

## Research Paper

## Depression, Anxiety and Stress in Formal and Informal Caregivers of Autistic Children in Karachi



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**ABSTRACT**

**Objectives:** This study assesses the frequency of depression, anxiety, and stress in formal and informal caregivers of autistic children in Karachi City, Pakistan.

**Methods:** This cross-sectional study was conducted among caregivers of autistic children in specified centers in Karachi City, Pakistan. There were 255 participants out of which 111 were formal caregivers and 144 were informal caregivers. Depression, anxiety, and stress scale (DASS) was used to collect the data. The chi-square test was used to determine the relationship between the frequency of depression anxiety and stress among the two groups.

**Results:** A total of 76.3% of informal caregivers were suffering from mild depression, 59.3% were moderately depressed, and 76.5% were severely depressed ( $P < 0.01$ ). Similarly, 72.4% had mild anxiety, 68.2% were moderately anxious, and 50.5% were severely anxious ( $P < 0.01$ ). In addition, 75.0% demonstrated mild, 71.1% moderate, 85.7% severe, and 95.0% extremely severe stress ( $P < 0.01$ ). However, there were no significant levels of depression, anxiety, and stress found among formal caregivers.

**Discussion:** Depression, anxiety and stress were more commonly present in parents of autistic children (informal caregivers) as compared to formal caregivers.

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## Highlights

- Formal caregivers are paid and trained professionals who specialize in taking care of children with disabilities whereas informal caregivers are usually family and friends who are not paid. In the Pakistani context, mothers usually look after children with disabilities.
- Depression, anxiety, and stress are significantly higher in informal caregivers as compared to formal caregivers of autistic children.
- Job status, living in a joint family, education status, and financial burden are significantly associated with depression, anxiety, and stress among informal caregivers whereas age and satisfaction with a job are significantly associated with depression, anxiety, and stress among formal caregivers.

## Plain Language Summary

Taking care of an autistic child requires considerable patience and the job in is very challenging. Informal caregivers who are usually parents, especially mothers are required to look after their children in the local Pakistani context and are often suffering from depression, anxiety, and stress. This has also been reported among people who are trained for this job and considered formal caregivers. This study assesses the level of depression, anxiety, and stress among these groups of people who provide care to autistic children. This study was done on 225 (111 formal and 144 informal) caregivers of children with autism and found that depression, anxiety, and stress were higher among informal caregivers as compared to formal caregivers. Informal caregivers who were working, living in joint families, less educated, and had more financial burdens were found to have high depression, anxiety, and stress. However, younger age groups and individuals not satisfied with their jobs among formal caregivers had higher depression, anxiety, and stress.

## Introduction

**A**utism spectrum disorder (ASD) is characterized by impaired social behavior, communication, and language, a lack of interests, and repetitive activities that are unique to the individual [1]. The average age for the symptoms of autism to appear is before the age of 3 years [2]. About 1 out of 100 children are suffering from ASD [3]. The worldwide prevalence of autism is 1-2 per 1000 children and according to the [Centre for Disease Control](#), 9 out of 1000 children have been diagnosed with autism in the United States [4]. Autism is associated with a high incidence of stress, anxiety, and depression in its caregivers. A study conducted on a sample of 220 caregivers of ASD in Oman in 2016 reported 45.9% and 48.6% of anxiety and stress, respectively [5]. A study in Thailand in 2010 showed the prevalence of depression at 25.6% [6].

Children with ASD may have various symptoms, such as hyperactivity, self-injurious behavior, cognitive impairment, or the presence of repetitive movements [7, 8]. These lead to an array of factors, including social criticism, affected interpersonal relationships, uncontrolled behaviors, and reduced care which can then affect the quality of life [4, 5, 9]. It is also

reported that psychological distress is higher among caregivers of ASD, especially mothers, who are informal caregivers. They are more prone to depression, stress, and anxiety as compared to mothers of children with mild intellectual disability and normal developmental children [4, 5, 10]. Families with special needs face everyday challenges, and experience more psychological burdens that include somatic complaints, heart pain, breathing difficulties, stress, financial burden, and reduced interpersonal relationships [5, 11].

Behavior problems of autistic children are the most common cause of high parental stress, anxiety, and depression; however, the relation between behavior problems and these three issues receives little attention in the population. Formal caregivers who include trained professionals who care for children with ASD are largely ignored when reporting caregiver burden. According to our knowledge, no studies have been focused on formal caregivers of ASD in Pakistan.

This study helps to identify the gravity of the issue in both formal and informal caregivers so that support and non-pharmacological intervention can be provided to the caregivers. This will eventually help the sufferers of autism. Therefore, this study evaluates depression, stress, and anxiety among formal and informal caregivers of ASD.

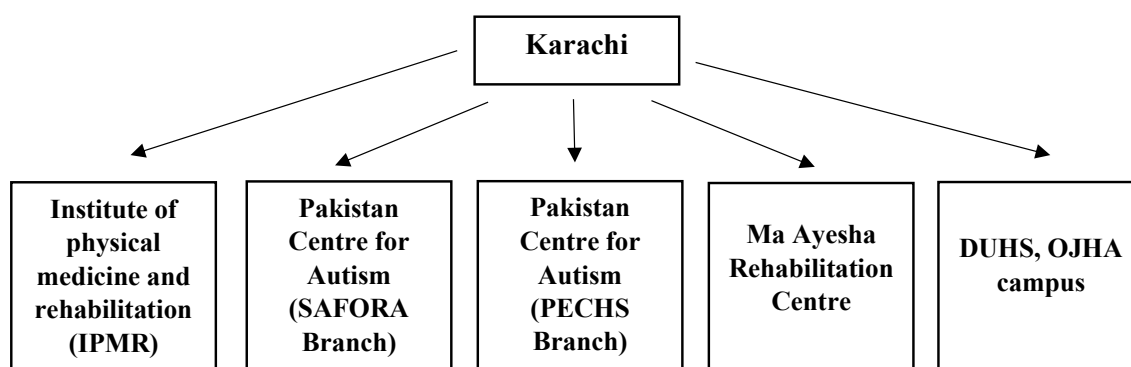


Figure 1. Centers for caregivers of autism in Karachi, Pakistan

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## Materials and Methods

This was a cross-sectional study conducted among the formal and informal caregivers of autistic children in the following centers in Karachi (Figure 1).

The duration of the study was 6-8 months, but due to the COVID-19 pandemic and the sudden complete lockdown of the city in 2020, the data collection process was delayed. Due to precautionary measures, it took around 2 years to complete the data collection procedure.

The sample size was calculated using the open access online sample size calculator (Open Epi calculator), by using a previous study in Australia with the prevalence of depression at 21%, anxiety at 17.1% and stress at 13.3% among caregivers of autistic children. The estimated sample size calculated for the prevalence of depression was 255, for anxiety 218, and stress 178 subjects. Accordingly, the highest prevalence of depression was taken as the anticipated frequency at the confidence level of 95%, and bound on the error of 5%, the sample size was obtained at 255 [12]. There were 255 participants out of which 111 were formal caregivers working with autism in specified centers of Karachi City, Pakistan, and 144 were informal caregivers. There were mostly females (mothers) because most fathers were not available in the therapy center and they did not have the time to complete the questionnaire due to their tough job.

Since a sampling frame was not available, the convenience sampling method was used to recruit the participants. Study participants who were available at the time of data collection and willing to be part of the survey were invited to the study. Formal caregivers were operationalized as trained professionals who spent 30 min to 1 h of their time with the autistic child and were paid for their services [13]. In this context, formal caregivers included employees working in the institute with ASD

children for >3 months, both genders and the ones who gave informed written consent. The informal caregivers were operationalized as parents with one or more autistic children who gave informed written consent. Caregivers who were tending to children with any physical disabilities or those who had any history of psychological disorder or a history of drug addiction, and who did not provide consent to participate were excluded from this study.

The data collection tool was the depression anxiety stress scale 42 (DASS-42) developed by Lovibond (1995) [14]. Before the use of scale, permission was taken from the author through email. The DASS-42 is a set of three self-report scales designed to measure the negative emotional states of depression, anxiety, and stress. The test-retest reliability of the three scales was considered adequate with a Cronbach  $\alpha$  of 0.71 for depression, 0.79 for anxiety, and 0.81 for stress. The participants were asked to use 4-point severity/frequency scales to rate the extent to which they have experienced each state. Scores for depression, anxiety and stress were calculated by summing the scores for the relevant items.

Each of the three DASS-42 scales contains 14 items, which are divided into subscales of 2-5 items with similar content. The scale was comprised of normal, mild moderate, severe, and highly severe with scores ranging from 0 to 32. The higher the scores for each domain reflected greater levels of depression, anxiety, and stress. A semi-structured questionnaire was also used to gather information on socio-demographic characteristics, including age, gender, occupation, socioeconomic status, education, financial issues faced, family system, working hours and job satisfaction along with DASS-42.

The participants were invited directly from the selected institutes for quantitative assessment. Subjects who fulfilled the criteria of the study and provided their consent

**Table 1.** Relationship of formal and informal caregivers with depression, anxiety and stress (n=255)

Outcomes	Total	No. (%)		$\chi^2$ , P
		Formal (n=111)	Informal (n=144)	
Depression	Normal	87(54.4)	73(45.6)	26.61, <0.001 <sup>^</sup>
	Mild	09(23.7)	29(76.3)	
	Moderate	11(40.7)	16(59.3)	
	Severe	04(23.5)	13(76.5)	
	Extreme severe	0	13(100)	
Anxiety	143	78(54.5)	65(45.5)	19.58, <0.001 <sup>^</sup>
	Mild	08(27.6)	21(72.4)	
	Moderate	14(31.8)	30(68.2)	
	Severe	06(50.0)	06(50.5)	
	Extreme severe	05(18.5)	22(81.5)	
Stress	139	86(61.9)	53(38.1)	45.40, <0.001 <sup>^</sup>
	Mild	11(25.0)	33(75.0)	
	Moderate	11(28.9)	27(71.1)	
	Severe	02(14.3)	12(85.7)	
	Extreme severe	01(5.0)	19(95.0)	

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<sup>^</sup>Chi-square test, <sup>^</sup>Fisher exact test.

were approached. The data were entered with caution to avoid any missing values.

### Statistical analysis

All the data was entered and analyzed using the SPSS software, version 22. Percentages were reported for all the categorical variables, including gender, occupation, and education. Since we hypothesized that DASS-42 is more common among informal caregivers as compared to formal caregivers we applied the Fisher exact test to determine the relationship between the frequency of depression anxiety and stress among both the groups. The statistical significance was set at 0.05.

### Results

The relationship of formal and informal caregivers with depression, anxiety, and stress is shown in Table 1. Accordingly, 76.3% of informal caregivers were suffering from mild depression, 59.3% were moderately de-

pressed, and 76.5 % were severely depressed ( $P<0.01$ ,  $\chi^2=26.61$ ). Similarly, 72.4% had mild anxiety, 68.2% were moderately anxious and 50.5% were severely anxious ( $P<0.01$ ,  $\chi^2=19.58$ ). Also, 75.0% had mild stress, 71.1% had moderate stress, 85.7% had severe stress, and 95.0% had extremely severe stress ( $P<0.01$ ,  $\chi^2=45.4$ ).

Formal caregivers who were aged between 20-30 years showed more stress ( $P=0.017$ ,  $\chi^2=7.37$ ). In terms of occupation, the special educators showed a significant anxiety score ( $P=0.011$ ,  $\chi^2=17.67$ ) (Table 2). Meanwhile, satisfaction with the job was the main factor that was also associated with depression and anxiety in formal caregivers. Some of the participants were significantly depressed ( $P=0.013$ ,  $\chi^2=16.68$ ) and had significant anxiety scores ( $P=0.012$ ,  $\chi^2=17.06$ ).

Most of the informal caregivers were literate with graduates having more depression scores ( $P=0.015$ ,  $\chi^2=17.11$ ) and stress scores ( $P<0.001$ ,  $\chi^2=29.06$ ) (Table 3). Significant depression, anxiety, and stress were ob-

**Table 2.** Relationship of baseline characteristics of formal caregivers with depression, anxiety and stress (n=111)

Demographics		No. (%)											
		Depression				Anxiety				Stress			
		Normal	Mild-Moderate	Severe	$\chi^2, P$	Normal	Mild-Moderate	Severe	$\chi^2, P$	Normal	Mild-Moderate	Severe	$\chi^2, P$
Gender	Male	2(2.3)	1(5.0)	0	1.63, 0.522	2(2.6)	0	1(9.1)	2.27, 0.359	2(2)	1(4.5)	0	1.69, 0.539
	Female	85(97.7)	19(95)	4(100)		76(97.4)	22(100)	10(91)		84(98)	21(95.5)	3(100)	
Age	20-30	70(80.5)	19(95.5)	3(75)	2.85, 0.263	64(82.1)	18(82)	10(91)	0.39, 0.849	68(79)	22(100)	2(66.7)	7.37, 0.017
	31-40	17(19.5)	1(5.0)	1(25)		14(17.9)	4(18.2)	1(9.1)		18(21)	0	1(33.3)	
Occupation	Occupation therapist	24(27.6)	2(10)	0	8.79, 0.261	20(25.6)	6(27.6)	0	17.67, 0.011	21(24.4)	5(22.7)	0	8.52, 0.280
	Speech therapist	12(13.8)	1(5.0)	1(25)		12(15.4)	0	2(18)		12(14)	1(4.5)	1(33.3)	
	Psychologist	12(13.8)	2(10)	1(25)		13(16.7)	0	2(18)		12(14)	2(9.1)	1(33.3)	
	Special education	25(28.7)	9(45.0)	1(25)		23(29.5)	9(40.9)	3(27)		28(32.6)	6(27.3)	1(33.3)	
	Others	14(16.1)	6(30.0)	1(25)		10(12.8)	7(31.8)	4(37)		13(15.1)	8(36.4)	0	
Job satisfaction	Not at all	1(1.1)	1(5.0)	0	16.68, 0.013	1(1.3)	1(4.5)	0	17.06, 0.012	1(1.2)	1(4.5)	0	11.54, 0.127
	A little	10(11.5)	2(10)	1(25)		10(12.8)	2(9.1)	1(9.1)		10(11.6)	3(13.6)	0	
	Rather	13(14.9)	5(25)	3(75)		14(17.9)	1(4.5)	6(54)		12(14)	7(31.8)	2(66.7)	
	Much	46(52.9)	12(60)	0		37(47.4)	17(77)	4(37)		47(54.7)	10(45.5)	1(33.3)	
	Very much	17(19.5)	0	0		16(20.5)	1(4.5)	0		16(18.6)	1(4.5)	0	

served in females ( $P<0.001$ ,  $\chi^2=16.95$ , 16.65, 16.12, respectively). Participants who were not working were severely depressed ( $P<0.001$ ,  $\chi^2=13.22$ ), were severely anxious ( $P=0.002$ ,  $\chi^2=12.52$ ), and were in extremely severe stress ( $P=0.004$ ,  $\chi^2=11.12$ ). Parents of autistic children living separately were severely anxious ( $P=0.003$ ,  $\chi^2=11.41$ ) and had significant stress ( $P=0.026$ ,  $\chi^2=7.33$ ). Due to financial burden, parents were mild to moderately depressed ( $P=0.001$ ,  $\chi^2=26.02$ ), mild to moderately anxious ( $P=0.007$ ,  $\chi^2=20.22$ ), and mild to moderately stressed ( $P=0.023$ ,  $\chi^2=17.27$ ).

## Discussion

Parents of children with ASD often have more stress, anxiety, and depression [15]. This study compared depression, anxiety and stress among the formal and informal caregivers of children with ASD and results show

that informal caregivers are more prone to depression, anxiety, and stress as compared to the formal caregivers.

Almost 50% of the formal caregivers, including occupational therapists, speech therapists, psychologists, and special educators had normal depression, anxiety and stress levels. Formal caregivers are satisfied with their jobs and the profession with active involvement with the environment and have financial stability. Therapists usually took 30-40 min sessions and were not involved emotionally. Additionally, this limited time spent with the ASD child could account for this finding as compared to parents who spend all the time with their children. Furthermore, therapists probably had more training, resources, and experience with children with ASD and behavior problems than parents [16].

**Table 3.** Relationship of baseline characteristics of informal caregivers with depression, anxiety and stress (n=144)

Demographics		No. (%)											
		Depression				Anxiety				Stress			
		Normal	Mild-Moderate	Severe	$\chi^2, P$	Normal	Mild-Moderate	Severe	$\chi^2, P$	Normal	Mild-Moderate	Severe	$\chi^2, P$
Gender	Male	26(35.6)	2(4.4)	5(19.2)	16.95, <0.001	24(36.9)	3(5.9)	6(21.4)	16.65, <0.001	22(41.5)	6(10.0)	5(16.1)	16.12, <0.001
	Female	47(64.4)	43(95.6)	21(80.8)		41(63.1)	48(94.1)	22(78.6)		31(58.5)	54(90.0)	26(83.9)	
Age	20-30	21(28.8)	14(31.1)	11(42.3)	5.44, 0.463	17(26.2)	19(37.3)	10(35.7)	4.02, 0.682	13(24.5)	21(35)	12(38.7)	8.81, 0.142
	31-40	41(56.2)	28(62.2)	11(42.3)		38(58.5)	28(54.9)	14(50)		29(54.7)	36(60)	15(48.4)	
	41-50	9(12.3)	2(4.4)	4(15.4)		8(12.3)	3(5.9)	4(14.3)		8(15.1)	3(5.0)	4(12.9)	
	51-60	2(2.7)	1(2.2)	0		2(3.1)	1(2.0)	0		3(5.7)	0	0	
Education	Matric	6(8.2)	6(13.3)	2(7.7)	17.11, 0.015	6(9.2)	5(9.8)	3(10.7)	10.05, 0.221	6(11.3)	6(10.0)	2(6.5)	29.06 <0.001
	Intermediate	6(8.2)	10(22.2)	0		6(9.2)	9(17.6)	1(3.6)		2(3.8)	13(21.7)	1(3.2)	
	Graduation	44(60.3)	19(42.2)	22(84.6)		36(55.4)	27(52.9)	22(78.6)		28(52.8)	29(48.3)	28(90.3)	
	Masters	16(21.9)	10(22.2)	2(7.7)		16(24.6)	10(19.6)	2(7.1)		16(30.2)	12(20)	0	
Job status	PhD	1(1.4)	0	0	13.22, 0.001	1(1.5)	0	0	12.52, 0.002	1(1.9)	0	0	11.12, 0.004
	Working	34(46.6)	35(77.8)	19(73.1)		30(46.2)	35(68.6)	23(82.1)		23(43.4)	44(73.3)	21(67.7)	
Joint family	Non-working	39(53.4)	10(22.2)	7(26.9)	5.82, 0.058	35(53.8)	16(31.4)	5(17.9)	11.41, 0.003	30(56.6)	16(26.7)	10(32.3)	7.33, 0.026
	Yes	33(45.2)	27(60)	8(30.8)		31(47.7)	31(60.8)	6(21.4)		22(41.5)	36(60)	10(32.3)	
Financial issues	No	40(54.8)	18(40)	18(69.2)	26.02, 0.001	34(52.3)	20(39.2)	22(78.6)	0.22, 0.007	31(58.5)	24(40)	21(67.7)	17.27, 0.023
	Not at all	15(20.5)	4(8.9)	0		12(18.5)	7(13.7)	0		13(24.5)	6(10.0)	0	
	A little	36(49.3)	16(35.6)	11(42.3)		31(47.7)	21(41.2)	11(39.3)		19(35.8)	30(50)	14(45.2)	
	Rather	4(5.5)	9(20)	1(3.8)		4(6.2)	9(17.6)	1(3.6)		5(9.4)	4(6.7)	5(16.1)	
	Much	11(15.1)	12(26.6)	4(15.4)		8(12.3)	11(21.6)	8(28.6)		11(20.8)	12(20)	4(12.9)	
Relation with the child	Very much	7(9.6)	4(8.9)	10(38.5)	15.91, <0.001	10(15.4)	3(5.9)	8(28.6)	19.10, <0.001	5(9.4)	8(13.3)	8(25.8)	18.49, <0.001
	Mother	49(67.1)	43(95.6)	23(88.5)		42(64.6)	49(96.1)	24(85.7)		32(60.4)	55(91.7)	28(90.3)	
	Father	24(32.9)	2(4.4)	3(11.5)	23(35.4)	2(3.9)	4(14.3)	21(39.6)	5(8.3)	3(9.7)			



A previous study conducted in Australia shows a higher prevalence of anxiety among informal caregivers, 17.1% as compared to the normal adult population which was reported as 9.1%; similarly, 60% of the parents of children with autism experience depression compared to 15% of the general Australian population [11]. Another study conducted in Australia in 2017 reported that 10% of caregivers of ASD were depressed and 13.3% were anxious and stressed [9].

In this study, mothers of autistic children experienced more depression, anxiety and stress as compared to fathers. These results are comparable with a study conducted by Hodapp et al. [19] and Dabrowska et al. [20]. It may be because mothers spend more time with their children as compared to fathers as in our part of the world, fathers are the main breadwinners of families and this usually requires late working hours [17]. In addition, participants in our study were predominantly females.

In addition, the level of education of parents of autistic children was not significantly associated with anxiety but parents with higher education status reported moderate to severe depression and stress. In contrast, previous studies showed that the educational level was not significantly associated with stress but found that depression and anxiety were higher among more educated caregivers [4]. This may be because higher education status leads to more awareness about the condition and eventually results in worries about the child's future.

A contributing factor for depression, anxiety, and stress in our study was financial stability. The informal caregivers reported 35.6%, 41.2% and 50% of mild to moderate depression, anxiety, and stress, respectively, who were facing a little financial issue [18]. These financial challenges could be because of expensive treatment and therapies for ASD children.

## Conclusion

Depression, anxiety and stress are more common in parents of autistic children (informal caregivers) as compared to formal caregivers. Formal caregivers coped better with depression, stress, and anxiety as compared to informal caregivers. Further studies are warranted with gold-standard interviews and qualitative approaches which should focus on the correlation of these indices. Intervention-based approaches and strategies should be included. To gain more insight, various measures, such as counseling, building community, and family and social support to the affected child's parents must be incorporated.

## Study limitations

To the best of our knowledge, this was the kind of the first study conducted in Pakistan on the mental states of especially formal caregivers. However, our study is subjected to certain limitations. The male-to-female ratio of participants was unbalanced. This study used the DASS-42 scale, which comprises on symptoms checklist only so it is inferior to the gold standard interviews or qualitative approach. In addition, the chances of reporting bias cannot be ignored. The results from the present study are limited in their generalizability due to the relatively small study sample.

## Ethical Considerations

### Compliance with ethical guidelines

The study was approved by the Institutional Review Board (IRB) of **Jinnah Sindh Medical University** (Code: JSMU/IRB/2019/-171). All procedures performed in studies involving human participants were following the ethical standards of the institutional and/or National Research Committee and with the Helsinki Declaration.

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### Authors' contributions

Study design, conceptualization, data collection and data analysis: Aliza Zehra; Formal analysis: Uzma Qadri Writing the original draft: Muhammad Ovais; Supervision, review and editing: Zaema Ahmer.

### Conflict of interest

The authors declared no conflict of interest.

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