




## Somatic Symptoms and Mental Health in Parents of Children with and without Autism: A Comparative Study

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### Quantitative Study

#### Abstract

**Background:** Autism spectrum disorder (ASD) affects families, especially the parents of people with this disorder. The purpose of this study was to investigate psychosomatic symptoms and mental health in parents of children with and without autism.

**Methods:** This casual-comparative study was performed on parents of children with and without autism who referred to an outpatient autism specialty clinic located in Tehran, Iran, in 2020-2021. The statistical population included all parents of children with and without autism and the sample consisted of 80 parents selected through random sampling method. Therefore, randomized sampling was conducted and the parents were selected based on the inclusion criteria. The data collection tools used included the Patient Health Questionnaire-15 (PHQ-15) and General Health Questionnaire-28 (GHQ-28). Data were analyzed using descriptive statistics (mean and standard deviation) and MANOVA in SPSS software.

**Results:** The results showed that parents of autistic children had higher GHQ-28 and PHQ-15 scores than parents of children without autism ( $F= 18.47; 11.901; P = 0.001$ ).

**Conclusion:** Our results showed that the rate of psychosomatic symptoms and all dimensions of mental health was higher in parents of autistic children compared to that in the parents of children without autism. Thus, governments and other relevant institutions should provide support to parents of autistic children.

**Keywords:** Somatic symptoms; Mental health; Autism; Anxiety; Depression

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## Introduction

Autism spectrum disorder (ASD) is a heterogeneous, lifelong, neurodevelopmental condition that is defined by delays in social communication and the presence of restricted and repetitive behaviors (Roehr, 2013). The prevalence of ASD, especially autism, has risen over the last several decades (Licinio & Wong, 2021). The Centers for Disease Control and Prevention estimates that 1 in 54 (1.7%) children in the United States has autism (Maenner et al., 2020). While the prevalence of autism continues to rise, there are still many obstacles to receiving a timely diagnosis. The American Academy of Pediatrics has presented the latest guidelines on identifying, evaluating, and managing autistic children (Hyman, Levy, & Myers, 2020). These guidelines include standardized autism screening for all children aged 18–24 months, followed by continuous developmental monitoring by primary care providers (Hyman et al., 2020). This time period, between 12 and 24 months, is generally when parents begin to identify developmental abnormalities in their child (Cheng, Iao, & Wu, 2021). While a reliable clinical autism diagnosis can occur as early as 18 months (Cheng et al., 2021), there is often a gap of several years between first noticing developmental delays and diagnostic confirmation (Edwards, McKenney, Niekra, Hupp, & Everett, 2021). Noticeably, the national age at autism diagnosis among children under 8 years of age in the United States is 4.2 years (Maenner et al., 2020).

Much has been written about the numerous barriers to receiving an autism diagnosis (Haghighat, Mirzarezaee, Nadjar Araabi, & Khadem, 2022). The Andersen model for healthcare utilization can be used to organize these obstacles into the 3 components of predisposing (sociodemographic and societal influences), enabling (organization of healthcare infrastructures), and need (clinical characteristics) (Rigles, 2021). Among the predisposing factors, higher age at diagnosis is associated with non-White race and Hispanic ethnicity (Mazurek et al., 2021), lower parental education and socioeconomic status (Gibbs, Hudson, Hwang, Arnold, Trollor, & Pellicano, 2021), younger maternal and paternal age (Beenstock, 2021), being a first-born child (McLean, Eack, & Bishop, 2021), and rural geographic region (Song et al., 2021). The enabling factors linked to delay in diagnosis include no prior connection to the healthcare system (Clarke, Hull, Loomes, McCormick, Sheinkopf, & Mandy, 2021) and distance from treatment centers (Feeney & Burke, 2021). Among the need factors, high IQ (Calio & Higgins-D'Alessandro, 2021), low autism symptom severity (Guner, Gunay, & Demir Acar, 2021), and the presence of comorbid psychiatric disorders (Cederlund, 2021) have all been connected to older age at diagnosis. It is important to note that a recent systematic review reported contradictory findings across studies in terms of the factors that influence age at diagnosis (May, Vollenhoven, & Williams, 2021).

In terms of mental disorders, one area that has received surprisingly little attention is the parents and their mental health (Ebrahimi, Nasiri-Dehsorkhi, Hosseini, Afshar-Zanjani, & Schroeder, 2021). Caregivers, often the parents, of children with autism report a lower health-related quality of life (QoL) compared to general population norms (Kaur, Eigsti, & Bhat, 2021). Shanok, Lozott, Sotelo, and Bearss (2021) have reported that these caregivers are at a higher risk of mental health problems, such as stress, depression, and anxiety disorders. Somatic symptoms have always been described in various forms and often with interchangeable terms, all of which recognize the interaction between the mind and the body of an individual. The DSM-5 *Somatic Symptom Disorder* emphasizes diagnosis on the basis of positive

symptoms and signs (distressing somatic symptoms plus abnormal thoughts, feelings, and behaviors in response to these symptoms) rather than the absence of a medical explanation for somatic symptoms. A distinctive characteristic of many individuals with somatic symptom disorders is not the somatic symptoms per se, but the way they present and interpret them (American Psychiatric Association, 2013).

Kim and Lecavalier (2021) found a higher chance of dying at a young age in mothers of children with autism. Qualitative data also show that parenting a child with autism is demanding and affects the caregiver's health-related QoL negatively (Rinaldo, Anagnostou, Georgiades, Ayub, Nicolson, & Kelley, 2021). In addition to these health problems, caregivers may also experience many challenges because of the care procedures, such as problems combining care with other daily activities or relational problems with the child they care for (Kim & Lecavalier, 2021). Kakabraee, Saleh, Afrooz, and Lavasani (2016) found that 56% of parents of autistic children experience physical symptoms and anxiety. Furthermore, 85% of these parents do not feel satisfied with their marital life (Hoseinnejad, Chopaniyan, Sarvi Moghanlo, Rostami, & Dadkhah, 2020). The need to pay attention to this issue becomes more prominent when we know that parents as caregivers have other responsibilities such as work activities and taking care of routine life activities, and that the occurrence of psychological problems in parents will be a heavy burden. Considering the importance of paying attention to the physical and mental health of parents of children with and without autism, this study was conducted with the aim to compare mental health and somatic symptoms in parents of children with and without autism.

## Methods

The study data were obtained from parents referred to an urban, outpatient autism specialty clinic located in Tehran, Iran. Autism evaluation was conducted between the years 2020 and 2021. The studied clinic provides medical, psychological, speech/language, occupational, and social work services. A primary goal of the clinic is to diagnose, monitor, and treat ASD.

This casual-comparative study was extracted from a comprehensive study in Tehran University of Medical Sciences (Somatic Research Center), Iran. The study participants included 80 individuals (40 parents of autistic children and 40 parents of children without autism) selected through random sampling method based on the following formula.

$$X1=3.8, X2=3.2, S1=1.5, S2=1.2, Za=1.96, Zb=0.84, n=85$$

$$n_1 = n_2 = \frac{(S_1^2 + S_2^2)(Z_{1-\frac{\alpha}{2}} + Z_{1-\beta})^2}{(\bar{X}_1 - \bar{X}_2)^2}$$

The inclusion criteria for the families of parents of children with and without autism included 33 to 65 years of age, literacy, absence of serious psychiatric and neurological diseases, and lack of any disability. The exclusion criteria for the two groups included unwillingness to continue participation and failure to respond to at least 20% of the items in each questionnaire.

## Measuring tools

### *Demographic and disability information questionnaire*

*Patient Health Questionnaire-15:* The Patient Health Questionnaire-15 (PHQ-15) was developed by Spitzer (2002). Its items include the somatization disorder/somatic

symptoms of the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV). The participants were asked to rate the severity of 15 symptoms as 0 ("not bothered at all"), 1 ("a little bothered"), or 2 ("bothered a lot") for the preceding 4 weeks. Thus, the total PHQ-15 score ranges from 0 to 30, and scores of  $\geq 5$ ,  $\geq 10$ , and  $\geq 15$  represent mild, moderate, and severe somatization/somatic symptoms, respectively. The validity and reliability of the PHQ-15 are high in clinical and vocational health care settings. The Cronbach's alpha of the original English version of the PHQ has been reported within the range of 0.79-0.89 in different studies (Kroenke, Spitzer, Williams, 2002; Kroenke, Spitzer, Williams, & Lowe, 2010). In this research, the Cronbach's alpha of the PHQ-15 was 0.78.

**General Health Questionnaire:** The General Health Questionnaire-28 (GHQ-28) is currently being applied as the primary outcome measurement. The GHQ-28 asks participants to indicate how their general health has been over the past few weeks. The behavioral items are scored on a 4-point scale indicating the following frequencies of experience: "not at all", "no more than usual", "rather more than usual", and "much more than usual". The minimum score for the 28 version is 0, and the maximum is 84. Higher GHQ-28 scores indicate higher levels of distress. In the present study, the Cronbach's alpha reliability of 0.89 was calculated for this questionnaire.

**Data analysis method:** Descriptive data are presented as mean and standard deviation, and frequency distribution. Moreover, analysis of variance (ANOVA) was used to compare the mental health and somatic symptoms of people with disabilities and their families according to the type of disability, and SPSS software (version 23; IBM Corp., Armonk, NY, USA) was used for the statistical analyses.

## Results

In this study, 80 people (40 parents without children with autism and 40 parents with children with autism) participated. The age range of the participants was 35-55 years. In addition, 35 (66.3%) participants were employed and 27 (33.7%) were not employed. Descriptive statistics for the research variables are presented in table 1.

**Table 1.** Mean and standard deviation of research variables (n = 80)

Variables	Groups	Mean $\pm$ SD
Age	With autism	44.82 $\pm$ 6.09
	Without autism	44.47 $\pm$ 5.90
	Total	44.65 $\pm$ 5.96
Defects in physical symptoms	With autism	14.85 $\pm$ 3.46
	Without autism	11.80 $\pm$ 4.41
	Total	13.32 $\pm$ 4.23
Anxiety	With autism	15.40 $\pm$ 2.91
	Without autism	12.60 $\pm$ 4.17
	Total	14.00 $\pm$ 3.84
Defects in social functioning	With autism	14.80 $\pm$ 3.60
	Without autism	12.67 $\pm$ 4.18
	Total	13.74 $\pm$ 4.02
Depression	With autism	15.32 $\pm$ 2.64
	Without autism	12.90 $\pm$ 2.99
	Total	14.11 $\pm$ 3.06
General health total	With autism	60.37 $\pm$ 9.43
	Without autism	49.97 $\pm$ 12.05
	Total	55.17 $\pm$ 11.96
Somatic symptoms	With autism	14.97 $\pm$ 3.35
	Without autism	12.50 $\pm$ 3.06
	Total	13.74 $\pm$ 3.42

SD: Standard deviation

The mean and standard deviation of the research variables are presented for both groups of parents of children with and without autism in table 1. The results presented in the table show that for all of the study variables, the average of parents of children without autism was lower than the average of parents of autistic children. In order to compare the research variables between the two groups of parents, multivariate analysis of variance (MANOVA) was used. Before performing the test, its hypotheses were tested. The results of Box's M test for the similarity of the covariance matrix showed that this assumption holds ( $P = 0.061$ ,  $F = 1.616$ , and  $M = 0.030$ ). In addition, another precondition is the equality of variances of error. The results of Levene's test showed that this statics is 0.034 and 0.78 for general health and somatic symptoms, respectively.

Therefore, the results of Levene's test showed that this assumption holds for some variables, but does not hold for some others. Therefore, according to Tabachnick and Fidel (2001), when this assumption is not established, instead of Wilks' Lambda effect, Pillai's effect should be reported. Therefore, the results of MANOVA showed a significant difference in the linear composition of the research variables according to the group ( $P = 0.0005$ ,  $F = 7.231$ , and Pillai's  $V = 0.328$ ). The results of MANOVA are presented in table 2.

The results presented in table 3 show significant differences between the two groups of parents in terms of the scores of all dimensions of mental health and its total score. Moreover, in the somatic symptoms variable, this difference between the groups was significant. Based on the descriptive findings, it can be concluded that the group of parents of children without autism have higher general health and have reported fewer psychological symptoms ( $P < 0.0001$ ).

## Discussion

This study was performed with the aim to determine the mental health status and somatic symptoms of the parents of children with and without autism. To the best of our knowledge, our study is the first study to assess and compare the mental health status and somatic symptoms of the parents of children with and without autism. The results of our study showed that mental health indicators and somatic symptoms are worse in parents of autistic children than parents of children without autism. These results are consistent with those of previous studies (Conner, White, Scahill, & Mazefsky, 2020; Guner et al., 2021; Licinio & Wong, 2021).

The results of the present study showed that the mental health of parents of children with autism in the physical dimensions, anxiety, depression, and social functioning is lower than the other group. Anxiety is recognized as an underlying cause of mental disorders in parents of children with autism, and in many other disabilities. Anxiety weakens the immune system and deteriorates the physical health. With the deterioration of physical and mental health, parents report more and more deterioration.

**Table 2.** Results of multivariate analysis of variance in the comparison of the research variables between the two groups of parents

Effects	Value	F	df hypothesis	df error	P-value
Pillai's Trace	0.328	7.231	5	74	0.0005
Wilks' Lambda	0.672	7.231	5	74	0.0005
Hotelling's Trace	0.480	7.231	5	74	0.0005
Roy's Largest Root	0.489	7.231	5	74	0.0005

df: Degree of freedom

**Table 3.** Results of the effects between subjects on the scores of research variables in the two groups of parents with and without children with autism

Variables	SS	df	MS	F	P-value
Defects in physical symptoms	186.050	1	186.050	11.842	0.001
Anxiety	156.800	1	156.800	12.095	0.001
Defects in social functioning	90.312	1	90.312	5.944	0.017
Depression	117.612	1	117.612	14.740	0.0005
General health total	2163.200	1	2163.200	18.476	0.0005
Somatic symptoms	122.513	1	122.513	11.901	0.001

SS: Sum of squares; df: Degree of freedom; MS: Mean of squares

Clearly, parents worldwide are concerned about how to support their children best under these difficult conditions (Bellomo, Prasad, Munzer, & Laventhal, 2020; Liu, Bao, Huang, Shi, & Lu, 2020). Autism has negatively affected the mental health of parents with autistic children. Many factors play a role in increasing the stress levels of parents, and stress in turn may lead to different problems. Nevertheless, it is possible for children with autism to continue their lives in a healthy way with mentally healthy parents.

Another factor emphasized by researchers in parents of autistic children is somatic symptoms. This syndrome chronically affects the general health of parents over time. It was concluded that parents of children with autism had difficulty with their children being at home all day long and financial difficulties as they had to quit their jobs. The parents were also able to devote less time to themselves during this process, and their stress and anxiety levels increased (Feeney & Burke, 2021). Therefore, taking care of an autistic person disrupts all aspects of a parent's lifestyle. Sleep problems, anxiety, loneliness, and panic attacks are some of the problems that these parents complain about. In fact, the lifestyle of this group of parents is different from that of parents of children without autism, and all life plans of this group of parents has to be designed according to the needs of their child (Samanta, Mishra, Panigrahi, Mishra, Senapati, & Ravan, 2020). Emotion regulation is another factor that affects parents (Conner et al., 2020) and lack of emotion regulation leads to somatic problems and problems such as sleep disorders, migraines, severe rumination, and mood swings (Tajik-Parvinchi, Farmus, Cribbie, Albaum, & Weiss, 2020).

It is suggested that when face-to-face services are not possible, governments and relevant institutions provide support for parents of children with ASD, and institutions that provide support work to improve the quality of the support they provide. In this process, the investigation of new ways such as online health monitoring, online diagnosis systems, support groups for children and parents, increased telehealth services, teletherapies, and e-health support are recommended. Additionally, after the restrictions imposed by the pandemic are removed, it is important to support children with ASD and their parents in getting reaccustomed to their social lives. Support services, such as counseling and helplines, can be created to help parents share their concerns and receive assistance in dealing with specific situations. Parents should be evaluated in terms of mental health, and professional help should be provided for individuals who need support (Yılmaz, Azak, & Sahin, 2021).

Our study adds to the existing literature on mental health in parents of autistic children. A limitation of the present study is the cross-sectional nature of our study. Another limitation is the small sample size which reduces the potentiality of data generalizability. In addition, using other instruments along with questionnaires can increase the validity of the results. Moreover, although our analyses showed some



reasons for the important role of autism, we note that these results should always be evaluated using a longitudinal design to evaluate the cause and effect relationships. Furthermore, future researchers should consider applying a longitudinal design, using more valid sampling methods, and focusing on other statistical populations to further investigate these findings. Moreover, the use of other measurement instruments for the investigation of additional effects of autism should be considered in future studies.

## Conclusion

Our findings clearly demonstrate that somatic symptoms and mental health issues are higher in parents of autistic children than those of children without autism. The need to pay attention to this issue becomes more apparent when parents play a decisive role in the whole family and their mental health affects the health of the whole family. Overall, the findings of this study confirm the results of previous studies on parental health status. In recent years, attention to the services provided to this group of families has been a priority of health management programs.

## Conflict of Interests

Authors have no conflict of interests.

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