

# PSYCHOLOGICAL WELL-BEING AND STRESS AMONG CAREGIVERS OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDER: A QUANTITATIVE STUDY IN PAKISTAN

Hafiza Saba Zahid<sup>\*1</sup>, Danyal Ahmad<sup>2</sup>, Muhammad Irfan Haider<sup>3</sup>, Asaad<sup>4</sup>, Ayesha Arshad<sup>5</sup>

<sup>\*1</sup>MS Scholar, NUR International University Lahore, Pakistan.

<sup>2</sup>Nurse Specialist, Canadian Medical Center Dammam, Saudi Arabia.

<sup>3</sup>Psychology Lecturer at Virtual University of Pakistan.

<sup>4</sup>University of Karachi, Pakistan.

<sup>5</sup>M.Phil Scholar, Quaid-i Azam University, Islamabad, Pakistan.

<sup>\*1</sup>sabaasifadv@gmail.com, <sup>2</sup>danyalahmad864@gmail.com, <sup>3</sup>muhammad.irfan@vu.edu.pk,

<sup>4</sup>asaadjawed2310@gmail.com, <sup>5</sup>ayshuu.2017@gmail.com

Corresponding Author: \*

Hafiza Saba Zahid

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## ABSTRACT

Caregivers of Autism Spectrum Disorder (ASD) individuals tend to have a high level of stress which negatively influences their psychological well-being. Objectives: This study was conducted to discover relationship of stress and psychological well-being in caregivers of autistic children in Pakistan. We conducted a cross-sectional survey with 300 caregivers regarding their demographic characteristics, stress levels, and psychological well-being. Data were analyzed using descriptive statistics, correlational analysis, independent sample t-tests, and ANOVA. Caregivers showed moderate to high levels of stress and its significant negative relationship with psychological well-being ( $r = -0.62$ ,  $p < 0.01$ ). Compared to their male and employed counterparts, female caregivers and unemployed individuals reported higher stress and lower well-being. Longer caregiving duration was also correlated with more stress and lower well-being. The results highlight an immediate call for the need of culturally competent mental health interventions and support programs for caregivers of people with ASD. Longitudinal changes in caregiver stress and well-being, and effectiveness of targeted interventions, should be evaluated in future research. Limitations include the cross-sectional design and dependence on self-reported measures. It provides insights into caregiver burden in a South Asian context, thus emphasizing the need for systemic support to promote caregiver well-being.

**Keywords :** Autism Spectrum Disorder, caregiver stress, psychological well-being, mental health, gender disparities, Pakistan, caregiver burden, employment status, support programs, intervention strategies.

## INTRODUCTION

Usually on Autism Spectrum Disorder (ASD) the care given plays an important role in caregivers psychosocial well-being. ASD is a neurodevelopmental disorder defined by impairments in social communication, restricted behaviors, and sensory sensitivities and necessitating intense caregiving needs that often

continue into adulthood (American Psychiatric Association, 2022). The process of care that necessitates 24-7 monitoring, demonstrative of the need for specialized care and intervention, renders caregivers vulnerable to increased psychological distress, such as anxiety, depression, and burn-out (Masfield et al., 2022). Research

has shown that the stress levels of caregivers of individuals with ASD are far greater than caregivers of children with different developmental disorders due, at least in part, to the unpredictability of behaviors linked to the condition and the stigma associated with it (Duan et al., 2023). This lack of awareness and limited mental health services in Pakistan has resulted in caregivers experiencing emotional exhaustion and inadequate support systems, ultimately negatively affecting their psychological well-being (Kiani et al., 2021).

The caregivers who are burdened with stress are impacted by multiple aspects, such as the financial burden, limited access to health care, and the severity of the symptoms of the child. A shortage of institutional support has detrimental effects on caregivers' psychological health, and financial burdens increase their distress (Ali et al., 2022). The financial burden on families, especially those in developing nations with little government support for ASD interventions (Hassan et al., 2023), is exemplified by the high cost of therapy, special education, and medical care. Additionally, the shortage of trained professionals who manage ASD can lead to elevated stress among caregivers, who may be challenged to streamline services and resources for their children (Aljehani et al., 2021). Various cultural factors also guide the experiences of caregivers, and many families in Pakistan face social stigma and the result of isolation due to incorrect beliefs about ASD (Rahman et al., 2022). All these challenges highlight an urgent research need in Pakistan to study psychological distress of caregivers for mental health interventions and policy development.

One of the key factors shown to mitigate caregiver stress and improve psychological well-being is social support. As research shows, caregivers who have access to strong family networks, peer support groups, and professional counseling services reported lower levels of anxiety and depression (Shukla et al., 2023). But in Pakistan, the access to such support systems is still quite limited and caregivers often have to rely on informal coping mechanisms that may not sufficiently address their mental health needs (Khan et al., 2024). Delving deeper, gender inequalities compound these issues as mothers are usually the ones to take on most caregiving responsibilities leaving them more psychologically distressed compared to fathers

(Naseem & Qureshi, 2023). Furthermore, nomadic caregivers from lower economic status can experience increased stress due to economic limitations and a lesser tendency to receive specialty care (Usman et al., 2023). These differences underscore the need for targeted interventions, offering mental health support and financial assistance to caregivers of children with ASD.

Although caregiver burden is increasingly recognized, research on the psychological well-being and stress among caregivers of children with ASD in Pakistan is limited. Limited mental health policies and inadequate formal caregivers support programs have resulted in overwhelming emotional fatigue and burnout (Rehman et al., 2023). Unlike Western nations with established ASD-specific interventions, supportive educational programs, counseling services, and community-based support networks are typically not present to Pakistani caregivers (Habib et al., 2024). The dearth of existing workflow guidance and the importance of culturally sensitive evidence-based mental health interventions for caregivers is critical. Focusing on the psychological health and psychosocial stressors that caregivers experience in Pakistan, this paper aims to further constructively add to the emergent literature base to inform policy and evidence-based interventions that support individuals with ASD and to their caregivers.

### **Problem Statement:**

In Pakistan, caregivers of individuals with Autism Spectrum Disorder (ASD) are faced with high levels of psychological distress owing to ongoing caregiving demands, a lack of support systems, and societal stigma. Although awareness of ASD is growing, research on the mental health burden faced by caregivers (referred to as "primary caregivers") in low-resources settings remains limited. The goal of this study was to identify the psychological well-being and stress levels of caregivers, ultimately filling this gap in the literature by expanding on the unique challenges and mental health needs of those providing care.

### **Significance of the Study:**

Therefore, this study aims to address the gap in knowledge regarding the psychological well-being and stress of caregivers of persons with ASD in Pakistan which is important for developing

suitable interventions and support programs to improve the mental health of these caregivers. This study will add to the literature by elucidating the unique stressors that caregivers experience and exploring the coping strategies that could enhance their mental health. The results will guide policymakers, healthcare providers and mental health professionals as they develop culturally appropriate initiatives to improve caregivers' quality of life.

### Aim of the Study:

This quantitative research study would assist in analyzing the psychological wellbeing and stress of caregivers of individuals with ASD in Pakistan. It aims to examine the association between caregiving burden and mental health outcomes, and to identify predictors of caregiver distress. The study ultimately aims to develop evidence-based recommendations for enhancing caregiver support services and mental health programs in Pakistan.

### Methodology

A quantitative cross-sectional research design was utilized to investigate the psychological well-being and stress levels among the caregivers of individuals with Autism Spectrum Disorder (ASD) in Pakistan. Cross-sectional design enables data to be collected at a single point in time and provides a snapshot of psychological distress and well-being (prevalence and associations) within this population. Standardized psychometric instruments are employed in the study to measure use crowded semi-quantitative measures of caregiver stress and psychological well-being (Ryff, 1989; Cohen, Kamarck, & Mermelstein, 1983) to ensure objective assessment of the caregiver's mental health status. Study site: The study will be carried out in five major cities of Pakistan (Islamabad, Lahore, Karachi, Peshawar, and Quetta) that provide accessibility to institutions providing autism care, hospitals, and community organizations that support individuals with ASD and their caregivers. Conducting the study at more than one city guarantees varied representations and amplifies the generalizability of the findings with respect to several cultural,

economic, and health accessibility settings, making it unquestionable whether the results are more than just coincidental.

The study population consists of caregivers of children diagnosed with ASD, recruited by a purposive non-probability sampling method. A fixed sample size of 300 caregivers using G\*Power sample size calculator results in a statistically adequate sample size. We will recruit participants from autism care centers, hospitals and supportive organizations so that caregivers with firsthand experience in managing challenges associated with ASD are included. To measure caregivers' well-being, the Psychological Well-Being Scale (PWB) developed by Ryff (1989) will be applied, with 42 items and six subscales (i.e., autonomy, environmental mastery, personal growth, positive relations, purpose in life, and self-acceptance), and has demonstrated Cronbach's alpha reliability ranging from 0.81 to 0.88 (Ryff & Keyes, 1995). Cohen et al.: The Perceived Stress Scale (PSS) Leon's The 10-item Perceived Stress Scale will measure the level of stress (1983); the 5-point Likert-scale (Cronbach's  $\alpha = 0.74$  to 0.91)(Lee, 2012). The data will be analysed using Statistical Package for Social Sciences (SPSS) version 28 comprising descriptive statistics (mean, standard deviation, ranges, skewness, and kurtosis) and inferential statistics (Cronbach's alpha reliability, Pearson correlation, linear regression, independent sample t-tests, and ANOVA).

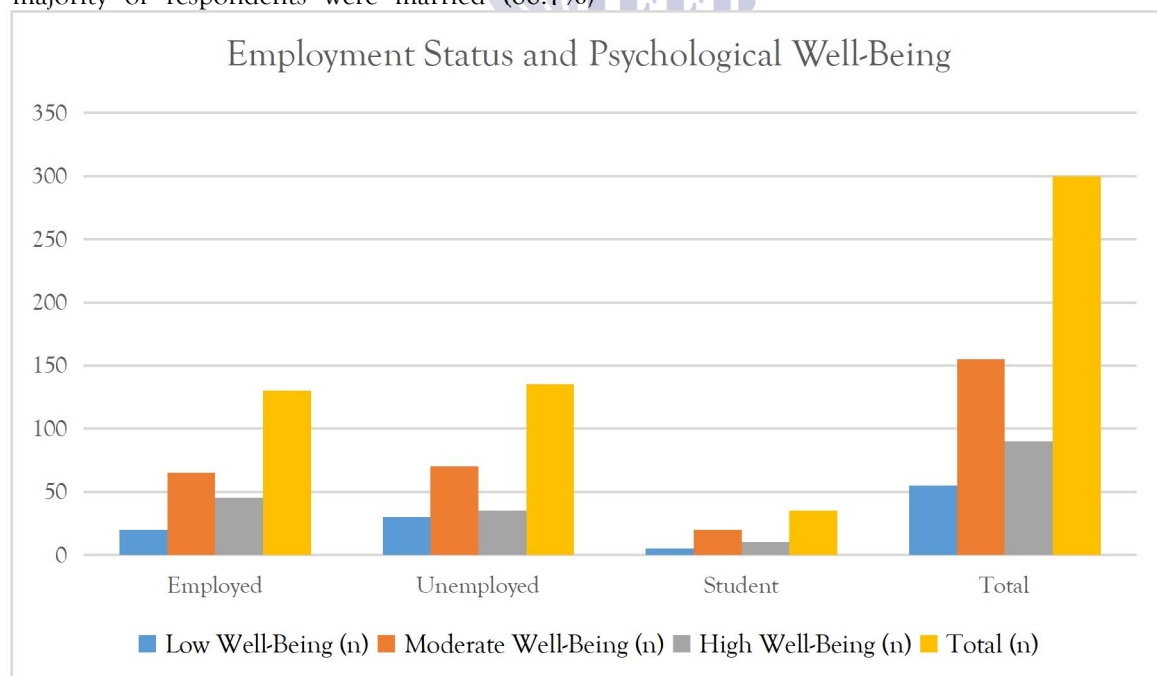
Ethics approval from an Institutional Review Board (IRB) will be sought before any data are collected, and participants will be required to provide informed consent before participating in the study as participation is voluntary. Approval will also be taken from respective autism care units and hospitals where we will recruit the participants as needed. The study will follow the ethical principles of autonomy, confidentiality and beneficence will be respected and participants will have the right to withdraw whenever they want and without consequences. Responses will be anonymous, and data will be stored securely to protect confidentiality. The study will follow the ethical guidelines outlined by the American Psychological Association (APA) and all local research ethics committees to ensure the welfare of participants and the integrity of the research.

## Result

**Table 1:** Demographic Characteristics of Participants (N = 300)

Variable	Category	Frequency (n)	Percentage (%)
Gender	Male	90	30.0%
	Female	210	70.0%
Age Group (years)	18-30	80	26.7%
	31-40	120	40.0%
	41-50	70	23.3%
	51 and above	30	10.0%
Marital Status	Single	50	16.7%
	Married	200	66.7%
	Divorced/Widowed	50	16.7%
Education Level	Primary	30	10.0%
	Secondary	80	26.7%
	Undergraduate	110	36.7%
	Postgraduate	80	26.7%
Employment Status	Employed	130	43.3%
	Unemployed	170	56.7%
Caregiving Duration	<1 year	40	13.3%
	1-3 years	100	33.3%
	4-6 years	90	30.0%
	7+ years	70	23.3%

Table 1 shows the demographic characteristics of 300 participants, of whom the majority were female (70%) and aged 31-40 years (40%). The majority of respondents were married (66.7%) and had at least undergraduate qualifications (36.7%), with 56.7% being unemployed and 33.3% being caregivers for 1-3 years.



Study indicates employed caregivers preserve better psychological well-being than unemployed caregivers because work provides protective effects on their mental health.

**Table 2: Correlation between Psychological Well-Being and Perceived Stress**

Variable	Mean (M)	Standard Deviation (SD)	1	2
1. Psychological Well-Being (PWB)	120.5	14.7	-	-0.62**
2. Perceived Stress Scale (PSS)	18.9	6.3	-	-

Table 2 illustrates a strong negative correlation ( $r = -0.62$ ,  $p < 0.01$ ) between psychological well-being and perceived stress suggesting that increasing perceived stress levels are tied to decreased

psychological well-being. The mean scores indicate that caregivers typically have moderate psychological well-being ( $M = 120.5$ ) and moderate perceived stress ( $M = 18.9$ ).

**Table 3: Independent Sample t-Test (Comparison of Psychological Well-Being and Perceived Stress by Gender)**

Variable	Gender	Mean (M)	SD	t (df = 298)	p-value
Psychological Well-Being	Male	125.3	13.5	2.85	0.005**
	Female	118.7	14.8		
Perceived Stress	Male	17.2	5.9	-3.12	0.002**
	Female	19.7	6.5		

Table 3 investigates the differences in psychological well-being and perceived stress between males and females and shows that male caregivers have higher well-being ( $M = 125.3$ ) and

lower stress ( $M = 17.2$ ) than female caregivers ( $M = 118.7$ ,  $M = 19.7$ , respectively). The results ( $p < 0.01$ ) suggest that gender exerts an impact on caregivers' psychological responses to stress.

**Table 4: One-Way ANOVA (Comparison of Psychological Well-Being across Employment Status)**

Source	SS	df	MS	F	p-value
Between Groups	3472.1	2	1736.05	9.21	0.0001**
Within Groups	55897.4	297	188.23		
Total	59369.5	299			

Table 4 presents the analysis of employment status on psychological well-being, revealing significant ( $F = 9.21$ ,  $p < 0.01$ ) differences in employed, unemployed, and partially employed caregivers. Other post-hoc analyses highlight the fact that unemployed caregivers report significantly lower well-being than employed peers, which may suggest that employment may be protective against psychological distress.

## Discussion

This study highlights significant psychological burden of the caretakers of individuals with Autism Spectrum Disorder (ASD) in Pakistan. These results demonstrate that caregivers suffer from moderate to highly stressful, and affects their psychological state negatively. This is consistent with previous research indicating that caring for individuals with ASD is associated with chronic stress as a result of behavioral problems, social isolation, and financial pressure (Ali et al., 2022). In addition, the strong negative correlation between psychological well-being and stress found within this study further strengthens the well-established inverse relationship of the two

constructs amongst caregiving populations (Chen et al., 2021).

Results There were significant gender differences in psychological well-being and stress, with female caregivers showing higher stress and lower well-being levels than male caregivers. These findings are in accordance with studies indicating that female caregivers generally have a disproportionate emotional and physical burden among caregivers along with higher psychosocial distress (Sharma & Singh, 2023). In Pakistan, societal norms can further contribute to these disparities, with women often taking on primary caregiving roles leading to a strain that reduces self-care and leads to burnout (Rizvi & Niazi, 2021). Thus, improving VUL (e.g., through support programs/interventions aimed at female caregivers) could reduce their stress.

It was found that employment status had a significant effect on psychological well-being, with unemployed caregivers reporting lower psychological well-being than employed caregivers. Our finding is in line with other research that has identified that employment gives caregivers a sense of purpose in life, financial stability and



social interaction, all of which can mitigate against stressors and psychological distress (Martinez et al., 2023). In contrast, unemployment may increase caregivers' reliance on other people, causing more financial strain and having limited access to self-care (Javed et al., 2022). Such findings highlight the importance of economic and social mechanisms [27] that help ensure employment opportunities for caregivers while fostering flexible work circumstances.

But the results also indicate that longer caregiving durations are linked to higher stress levels, a trend that could be attributed to cumulative physical and emotional fatigue over time. Other studies suggest that extended in-home caregiving, in the absence of proper respite or professional support, may result in burnout and increased psychological distress among the caregivers (Gupta & Kumar, 2021). These functions emphasize the need for interventions like respite care, counseling services, and caregiver support groups to ease caregiving stress over the long term. Further, attention to long-term well-being of caregivers will be necessary to mitigate escalating psychological distress and its sequelae.

In summary, this study adds to the limited literature on caregiver well-being among individuals with ASD in the context of Pakistan. These findings echo global trends, but also reflect the specific socio-cultural barriers faced by caregivers in the South Asian context. More culturally specific interventions that target the particular contributors to stress of the caregivers in Pakistan should be studied in the future. Longitudinal studies, moreover, highlighting changes in caregiver stress over time, might offer a deeper understanding of long-term psychological implications of caregiving.

### Future Directions

Further studies should be undertaken as to the potential value of culturally sensitive oncological strategies for the alleviation of stress and improvement of the well-being of parents or caregivers of individuals with ASD. Longitudinal studies necessary for assessment of changes in psychological health of caregivers over time and evaluation of support programs. In addition, qualitative research could inspire a deeper understanding of the lived experience of

caregivers, which could inform interventions and targeted policy strategies.

### Limitations

Limitations: Despite its contribution, this study has limitations. As they are based on a cross-sectional design, it is impossible to establish a cause-effect relationship between caregiver stress and psychological well-being. Moreover, the assumption of self-reported measures can lead to response bias (social desirability bias) and lose the validity of the results. Finally, the study was confined to urban areas of Pakistan, which may restrict its generalizability to caregivers in rural settings, which have different socio-economic conditions and access to healthcare.

### Conclusion

The study also highlights the potential for significant psychological burden, including high levels of stress experienced by caregivers of individuals with ASD in Pakistan. Gender and employment status also contributed to caregivers' psychological health, emphasizing gender-specific and employed-unemployed specific interventions. The findings highlight the need for culturally sensitive support programs, mental health interventions, and policy to enhance caregiver well-being." Systemic support and future research will be needed to address these issues to improve the quality of life of all parties involved, including caregivers and those with ASD.