

Original article

The Psychological Symptoms and Difficulties Experienced By Parents of Children with Autism

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Abstract:

Objective: This study investigated the psychological symptoms and difficulties experienced by parents of children with autism. **Method:** This descriptive and cross-sectional study was conducted between November 2021 and June 2022. The sample consisted of 218 parents of children aged 3-18 living in XX. The sample was divided into two: 110 parents of children with autism and 108 parents of healthy children. **Results:** Parents of children with autism had a mean age of 36.15±6.142, while parents of healthy children had a mean age of 36.65±7.057. More than half of the parents of children with autism stated that they worried about their children's future and had difficulty taking care of other children of theirs, making time for themselves, and maintaining daily life. On the other hand, only a quarter of the parents of healthy children stated that they worried about their children's future and had difficulty taking care of other children of theirs, making time for themselves, and maintaining daily life. Parents of children with autism had a significantly higher mean anxiety, depression and hostility subscale score than parents of healthy children (p<0.05). **Conclusions:** Parents of children with autism experience more difficulties and present with more symptoms of anxiety, depression, and hostility than parents of healthy children. Parents of children with special needs need to be psychologically reassured and supported.

Keywords: Parent; nursing; autism spectrum disorder; psychological symptoms; difficulties

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Introduction:

Autism Spectrum Disorder (ASD) is a behavioral and developmental disorder characterized by communicative and interactive deficits and limited-repetitive behavior patterns¹. Autism starts at an early developmental stage and causes significant impairment in areas of social functioning². Autism, Rett syndrome, Asperger syndrome, pervasive developmental disorder-not otherwise specified (PDD-NOS), and childhood disintegrative disorder were called pervasive developmental disorders until DSM-V, but today they are included in the autism spectrum disorder^{3,4}.

Although it has been reported that ASD prevalence

would likely be lower (21% reduction) under the current Diagnostic and Statistical Manual of Mental Disorders (DSM-5) than under DSM-IV-TR diagnostic criteria, there has been an accelerate in the prevalence of ASD world-wide in last decade⁵. In the United States, one in 59 children was reported to have ASD in 2018⁶. Similarly, one in every 68 children is diagnosed with ASD in Türkiye. Boys are five times more likely to be diagnosed with autism than girls⁷ conducted a study on children aged 18-24 months and reported that the prevalence of autism was 1/1000. Oner and Munir (2020) conducted a study on children aged 16-36 months and documented the prevalence of autism as 8.5/1000. Children with

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ASD have the following symptoms: inability to learn language, introversion, excessive reaction to change, difficulty learning abstract concepts, inability to learn the concept of time, inability to perceive speech, and limited relationships with their environment⁸. The most common symptoms of ASD are repetitive behaviors and inadequate language development and social skills⁹.

Children with autism change how their parents live and significantly impact their mental health. Every parent expects a healthy child. Therefore, they feel disappointed when their child is diagnosed with autism¹⁰. In addition, not being able to explain their child's condition to other people fully has a significant impact on parents' mental health¹⁰⁻¹². Their mental health is also affected because they do not know enough about the challenges posed by autism and the additional health problems caused by it^{10,13}. Parents find it difficult at times to take care of their healthy children. Therefore, it is exhausting and stressful for parents to meet the needs of their children with autism because they cannot communicate with them. What is more, they need to keep the family together, cope with strange and unusual behaviors, supervise their children with autism who have difficulty recognizing and avoiding dangers, and all the while, try to meet personal needs and the needs of other family members^{14,15}. Parents also struggle with prejudice and discrimination. They feel worn out as they do not know how to overcome the emotional pressure to lead a healthier and better life¹⁶.

Consequently, they experience frustration, guilt, panic, and depression, which makes them more socially isolated and mentally vulnerable. Therefore, they have difficulty fulfilling their roles within the family¹⁷⁻¹⁹. They also suffer from anxiety because of diagnostic uncertainty, the disorder's severity and duration, and the child's lack of compliance with social rules^{20,21}.

Children with autism need constant attention, education, and care, putting parents in a situation where they have to assume more responsibilities but have to deal with the dependent relationship their children develop during this process. Therefore, parents have psychological disorders¹¹. Over time, all these problems cause parents to experience stress^{18,22,23}, anxiety, low self-esteem, and depression, making them less able to maintain activities of daily living and interpersonal relationships^{24,25}. Parents are exposed to more stress than parents of children with other developmental disabilities^{25,26}.

Nurses spend a lot of time with children with autism and their parents. They use their knowledge and skills (communication, leadership, professionalism, critical thinking, and decision-making) to help parents of children with autism²⁷. Although many researchers have focused on parents of autistic children^{28,29}, there is a limited number of studies comparing parents of autistic children and parents of healthy children in terms of the psychological symptoms and difficulties they experience^{25,30}.

Research Questions:

Do parents of children with autism and those of healthy children experience similar difficulties?

Do parents of children with autism and those of healthy children present with similar psychological symptoms?

Do the difficulties and psychological symptoms experienced by parents of children with autism and those of healthy children affect each other?

Method and Materials:

Study Design

The study was descriptive and cross-sectional study compared parents of autistic children with those of healthy children to determine whether they experience similar difficulties and present with similar psychological symptoms. Study was conducted between November 2021 and June 2022 in XX.

Sampling and recruitment

The population consisted of all parents of autistic children 3-18 years of age. Different institutions diagnose autism differently, but children are diagnosed with autism at about two years of age³¹. Therefore, we focused on autistic children 3-18 years of age. To achieve homogeneity, we also aimed to recruit parents of healthy children 3-18 years of age. A power analysis was performed based on the mean depression scores of parents of children with autism (13.42±12.83) and healthy children (19.27±9.59) reported by Hasircı (2019). The results showed that a sample of 164 would be large enough to detect significant differences between groups (95% confidence interval and 5% margin of error). The sample consisted of 218 parents (n=110 parents of children with autism and n=108 parents of healthy children) who volunteered to participate in the study between the specified dates. Participants were recruited using snowball sampling, by which the researchers contacted one parent and then asked

her to refer to other potential subjects who met the inclusion criteria of interest³².

Study's inclusion criteria for parents of children with autism were (1) having an autistic child between the ages of 3-18, (2) being diagnosed with autism at least six months ago, (3) not having audiovisual, mental, psychological, and speech problems, and (4) volunteering. The inclusion criteria for parents of healthy children were (1) having a healthy child between the ages of 3-18, (2) not having audiovisual, mental, psychological, and speech problems, and (3) volunteering.

Data Collection Tools

Personal information form, the Difficulties Identification Form (DIF), and the Brief Symptom Inventory (BSI) were used for it^{27,33}.

Personal Information Form

The personal information form was based on a literature review conducted by the researchers. The form consisted of items on the sociodemographic characteristics of parents (age, gender, place of residence, family type, socio-economic status, educational status, occupation, number of children, presence of chronic disease, knowledge about the child's disease) and children (age, gender, time of diagnosis, time spent in rehabilitation center). The form was checked by three experts (pediatric health and disease nursing) for intelligibility and relevance. It was revised and finalized based on their feedback.

Difficulties Identification Form (DIF)

The DIF was based on a literature review conducted by the researchers³⁴⁻³⁶. The form was developed to determine the care-related difficulties (roles, activities of daily living, etc.) experienced by parents of children with autism. The form was checked by three parents of autistic children and three rehabilitation specialists for intelligibility and relevance. It was revised and finalized based on their feedback.

Brief Symptom Inventory (BSI)

The BSI was developed by Derogatis in 1992. It is a 53-item measure that identifies self-reported psychological symptoms in adolescents and adults. It is a short form of the Symptom Distress Check List (SCL 90-R)³⁷. It is a short scale with a similar structure that can be administered in 5-10 minutes by selecting a total of 53 items with the highest loadings on nine factors of the SCL-90-R. The inventory consists of five subscales (anxiety, depression, negative self, hostility, and somatization) and three

global indices. The items are statements based on self-report. The items are rated on a five-point Likert-type scale ranging from 0 (not at all) to 4 (extremely). The total score ranges from 0 to 212, with higher scores indicating higher levels of psychopathology³³.

Data Collection

The data were collected through face-to-face interviews. Participants were interviewed at their convenience. During the interviews, we took the preventive measures (mask, distance, and hygiene) defined by the Turkish Ministry of Health. Since the data collection tools were based on self-report, participants were asked to fill them out by themselves, with an interviewer available for questions at all times. The interviewer read out the questions to illiterate participants. It took each participant 25 minutes to fill out the data collection forms.

Data Analysis

The data were analyzed using the Statistical Package for Social Sciences (SPSS, IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.) at a significance level of 0.05. Descriptive statistics (mean, standard deviation, median value, minimum, maximum, number, and percentile) were used for categorical and continuous variables. Variance homogeneity was determined using Levene's test. The Shapiro-Wilk test was used for normality testing. The normally distributed data were analyzed using the independent samples t-test, while the nonnormally distributed data were analyzed using the Mann-Whitney U test. The relationships between categorical variables were analyzed using Fisher's Exact and Chi-Square tests. In cases where the expected frequencies were less than 20%, the "Monte Carlo Simulation Method" was used to include these frequencies in the analysis.

Ethical Considerations:

The study was approved by the non-interventional clinical research ethics committee of the faculty of nursing of Selcuk University Ethics Committee (E-2021/68). All participants were informed about the purpose and method of the study, and consent was obtained from those who agreed to participate. The study was conducted by considering the ethical principles of the Declaration of Helsinki.

Results:

Parents of children with autism had a mean age of 36.15±6.142. Most parents were mothers (88%) who lived in the city center (80%). Almost half the

parents had primary school degrees (47%). Most were housewives (78%) with health coverage (76%). More than half of the parents of children with autism had a neutral income (income = expense) (75%) and nuclear families (73%). Less than half of the parents had two children (41%) and chronic diseases (24%). More than half the parents were well-informed about autism (53%).

Parents of healthy children had a mean age of 36.65 ± 7.057 . Most parents were mothers (81%) living in the city center (87%). More than half of the parents were housewives (63%) with primary school degrees (65%). Most parents had health coverage (80%), a neutral income (77%), and nuclear families (81%). Less than half of the parents had two children (42%) and chronic diseases (16%). Both the case and control families had similar sociodemographic characteristics ($p > 0.05$) (Table 1).

Children had a mean age of 8.44 ± 3.97 . More than half of the children were boys (50.5%). Children with autism and healthy children had similar sociodemographic characteristics ($p > 0.05$)

Table 2 compares the groups in terms of the difficulties they experienced. Most parents of children with autism had difficulty taking care of other children of theirs (78%), getting information about autism, treatment, and care (80%), fulfilling their parenting roles (74%), making time for themselves (63%), affording treatment and care costs (79%), maintaining their relationship with their spouses (73%) and family members, relatives, and friends (72%), and carrying out activities of daily living (75). More than half of the parents were worried about the future of their children with autism (65%).

Less than a quarter of the parents of healthy children had difficulty taking care of other children of theirs (22%), getting information about autism, treatment, and care (20%), and affording treatment and care costs (21%). A quarter of the parents had difficulty carrying out activities of daily living (25%). More than a quarter of the parents had difficulty fulfilling their parenting roles (26%), making time for themselves (37%), and maintaining their relationship with their spouses (27%) and family members, relatives, and friends (28%). Less than half of the parents were worried about the future of their children (38%).

These results showed that parents of children with autism experienced difficulties significantly more than parents of healthy children ($p < 0.001$; Table 2).

Parents of children with autism had a significantly

higher mean BSI total score (89.67 ± 31.980) than parents of healthy children (80.69 ± 29.304) ($z = -3.395$ $p = 0.001$ $d = 0.266$). Parents of children with autism had a significantly higher mean BSI "anxiety" subscale score (20.98 ± 8.283) than parents of healthy children (18.87 ± 7.154) ($z = -2.944$ $p = 0.003$ $d = 0.230$). Mothers of children living with autism had a higher BSI "depression" subscale score (23.72 ± 8.022 ; 19.41 ± 7.902 ; $z = -4.933$ $p = 0.001$ $d = 0.386$). Parents of children with autism had a significantly higher mean BSI "hostility" subscale score (13.00 ± 4.687) than parents of healthy children (11.76 ± 4.961) ($z = -2.786$ $p = 0.006$ $d = 0.215$)

Discussion:

When the difficulties experienced by families with children living with autism and psychological symptoms are not detected in a timely and effective manner, many problems that are difficult to compensate for both parents and children may arise. This study aimed to determine the psychological symptoms and difficulties experienced by parents. The study also compared parents of autistic children with those of healthy children to determine whether they experienced similar difficulties and psychological symptoms. Both groups had significantly similar sociodemographic characteristics. This result suggested that sociodemographic characteristics did not affect how often parents of children with autism experienced difficulties and psychological symptoms.

In another problem, mothers with children living with autism and those with healthy children were compared in terms of the difficulties they experienced. The results of the studies revealed that parents of children with autism experience significantly more difficulties³⁸. For example, they had much more difficulty taking care of other children of theirs, getting information about autism, fulfilling their parenting roles, making time for themselves, affording treatment and care costs, maintaining their relationship with their spouses and family members, relatives, and friends, and carrying out activities of daily living than parents of healthy children. In addition, parents of children with autism were more worried about their sick children's future than parents of healthy children. Children with autism are more dependent on their parents to perform activities of daily living than healthy children³⁹. This causes parents of children with autism to experience some difficulties in care and daily life. While parenting even a healthy child is a stressful experience, it is no surprise that parents

of children with special needs have more difficulties than those of healthy children^{40,41}.

These parents may experience problems in their social and professional lives due to the difficulties of the process. For example, mothers who have children living with autism give less importance to working life because they want to spend more time with their children and have to spare less time for themselves⁴². Mothers of children with autism present with more psychological symptoms because they take more responsibility and make less time for themselves than mothers of healthy children⁴³⁻⁴⁵.

Gray (2006) conducted a study with parents of children with autism and found that fathers and some segments of society blamed mothers for their children's behavioral problems. This indirectly explains why mothers of children with autism have difficulty maintaining their parenting roles and relationships with their spouses, family members, and relatives⁴⁶. Korkmaz (2017) determined that alexithymia and depression were more prevalent among mothers of children with autism than those of healthy children. Parents of children with autism have challenging family dynamics because they plan their whole life according to their children with autism⁴⁷. Therefore, they suffer from restricted social relations and financial problems⁴⁸⁻⁵⁰. Parents of children with autism are worried about possible problems in the future. They are particularly concerned about the safety of their children^{51,52}. Parents are concerned also because they believe that there are too many responsibilities that their children will fail to fulfill in the future. In conclusion, the findings show that the parents of these children with special needs experience much more difficulties than those of healthy children. Because it draws attention that there are very few programs or policies adapted to autistic children. Parents are initially shocked when their children are diagnosed with autism. Afterward, they experience an increased burden of care, putting them in a more disadvantaged position physically and psychosocially⁵³⁻⁵⁵. Our results showed that parents of children with autism had a significantly higher mean BSI total score than parents of healthy children. Parents of children with autism also had significantly higher mean BSI "anxiety," "depression," and "hostility" subscale scores than parents of healthy children. Ölmez (2015) conducted a study on 80 parents of children with autism to determine the psychological symptoms and difficulties they experienced. He found that parents of children with autism were worried about the future

of their children and had difficulty making time for themselves and maintaining activities of daily living. He also determined that parents' psychological symptom scores changed in proportion to these difficulties⁴⁵.

Being diagnosed with autism and its aftermath is very painful for parents. The intense anxiety in the family before diagnosis makes some changes in the family process compulsory and necessary after the diagnosis is confirmed. Post-diagnosis anxiety, followed by depression, results in decreased family relationships and hostility (towards oneself and perhaps the child)^{56,57}. It takes time for parents to accept the process after the diagnosis and adapt to the change. Parents struggling with the difficulties of autism find it difficult to find a place in social life due to intense anxiety and depression after diagnosis^{58,59}. Parents' failure to accept their child's health status despite a confirmed diagnosis may also increase the severity of psychological symptoms^{39,46}. Hutton and Caron (2005) found that all parents experienced complex emotions (anxiety, shock, denial, helplessness, and depression) after diagnosis. Ludlow et al. (2012) determined that mothers with a child living with autism have difficulty in coping with chronic emotional changes after diagnosis due to the lack of social support systems such as the living environment, spouse and relatives. Parents present with various psychological symptoms when their child is diagnosed with ASD, which is consistent with the literature^{30,60}. Healthcare professionals should develop family-centered approaches that include not only children with autism but also their parents and monitor those parents' psychological well-being regularly.

Conclusions:

The lifestyle of parents with autistic children is changing. Every parent expects a healthy child, so families can be disappointed when their child is diagnosed with autism. Their mental health is also affected because they do not have enough information about the difficulties brought by autism and the additional health problems it brings. Nurses use their knowledge and skills (communication, leadership, professionalism, critical thinking, and decision-making) to help parents of children with autism. Although many researchers have focused on parents of autistic children, there is a limited number of studies comparing parents of autistic children and parents of healthy children in terms of the psychological symptoms and difficulties

they experience. We compared parents of autistic children with those of healthy children to determine whether they experience similar difficulties and present with similar psychological symptoms. The approach to children with autism and their families, which is a special group among pediatric patients, is extremely important for the field of nursing. Parents' failure to accept their child's health status despite a confirmed diagnosis was also increased the severity of psychological symptoms. Compared to families with healthy children, it was determined that their psychological symptoms and anxiety increased over time. Healthcare professionals should develop family-centered approaches that include not only children with autism but also their parents and monitor those parents' psychological well-being regularly.

Limitations

The study had one limitation. The results are sample-specific and cannot be generalized to all parents of children with autism.

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Credit authorship contribution statement

Semra KOSE: Conceptualization, methodology, formal analysis, data collection, evaluation, manuscript writing, original design. Hilal KURT SEZER: Methodology, formal analysis, evaluation, manuscript writing, original design, review. Sibel KÜÇÜKOĞLÜ: Conceptualization, methodology, evaluation, review, and corrections

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Table 1: Parents' Sociodemographic Characteristics (n=218)

		Parents of Children with Autism (n=110)	Parents of Healthy Children (n=108)	Test	p	Effect Size (%95 CI)
Age (year)		36.15±6.142 36 (32;40)	36.65±7.057 37 (31;42)	-1.007	0.314 ²	-0.228 (-0.079;0.075)
Parent	Mother	97 (88%)	87 (81%)	2.408	0.121 ³	0.105
	Father	13 (12%)	21 (19%)			
Place of residence	City	80 (73%)	85 (79%)	4.588	0.101 ³	0.145
	District	21 (19%)	21 (19%)			
	Village	9 (8%)	2 (2%)			
Education (degree)	Illiterate	4 (4%)	2 (2%)	4.248	0.236 ³	0.140
	Primary school	40 (36%)	28 (26%)			
	High school	52 (47%)	65 (60%)			
	Bachelor's	14 (13%)	13 (12%)			
Occupation	Unemployed	0 (0%)	1 (1%)	1.825	0.177 ³	0.187
	Self-employed	11 (10%)	23 (21%)			
	Housewife	86 (78%)	69 (64%)			
	Public official	13 (12%)	16 (15%)			
Health coverage	Yes	84 (76%)	86 (80%)	0.339	0.561 ³	0.039
	No	26 (24%)	22 (20%)			

		Parents of Children with Autism (n=110)	Parents of Healthy Children (n=108)	Test	p	Effect Size (%95 CI)
Income	Positive (income > expense)	10 (9%)	12 (11%)	0.697	0.706 ³	0.057
	Neutral (income = expense)	83 (75%)	83 (77%)			
	Negative (income < expense)	17 (15%)	13 (12%)			
Family type	Nuclear	80 (73%)	88 (81%)	1.765	0.184 ³	0.133
	Extended	30 (27%)	20 (19%)			
Number of children	1	13 (12%)	17 (16%)	1.477	0.831 ³	0.082
	2	45 (41%)	45 (42%)			
	≥3	33 (47%)	27 (43%)			
Chronic disease	Yes	26 (24%)	17 (16%)	2.146	0.143 ³	0.099
	No	84 (76%)	91 (84%)			
Being well-informed about autism*	Yes	58 (53%)	-	0.327	0.567 ³	0.052
	No	52 (47%)	-			

*p<0.05; **p<0.01; X: Mean SD: Standard Deviation; M: Median; n: No; %: Percentage; ¹: Independent t-test (t); ²: Mann-Whitney U test (z); ³: Chi-square test

Table 2: Parents' Difficulties (n=218)

Parents of Children with Autism (n=110)		Parents of Healthy Children (n=108)		Test Stat.	p	Effect Size (%95 CI)
Difficulty taking care of other children	Yes	72 (%78)	20 (%22)	49.218*	0.001 **	0.475
	No	38 (%30)	88 (%70)			
Difficulty getting information about autism, treatment, and care	Yes	66 (%80)	17 (%20)	45.276*	0.001 **	0.456
	No	44 (%33)	91 (%67)			
Difficulty fulfilling your parenting roles	Yes	69 (%74)	24 (%26)	36.551*	0.001 **	0.409
	No	41 (%33)	84 (%67)			
Worrying about your child's future	Yes	98 (%62)	60 (%38)	30.723*	0.001 **	0.375
	No	12 (%20)	48 (%80)			
Difficulty making time for yourself	Yes	96 (%63)	56 (%37)	32.389*	0.001 **	0.385
	No	14 (%21)	52 (%79)			
Difficulty affording treatment and care costs	Yes	77 (%79)	20 (%21)	58.481*	0.001 **	0.518
	No	33 (%27)	88 (%73)			
Difficulty maintaining your relationship with your spouse	Yes	53 (%73)	20 (%27)	21.529*	0.001 **	0.314
	No	57 (%39)	88 (%61)			
Difficulty maintaining your relationship with family members, relatives, and friends	Yes	68 (%72)	27 (%28)	30.045*	0.001 **	0.371
	No	42 (%34)	81 (%66)			
Difficulty maintaining daily life	Yes	81 (%75)	27 (%25)	51.568*	0.001 **	0.486
	No	29 (%26)	81 (%74)			

* Chi-square test; **p<0.01; n: No; %: Percentage

Table 3: Parents' SBI Scores (n=218)

	X±SD			Test Stat.	p	Effect Size (95% CI)
		Parents of Children with Autism (n=110)	Parents of Healthy Children (n=108)			
Anxiety	19.94±7.798	20.98±8.283 18 (15;24)	18.87±7.154 16 (14;22)	-2.944	0.003 ^{2**}	0.230 (0.080;0.369)
Depression	21.58±8.233	23.72±8.022 22 (17;28)	19.41±7.902 17 (14;23)	-4.933	0.001 ^{2**}	0.386 (0.248;0.509)
Negative self	18.27±7.629	18.75±8.362 16 (14;20)	17.79±6.807 16 (13;20)	-0.764	0.445 ²	0.060 (-0.094;0.210)
Somatization	13.05±5.154	13.23±5.676 11 (10;15)	12.87±4.582 11 (9;14)	-0.054	0.957 ²	0.004 (-0.157;0.148)
Hostility	12.39±4.853	13.00±4.687 12 (10;14)	11.76±4.961 10 (8;14)	-2.753	0.006 ^{2**}	0.215 (0.065;0.356)
Total	85.22±30.941	89.67±31.980 78 (71;97)	80.69±29.304 70 (60;91)	-3.395	0.001 ^{2**}	0.266 (0.118;0.402)

*p<0.05; **p<0.01; X: Mean; SD: Standard deviation; M: Median; Q₁:1. Quartile; Q₃:3. Quartile; n: Number; %: Percentage; ¹: Independent t-test (t); ²: Mann-Whitney U test (z); ³: Chi-Square test

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