

## ORIGINAL ARTICLE

# Psychological Health of Primary Caregivers: An Association of Primary Caregiver's stress and Depression with Behavior Severity of Autistic Children

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## ABSTRACT

**Aim:** To assess the prevalence of stress and depression among primary caregivers and determine its association with the behavior severity of children with Autism.

**Study design:** Cross-sectional, analytical study using non-probability purposive sampling

**Place & duration:** The study was conducted at the department of Developmental & Behavioral Pediatrics of Children Hospital, WAPDA teaching hospital complex, and Global Institute for Autism and Special Needs, Lahore 1<sup>st</sup> March to 1<sup>st</sup> Oct 2020.

**Methodology:** Primary caregivers include the mother, father, and grandparents/siblings (n=96) of children confirmed diagnosed with Diagnostic and Statistical Manual-TR (DSM-IV), who were attending to behavior, sensory and speech therapies of their autistic children. To assess stress and depression; self-administered, structured questionnaires Parenting Stress Scale (PSS) and Beck Depression Inventory (BDI-0) were used respectively.

**Results:** The current study highlighted that, overall, mean stress score was 52.3±7.3, ranging from 36.0 to 70.0, and the depression score was 62.5%, where 25% mildly, 11.5% borderline/clinical, 16.7% moderately and 9.4% were severely depressed. Likewise, mothers 76(79.2%) are more embedded in caregiving responsibilities of their child with autism and reported more pronounced level of stress as compared to fathers (p=0.003).

**Conclusion:** The prevalence of depression was found higher than stress among primary caregivers. These study findings are crucial for Sustainable Development Goals by the United Nations (SDG-3); to ensure healthy lives and to promote the well-being of all, all ages.

**Keywords:** Stress, Depression, Parents, Autism Spectrum Disorder, Developmental Disability

## INTRODUCTION

According to American Psychiatric Association (APA), autism spectrum disorder (ASD) is defined as a heterogeneous neuro-developmental disorder mainly comprised of Asperger's syndrome, Rett's disorder, childhood disintegrative disorder, and pervasive developmental delays<sup>1</sup>. It is labeled as distinct symptomatology among children aged 2-3 years, from mild to severe; a deficit in social interaction, ineffective communication, and repetitive sensory and motor behavior pattern. In addition, ASD influences all races and social groups alike; more prevalent in males than females (4:1).<sup>2,3</sup> Ever since it came to attention in the fourth and fifth decade of the twentieth century, the prevalence of Autism has been inflation. The autism prevalence rate reached, 1:44 children with the rate increase in the United States which represents a 120% increase in diagnoses since 2002<sup>4,5</sup>.

According to the Pakistan Autism Society (PAS), there is no reliable and population-based data available in Pakistan owing to a lack of research in this particular discipline, however, the affected population is snowballing<sup>6</sup>. According to South Asian Development bodies reported 350,000 cases of ASD in Pakistan, not significantly differ from the rest of the world. These statistics affirm the findings of this study substantially in the context of Pakistan<sup>7</sup>. Moreover, despite these momentous challenges such as the scarcity of research and clinical resource centers in this eminent discipline, the picture of the treatment and management of Autism in Pakistan is more penitent than these statistics<sup>8</sup>.

Additionally, ASD is a chronic disorder, its enduring nature with no cure and attributed massive variation of symptoms among the affected population ascribed to lack of communication, social tremendous burden physically and psychologically and economically on the parents/ primary caregivers, and families<sup>9</sup>. Majority of children reported significant sensory processing issues

marked by troubles and unusual interest in responding to various environmental stimuli such as changes in the physical environment, person, and place<sup>10,11</sup>. Due to these potential challenges and looming child behavior restricting the social activities of parents and primary caregivers, high dependency in performing their routine tasks, subsequent intensifying primary caregiver's mental exhaustion, psychological burnout, stress, and depression<sup>4,12</sup>.

Certainly, there are several characteristics of children with Autism that can worsen parenting difficulties with a considerable economic impact in terms of direct (medical or treatment) and indirect (ADLs and family-related) costs, which is more eminent than asthma, diabetes, or any intellectual impairment. Consequently, ASD is a priority for the global mental health plan and WHO mental health Gap Action Program<sup>13</sup>.

Previous literature imparts validation to the fact that the excessive demands, responsibilities, and disruptive behavioral issues of autistic children are associated with an increase in the parental burden. Autism severity is denoted as hyper-irritability, seizures, dysmorphic features, and self-injurious activities. Existing literature illuminated, that parental stress has influenced by the severity of autistic symptomatology of a child<sup>14</sup>. Psychological dynamics of the primary caregiver and inevitable autistic child behavior attributes are equally interlinked to the well-being of both personalities.

In brief, stress is more pronounced when the child exhibits abstruse or aberrant behavior. Once, the psychological well-being of primary caregivers gets upset, it has detrimental effects on the primary caregivers' personalities as well as on the development of the autistic child. Likewise, it jumbles the family functioning, dissatisfied marital relationships, jealous and neglecting issues of siblings, and hindrance in pursuing outdoor activities. The study aimed to assess the level of stress and depression in the primary caregivers and to determine the association of a child's behavior severity with stress and depression levels of primary caregivers of autistic children.

Received on 13-06-2022

Accepted on 23-11-2022

## METHODOLOGY

A descriptive cross-sectional, analytical study design was used. Non-probability purposive sampling technique used for recruitment of study participants. Upon receiving ethical approval from the Ethical Review Committee and Institutional Review Board (IRB) /administrative approval from, government and non-government autism resource centers of Lahore, and data were collected within six months from 1<sup>st</sup> March to 1<sup>st</sup> Oct 2020.

The primary caregivers such as mothers/ fathers/ grandparents/siblings of the child, spending a minimum of 8 hours with the autistic child, were included from the non-government and government Autism resource centers/institutions of Lahore. An autistic child diagnosed with autism, according to *DSM-IV-TR* criteria (APA, 2004) minimum for the last 6 months and Childhood Autism Rating Scale (CARS) Autism Index (AI) Score  $\geq 30$ .<sup>15</sup>The primary caregivers with chronic illness or any psychiatric illness and those having more than one child with a disability were excluded.

After rapport building with the study participants, written informed consent was obtained. Self-administered, structured questionnaire were used and the purpose of the study was explained along with queries answered by participants. All the questionnaires were filled by the primary caregivers and no withdrawal from the study; the response rate was 100%.The first section was consisting of demographic data such as gender, marital status, education, family Type, respite care/support system of primary caregiver. The second section was the parental stress scale (PSS) to assess parental stress for primary caregivers (mother, father, grandparents / siblings).<sup>16</sup>The third section was comprised of the Beck Depression Inventory (BDI) to assess the severity of depression among the primary caregivers<sup>17</sup>.

**Statistical Analysis:** The normality of the data was checked by the Shapiro-Wilk test. The data were analyzed by using SPSS 23. Mean and Standard Deviation were calculated for the age of the child and primary caregivers; duration until the diagnosis of the condition, age at the time of diagnosis, and stress score of the primary caregivers. Frequency and percentage were given for the primary caregiver's characteristics and depression status. Independent sample t-test and ANOVA were used to compare the mean stress scores among the primary caregivers. Chi-square was used to determine the association of stress and depression in primary caregivers with CARS Index  $>30$  of Autistic children. At a 95 % confidence interval with a 5% margin of error, P-value  $\leq 0.05$  was taken as significant.

## RESULTS

Out of 96 primary caregivers, 76(79.2%) were mothers and 20(20.8%) were fathers, and others (grandparents and siblings). Table I presented that, 86(89.6%) of the Primary Caregivers were married and 10(10.4%) were unmarried. Most of the primary caregivers 53(55.2%) were receiving respite care or an informal social support system from friends and family, and 43(44.8%) did not have any kind of informal social support, they only had a formal support system or professional help. The majority 60(62.5%) of the primary caregivers lived in a joint family system, 27(28.1%) lived in

the nuclear family system and 9(9.4%) lived in the extended family system.

Table I: Socio-demographic characteristics of the primary caregivers (n= 96)

Variables	Frequency	Percent
<b>Relationship</b>		
Mothers	76	79.2%
Fathers+ Others	20	20.8%
<b>Marital Status</b>		
Married	86	89.6%
Unmarried	10	10.4%
<b>Family Type</b>		
Nuclear	27	28.1%
Extended	9	9.4%
<b>Education</b>		
M.A /Mphil	47	49.0 %
B.A	26	27.1 %
Secondary/ Vocational	23	24.0%
<b>Social Support</b>		
Yes	53	55.2%
No	43	44.8%

Table II depicted that the mean stress score of mothers was significantly higher as compared to the mean stress score of father caregivers ( $p=0.003$ ). Those caregivers who were married had also higher stress scores as compared to unmarried caregivers ( $p=0.020$ ). The primary caregivers living in the nuclear family system had significantly higher stress scores as compared to those who lived in the joint and extended family system ( $p=0.023$ ). The stress score of caregivers who had family support/assistance was significantly lower as compared to those who had no assistance ( $p=0.032$ ). Similarly, overall mean stress score  $52.3 \pm 7.3$  with a range of 36.0 to 70.0 was found among primary caregivers of child with autism. Overall depression score was 62.5%, where 25% were mildly depressed, 11.5% were borderline/clinical depressed, 16.7% were moderately depressed and 9.4% were severely depressed.

Table IV represented that to compare the depression level between mothers and fathers a chi-square test was used. 36.8% of mother caregivers had no depression whereas 40.0% of father caregivers had no depression. This difference was found to be statistically insignificant ( $p=0.373$ ). Results showed that 60% of the primary caregiver who was married had mild to severe depression, and 100% of caregivers who were unmarried had severe depression. 62.9% of the primary caregivers who lived in the nuclear family system were depressed, 59.9% of the primary caregivers who lived in the joint family system were depressed and 77.7% of the primary caregivers who lived in the extended family system were mild to severely depressed. This difference was found to be statistically insignificant ( $p=0.604$ ).

Table IV depicted that, the Pearson correlation test was applied to disclose the association of autism severity with stress and depression of primary caregivers and reported that an association was found ( $r= 0.172, 0.317$ ); which means that the greater autism severity has no impact on the level of stress and depression.

Table II: Comparison of mean stress scores of primary caregivers' relationship, marital status, family type, any assistance or support, and autism score.

Variables	Categories	Mean $\pm$ SD	Minimum	Maximum	p-value
Relationship	Mother	53.4 $\pm$ 7.1	36	70	0.003*
	Father + others	48.0 $\pm$ 6.7	36	62	
Marital Status	Married	52.9 $\pm$ 7.0	36	70	0.020*
	Unmarried	50.4 $\pm$ 10.4	36	59	
Family Type	Nuclear	55.5 $\pm$ 8.1	36.0	67.0	0.023*
	Joint	51.0 $\pm$ 6.6	36.0	70.0	
	Extended	51.2 $\pm$ 7.5	43.0	61.0	
Any assistance	No	54.1 $\pm$ 7.0	36	67	0.032*
	Yes	50.8 $\pm$ 7.4	36	70	
Stress Score		52.3 $\pm$ 7.3	36.0	70.0	

Significant \* P value  $< 0.05$

Table III: Comparison of depression levels among the primary caregivers according to their marital status, family type, and Autism Score.

Variables	Categories	Depression Status					p-value
		Normal	Mild	Borderline/ clinical	Moderate	Severe	
Marital status	Married	36	19	8	15	8	0.008*
		41.9%	22.1%	9.3%	17.4%	9.3%	
	Unmarried	0	5	3	1	1	
		0.0%	50.0%	30.0%	10.0%	10.0%	
Family types	Nuclear	10	8	2	4	3	0.604
		37.0%	29.6%	7.4%	14.8%	11.1%	
	Joint	24	15	8	8	5	
		40.0%	25.0%	13.3%	13.3%	8.3%	
	Extended	2	1	1	4	1	
		22.2%	11.1%	11.1%	44.4%	11.1%	

Significant \* P value<0.05

Table IV: Correlation of autism severity with stress and depression scores in the Primary caregivers of Autistic children.

Variables	Stress Score	Depression Score
Autism Severity	r	0.103
	p-value	0.317

**DISCUSSION**

The study aimed to assess the stress and depression levels among primary caregivers of children with ASD and results revealed that, out of 96 study participants, 76(79.2%) were mothers and 20(20.8%) fathers, grandparents, and siblings involved in caretaking responsibilities of Autistic child. Another explorative study conducted in Karachi, Pakistan stated that mothers are more embedded in the caretaking responsibilities of children, and fathers are considered as bread earners only.<sup>18</sup>In consistent with these findings, an explorative study conducted in Egypt stated that mothers are more liable for the caretaking responsibility of their children in lower-middle-income countries<sup>19</sup>. Majority were receiving 53(55.2%) respite care or informal social support system from friends and family and 60(62.5%) lived in a joint family system. In parallel with these statistics, another survey performed in China explained that the social support system is positively associated with family cohesion and adaptability to the caregiving demands of the autistic child<sup>20</sup>. Current findings echoed that the mean stress score among primary caregivers was 52.3±7.3 with a range of 36.0 to 70.0 and the depression score was 62.5%. Consistent with these findings, an exploration performed in the child and adolescent department in Turkey propagated that stress, psychological burnout, and depress<sup>21</sup>. Another study conducted in Istanbul, Turkey, reported that parents had higher caregiving burdens resulting in helplessness, low self-esteem, and seeking social support systems (p< 0.05)<sup>22</sup>.

Current findings depicted that the mean stress score of mothers was significantly higher as compared to the mean stress score of father caregivers (p=0.003). Similar results were reported by a survey conducted on Slovenian parents, mothers are more prone to stress and depress.

In regards to marital status, married primary caregivers 86(89%) reported higher stress levels than unmarried (p=0.020). Likewise, an internet-based study reported that parental stress is a mediating factor in marital dissatisfaction among primary caregivers<sup>24</sup>. On the other hand, 100% of unmarried primary caregivers had severe depression (p = 0.008).It may be owing to their extra caregiving responsibilities; future insecurities and their emotional instabilities that lead to mental burnout or hopelessness.

Another statistic of the current study illuminated that lessened stress scores were reported by primary caregivers with family support/assistance (p=0.032).In congruent with these findings, a cross-sectional study reported that family collaboration and siblings' assistance act as a buffer in the reduction of parents' stress and lassitude.<sup>20</sup>

Similarly, no association was found between autism severity with stress and depression of primary caregivers (r= 0.172, 0.317); which means that the greater autism severity has no impact on the level of stress and depression. In contrast to these findings, a cross-sectional analytical study conducted at Namik Kemal

University, Turkey confirmed a positive association was found between autism severity in children and parental depressive symptoms<sup>14</sup>.

**CONCLUSION / RECOMMENDATIONS**

The main tenet of the study was to assess the prevalence of stress and depression among primary caregivers and the net findings echoed that, the primary caregivers of Autistic children have persuasive and dynamic psychological problems such as mental burnout, anxiety, stress, and depression. Overall, depression is more pronounced than stress among parents, and primary caregivers. The current study gives a vivid sense to acknowledge the mental, physical, and social problems of primary caregivers along with therapeutic interventions for an autistic child in public and non-public. It has been asserted that mothers are more prone to stress than fathers, and it mediates marital dissatisfaction consequently family dysfunction has an immense impact on the education and career of other children. These studyfindings are crucial for Sustainable Development Goals by the United Nations (SDG-3) to ensure healthy lives and to promote the well-being of all, all ages<sup>25</sup>.

Current findings give explicit measures to bring attention to challenges faced by parents while rearing an autistic child. Adult mental health issues are decisively taken into consideration as an integral part of the child intervention program. Parenting and parent-support interventions need to be developed and implemented in government and non-government organizations.To enhance the psychological well-being of primary caregivers, health professionals are expected to take responsibility for conducting the training and intervening sessions of parents and primary caregivers of a child with Autism.

**Limitation:** One of the pitfalls is lack of differentiation of the childgroups according to their dominant autistic features; like speech disability, sensory disability, and verbal and non-verbal IQ impairment.

**Acknowledgments:** We are grateful to all Primary Caregivers who participated in this study, without their support our research would not be possible.

**Conflict of Interest:** None to disclose

**Funding & Financial support:** None

**Contribution of Authors:** **ZA:** Acquisition of data, drafting of manuscript, Intellectual input to manuscript, **MG:** Conception and design of study, Intellectual input to manuscript, **SK:** important intellectual input with critical revision, **SM:** Acquisition of data, **FM & MQ:** Analysis and interpretation of data

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