DSM-III-R and "autistic disorder", "Asperger's disorder" and PDD-NOS as per DSM-IV and IV-TR criteria. To this end, patients with ICD-10 codes F84.0 ("Childhood Autism"), F84.1 ("Atypical Autism"), F84.5 ("Asperger's Syndrome") and ICD-9 codes 299.0 ("infantile autism") and 299.8 ("other"/"atypical child psychosis") at the study centers were screened for. Parents and their verbal children were interviewed about other families and their children they knew about and those were contacted as well. Informed consent was obtained from the parents of young adults with ASD, as well as verbal individuals with ASD, for inclusion in the study. Patients with epilepsy and psychiatric or other neurodevelopmental comorbidities were included, and the effects of these confounders were controlled for in the analyses. Individuals were excluded if they had a known genetic or neurogenetic syndrome associated with ASD (e.g., Fragile X, Down, or Rett syndrome), a multiplex family history of ASD, or a first diagnosis of ASD after 12 years of age. Eligible individuals whose charts could not be located, who could not be contacted, or whose parents declined participation or withdrew consent were not enrolled. Cases with incomplete core data on functional outcome or parental measures were retained for the analyses for which complete data were available; missing data were not imputed, and the number of valid observations therefore varies across analyses. The extent of missing data for each primary variable included in the regression analyses can be determined from the denominators reported in Tables 5 and 6 alongside the total enrolled sample of 1500 participants. For non-verbal individuals and those with severe intellectual disability who were unable to provide informed consent, written informed consent was obtained from a parent or legal guardian, and assent was sought from the individual whenever feasible; consistent with the Declaration of Helsinki, no individual was enrolled against expressed unwillingness. In these subgroups the

sociodemographic form, functional outcome ratings, and developmental and adaptive-functioning items were completed by the treating child and adolescent psychiatrist on the basis of parental report, hospital records, and direct clinical observation rather than by self-report, and direct interview was undertaken only with verbal individuals who were able to participate.

Ethics

The study was conducted in accordance with the Declaration of Helsinki and local laws and regulations. The study protocol was approved by the Bolu Abant İzzet Baysal University Clinical Research Ethics Committee (date: 08.11.2022, No: 2022/275). The medical directorates of the participating centers also approved the study protocol.

Study measures

Sociodemographic form

This form was created by the authors to collect sociodemographic information on the participants. The questions included the educational and vocational status of parents, age at diagnosis of ASD in children, family history of psychopathology requiring treatment, activities of daily living (ADL), developmental milestones, comorbidities (including epilepsy), and past medical history of children with ASD. The functioning of the children with ASD was evaluated by interviewing them where feasible.

Beck Depression Inventory (BDI)

The BDI was developed to evaluate the symptoms of depression according to self-reports, and the reliability and validity of the Turkish version have been established previously[33,34]. It includes 21 Likert-type items evaluating the motivational, cognitive, somatic, social, and vegetative symptoms of depression. Previous studies on parents of children with disabilities, including ASD, have supported its reliability and validity[23,35]. Parents of young adults with ASD completed the BDI in the current study. Cronbach's alpha for the present sample was 0.86. Seventeen was taken as the cutoff score for clinically significant depressive symptoms, as in previous studies[34].

Maslach Burnout Inventory (MBI)

The MBI is a 22-item Likert-type self-report measure consisting of three subscales (emotional exhaustion, depersonalization, and personal accomplishment) that evaluate the symptoms of burnout[36]. It was initially translated into Turkish and validated among healthcare workers[37]. A later revision found that it was also valid and reliable to evaluate burnout among parents of children with disabilities, although a two-factor model subsuming depersonalization under emotional exhaustion (emotional exhaustion and personal accomplishment) was more appropriate for this sample[38]. In this study, a two-factor solution was used. Mothers and fathers of young adults with ASD completed the MBI in the current study. The Cronbach's alpha for the present sample was 0.85.

Determination of functional outcome

Functional outcomes in our study were determined according to Howlin-Rutter criteria[26], and items in the composite score were determined according to the combination of parental and adult interviews (for verbal adults), occupational records, and reports of psychiatrists following young adults with ASD at the time of the study. Composite ratings were controlled by the first three authors for ambiguous cases ($n = 127$, 8.5%) and were classified by adjudication.

Study procedure

Young adults (≥18 years, henceforth termed "adults" for ease of use) diagnosed with ASD were identified by hospital charts and contacted. Contacted parents were also interviewed about other parents who had adult offspring diagnosed with ASD in childhood, and those identified were recruited. Clinicians completed the sociodemographic form, while mothers and fathers of individuals with ASD completed the BDI and MBI.

Statistics

In a previous study 5.4% of Turkish adults with ASD were classified as having "very good"/"good" outcome[24] and it is known that the proportion having "very good"/"good" outcome may vary between 3.0–62.0%[8]. To determine a rate in this range at a 95.0% confidence interval, at an alpha level of 0.05, and at 95.0% power 1243 participants would be required[39]. As the final sample included 1500 participants, we achieved 98.0% power[39]. Statistical Program for Social Sciences (SPSS™, IBM Inc., Armonk NY) version 22.0 for Windows ™, JASP (JASP Team (2023). JASP (Version 0.16.4). [Computer software] (Retrieved from https://jasp-stats.org), and JAMOVI (Jamovi Project (2023). Jamovi (version 2.3) [Computer software] (Retrieved from https://www.jamovi.org) were used in analyses. Quantitative data are expressed as means and standard deviations (SD) or medians and interquartile ranges (IQR), depending on the assumptions of normality. Categorical data were reported as counts and frequencies, and bivariate analyses of categorical data were conducted using the chi-square test and Fisher's exact test. Yates and likelihood ratio corrections were used as appropriate. The Shapiro-Wilk test was used to evaluate normality. Correlations among the variables were analyzed using Spearman's rank-order correlation coefficient. Bivariate comparisons of quantitative variables between groups were conducted using t-tests. Factors associated with "very good"/"good" functioning in adulthood were evaluated using logistic regression (enter method). P was set at 0.05 (two-tailed). Bonferroni-Holm correction for controlling family wise error was used in bivariate analyses of factors associated with parental depression and burnout (p', Gaetano, J. (2018). Holm-Bonferroni sequential correction: An Excel calculator (1.3) [Microsoft Excel workbook]. Retrieved from: https://www.researchgate.net/publication/322568540_HolmBonferroni_sequential_correction An_Excel_calculator_13). The effect sizes of the significant findings are also reported.

Results

1500 participants with ASD (81.5%, $n=1222$ male) with a median age of 21.0 (IQR = 4.0) years were enrolled. More than half ($n=789$, 52.6%) were high school graduates or students. Others were middle ($n=191$, 12.7%) or primary ($n=116$, 7.7%) school graduates. A minority of participants ($n=88$, 5.9%) were university graduates or students. The median ages of fathers and mothers were 52.0 (IQR = 9.0) and 48.0 (IQR = 9.0) years, respectively. The sociodemographic characteristics of the participants and their families are presented in Table 1.

The median ages at diagnosis of ASD and at the onset of special education services were 36.0 (IQR = 18.0) and 42.0 (IQR = 30.0) months, respectively. The majority (59.9%, $n=899$) continued special education/rehabilitation services at the time of the study and the median duration of receiving special education/rehabilitation was 15.0 (IQR = 6.0) years. More than half of the young adults with ASD had lifetime ($n=918$, 61.2%) and current ($n=828$, 55.2%) comorbid neurodevelopmental/psychiatric disorders. The median number of past and current comorbidities was 1.0 (IQR = 2.0) and 0.0 (IQR = 1.0), respectively. Lifetime and current comorbidities associated with ASD are presented in Table 2.

Most young adults with ASD ($n=1023$, 68.2%) received psychopharmacological treatment at the time of study participation. The majority of patients received either one ($n=516$, 34.4%) or two ($n=376$, 25.1%) treatments. The median number of treatment agents was 1.0 (IQR = 2.0). Typical and atypical antipsychotics ($n=863$, 57.5%), selective serotonin reuptake inhibitors (SSRI; $n=262$, 17.5%), and valproate ($n=227$, 15.1%) were the

Table 1 Sociodemographic features of Turkish young adults diagnosed with ASD in childhood and their families.

		N (%)
Maternal education	Primary school or lower	747 (51.0)
	High school	360 (24.0)
	University or higher	359 (24.0)
Maternal vocation	Housewife	1030 (68.7)
	Civil servant	170 (11.3)
	Worker	52 (3.5)
	Artisan	65 (4.3)
	Manager	15 (1.0)
	Retired	116 (7.7)
Paternal education	Primary school or lower	537 (37.9)
	High school	380 (25.3)
	University or higher	501 (33.4)
Paternal vocation	Jobless	29 (1.9)
	Civil servant	293 (19.5)
	Worker	237 (15.8)
	Artisan	440 (29.3)
	Manager	48 (3.2)
	Retired	346 (23.1)
Maternal chronic medical disorder		525 (35.0)
Maternal psychopathology requiring treatment*		318 (21.2)
Paternal chronic medical disorder		507 (33.8)
Paternal psychopathology requiring treatment*		133 (8.9)
Family status	Intact/nuclear	1220 (81.3)
	Separated/divorced/widowed	246 (16.4)

*Major depressive disorder was the most common diagnosis for both mothers ($n=197$, 62.0%) and fathers ($n=55$, 41.4%).

Table 2 Lifetime and current comorbid diagnoses of young adults diagnosed with ASD during childhood ($n=1500$).

N (%)	Lifetime	Current
Attention deficit/hyperactivity disorder	542 (36.1)	177 (11.8)
Mental retardation/intellectual disability	289 (19.3)	282 (18.8)
Conduct disorder	287 (19.1)	187 (12.5)
Anxiety disorders	140 (9.3)	100 (6.7)
Major depressive disorder	89 (5.9)	49 (3.3)
Obsessive compulsive disorder	38 (2.5)	44 (2.9)
Bipolar disorders	35 (2.3)	36 (2.4)
Sleep disorders	24 (1.6)	24 (1.6)
Specific learning disorders	11 (0.7)	0 (0.0)
Psychotic disorders	10 (0.7)	11 (0.7)
Tic disorders	10 (0.7)	4 (0.3)

most common agents. More than one-third ($n=583$, 38.9%) of the patients had chronic medical disorders requiring treatment, with the median number of disorders being 0.0 (IQR = 1.0). The most common chronic medical disorders were epilepsy ($n=334$; 22.3%), obesity ($n=89$; 5.9%), and diabetes ($n=30$; 2.0%).

Developmental milestones and current adaptive functioning of young adults with ASD are shown in Table 3.

According to Howlin-Rutter criteria, 85 participants (5.8%) had "very good"/"good" adult outcomes. Variables associated with "very good"/"good" outcomes in the bivariate analyses are illustrated in Table 4.

In bivariate analyses, "very good"/"good" outcome was associated with lack of lifetime and current diagnoses of ID and MDD, lack of self-harm/suicidality, harm to others and inappropriate social behaviors, higher maternal education and maternal participation in work force, higher paternal education and a paternal occupation involving semi-skilled/skilled vocations. Mean age (23.4 ± 3.9 vs. 21.7 ± 3.9 years) and age at ASD diagnosis (65.5 ± 66.9 vs. 46.0 ± 29.5 months) were also significantly higher among those with "very good"/"good" outcome ($p=0.000$, Cohen's d = 0.44 and $p=0.009$, Cohen's d = 0.38; respectively). Young adults with ASD having

Table 3 Developmental milestones and current adaptive functioning of Turkish young adults with ASD.

Onset of functional speech (months)		Mean (SD)
		58.8 (36.5)
Onset of continence (months)		61.2 (36.8)
		N (%)
Presence of speech		1059 (70.6)
Current level of functional speech	Single words	156 (10.4)
	Two-word combinations	212 (14.1)
	Sentences with ≥3 words	691 (46.1)
Continence		1291 (86.1)
Grooming abilities	None	454 (30.3)
	With help	492 (32.8)
	Able to self-groom	554 (36.9)
Ability to shop alone		363 (24.2)
Ability to use public transport alone		256 (17.1)
Ability to travel between cities alone		125 (8.3)
Ability to use telephone for some communication*		539 (35.9)
Having social media account†		357 (23.8)
Ability to drive/having driver's permit		61 (4.1)
Attending compulsory military service††		0 (0.0)
Having peer circle to socialize≥3 h/week		230 (15.3)
History of a romantic affair		55 (3.7)
History of marriage		0 (0.0)
History of paid work**		161 (10.7)
History of self-harm		575 (38.3)
History of suicide attempt		57 (3.8)
History of harmful behavior to others***		551 (36.7)
Inappropriate social behavior (touching, masturbation, etc.)		223 (14.9)
History of hospitalization		599 (39.9)
Nicotine/alcohol use		35 (2.3)
Involvement in legal proceedings†††		41 (2.7)
Participation in nation-wide examinations for high-school/university entry		271 (18.1)
Functional outcome according to Howlin- Rutter criteria	Very good	19 (1.3)
	Good	67 (4.5)
	Fair	169 (11.3)
	Poor	163 (10.9)
	Very poor	1082 (72.1)

SD: Standard Deviation, *including conversation and messaging, **mean duration of 13.9 (SD = 21.4) months, ***due to irritability, social communication problems, repetitive behaviors and restrictive interests, †includes social media accounts set up by parents for their children and those that the parents help to manage, ††Only two participants (0.1%) tried attending military service and they both had to be discharged after a month due to adjustment problems, †††due to irritability, social communication problems, repetitive behaviors and restrictive interests and including both victims and perpetrators.

"very good"/"good" outcome acquired speech (50.2 ± 28.0 vs. 59.6 ± 37.0 months) and continence (46.4 ± 26.9 vs. 62.2 ± 37.2 months) significantly earlier ($p = 0.021$, Cohen's d = 0.29 and $p = 0.000$, Cohen's d = 0.49; respectively, t test for independent groups).

Lastly, we used binomial logistic regression with enter method to identify factors associated with "very good"/"good" adult outcomes. Age at diagnosis of ASD, age at onset of continence, and age at onset of speech were entered in step 1; lifetime MDD, lifetime ID presence of self-harm, and inappropriate social behaviors were entered in step 2 (current MDD and ID along with suicidality and harm to others displayed multi-collinearity and were removed); maternal and paternal higher education, maternal participation in the workforce, and paternal semi-skilled/skilled vocation were entered in step 3. Model fit measures and comparisons are presented in Table 5, and the final step is illustrated in Table 6.

In the first step the model could predict only one of the participants with "very good"/"good" outcome correctly (1.2%) while it could classify those without 100.0% with sensitivity, specificity, and area under curve (AUC) reaching 0.01, 1.00 and 0.63; respectively. Addition of the second step increased the number of participants with "very good"/"good" outcome correctly classified to four (4.8%) while 99.9% those without good outcome were correctly classified. The sensitivity, specificity, and AUC at this step were 0.05, 0.99, and 0.68,

Table 4 Variables associated with "very good"/"good" adult outcomes ($n=85$) among Turkish young adults with ASD ($n=1500$).

N (%)		"Very good"/"good" outcome ($n=85$)	χ^2/dF	*P**	Effect size**
Gender	Male	73 (84.9)	0.5/1	0.486	-
	Female	13 (15.1)			
Lifetime MR/ID		7 (8.1)	6.5/1	*0.011*	*0.07*
Current MR/ID		2 (2.3)	16.2/1	*0.000*	*0.10*
Lifetime MDD		14 (16.3)	15.6/1	*0.000*	*0.11*
Current MDD		10 (11.6)	17.5/1	*0.000*	*0.12*
Epilepsy		13 (15.1)	2.3/1	0.132	-
Psychopharmacological treatment		59 (68.6)	0.1/1	0.934	-
History of self-harm		19 (22.1)	10.0/1	*0.002*	*0.09*
History of suicide attempt		7 (8.1)	3.4/1	0.065	0.06
History of harm to others		21 (24.4)	5.8/1	*0.016*	*0.07*
Inappropriate social behavior (touching, masturbation, etc.)		5 (6.9)	6.0/1	*0.011*	*0.07*
Maternal education	Primary school or lower	23 (27.1)	25.7/2	*0.000*	*0.13*
	High school	24 (28.2)			
	University or higher	38 (44.7)			
Maternal vocation	Housewife	35 (41.2)	37.7/1	*0.000*	*0.19*
	Paid work	50 (58.8)			
Paternal education	Primary school or lower	19 (22.9)	9.0/2	*0.011*	*0.09*
	High school	25 (30.1)			
	University or higher	39 (47.0)			
Paternal vocation	Jobless	2 (2.4)	8.0/3	*0.047*	*0.12*
	Semi-skilled†	39 (47.6)			
	Skilled††	29 (35.4)			
	Retired	12 (14.6)			
Maternal chronic medical disorder		34 (39.5)	0.8/1	0.364	-
Maternal psychopathology requiring treatment		14 (16.3)	1.0/1	0.311	-
Paternal chronic medical disorder		27 (32.9)	0.2/1	0.680	-
Paternal psychopathology requiring treatment		8 (9.3)	0.0/1	1.000	-

*Chi square or Fisher's exact test, Yates' correction was used as needed, **Effect size is Phi for 2 × 2 and Cramer's V for larger tables, †Worker/Artisan, ††civil servant/manager.

Table 5 Predictor models of "very good"/"good" adult outcomes ($n=85$) among Turkish young adults with ASD ($n=1500$).

Step	Deviance	AIC	BIC	Nagelkerke R2	χ^2/dF	*p*	Comparing models*
1	550	558	577	0.055	24.0/3	< 0.001	–
2	529	549	598	0.099	44.0/9	< 0.001	20.0 [6], 0.003
3	507	*537*	610	0.149	66.9/14	< 0.001	22.9 [5], < 0.001

AIC: Akaike Information Criterion, BIC: Bayesian Information Criterion, dF: degrees of freedom, *step 1 and 2 and step 2 and 3 with χ^2 tests.

respectively. In the last step, five participants with good outcomes (6.0%) were correctly classified, whereas 99.9% of those without good outcomes were correctly grouped. The sensitivity, specificity, and AUC at the last step were 0.06, 0.99, and 0.74, respectively. In addition, at the last step, the 95% C.I. of odds ratios for age at ASD diagnosis and paternal vocation included 1.0, denoting limited importance. Thus, although the final model achieved high specificity (0.99) and an acceptable AUC (0.74), it correctly identified only 5 of the 85 participants with a "very good"/"good" outcome, corresponding to a sensitivity of approximately 6%. This limited sensitivity should be interpreted in the context of the marked class imbalance in the sample (85 of 1500 participants, 5.8%, had a favourable outcome), which constrains the ability of the model to correctly classify the minority class and

Table 6 Predictors of achieving "very good"/"good" adult outcomes ($n=85$) among Turkish young adults with ASD ($n=1500$).

Predictor		O.*R*	95% CI	*p*	VIF	Tolerance
Age at diagnosis of ASD (mo)		1.01	1.00–1.01	*0.016*	1.07	0.94
Age at onset of continence (mo)		0.99	0.98–1.00	0.174	1.09	0.92
Age at onset of speech (mo)		0.99	0.99–1.01	0.769	1.10	0.91
Lifetime MDD		2.76	1.32–5.75	*0.007*	1.04	0.96
Lifetime MR/ID		0.58	0.25–1.33	0.196	1.03	0.98
Self-harming behavior		0.49	0.28–0.87	*0.016*	1.01	0.99
Inappropriate social behavior		0.52	0.20–1.35	0.178	1.02	0.98
Maternal higher education		1.14	0.58–2.26	0.705	1.44	0.70
Maternal participation in workforce		2.87	1.61–5.10	*< 0.001*	1.22	0.82
Paternal higher education		0.73	0.38–1.44	0.365	1.42	0.70
Paternal vocation	Semi-skilled†	1.93	1.04–3.59	*0.038*	1.09	0.92
	Skilled††	2.01	0.98–4.12	0.057		

O.R: Odds Ratio, CI: Confidence Interval, VIF: Variance Inflation Factor, ASD: Autism Spectrum Disorder, mo: months, MDD: Major depressive disorder, MR/ID: Mental retardation/Intellectual disability, †Worker/Artisan, ††civil servant/manager.

Table 7 Self-reported depression and burnout scores of mothers and fathers of Turkish young adults diagnosed with ASD in childhood ($n=1500$).

Mean (SD)	Mothers	Fathers	t/dF	*P**
Beck Depression Inventory	12.6 (8.4)	9.1 (7.5)	10.4/594	0.000
MBI- Emotional burnout	15.7 (9.4)	12.4 (8.6)	9.6/590	0.000
MBI- Personal accomplishment	8.7 (6.0)	9.2 (6.2)	−2.0/590	0.049
MBI-Total	24.4 (13.1)	21.6 (12.4)	5.9/592	0.000

SD: Standard deviation, dF: degrees of freedom, *:t test for dependent groups, MBI: Maslach Burnout Inventory.

indicates that important explanatory variables were not captured by the available data. Accordingly, the variables identified in the regression model should be regarded as factors associated with outcome rather than clinically applicable predictors.

The self-reported depression and burnout among mothers and fathers of young Turkish adults with ASD are shown in Table 7.

Mothers had significantly elevated depression and emotional and total burnout scores compared with fathers. Although the difference in personal accomplishment scores between parents was at the threshold of significance, the 95% Confidence Interval (−1.0-0.0) included zero, denoting non-significance.

According to the cutoff scores, less than one-fourth of the mothers ($n=339$, 22.6%) and less than one-tenth of the fathers ($n=97$, 6.5%) reported clinically significant depressive symptoms. Clinically significant depressive symptoms in mothers were negatively associated with high school or higher education among their offspring with ASD (χ^2 [1]=12.5, $p<0.001$, O.$R=0.65$ [95% CI=0.51–0.82], Phi=0.09), achievement of continence (χ^2 [1]=7.2, $p=0.007$, O.$R=0.63$ [95% CI=0.44–0.90], Phi=0.07), ability to self-groom (χ^2 [1]=9.6, $p=0.002$, O.$R=0.7$ [95% CI=0.5–0.9], Phi=0.08), achievement of "very good"/"good" adult outcome (χ^2 [1]=3.9, $p=0.048$, O.$R=0.54$ [95% CI=0.3–1.0], Phi=0.05),), lack of self-harm (χ^2 [1]=19.2, $p<0.001$, O.$R=0.6$ [95% CI=0.5–0.7], Phi=0.11), lack of inappropriate social behavior (χ^2 [1]=21.3, $p<0.001$, O.$R=0.5$ [95% CI=0.4–0.7], Phi=0.13), maternal participation in paid work (χ^2 [1]=12.2, $p<0.001$, O.$R=0.6$ [95% CI=0.5–0.8], Phi=0.09),and living in an intact-nuclear family (χ^2 [1]=11.8, $p<0.001$, O.$R=0.6$ [95% CI=0.5–0.8], Phi=0.09). However, they were positively associated with the lack of a peer group to socialize their offspring with ASD (χ^2 [1]=5.0, $p=0.026$, O.$R=1.5$ [95% CI=1.1–2.2], Phi=0.06),lifetime ID comorbidity (χ^2 [1]=24.6, $p<0.001$, O.$R=2.0$ [95% CI=1.5–2.7], Phi=0.13), comorbid epilepsy (χ^2 [1]=5.3, $p=0.021$, O.$R=1.4$ [95% CI=1.1–1.8], Phi=0.06), and the presence of significant paternal depressive symptoms (χ^2 [1]=10.8, $p=0.001$,

Table 8 Correlations among parental burnout and depression scores among Turkish young adults with ASD.

Rho	1	2	3	4	5	6	7	8
Paternal MBI- Emotional exhaustion	–							
Paternal MBI- Personal achievement	0.45**	–						
Paternal MBI- total	0.87**	0.80**	–					
Paternal BDI	0.59**	0.32**	0.53**	–				
Maternal MBI- Emotional exhaustion	0.56**	0.34**	0.52**	0.33**	–			
Maternal MBI- Personal achievement	0.36**	0.44**	0.47**	0.25**	0.50**	–		
Maternal MBI- Total	0.53**	0.44**	0.58**	0.33**	0.91**	0.77**	–	
Maternal BDI	0.36**	0.25**	0.34**	0.46**	0.62**	0.36**	0.59**	–

Rho: Spearman's rank order correlation, MBI: Maslach Burnout Inventory, BDI: Beck Depression Inventory, *$p<0.05$, **$p<0.001$, Effect sizes (Fisher's Z) between 0.3–1.5.

O.R=2.0 [95% CI=1.3–3.1], Phi=0.09).After correction for sequential analyses, comorbid epilepsy, lack of peer group and achievement of "very good"/"good" outcome lost significance (p'=0.063).

Clinically significant depressive symptoms in fathers were negatively associated with high school or higher education among their offspring with ASD (χ^2 [1]=15.9, $p<0.001$, O.R=0.4 [95% CI=0.3–0.7], Phi=0.10), achievement of continence (χ^2 [1]=6.0, $p=0.014$, Yates' correction, O.R=0.5 [95% CI=0.3–0.9], Phi=0.07), and ability to self-groom (χ^2 [1]=5.1, $p=0.025$, Yates' correction, O.R=0.6 [95% CI=0.4–0.9], Phi=0.06). They were positively associated with achievement of "very good"/"good" adult outcome (χ^2 [1]=4.2, $p=0.039$, Fisher's exact test, O.R=6.2 [95% CI=0.9–45.0], Phi=0.05), presence of significant maternal depressive symptoms (χ^2 [1]=10.8, $p=0.001$, O.R=2.0 [95% CI=1.3–3.2], Phi=0.09) and, living in an intact-nuclear family (χ^2 [1]=4.2, $p=0.040$, Yates' correction, O.R=2.1 [95% CI=1.1- 4.0], Phi=0.06). There was also a tendency for less frequent clinically significant depressive symptoms among fathers whose wives worked for pay (χ^2 [1]=3.2, $p=0.074$, O.R=0.6 [95% CI=0.4- 1.0], Phi=0.05), although this did not reach significance. Confidence intervals for having an offspring with ASD displaying "very good"/"good" adult outcome included 1.0, denoting limited importance. After correction for family wise error, only relationships with higher education among offspring with ASD and maternal depressive symptoms remained significant (p'= 0.0035 and 0.0060, respectively). The correlations between depression and burnout scores are presented in Table 8.

Discussion

This multicenter study employing retrospective chart reviews was designed to evaluate young adult outcome of Turkish children diagnosed with ASD, depression and burnout levels of their parents and factors associated with "very good"/"good" adult outcome. We found that among our participants 5.8% had "very good"/"good" outcome while 11.3% had "fair" and 83.0% had "very poor"/"poor" outcomes according to Howlin- Rutter criteria; respectively. Variables significantly associated with "very good"/"good" adult outcome included higher age at ASD diagnosis, lifetime comorbid depression, self-harming behavior, maternal participation in work force and paternal semi-skilled occupation. Less than one-fourth of mothers and less than one-tenth of fathers reported clinically significant depressive symptoms. Mothers had significantly elevated self-reported depression and burnout compared to fathers. Maternal depression was negatively associated with increased ADL among children and participation in the workforce, while it was positively associated with comorbid ID, epilepsy, and paternal depression. Paternal depression was negatively associated with higher education among offspring, and positively associated with maternal depression.

Interest in adult psychosocial outcomes in children diagnosed with ASD has increased[8,24–26,30]. Psychosocial functioning encompasses several domains of daily living, including vocational functioning, social relationships, independent living, physical health, and freedom from distress[40]. According to World Health Organization[41]; disability is "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner,

or within the range considered to be normal for a human being" and optimal outcome may be defined as the goal of living a full and decent life with dignity, self-reliance, and active community participation[42–44]. Non-governmental organizations, as well as parents of youth with ASD from Western countries, have found that the most important long-term goals for those with ASD are happiness and freedom from distress[45]. Regardless of the varied definitions, recent research on adult outcomes of children diagnosed with ASD mostly used the Howlin-Rutter criteria, which focused on vocation, social relationships, and independent functioning[8,26]. In studies using those criteria there is a temporal trend of increasing "very good"/"good" outcome among youth with ASD in adulthood[8]. The rates of these outcomes have varied between 10.9 and 49.0% in recent studies and between 3.0% and 62.0% in earlier studies[25,26,30,31]. In a previous study[24] we found the rate of "very good"/"good" functioning as 5.4% while in this study this rate was 5.8%. As such, the rate of optimal functioning in adulthood among Turkish children with ASD may be in the lower range of earlier studies from Western countries and may be lower than the recently reported rates. The variability in adult outcome rates between studies may be explained by the use of variable criteria for functioning, different sampling methods, enrollment of participants with ID and other comorbidities, presence/range of social/education support, and selective attrition of those with poorer outcomes[8,25]. In addition, studies on outcomes focus less on subjective feelings of happiness/fulfillment, subjective well-being, and quality of life (QoL)[40,45]. The overlap between the Howlin-Rutter criteria and disability/functionality, as defined by the WHO, may also be limited[41–44]. Future studies on adult outcomes of Turkish children diagnosed with ASD may use the WHO definitions of functionality to evaluate subjective well-being and QoL in young adults. More broadly, the Howlin-Rutter criteria, although valuable for comparison with previous cohorts, capture mainly independence, employment, and social functioning and do not reflect the full range of meaningful adult outcomes. Contemporary frameworks increasingly emphasise quality of life, self-determination, subjective well-being, and the attainment of personally valued goals, which may diverge substantially from externally rated "objective" outcomes. Incorporating such person-centred and self-reported indicators alongside the Howlin-Rutter composite would provide a more balanced and ecologically valid picture of how autistic adults are faring. In addition, despite our use of a priori power analysis to achieve adequate power and despite sampling from 61 county centers, we could not reach 20 counties, of which almost half were located in the Eastern and Southeastern Anatolian regions (Supplemental Table 1). Additionally, the Eastern and the Southeastern Anatolian regions were disproportionately affected by the Turkey- Syria earthquakes of 2023[46], and youths with ASD living in these regions were significantly affected[47,48], further biasing our results. Sampling rates among counties as well as elevated rates of missing data added further variability. Our results may also be not valid for multiplex cases of ASD and those associated with neurogenetic syndromes. Parents and youth contacted by snowball sampling and accepting participation may reflect better adult outcomes and may have affected the results. Lastly, it is known that the functioning of individuals with ASD may further improve from young adulthood onwards[8,25,40] and longitudinal evaluations of participants may better reflect dynamic changes in functionality and ASD symptoms. Further studies on adult outcomes among Turkish children with ASD are required to evaluate the effects of these limitations.

In previous studies, positive psychosocial outcomes in adulthood have been predicted by higher intellectual and verbal abilities, milder ASD symptoms, lack of comorbidity, and better adaptive functioning[8,25,27–31,59,60]. In a previous study by our group, positive outcomes were predicted by maternal participation in the workforce and lifetime ID (at the trend level)[24]. The factors associated with positive outcomes in the current sample were higher age at ASD diagnosis, lifetime depression, self-harming behavior, maternal participation in the workforce, and paternal semi-skilled occupation. Interestingly, depression increased the odds of better adult outcomes, whereas self-harming behavior reduced it. Although the cross-sectional nature of our study precludes hypotheses on causality and temporal precedence, it may be argued that a later diagnosis of ASD correlates with milder symptoms. As for the opposite effects of depression and self-harm De Filippis[49] reported that depression in ASD was associated with insight into the social differences between oneself and others while Hand et al.[50] found that self-harming behaviors were more frequent among adults with ASD and ID. Therefore, it may be posited that the conflicting effects of depression and self-harm behaviors in our sample reflect the effects of insight into one's

condition and ID comorbidities. Maternal work outside the home and a skilled paternal occupation may increase financial security and enable parents to seek more intensive interventions for their offspring with ASD, thereby increasing the odds of positive psychosocial outcomes. Supporting this view, previous studies[51] found that financial problems were among the most important reasons for stress among parents of children with ASD, while the diagnosis of ASD also increases the risk of unemployment among parents. Further studies on factors associated with better psychosocial functioning in adulthood among children with ASD may evaluate the effects of parenting stress using formal psychometric measures, and determine the importance of improved financial stability in accessing services by elucidating the average yearly income and hours/week of rehabilitation services used.

These associations should, however, be interpreted with considerable caution, as the regression model showed limited ability to identify the participants who actually achieved a favourable outcome (sensitivity ≈ 6%). The variables identified here are therefore better regarded as correlates rather than robust predictors of positive adult functioning. Several findings are open to alternative explanations. The counter-intuitive association between lifetime depression and better outcome may reflect greater insight into one's social differences, higher cognitive and verbal ability, more active help-seeking, or ascertainment bias (depression being more readily recognised in more able individuals) rather than a genuinely protective effect. Likewise, a later age at ASD diagnosis may be a marker of milder baseline symptom severity and better early language rather than a beneficial factor in itself. Crucially, the model could not include several of the strongest known determinants of adult outcome—childhood cognitive and intellectual ability, adaptive functioning, ASD symptom severity, socioeconomic status, and the type, intensity, and duration of educational and behavioural interventions received. The absence of these unmeasured variables, together with the marked class imbalance described above, most likely accounts for the limited classification performance of the model and means that our findings should be read as hypothesis-generating rather than confirmatory.

In our sample, less than one-fourth of the mothers and less than one-tenth of the fathers reported clinically significant depressive symptoms. Mothers had significantly elevated self-reported depression and burnout compared to fathers. Previous studies have found that ASD diagnosis in offspring is associated with elevated parenting stress, reduced parental QoL, and elevated symptoms of depression/anxiety[12–15]. It was also found that mothers were more frequently and significantly affected by stress than fathers were[14,24]. The rate of clinically significant depressive symptoms among the mothers and fathers was similar to that reported in a previous study[24]. In the current study, depressive symptoms in both mothers and fathers were associated with lower education of the offspring, limited ability to self-groom, worse psychosocial outcomes, maternal participation in paid work, living in intact families, and depressive symptoms in the other parent. Comorbid epilepsy, comorbid ID, inappropriate social behaviors, and limited peer relations for offspring with ASD were significantly related only with maternal depressive symptoms. These results underscore the importance of reduced parental stress among offspring with ASD who achieve higher education, greater independence, and social support and suggest that financial stress and spillover effects may also contribute to parental depression in families with children diagnosed with ASD. Supporting the results of a previous study, we found that maternal and paternal depressive symptoms are related to increased parenting stress, limited autonomy among offspring with ASD, and spillover effects between partners[24]. Furthermore, the strongest positive correlations in the current study (albeit in the moderate range) were observed between the emotional exhaustion and depression scores. Previous studies have found that chronic parenting stress may be associated with anxiety, depression, and burnout among parents of young adults whose children were diagnosed with ASD in childhood, that parental stress may spill over to other family members, and may display bidirectional associations with behavioral problems in offspring with ASD[11–13,15,22,23,35]. Future studies should employ longitudinal designs and structured interviews to evaluate the dynamic relationships among parental burnout, stress, depression, and anxiety symptoms among parents of adults with ASD. The stronger associations observed for maternal than paternal mental health are likely to be multidetermined. In the present cultural context mothers typically assume the role of primary caregiver and therefore carry a disproportionate share of daily care, supervision, and care-coordination, which increases their exposure to chronic caregiving stress and emotional exhaustion; mothers may also be more likely to reduce or relinquish paid employment, with attendant

losses of income, social contact, and respite. These mechanisms are consistent with the negative association between maternal depression and maternal workforce participation observed here. It should be emphasised that the cross-sectional design does not permit causal inference, and the relationship between parental well-being and offspring functioning is very likely bidirectional: poorer offspring functioning and more challenging behaviour may erode parental mental health, while parental depression and burnout may in turn reduce the parent's capacity to support the offspring's development, generating reciprocal and potentially self-reinforcing effects that only longitudinal designs can disentangle.

Our results should be evaluated in light of several limitations, which can be grouped into methodological limitations (selection bias and selective attrition arising from the large proportion of non-contactable individuals and from snowball sampling, the cross-sectional design, and reliance on retrospective chart review), measurement limitations (the absence of standardized contemporary assessments and dependence on clinical records and self-report), and generalizability concerns (under-representation of the Eastern and Southeastern Anatolian regions, earthquake-related attrition, and non-applicability to multiplex and syndromic ASD). With respect to measurement, the lack of standardized current measures of intellectual ability, adaptive functioning, ASD symptom severity, and psychiatric comorbidity is particularly important, as these are among the strongest predictors of adult outcome in previous longitudinal studies and their absence constitutes a major potential confounder when interpreting the associated factors identified here. First, the majority of the participants could not be contacted, and their medical records were incomplete, preventing us from evaluating the effects of baseline IQ subscales, adaptive functioning, ASD symptom severity, and the effects of specific symptoms such as restricted repetitive behaviors and interests. Parents of more impaired adults may refuse participation outright, withdraw their consent, or may have moved to other addresses, introducing selection bias/selective attrition into the results. Dependence on clinical records, exclusion of neurogenetic syndromes, and multiplex cases may further increase the bias. Second, we did not evaluate adults with ASD using clinical interviews and depended on the medical records and reports of psychiatrists following them at time for comorbid diagnoses. Third, we evaluated depression and burnout among parents with self-reports, and these results may have been affected by recall and reporting bias as well as shared method variance. Fourth, we depended on the parents' own reports of their psychopathologies and medical disorders requiring treatment, which may be subject to bias. Fifth, rather than depending on the MBI adapted in the past for parents of youth with ASD, we may have used a more direct measure, such as the Parental Burnout Assessment[55]. Sixth, rather than using discrete questions regarding social participation, we could have used a psychometric scale to evaluate social competence among adults with ASD (for example, the Global Assessment of Functioning or WHO definitions)[42,56]. Lastly, we compared our regression models only in terms of variance explained and in model improvement by means of chi-square comparisons and refrained from using AIC or BIC[57]. Because lower AIC and BIC values are preferred in model selection and BIC penalizes additional parameters more significantly than AIC, our model may be subject to overfitting. However, lower BIC values do not suggest more parsimonious models, especially if the terms are nested, as in our study, and likelihood ratio tests are more advantageous for these models[57]. Regardless of these limitations, our study is only the second on adult functioning of Turkish children diagnosed with ASD and supports our previous results[24]. Further studies on adult outcomes of ASD in low- and middle-income countries such as Turkey are needed.

Conclusion

The transition to adulthood is challenging for individuals with ASD and for their families. In many countries, including Turkey, services offered to children with ASD are limited or no longer available once they reach adulthood, which may exacerbate the symptoms of youth as well as the stresses experienced by parents. Structured support that facilitates the transition to adult services may limit these problems. Even with this support, young adults may be socially isolated and have limited opportunities to participate in the community. Lack of education among healthcare workers with ASD in adulthood may add further barriers to receiving help. This may lead to

embitterment among adults with ASD and their parents[8,10,11]. Our results may support the importance of a structured transition plan for families of adults with ASD as well as adults for adult mental health services (for example, STEPS)[58]. Additionally, modifications for adults with ASD may have to be made for support in the workplace, achieving driving licenses, using public transportation, and attending tertiary education. Children with ASD may be screened for risk factors and symptoms of depression, as well as self-harming behaviors, starting from adolescence. In addition, parents of children with ASD may benefit from interventions preventing depression/burnout, as well as those focusing on promoting their mental health and well-being. These interventions may first focus on mothers to prevent spillover effects on other family members. Financial support for families of youths with ASD and interventions supporting maternal participation in the workforce may also be beneficial.

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Data availability The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Competing interests The authors declare no competing interests.

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Authors and Affiliations

Meryem Özlem Kütük[1] · Ali Evren Tufan[2] · Fethiye Kılıçaslan[3] · Burçin Şeyda Buran[4] · Neslihan Taştepe[1] · Nagihan Cevher Binici[5] · Fatma Sibel Durak[5] · Yadigar Düğüncü Terlemez[5] · Ayşe Kutlu[6] · Canem Kavurma[5] · Enes Şamdan[5] · Mehrişah Usta[5] · Aylin Yılmaz[5] · Oğuzhan Koyuncu[7] · Alperen Bıkmazer[7] · Aynur Görmez[8] · Vahdet Görmez[7] · Rabia Can[9] · Müjdat Erarkadaş[9] · Burcu Kardaş[9] · Ömer Kardaş[9] · İrem Damla Çimen[9] · Özlem Yıldız Gündoğdu[9] · Caner Mutlu[10] · Ferhat Yaylacı[11] · Barış Güller[11] · Pınar Vural[12] · Gonca Özyurt[13] · Perihan Çam Ray[14] · Burak Kamış[14] · Rezan Karabulut Kılıç[14] · Gonca Gül Çelik[14] · Ayşegül Yolga Tahiroğlu[14] · Fevziye Toros[15] · Gülen Güler Aksu[15] · Şafak Eray Çamlı[10] · Serkan Turan[10] · Bahtım Kütük[16] · Sevay Alşen Güney[17] · Neslihan İnal[17] · Yasemin İmrek[18] · Zeynep Vatansever Pınar[19] · Şeyma İlhan[19] · Hasan Kandemir[20] · Sibelnur Avcil[21] · Günay Budagova[22] · Çisem Erdaş[23] · Esra Demirci[24] · Sevgi Özmen[24] · Leyla Seviçin[57] · Tuba Mutluer[25] · Eren Yavuz Açıkalın[25] · Leyla Bozatlı[26] · Hasan Cem Aykutlu[26] · Işık Görker[26] · Tilbe Erten Almak[27] · Esen Yıldırım Demirdöğen[28] · Abdullah Bozkurt[28] · Mehmet Akif Akıncı[28] · Tuğba Nur Saylan Yavuz[28] · Onur Burak Dursun[29] · Esra Hoşoğlu[30] · Bahadır Turan[30] · Onur Tuğçe Poyraz Fındık[31] · Bedia Sultan Önal[32] · Cansu Çobanoğlu Osmanlı[32] · Gülsüm Yitik Tonkaz[33] · Berkan Şahin[32] · Öznur Adıgüzel Akman[34] · Hatice Altun[35] · Funda Özyay Eroğlu[36] · Fadime Hande Özer[37] · Esma Nur Pamuk[38] · Şeyma Çelikcan Yeşilmeşe[38] · Şermin Yalın Sapmaz[20] · Veysel Özdağ[39] · Ceylan Carık[3] · Bahaddin Çolak[3] · Adem Türk[40] · Ömer Akça[40] · Ahmet Büber[41] · Elif Abanoz[42] · Ayla Uzun Çiçek[42] · Cansu Mercan Işık[42] · Öznur Bilaç[20] · Rahime Mutlu Yaprakçı[43] · Çağla Çelikkol Sadıç[44] · Yekta Özkan[44] · Aziz Kara[44] · Masum Öztürk[45] · Fatma Subaşı Turgut[45] · Cem Gökçen[46] · Mehmet Karadağ[47] · Zehra Hangül[48] · Yasemin Hoşgören Alıcı[49] · Hande Ayraler Taner[49] · Yüksel Sümeyra Naralan[50] · Hüseyin Altuğ Yenice[51] · Mehmet Hamid Boztaş[51] · Çilem Bilginer[52] · Nilfer Şahin[53] · Enes Sarıgedik[54] · Mustafa Tolga Tunagür[55] · Pınar Algedik[56] · Özlem Kahraman[57] · Halil Kara[58] · Bürge Kabukçu Başay[41] · Ömer Başay[41] · Özlem Çiçek Zekey[59] · Fatih Hilmi Çetin[60] · Halit Necmi Uçar[60] · Serhat Türkoğlu[61] · Alperen Aşanbuğa[62] · Tuğba Eseroğlu Söylemez[63] · Neslişah Gür Kurçaloğlu[64] · Semiha Cömertoğlu Arslan[35] · Fatma Dilan Taş[35] · Seda Özcan[65] · Sezen Köse[65] · Nazlı Burcu Özbaran[65] · Sadettin Burak Açıkel[66] · Nesrin Türk[67] · Nurgül Bakman İsnaç[68] · Fırat Öz[68] · Pelin Dağ[69] · Nazan Gündoğan[70] · Özüm Sueda Tasak[17] · Hüseyin Burak Baykara[17] · Hatice Ünver[71] · Neşe Perdahlı Fiş[71] · İsmet Aşıkhasan[72] · Hande Şirin[73] · Yasemin Taş Torun[74] · Aybike Aydın[75] ·

Mahmut Cem Tarakçıoğlu[75] · Burak Doğangün[75] · Süleyman Kızıldağ[76] · Nihal Yurteri[77] · Rahime Kaya[77] · Hanım Hülya Alınay[78] · Tuğçe Görkemli[79] · Ayşe Irmak Taşdemir[80] · Duygu Kınay Ermiş[81] · Berna Polat Tüysüz[82] · Burçin Özlem Ateş[83] · Mehmet Ayhan Congöloğlu[83] · Arif Önder[84] · Emine Esra Varkal Toprak[84] · Didem Ayyıldız[11] · Hasan Durak[85] · Özge İpek Doğan[86] · Hakan Kayış[87] · Süleyman Emre Özyürek[88] · Begüm Şahbudak[89] · Rabia Yılmaz[90] · Abdullah Ata[91] · Saliha Baykal[91] · Ümit Işık[92] · Evrim Aktepe[88] · Selma Tekeş Özdeş[93] · Berna Kaymaz[93] · Ipek Perçinel Yazıcı[93] · Kemal Utku Yazıcı[93] · Merve Yazıcı[50] · Tuğçe Canol Özbek[94] · Senay Çelenay Özyaşar[95] · Hatice Doğan[96] · Hakan Öğütlü[97] · Büşra Balta Kesikbaş[98] · Uğur Onur Günden[99] · Tuğçe Sinoğlu Günden[100] · Özlem Keskiner[101] · Asiye Arıcı Gürbüz[102] · Fatma Benk Durmuş[103] · Cantekin Can[102] · Fatma Coşkun[40] · Nazan Ekinci[104] · Hurşit Ferahkaya[105] · Seda Güneysu[106] · Mutlu Muhammed Özbek[94] · Tuğçe Öncü Sartekin[107] · Esra Sizer[108] · İrem Şahin[109] · Mustafa Esad Tezcan[110] · Deniz Yıldız[111] · Ilgın Senat[112] · Erman Esnafoğlu[112] · Aylin Deniz Uzun Çakır[113] · Burak Çakır[113] · Zeynep Seda Albayrak[25] · Güler Göl Özcan[114] · Süheyla Tağcı[115] · Çigdem Yektaş[116] · İbrahim Zeyrek[117] · Mehmet Akif Cansız[118] · Cansın Ceylan[119] · Berire Çekin Yılmaz[120] · Mehmet Sertçelik[121] · Esra Nisa Arslan[122] · Erdal Görkem Gavcar[123] · Seçil Gündüz Ünsal[124] · Fulya Şimşek[125] · Akın Tahıllıoğlu[126] · Zehra Algan[127] · Ebru Altıntaş[128] · Özgur Kütük[129] · Eyüp Sabri Ercan[65]

✉ Ali Evren Tufan
tevrenus@yahoo.com

[1] Department of Child and Adolescent Psychiatry, Baskent University Faculty of Medicine, Adana Dr. Turgut Noyan Medical and Research Center, Adana, Turkey

[2] Department of Child and Adolescent Psychiatry, Bolu Abant Izzet Baysal University, Faculty of Medicine, Bolu, Turkey

[3] Department of Child and Adolescent Psychiatry, Harran University Faculty of Medicine, Sanliurfa, Turkey

[4] Department of Child and Adolescent Psychiatry, Balıkesir Ataturk City Hospital, Balıkesir, Turkey

[5] Department of Child and Adolescent Psychiatry, University of Health Sciences Dr. Behçet Uz Child Disease and Pediatric Surgery Training and Research Hospital, Izmir, Turkey

[6] Department of Psychology, Istanbul Esenyurt University, Istanbul, Turkey

[7] Department of Child and Adolescent Psychiatry, Istanbul Medeniyet University Faculty of Medicine, Istanbul, Turkey

[8] Department of Psychiatry, Istanbul Medeniyet University Faculty of Medicine, Istanbul, Turkey

[9] Department of Child and Adolescent Psychiatry, Kocaeli University Faculty of Medicine, Kocaeli, Turkey

[10] Department of Child and Adolescent Psychiatry, Bursa Uludag University Faculty of Medicine, Bursa, Turkey

[11] Department of Child and Adolescent Psychiatry, Bursa Dörtçelik Pediatric Hospital, Bursa, Turkey

[12] Division of Child and Adolescent Psychiatry, Fatih Sultan Mehmet University Faculty of Social and Human Sciences, Istanbul, Turkey

[13] Department of Child and Adolescent Psychiatry, İzmir Katip Çelebi University, Faculty of Medicine, Izmir, Turkey

[14] Department of Child and Adolescent Psychiatry, Cukurova University, Faculty of Medicine, Adana, Turkey

[15] Department of Child and Adolescent Psychiatry, Mersin University Faculty of Medicine, Mersin, Turkey

[16] Department of Psychology, Ege University, Izmir, Turkey

[17] Department of Child and Adolescent Psychiatry, Dokuz Eylul University Faculty of Medicine, Izmir, Turkey

[18] Child and Adolescent Psychiatry Clinic, Toros State Hospital, Mersin, Turkey

[19] Department of Child and Adolescent Psychiatry Unit, Kartal Dr. Lutfi Kirdar City Hospital, University of Health Science, Istanbul, Turkey

[20] Department of Child and Adolescent Psychiatry, Manisa Celal Bayar University, Faculty of Medicine, Manisa, Turkey

[21] Department of Child and Adolescent Psychiatry, Aydın Adnan Menderes University Faculty of Medicine, Aydın, Turkey

[22] Department of Child and Adolescent Psychiatry, Biruni University of Medicine, Istanbul, Turkey

[23] Department of Child and Adolescent Psychiatry, Van Training and Research Hospital, Van, Turkey

[24] Department of Child and Adolescent Psychiatry, Erciyes University Faculty of Medicine, Kayseri, Turkey

[25] Department of Child and Adolescent Psychiatry, Koc University Faculty of Medicine, Istanbul, Turkey

[26] Department of Child and Adolescent Psychiatry, Trakya University Faculty of Medicine, Edirne, Turkey

[27] Department of Child and Adolescent Psychiatry, Tepecik Training and Research Hospital, Izmir, Turkey

[28] Department of Child and Adolescent Psychiatry, Atatürk University Faculty of Medicine, Erzurum, Turkey

[29] Department of Turkish Ministry of Health, General Directorate of Health Services, Ankara, Turkey

[30] Department of Child and Adolescent Psychiatry, Karadeniz Technical University Faculty of Medicine, Trabzon, Turkey

[31] Department of Psychiatry, Istanbul Health & Technology University Faculty of Medicine, Istanbul, Turkey

[32] Department of Child and Adolescent Psychiatry, Giresun University, Faculty of Medicine, Giresun, Turkey

[33] Department of Child and Adolescent Psychiatry, Giresun Maternity and Children Training and Research Hospital, Giresun, Turkey

[34] Department of Child and Adolescent Psychiatry, BlackSea Ereğli State Hospital, Zonguldak, Turkey

[35] Department of Child and Adolescent Psychiatry, Kahramanmaraş Sütçü İmam University Faculty of Medicine, Kahramanmaraş, Turkey

[36] Child and Adolescent Psychiatry, Funda Özyay Eroğlu Private Practice, Kırşehir, Turkey

[37] Department of Psychology, Hasan Kalyoncu University, Gaziantep, Turkey

[38] Department of Psychology, Çağ University, Mersin, Turkey

[39] Department of Child and Adolescent Psychiatry, Cizre Dr. Selahattin Cizrelioglu State Hospital, Sırnak, Turkey

[40] Department of Child and Adolescent Psychiatry, Necmettin Erbakan University Faculty of Medicine, Konya, Turkey

[41] Department of Child and Adolescent Pscyhiatry, Pamukkale University Faculty of Medicine, Denizli, Turkey

[42] Department of Child and Adolescent Psychiatry, Sivas Cumhuriyet University Faculty of Medicine, Sivas, Turkey

[43] Department of Child and Adolescent Psychiatry, Afyonkarahisar State Hospital, Afyonkarahisar, Turkey

[44] Department of Child and Adolescent Psychiatry, Afyonkarahisar Health Sciences University Faculty of Medicine, Afyonkarahisar, Turkey

[45] Department of Child and Adolescent Psychiatry, Dicle University Faculty of Medicine, Diyarbakır, Turkey

[46] Department of Child and Adolescent Psychiatry, Cem Gökçen Private Practice, Istanbul, Turkey

[47] Department of Child and Adolescent Psychiatry, Gaziantep University, Faculty of Medicine, Gaziantep, Turkey

[48] Department of Child and Adolescent Psychiatry, Zehra Hangül Private Practice, Adana, Turkey

[49] Department of Psychiatry, Baskent University, Faculty of Medicine, Ankara, Turkey

[50] Department of Child and Adolescent Psychiatry, Recep Tayyip Erdoğan University School of Medicine, Rize, Turkey

[51] Department of Psychiatry, Bolu Abant Izzet Baysal University Faculty of Medicine, Bolu Izzet Baysal Training and Research Hospital, Bolu, Turkey

[52] Department of Child and Adolescent Psychiatry, Karadeniz Technical University, Faculty of Medicine, Trabzon, Turkey

[53] Department of Child and Adolescent Psychiatry, Muğla Sıtkı Koçman University, Faculty of Medicine, Muğla, Turkey

[54] Department of Child and Adolescent Psychiatry, Sakarya University, Sakarya Training and Research Hospital, Sakarya, Turkey

[55] Department of Child and Adolescent Psychiatry, Sakarya Training and Research Hospital, Sakarya, Turkey

[56] Department of Psychiatry, Halic University Faculty of Medicine, Istanbul, Turkey

[57] Department of Child and Adolescent Psychiatry, Kayseri Education and Research Hospital, Kayseri, Turkey

[58] Department of Child and Adolescent Psychiatry, Freelance Physician, Aksaray, Turkey

[59] Department of Child and Adolescent Psychiatry, Sivas Numune Hospital, Sivas, Turkey

[60] Department of Child and Adolescent Psychiatry, Diamind Zihin Akademisi, Konya, Turkey

[61] Department of Child and Adolescent Psychiatry, Selcuk University Faculty of Medicine, Konya, Turkey

[62] Eker Dairy Product, Bursa, Turkey

[63] Department of Child and Adolescent Psychiatry, Tuğba Eseroğlu Söylemez Private Practice, Istanbul, Turkey

[64] Department of Child and Adolescent Psychiatry, Samsun Education and Research Hospital, Samsun, Turkey

[65] Department of Child and Adolescent Psychiatry, Ege University Faculty of Medicine, Izmir, Turkey

[66] Department of Child and Adolescent Psychiatry, Ankara University, Faculty of Medicine, Ankara, Turkey

[67] Department of Child and Adolescent Psychiatry, Osmaniye State Hospital, Osmaniye, Turkey

[68] Department of Child and Adolescent Psychiatry, Siirt Training and Research Hospital, Siirt, Turkey

[69] Department of Child and Adolescent Psychiatry, Mersin City Training and Research Hospital, Mersin, Turkey

[70] Department of Child and Adolescent Psychiatry, Elazığ Mental Health Diseases and Hospital, Elazig, Turkey

[71] Department of Child and Adolescent Psychiatry, Marmara University Faculty of Medicine, Istanbul, Turkey

[72] Department of Child and Adolescent Psychiatry, Tekirdag Dr. İsmail Fehmi Cumalıoglu Sehir Hastanesi, Tekirdag, Turkey

[73] Department of Child and Adolescent Psychiatry, Health Sciences University Bursa Yüksek Ihtisas Education and Research Hospital, Bursa, Turkey

[74] Department of Child and Adolescent Psychiatry, Gazi University Faculty of Medicine, Ankara, Turkey

[75] Department of Child and Adolescent Psychiatry, Istanbul University-Cerrahpasa, Cerrahpasa Medical Faculty, Istanbul, Turkey

[76] Department of Child and Adolescent Psychiatry, Dicle University, Faculty of Medicine, Diyarbakır, Turkey

[77] Department of Child and Adolescent Psychiatry, Kutahya Health Sciences University Faculty of Medicine, Kutahya, Turkey

[78] Department of Child and Adolescent Psychiatry Basaksehir Cam and Sakura City Hospital, Istanbul, Turkey

[79] Department of Child and Adolescent Psychiatry, Nevşehir State Hospital, Nevşehir, Turkey

[80] Department of Child and Adolescent Psychiatry, Karamanoglu Mehmetbey University Faculty of Medicine, Karaman, Turkey

[81] Department of Child and Adolescent Psychiatry, Basaksehir Cam ve Sakura City Hospital, Istanbul, Turkey

[82] Department of Child and Adolescent Psychiatry, Mehmet Akif İnan Training and Research Hospital, Sanliurfa, Turkey

[83] Department of Child and Adolescent Psychiatry, Gülhane Training and Research Hospital, Ankara, Turkey

[84] Department of Child and Adolescent Psychiatry, Akdeniz University Faculty of Medicine, Antalya, Turkey

[85] Department of Child and Adolescent Psychiatry, Diyarbakır Training and Research Hospital, Diyarbakır, Turkey

[86] Department of Child and Adolescent Psychiatry, Nevşehir State Hospital, Nevşehir, Turkey

[87] Department of Child and Adolescent Psychiatry, Bitlis Tatvan Hospital, Tatvan, Turkey

[88] Department of Child and Adolescent Psychiatry, Süleyman Demirel University, Faculty of Medicine, Isparta, Turkey

[89] Child and Adolescent Psychiatry Clinics, Manisa City Hospital, Sehzadeler, Manisa, Turkey

[90] Department of Child and Adolescent Psychiatry, Kilis State Hospital Child Psychiatry Outpatient Clinic, Kilis, Turkey

[91] Department of Child And Adolescent Psychiatry, Tekirdağ Namık Kemal University Faculty of Medicine, Tekirdağ, Turkey

[92] Department of Child and Adolescent Psychiatry, Ümit Işık Akademi, Isparta, Turkey

[93] Department of Child and Adolescent Psychiatry, Fırat University Faculty of Medicine, Elazig, Turkey

[94] Department of Child and Adolescent Psychiatry, Kars Harakani State Hospital, Kars, Turkey

[95] Department of Child and Adolescent Psychiatry, Adıyaman Traınıng and Research Hospıtal, Adiyaman, Turkey

[96] Department of Child and Adolescent Psychiatry, Hatice Doğan Private Practice, Kayseri, Turkey

[97] Department of Child and Adolescent Psychiatry, Cognitive Behavioral Psychotherapies Association, Ankara, Turkey

[98] Department of Child and Adolescent Psychiatry, Kocaeli City Hospital, Kocaeli, Turkey

[99] Research Institute for Individuals with Developmental Disabilities, Anadolu University, Eskisehir, Turkey

[100] Department of Early Childhood Education, Anadolu University, Eskisehir, Turkey

[101] Child and Adolescent Psychiatry, Private Outpatient Clinic, Eskisehir, Turkey

[102] Department of Child and Adolescent Psychiatry, Dr. Ekrem Tok Mental Health Diseases and Hospital, Adana, Turkey

[103] Department of Child and Adolescent Psychiatry, Fatma Benk Durmuş Private Practice, Istanbul, Turkey

[104] Department of Child and Adolescent Psychiatry, İstanbul Beykoz State Hospital, Istanbul, Turkey

[105] Department of Child and Adolescent Psychiatry, Dr. Ali Kemal Belviranlı Obstetrics, Gynecology and Pediatrics Hospital, Konya, Turkey

[106] Department of Child and Adolescent Psychiatry, Tokat Gaziosmanpasa University Faculty of Medicine, Tokat, Turkey

[107] Department of Child and Adolescent Psychiatry, Burdur State Hospital, Burdur, Turkey

[108] Department of Child and Adolescent Psychiatry, Diyarbakir Children's Diseases Hospital, Diyarbakır, Turkey

[109] Department of Child and Adolescent Psychiatry, Amasya University Faculty of Medicine, Sabuncuoglu Serefeddin Training and Research Hospital, Amasya, Turkey

[110] Department of Child and Adolescent Psychiatry, Konya City Hospital, Konya, Turkey

[111] Department of Child Development, Istanbul Gelisim University Faculty of Health Sciences, Istanbul, Turkey

[112] Department of Child and Adolescent Psychiatry, Ordu University Faculty of Medicine, Ordu, Turkey

[113] Department of Child and Adolescent Psychiatry, Uşak University Faculty of Medicine, Uşak, Turkey

[114] Department of Child and Adolescent Psychiatry, Bilecik Şeyh Edebali University Faculty of Medicine, Bilecik, Turkey

[115] Child and Adolescent Psychiatry Clinic, Manisa Mental Health and Diseases Hospital, Manisa, Turkey

[116] Department of Child and Adolescent Psychiatry, Doç. Dr. Çiğdem Yektaş Private Practice, Istanbul, Turkey

[117] Department of Child and Adolescent Psychiatry, Bingol State Hospital, Bingol, Turkey

[118] Department of Child and Adolescent Psychiatry, Yalova University, Faculty of Medicine, Yalova, Turkey

[119] Department of Child and Adolescent Psychiatry, Kirklareli University Faculty of Medicine, Kirklareli, Turkey

[120] Department of Child and Adolescent Psychiatry, Lüleburgaz State Hospital, Kırklareli, Luleburgaz, Turkey

[121] Department of Child and Adolescent Psychiatry, Hitit University Faculty of Medicine, Çorum, Turkey

[122] Department of Child and Adolescent Psychiatry, Patnos State Hospital, Agrı, Turkey

[123] Department of Child and Adolescent Psychiatry, Kırıkkale Yüksek Ihtisas Hospital, Kirikkale, Turkey

[124] Child and Adolescent Psychiatry, Seçil Gündüz Ünsal Private Practice, Uşak, Turkey

[125] Department of Child and Adolescent Psychiatry, Konya Training and Research Hospital, Konya, Turkey

[126] Department of Child and Adolescent Psychiatry, Private Outpatient Clinic, Izmir, Turkey

[127] Department of Child and Adolescent Psychiatry, Health Sciences University, Bagcilar Training and Research Hospital, Istanbul, Turkey

[128] Department of Psychiatry, Baskent University Faculty of Medicine, Adana Dr. Turgut Noyan Medical and Research Center, Adana, Turkey

[129] Department of Immunology, Baskent University, Adana Dr. Turgut Noyan Medical and Research Center, Adana, Turkey