

Comparison of parental stress among mothers and fathers of children with autistic spectrum disorder in Iran

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ABSTRACT

Background: Most of the studies about parenting stress among parents of children with autistic spectrum disorder (ASD) have been conducted in western societies. The objective of this research, conducted in Iran, is to evaluate the parenting stress among fathers and mothers of children with ASD and find the correlation between severity of the disorder in children and the level of parental stress.

Materials and Methods: Participants included 42 couples having children aged between 2 and 12 diagnosed with ASD based on Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria. The diagnosis was made by two child and adolescent psychiatrists. Demographic information of the participants was collected using a questionnaire. The severity of pervasive developmental disorder in children was determined based on Childhood Autism Rating Scale (CARS); stress of parents was measured using Parenting Stress Index (PSI). Collected information was analyzed by the SPSS (version 16) software.

Results: Evaluation of subscales in participants' data showed a positive correlation coefficient between the PSI-parent domain and Childhood Autism Rating Scale-Parent form CARS-P rating ($r = 0.339$, $P = 0.028$) and also between the total stress index and CARS-P rating ($r = 0.333$, $P = 0.031$) for fathers. It is thus suggested that fathers of children with more severe developmental disorders experience more stress. The results showed significant differences between fathers and mothers in the three PSI subscales including PSI-child domain score ($P < 0.005$), PSI-parent domain score ($P < 0.005$), and the total stress index ($P < 0.005$). Mothers had significantly more stress than fathers.

Conclusions: These findings show that parents with ASD children have many emotional needs which should be considered in planning the effective treatment strategies for their children.

Key words: Autism spectrum disorder, fathers, mothers, parental stress, pervasive developmental disorders

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INTRODUCTION

Autistic spectrum disorder (ASD) is seen in all races, cultures, and societies.^[1] ASDs are also known as pervasive developmental disorders (PDDs). In Diagnostic and Statistical Manual-Text Revised (DSM-IV-TR), PDDs included autism, Asperger's, PDD-not otherwise specified (PDD-NOS), disintegrative disorder, and Rett's disorder. But in the new classification of Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), autism, PDD-NOS, Asperger's, and disintegrative disorder are all named as autism spectrum disorders (ASDs).^[2] Children with ASD have fundamental impairment of communication and social interactions. They also have restricted pattern of interests and stereotyped movements. They might also have developmental delays and intellectual disabilities, in addition to difficulties in processing social and emotional information and expressing their emotion. In sum, the disorder results in developmental and functional deficits.^[3]

Having children naturally changes the family function. Parental role could be a source of stress for many parents. Parenting a child with autistic disorder is expected to cause an enduring stress and is a demanding responsibility for the parents.^[4] Several studies have reported higher level of stress among mothers of children with autism.^[5-10] In comparison to parents of normal children, parents of autistic children show an inclination to report higher family stress, and they experience severe physical and psychological problems.^[6] The enduring stress eventually shows in the form of various psychological problems such as depression, anxiety, lack of satisfaction in life, and sleep disorders.^[11-13] These problems not only lead to parents having an anxious and sad life, but also decrease the effect of early educational and therapeutic interventions for autistic children.^[14] These parents need to be evaluated for psychological problems, and they need to have a strong social support network. Perceived social support network can increase the feeling of satisfaction and competence as a parent.^[15]

In Iran, as an eastern society, mothers are mainly responsible for raising children at home. Mothers are more concerned than fathers about the psychological and behavioral problems of autistic children, and they get the most referrals to specialists. Although mothers historically have been the primary caregivers of children in Iran, the importance of the role of fathers belonging to younger generation in Iran and the necessity of their involvement in the process of assessment and treatment of children with ASD are clinically obvious. In spite of the increased recognition of the fact that both mothers and fathers have significant challenges in bringing up a child with ASD, even in the western countries, very few studies have compared the profile of their stress.^[16]

Most of the studies about parental stress among parents of children with ASD have been conducted in the western societies. Cultural issues might be important factors in parents' reactions and parenting stress. Since the stress experienced by fathers and mothers of children with ASD can affect their ability to effectively raise and respond to the needs of these children, recognizing the differences in parental stress among the mothers and fathers of children with ASD and their related factors could help the mental health professionals to plan and implement effective interventions for reducing these stresses and help these parents. In fact, obtaining more information about the thoughts, feelings, and experiences of such parents would play a special role in designing more effective and specific interventions for both mothers and fathers of children with ASD.^[10] In addition, research shows that one of the most significant sources of parental stress among parents of children with ASD is lack of adequate support from professionals.^[17] Since there exists no systematic patient referral system in Iran, going to a healthcare center and choosing a doctor is related to the

level of awareness in families. Therefore, many patients do not receive appropriate assessment and treatment, and this can lead to much more frustration after a long period of time. Also, past theories about the psychogenic cause of ASD, such as refrigerator mothers, have caused a climate of distrust and suspicion in the relationship between parents and mental health professionals such as nurses who work in this field. Findings of another study suggest that parents of these children perceived the professionals as being controlling and judgmental.^[18] Therefore, knowing the nature and profile of parental stress among the mothers and fathers of children with ASD may help the professionals such as mental health nurses to have more effective communication with these parents and be more supportive.

Considering these issues, this research aims to evaluate the parental stress among the fathers and mothers of children with ASD and find the relationship between the severity of the disorder in children and the level of parental stress.

MATERIALS AND METHODS

Participants

This research aimed at better understanding and increase in scientific and practical information regarding ASD was carried out for the first time in Iran. Forty-two parents of children aged between 2 and 12 diagnosed with ASD based on the new approach of DSM-5 were selected. Based on DSM-IV-TR criteria, the sample consisted of two groups; the first group included 21 couples with autistic children and the second group consisted of 21 couples whose children were diagnosed with PDD-NOS. Diagnoses were made by a child and adolescent psychiatrist and was confirmed by another one. Participants were selected by convenient sampling method from two educational-therapeutic centers, namely "Noore Hedayat" (private center) and "Tabasom" (public center), in Mashhad over a period of 12 months from the summer of 2011 to the summer of 2012.

Parents who agreed to take part in the research signed the informed consents before participating in the study. The protocol of research was approved by the ethical committee of Mashhad University of Medical Sciences.

Demographic information of the participants was collected using a questionnaire. The severity of PDD in children was determined based on Childhood Autism Rating Scale (CARS) and the stress of parents was measured using Parenting Stress Index (PSI).

Assessment tools

Childhood autism rating scale

This scale is used to determine the severity of ASD. Based on the final score, patients are classified as follows: 15–30

shows no autism, 30–37 represents mild to moderate autistic disorder, and 37–60 represents severe autistic disorder.^[19,20]

Parenting stress index

The PSI is a 120-item self-report (filled up by parents) questionnaire. Parents rate their agreement or disagreement on a 4-point scale to the questions which investigate parents' feelings about their children (e.g. "I worry" or "I have difficulty leaving the house because of my child"). Multiple-choice questions assess total stress and three other important domains:

- Child domain: Represents stress attributed to the child
- Parental domain: Represents stress attributed to parents
- Life stress index: Represents stressful dimensions in the life of parents.

The scores of child domain for children, parental domain, life stress index, and total stress were registered separately. For the child domain, parental domain, and total stress scores, the percentile values were calculated based on the table of percentiles standardized according to children's age (presented by Abidin), and the resulting percentile values were used in statistical calculations, instead of index scores.^[21,22]

Wechsler intelligence scale-fourth edition

The current version, the Wechsler Intelligence Scale-Fourth Edition (WISC-IV), was designed in 2003. The WISC-IV is divided into 15 subtests, 10 of which formed part of the previous WISC-III. The five new subtests include three core tests (picture concepts, letter-number sequencing, and matrix reasoning) and two supplemental tests (cancellation and word reasoning). The WISC-IV generates a Full Scale IQ (FSIQ) which represents overall cognitive ability; the four other composite scores are Verbal Comprehension index (VCI), Perceptual Reasoning Index (PRI), Processing Speed Index (PSI), and Working Memory Index (WMI). Some studies were conducted to examine the scale's reliability and validity in Iran. There was a significant correlation between WISC-IV, Raven's Progressive Matrices, and WISC-II.^[23,24]

Table 2: Comparison of parents' education

Variable name	Educational level (years)	Autistic group		PDD-NOS group		Results of Mann-Whitney test
		Number	Percent	Number	Percent	
Fathers' education level	<6	2	9.5	5	23.8	0.220
	6-12	9	42.9	9	42.9	
	>12	10	47.6	7	33.3	
Mothers' education level	<6	3	14.3	3	14.3	1.000
	6-12	12	57.1	12	57.1	
	>12	6	28.6	6	28.6	

PDD-NOS: Pervasive developmental disorders-Not otherwise specified

Statistical analysis

The collected information was analyzed by the SPSS (version 16) software. Descriptive statistics were presented as tables, graphs, and indexes. For qualitative variables, Pearson's Chi-square test was performed and the results of two groups were compared. Correlation test was conducted between variables, subscale scores of the PSI, scores of CARS, and the age of children. If a correlation existed, appropriate correlational relationships, with the assistance of linear regression, were calculated and presented. Kolmogorov–Smirnov test was used for quantitative variables. Variables with normal distribution and non-normal distribution were determined. For normally distributed quantitative variables in both groups, *t*-test was performed, and for non-normally distributed quantitative variables in the two groups, square test was performed. Based on DSM-5 criteria for data analysis about the correlation between parenting stress and severity of disorder, we considered all participants as subjects with ASD.

RESULTS

Forty-two couples with ASD children aged between 2 and 12 were enrolled in the study. All participants were from Mashhad. No participant was excluded during the study.

Variables including age, sex, intellectual level, and history of seizure for children, as well as age, level of education, and the number of children for parents were compared between the two groups of participants, and they showed no significant difference. Age and education level of parents

Table 1: Comparison of parents' age

Variable name	Autistic group		PDD-NOS group		Results of Mann-Whitney test
	Mean	SD	Mean	SD	
Fathers' age (years)	35.5	4.4	39.3	10.8	0.544
Mothers' age (years)	31.7	5.0	33.0	8.2	0.559

PDD-NOS: Pervasive developmental disorders-Not otherwise specified, SD: Standard deviation

are shown in Tables 1 and 2, respectively. Intellectual level and history of seizure in all children have been presented in Table 3.

Correlation between the PSI subscales and those of the CARS in all participants was evaluated and positive correlation coefficients were obtained between the PSI-parent domain and CARS score ($r = 0.339$, $P = 0.028$) and also between the total stress index and CARS rating ($r = 0.333$, $P = 0.031$, Pearson's rank test) [Table 4] for fathers. It is thus suggested that fathers of children with more severe developmental disorders experience more stress.

In order to compare parental stress between fathers and mothers, Mann-Whitney test was used, as the data results had non-normal distribution.

The results showed significant differences between fathers and mothers in the three PSI subscales including PSI-child domain score (87.4 ± 14.6 vs. 95.0 ± 7.2 , respectively, $P < 0.005$), PSI-parent domain score (73.7 ± 20.2 vs. 87.0 ± 20.1 , respectively, $P < 0.005$), and the total stress index (83.1 ± 17.8 vs. 93.1 ± 22.4 , respectively, $P < 0.005$). As a result, mothers had significantly more stress than fathers [Table 5].

DISCUSSION

Parenting stress has been investigated in some studies in the western countries, but has not been studied in Iran. Also, many studies have focused only on mothers of children with ASD and have not examined the parenting stress among the fathers of these children. In the present study, parenting stress among the mothers and fathers of children with ASD and its association with the severity of ASD were evaluated.

Positive correlation coefficients were obtained between the PSI-parent domain score and CARS rating score and also between the total stress index and CARS rating score for fathers. It is thus suggested that fathers of children with more severe developmental disorders experience more stress.

Mothers showed significantly higher scores in the three PSI subscales including PSI-child domain score, PSI-parent domain score, and total stress index than fathers. In general, parenting stress indexes in fathers were lower than those in mothers. It was not surprising, as usually in Iranian culture, mothers are more involved than fathers in bringing up their children.^[25] This finding was also reported by Hastings *et al.*^[26]

Taken together, it seems that the severity of ASD is correlated with the parenting stress indexes of fathers, since this relation did not reach a significant level for mothers.

Table 3: IQ and history of seizure in all participants

	Variable name	Number	Percent
IQ	IQ>70	16	38 0.0
	50≤IQ≤70	8	19.0
	IQ<50	18	43
History of seizure	Positive	10	23.8
	Négative	32	76.2

IQ: Intelligence Quotient

Table 4: Correlations between the PSI quantitative variables and the CARS score of all participants

Variable	Correlation	P value
Fathers		
PSI-child domain score	0.293	0.059
PSI-parent domain score	0.339	0.028
Life stress index	-0.102	0.519
Total stress index	0.333	0.031
Mothers		
PSI-child domain score	0.090	0.572
PSI-parent domain score	0.216	0.169
Life stress index	0.007	0.967
Total stress index	0.230	0.144

PSI: Parenting stress index, CARS: Childhood autism rating scale

Table 5: Comparison of the PSI subscales between fathers and mothers

Variable name	Fathers		Mothers		Results of Mann-Whitney test
	Mean	SD	Mean	SD	
PSI-child domain	87.4	14.6	95.0	7.2	0.003
PSI-parent domain	73.7	20.2	87.0	20.1	0.000
Life stress index	8.9	4.9	8.6	6.9	0.813
Total stress index	83.1	17.8	93.1	11.4	0.000

PSI: Parenting stress index, SD: Standard deviation

So, mothers had more parenting stress than fathers and their stress did not have a significant correlation with the severity of symptoms. It might be because of more emotional reaction of mothers to the diagnosis of ASD in their children. However, the parenting stress of fathers is significantly correlated to the severity of disorder in children. A transactional model proposed by Hastings in 2002 could explain this correlation. According to this model, the severity of child's problems leads to more parenting stress, which in turn interferes with appropriate parenting strategies and results in more child behavior problems.^[27] These results are consistent with several other studies. For example, in a study by Tobing *et al.*, the total score of PSI was significantly different between the two groups of parents of autistic children and those of PDD-NOS children, although in that study, only mothers' problems were investigated.^[21] In another study, Pottie *et al.* evaluated parents of children with autism. They showed a significant correlation between

the severity of disruptive behaviors of children and parental stress or negative mood.^[28] Concurrently, Benson *et al.* showed positive correlations between disruptive behaviors of children and parental depression.^[29,30] Similar results were also obtained in other studies.^[16,17,25] On the other hand, a few studies like those of Phetrasuwan *et al.* and Phleps *et al.* did not show any significant correlation between child characteristics and parenting stress.^[10,31]

It should be noted that all the studies mentioned above evaluated the correlation between the severity of children's behaviors and the parenting stress in general indexes. In this study, however, we evaluated all PSI indexes and subscales.

This study had a few limitations like its small sample size. Furthermore, this was a cross-sectional study, and thus, we did not evaluate the longitudinal process of parenting stress among parents of children with ASD. Future studies are needed to propose a more complete model for related factors of parental stress among parents of ASD children.

To conclude, the findings of this study revealed that mothers of children with ASD had higher levels of parental stress than fathers. The amount of stress in fathers was correlated to the severity of disorder in the child. So, fathers whose children had more severe disorder reported higher levels of parenting stress. These findings, consistent with several previous studies, show that parents with ASD children have many emotional needs which should be considered in planning the effective treatment strategies for these children and their families. Knowing the nature of parental stress in parents with ASD children may help the mental health professionals such as nurses- who work with these children and their families- to provide more support for these parents. For example, considering the higher level of stress in fathers of children with more severe disorders, inclusion and assessment of these fathers in mental health programs seems necessary, although it seems that all mothers with different degrees of severity of disorders in their children need more support and intervention to reduce their stress level.

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