

## PARENTAL STRESS AND AUTISM: DIFFERENCES IN PERCEIVED STRESS AND COPING BEHAVIOR

NELOFAR KIRAN RAUF, M. ANIS-UL-HAQUE, RAIHA AFTAB

National Institute of Psychology (NIP), Quaid-i-Azam University, Islamabad

Submitted: October 28, 2016

Accepted: February 28, 2017

**CORRESPONDENCE: NELOFAR KIRAN RAUF**, E-mail: nelofar@nip.edu.pk

### ABSTRACT

#### OBJECTIVE

To study perceived stress and coping behaviors of parents of children with Autism.

#### STUDY DESIGN

Cross sectional study

#### PLACE AND DURATION OF THE STUDY

The data was collected from eight different special education schools situated in Rawalpindi and Islamabad between June 2015 to February 2016.

#### SUBJECTS AND METHODS

Parents, consisting of (n=103) mothers and (n=83) fathers of children with autism were included in the study. Parental stress was measured using Urdu version of questionnaire on resources and stress and coping behaviors were measured using Urdu version of family crisis oriented personal evaluation scales. Children with autism were diagnosed using childhood autism rating scale-2.

#### RESULTS

Mothers perceived more stress related to family problem and they were more pessimistic whereas fathers perceived more stress related to lack of available services for their children with autism. Fathers of children with autism perceived more stress as compared with mothers when the child was severely autistic. Employing more coping behaviors e.g. acquiring social support both formal and informal, reframing and more use of passive appraisal helped reduce stress in both mothers and fathers of children with autism. It was also found that spiritual coping was more effective for mothers than fathers of children with autism.

#### CONCLUSION

Mothers perceived more stress as compare with fathers on various dimensions of stress. However, when the child had severe autism fathers perceived more stress as compared with mothers of children with Autism. More use of coping behaviors led to less stress in both parents.

#### KEY WORDS

Autism, Mother/father's stress, Coping behaviors.

### INTRODUCTION

Individuals with autism show marked impaired in social interaction, restricted, and repetitive behaviour and communication. It can be detected by the age of 3 years<sup>1</sup>. Developing world has recently been open to the elements related to awareness, research and documentation on Autism that has existed in the developed world for decades. In Pakistan exact number of children having Autistic disorder is not available. Few small scale studies do report the prevalence of autistic children entering special education setup, however exact number is still not know<sup>2,3</sup>

In Pakistan Autism is a newly conceived phenomenon and families are not clear about what autism really means.<sup>4</sup> It's unique characteristics and unclear etiology creates stress for the families. Things become even more difficult when there is lack of proper educational and professional services for children with autistic disorder. Professionals in the field have various misconceptions regarding salient features of autism, which is one of the barrier in improving health and well-being of children with autistic disorder.<sup>5</sup> These factor are the sources of stress for parents of children with Autism. There are several negative consequences that are emerging from elevated stress in parents, beside, their own poor physical health<sup>6</sup> and psychological health<sup>7</sup>. It is also associated with the child's poor treatment outcomes, more behavior problem and the child development.<sup>8</sup>

Coping is a universal phenomenon and exhibit in cognitive and behavioral forms<sup>9</sup>. Research evidence depicts that to overcome the stress parents use coping strategies as mechanism to adapt to stressors associated with raising a child with autistic disorder<sup>10</sup>. Recent intervention plans are geared towards strengthening and maintaining family resources to protect the parents from demands of stressful encounters and reduce the sources of stress<sup>11,12</sup>. Therefore it is very essential to investigate stressors in the life of parents and how they cope with stressors. In a Pakistani cultural environment where research related to autistic disorder has received little attention, this research will amenable for future researchers in areas of intervention and prevention efforts for families. The study aims to investigate a) differences between perceived stress in mothers and fathers of children with autism b) differences in mothers' and fathers' stress with reference to autism symptom severity (Minimal to no symptoms, Mild to moderate symptoms and Severe Symptoms).c) relationship between stress and coping behaviors of parents with autistic children.

## SUBJECTS AND METHODS

## Participants

Parents of children with Autism were selected via using non probability purposive sampling technique. Parents of children between age ranged 6 to 12 years fulfilling the diagnosis criteria of autistic disorder on childhood autism rating scale 2 were included. Parents of children with any co- morbid disorders like epilepsy, genetic disorders, intellectual disability or global delays were not included in the present study.

## Instruments

Child hood autism rating scale -2 (CARS-2) was used to diagnose children with autism.<sup>13</sup> It is a diagnostic assessment tool that rates children on a scale from one to four on various dimensions, ranging from normal to severe and yields a composite score ranging from non-autistic to mildly autistic, moderately autistic, or severely autistic. Paternal stress was measured by Urdu version of Questionnaire on resources and Stress (QRS)<sup>14</sup>, it consist of 51 items that measure stress in five different dimensions that are "parent and family problems", "pessimism", "financial stress", "stress due to lack of Services" and "Stress due to lack of awareness". The items on QRS were rated on five point likert scale and high score is indicative of high stress. Urdu version of "The Family Crisis Oriented Personal Evaluation Scales" (FCOPES) was used to assess coping behaviors.<sup>15</sup> It consist of five subscales Acquiring Social Support, Reframing, Seeking Spiritual Support, Mobilizing Family Support and Passive Appraisal. It was rated on five point likert scale. High score on FCOPES is indicative of more use of coping behaviors to overcome stress.

## Procedure

Initially telephonic consent was taken from parents. Through initial screening (n=110) children were identified as the probable cases of autistic disorder. Each child was observed by two independent observers and later the diagnosis was confirmed by a clinical psychologist. At this stage, written consent was taken from parents of children with Autism, demographic sheet was filled in order to get back ground information. After screening the child on CARS-2, information was gathered regarding their stressors and coping behaviors. The data was analyzed using SPSS (statistical package for social sciences) VS 20.

## RESULTS

The sample characteristics depicted that 50% of the fathers and 70 % mothers fall in age range from 32 to 42 years. A good number of the mothers in the present sample were house wives (67%). 61.8 % parents living in nuclear family setups, whereas 38.2 % were residing in joint family setup. 60.4% of the sample was earning between 5,000 to 30,000 Pakistani rupees per month.

Initially the scales were subjected to reliability testing and it was found the inter-rater reliability of two independent observers on CARS-2 was excellent, Kappa = 0.89 at 95% CI (0.79, 1.00). The alpha reliability coefficient for QRS-F was .91 and FCOPES was .87, hence providing evidence that the instruments are reliable tools to be used with the present sample.

Table 1

Differences between mothers and fathers on various dimensions of stress scale.

	Mother		Father		p
	Mean	Standard deviation	Mean	Standard deviation	
	n = 103		n = 83		
Parent and family problems	69.23	17.45	59.56	16.95	.00
Pessimism	28.89	8.64	26.37	8.24	.04
Financial stress	11.44	4.74	11.14	4.36	.65
Stress due to lack of services	22.59	6.16	25.68	6.30	.00
Stress due to lack of awareness	12.93	3.07	12.87	3.17	.90
Total score Stress	145.10	31.04	135.64	28.38	.03

Independent sample t test was used to analyze the data. Mothers (M = 145.10, SD = 31.04) of children with autistic disorder were more stressed as compared with fathers (M = 135.64, SD = 28.38). Further analysis revealed that mothers perceived more stress related to "Parent and family problems" (M = 69.23, SD = 17.45) and "Pessimism" (M = 28.89, SD = 8.64) as compare with fathers (M = 59.56, SD = 16.95), (M = 26.37, SD = 8.24). Fathers of children with autistic disorder perceived more stress (M = 25.68, SD = 6.30) with reference to unavailability of services for their autistic children as compare with mothers (M=22.59, SD=6.16).

Table 2

Differences in level of stress experienced by mothers and father in relationship to severity of symptoms in children with autism

	Categories of Autism						F	Turkey post hoc
	Minimal to no symptoms		Mild to moderate symptoms		Severe Symptoms			
	(n=10)		(n=52)		(n= 48)			
	Mean	SD	Mean	SD	Mean	SD		
Mother stress	109.70	18.33	138.77	26.68	151.21	25.0	16.48	3>2>1
Father Stress	102.37	20.1	128.10	23.7	159.96	28.85	17.13	3>2>1

df=80, \* \*\*p &lt; 0.01

Results showed that mother's stress was high when the child had severe symptoms of autism (M = 159.96, SD = 28.85) as compare with mild to moderate symptoms (M = 138.77, SD = 26.68) and minimal to no symptoms (M = 109.70, SD = 18.33) Tukey post-hoc analysis revealed that stress in mothers of children with autism was more when their children suffer from severe autism symptom as compare with mild and moderate. Father's stress was high when the child had severe symptoms of autism (M = 151.21, SD = 25.0) as compare with mild to moderate symptoms (M = 128.10, SD = 23.7) and minimal to no symptoms (M = 102.37, SD = 20.1) and Tukey post-hoc analysis revealed that stress in fathers of children with autism was more when their children suffer from severe autism symptom as compare with mild and moderate. It was concluded that both mother and father perceived stress related to their child symptom severity group but fathers of children with severe autism perceived more stress as compare with mothers, when the child is severely autistic.



**Table 3**  
Relationship between stress and coping behaviors in parents of children with Autism

Coping behaviors	Fathers Stress	Mothers stress
Acquiring Social Support	-.24*	-.28**
Reframing	-.28*	-.34**
Seeking Spiritual Support	-.18	-.32**
Mobilizing Family to Acquire and Accept Help	-.24*	-.32**
Passive Appraisal	-.23*	-.39**
Coping behaviors	-.31**	-.42**

\*\* $p < .01$ , \* $p < .05$

## DISCUSSION

In the present study stress was high in mothers of children with autism as compare with their fathers.<sup>19, 20, 21</sup> Moreover, mothers had more stress related to their family problems and they are more pessimistic about their children future as compare with fathers, this may be because mothers are more involved in child rearing practices and interact more within family<sup>22</sup> Fathers of children with autism perceived more stress related to lack of services for children as compared with the mothers. In Pakistan unavailability of proper services related to screening, diagnosis, early intervention, educational facilitation etc is one of the major source of stress especially for fathers of children with autism.

In the present study it was found that impact of symptom severity of autism was more on father stress as compare with mother stress; previous research supported this.<sup>23</sup> It was identified in the past literature that fathers do feel difficulty in communicating with children with autism and certain behaviors of child do cause stress in fathers.<sup>24</sup> In previous research fathers of children with autism are often taken as invisible parents and researches are usually designed to capture concept of maternal care giving.<sup>25</sup>

Except for "Seeking Spiritual Support" all others dimensions of coping behaviors (acquiring social support; reframing; mobilizing family to acquire and accept help and passive appraisal) showed significant negative relationship with stress in fathers of children with autism. Moreover, there exists a significant negative relationship between different dimensions of coping behaviors and mother stress. More use of coping behaviors leads to less stress in mothers<sup>16</sup> as well as fathers of children with Autism<sup>17</sup>. Coping is an important interventional tool that can help reduce stress related to parenting a child with autism.<sup>18</sup>

## CONCLUSION

Overall stress was high in mothers as compare with fathers of children with autism. Mothers perceived more stress in areas related to family problems and they are more pessimistic as compare with fathers, whereas fathers perceived more stress because of unavailability of services for their children with autism. Fathers of children with autism perceive more stress as compare with mothers when the child is severely autistic. Employing more family coping behaviors help to reduce stress in both mothers and fathers of children with autism. More research related to parents of children



with autistic disorder is required so that better intervention plans can be formulated that can help in better psychological health of child and both parents.

## REFERENCES

- Jin J. Screening for Autism Spectrum Disorder. *JAMA*. 2016 Feb 16;315(7):718.
- Suhail K, Zafar F. Prevalence of autism in special education schools of Lahore. *Pakistan Journal of Psychological Research*. 2008 Dec 1;23(3/4):45.
- Rauf N, Haq A, Aslam N, Anjum U. Characteristic symptoms and adaptive behaviors of children with autism. *Journal of the College of Physicians and Surgeons*. 2014 Sep; 22 (9): 658-662.
- Imran N, Chaudry MR, Azeem MW, Bhatti MR, Choudhary ZI, Cheema MA. A survey of Autism knowledge and attitudes among the healthcare professionals in Lahore, Pakistan. *BMC pediatrics*. 2011 Nov 22; 11(1): 1
- Rahbar MH, Ibrahim K, Assassi P. Knowledge and attitude of general practitioners regarding autism in Karachi, Pakistan. *Journal of autism and developmental disorders*. 2011 Apr 1; 41(4): 465-74.
- Smith LE, Seltzer MM, Tager-Flusberg H, Greenberg JS, Carter AS. A comparative analysis of well-being and coping among mothers of toddlers and mothers of adolescents with ASD. *Journal of autism and developmental disorders*. 2008 May 1; 38(5): 876-89.
- Ablotsky B, Bradshaw CP, Anderson C, Law P. Involvement in bullying among children with Autism Spectrum Disorders: Parents' perspectives on the influence of school factors. *Behavioral Disorders*. 2012 May 1: 179-91.
- Osborne LA, Reed P. Stress and self-perceived parenting behaviors of parents of children with autistic spectrum conditions. *Research in Autism Spectrum Disorders*. 2010 Sep 30; 4(3): 405-14.
- McCubbin HI. Integrating coping behavior in family stress theory. *Journal of Marriage and the Family*. 1979 May 1: 237-44.
- Zablotsky B, Bradshaw CP, Stuart EA. The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *Journal of autism and developmental disorders*. 2013 Jun 1; 43(6): 1380-93.
- Willis K, Timmons L, Pruitt M, Schneider HL, Alessandri M, Ekas NV. The Relationship Between Optimism, Coping, and Depressive Symptoms in Hispanic Mothers and Fathers of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. 2016 Mar 26: 1-4.
- Lai WW, Goh TJ, Oei TP, Sung M. Coping and well-being in parents of children with autism spectrum disorders (ASD). *Journal of autism and developmental disorders*. 2015 Aug 1; 45(8): 2582-93.
- Schopler E, Van Bourgondien M, Wellman J, Love S. *Childhood Autism Rating Scale—Second edition (CARS2): Manual*. Los Angeles: Western Psychological Services. 2010.
- Friedrich WN, Greenberg MT, Cnic K. A short-form of the Questionnaire on Resources and Stress. *American journal of mental deficiency*. 1983 Jul.
- McCubbin HI, Olson D, Larsen A. Family crisis oriented personal scales (F-COPES). HI McCubbin, AI Thompson, & MA McCubbin (1996). *Family assessment: Resiliency, coping and adaptation-inventories for research and practice*. 1981: 455-507.

## Journal of Pakistan Psychiatric Society

16. Zaidman-Zait A, Mirenda P, Duku E, Vaillancourt T, Smith IM, Szatmari P, Bryson S, Fombonne E, Volden J, Waddell C, Zwaigenbaum L. Impact of personal and social resources on parenting stress in mothers of children with autism spectrum disorder. *Autism: the international journal of research and practice*. 2016 Apr 18; 1362361316633033.
17. Willis K, Timmons L, Pruitt M, Schneider HL, Alessandri M, Ekas NV. The Relationship Between Optimism, Coping, and Depressive Symptoms in Hispanic Mothers and Fathers of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. 2016 Mar 26:1-4.
18. Dardas LA, Ahmad MM. Coping strategies as mediators and moderators between stress and quality of life among parents of children with autistic disorder. *Stress and Health*. 2015 Feb 1; 31(1):5-12.
19. Huang CY, Yen HC, Tseng MH, Tung LC, Chen YD, Chen KL. Impacts of autistic behaviors, emotional and behavioral problems on parenting stress in caregivers of children with autism. *Journal of autism and developmental disorders*. 2014 Jun 1; 44(6):1383-90.
20. Estes A, Olson E, Sullivan K, Greenon J, Winter J, Dawson G, Munson J. Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain and Development*. 2013 Feb 28; 35(2):133-8.
21. Lecavalier L, Leone S, Wiltz J. The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*. 2006 Mar 1; 50(3):172-83.
22. Wang P, Michaels CA, Day MS. Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. *Journal of autism and developmental disorders*. 2011 Jun 1; 41(6):783-95.
23. Rivard M, Terroux A, Parent-Boursier C, Mercier C. Determinants of stress in parents of children with autism spectrum disorders. *Journal of autism and developmental disorders*. 2014 Jul 1; 44(7):1609-20.
24. Davis NO, Carter AS. Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of autism and developmental disorders*. 2008 Aug 1; 38(7):1278-91.
25. Hayes SA, Watson SL. The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of autism and developmental disorders*. 2013 Mar 1; 43(3):629-42.

Sr. #	Author Name	Affiliation of Author	Contribution	Signature
1	Ms Nelofar Kiran Rauf	National Institute of Psychology, Islamabad	Principal investigator: conceptualization of research, research designing, implementation, article writing.	
2	Prof Dr. M. Anis-ul-Haque	National Institute of Psychology, Islamabad	Supervisor: Over all supervision of the whole research process	
3	Raiha Aftab	Manchester Institute of Education, University of Manchester, UK	Co-researcher: data collection, manuscript preparation and analysis.	