

# Caregiver Burden, Stress, and Belief Systems in Attendants of Individuals Afflicted with Psychiatric Illnesses

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## ABSTRACT

**OBJECTIVE:** To explore the magnitude of caregiver burden, psychological stress, and belief systems among individuals attending to psychiatric patients.

**METHODOLOGY:** A cross-sectional study was conducted on 363 caregivers of psychiatric patients at Department of Psychiatry, PNS Shifa Karachi, using structured interviews and validated tools to assess caregiver burden, stress levels, and belief systems. The study was conducted from January - July 2024. Caregivers of patients with psychiatric disorders aged 18 years and above were included and those who had a psychiatric illness, a history of taking medication for such conditions, and those diagnosed with Alzheimer's or memory loss excluded. Reliability scores for the instruments were 76.3% and 71.6%, respectively. Data was analyzed using SPSS 26.

**RESULTS:** This study reported that most patients were suffering from depression (60.6%), followed by anxiety (30.0%), and psychosis (9.4%). Caregivers were predominantly female (59%). 51% of caregivers reported moderate to severe burden, and 64.7% experienced moderate stress. No significant differences in burden or stress were found by caregiver or patient gender and relationship ( $p > 0.05$ ). However, both burden and stress were significantly higher among caregivers of patients with depression ( $p < 0.001$ ). Belief in supernatural causes such as "Nazar" and "Jadu" was common, with 57% and 59% endorsing them, respectively.

**CONCLUSION:** Caregivers of psychiatric patients experience significant levels of burden and stress, particularly when dealing with depressive disorders. Belief in supernatural causes remains widespread and may influence perceptions and practices of caregiving. There is an urgent need for culturally tailored support systems, psychoeducation, and policy-level interventions.

**KEYWORDS:** Psychiatric illness, Caregiver burden, perceived stress, Depression, Belief systems, Zarit Burden Interview, Perceived Stress Scale.

## INTRODUCTION

Mental illnesses are among the leading contributors to the global burden of disease. According to the WHO, 970 million people are living with mental disorders<sup>1</sup>. These illnesses severely impair daily functioning, relationships, and productivity, contributing to a high number of disability-adjusted life years (DALYs)<sup>2,3</sup>. From 1990 to 2019, the total number of DALYs due to mental illnesses worldwide increased significantly, rising from 80.8 million to 125.3 million<sup>3</sup>. In Pakistan,

depressive disorders contributed the most to DALYs caused by mental disorders, accounting for 3.13%<sup>4</sup>. With the rising prevalence and impact of mental disorders, the need for long-term care and support is also increasing. Caring for individuals with psychiatric illnesses is a profoundly emotional and complex responsibility. Caregivers are not only expected to provide emotional and physical support but also manage the social stigma, financial strain, and psychological impact associated with psychiatric caregiving, resulting in a significant burden on them<sup>5</sup>. Caregiving burden refers to the stress that arises from looking after another person, whereas caregiver burden describes the emotional or physical strain experienced by those providing care<sup>5,6</sup>.

This concept was first proposed by Truedley in 1946, who stated that caregiving negatively influences the caregiver's mental health and overall quality of life<sup>7</sup>. It is a global phenomenon, affecting approximately 31% of individuals in caregiving roles for patients with mental illnesses<sup>8</sup>. The intensity of caregiver burden is influenced by the severity of the patient's illness, duration of caregiving, social support, caregiver's health, and cultural or personal belief systems<sup>2,9</sup>. The stress experienced by caregivers is also multifaceted, arising from prolonged caregiving duties, lack of professional support, disrupted personal routines, and

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doi: 10.22442/jlumhs.2025.01296

Received: 18-04-2025

Revised: 03-05-2025

Accepted: 16-05-2025

Published Online: 26-05-2025



the unpredictable course of mental illness<sup>10</sup>. Existing literature has explored various dimensions of burden and stress among caregivers of psychiatric patients<sup>5,11</sup>. A study on caregiver burden using the Involvement Evaluation Questionnaire (IEQ) in Saudi Arabia reported a mean IEQ burden score of  $38.4 \pm 17.5$ <sup>12</sup>. Hsiao et al. demonstrated that using the 22-item Zarit Burden Interview, the mean caregiver burden score was  $38.46 \pm 19.02$ . Moderate to severe burden was reported in 32.5% of caregivers<sup>13</sup>. Another study compared stress burden between caregivers of patients with chronic severe mental illness and those with cardiac disease, reporting mean scores of  $46.54 \pm 18.27$  and  $28.94 \pm 13.57$ , respectively<sup>14</sup>.

However, there is a need for a more holistic examination that also includes belief systems as a critical variable. This research aims to explore the magnitude of caregiver burden, psychological stress, and belief systems among individuals caring for psychiatric patients. It also highlights patterns and differences among caregivers in varying sociodemographic and clinical contexts. Such an approach can provide insights into risk factors for caregiver stress and burden. This study aims to inform the development of targeted interventions and support strategies for caregivers to improve outcomes for both caregivers and the individuals they support, promoting more sustainable and compassionate mental healthcare systems.

## METHODOLOGY

A cross-sectional study was conducted at the Department of Psychiatry, PNS Shifa, Karachi, from January to July 2024, after obtaining ethical approval from the institution's ethics committee (approval letter number PSY-2023-197-1036). Three hundred sixty-three caregivers were estimated using the Zarit Burden Interview, with a prevalence of burden of 38.05% (5% margin of error, 95% confidence level)<sup>8</sup>. Caregivers of patients with psychiatric disorders aged 18 years and above and of either gender were included in the study. They were taken from both the outpatient and inpatient departments of the Department of Psychiatry, PNS Shifa Karachi. Caregivers with an established diagnosis of a psychiatric or mental illness, a history of taking medication for such conditions, or those diagnosed with Alzheimer's disease or memory loss were excluded.

Informed consent was obtained from each attendant before being included in the study. Data were collected through face-to-face interviews using pre-structured questionnaires as the primary research tool. The questionnaire was divided into four sections. The first section collected demographic and clinical information about the patients, while the second section collected demographic and clinical information

regarding the caregivers. The third section consisted of two standardized instruments: the Zarit Burden Interview to assess caregiver burden and the Perceived Stress Scale to measure stress level. The final section included four questions designed to explore the belief systems of the caregivers.

Caregiver burden was assessed using the Zarit Burden Interview: Revised (22-item version). The total score ranged from 0 to 88. Scores between 0 and 21 indicated no to mild burden; scores from 22 to 40 represented mild to moderate burden; scores between 41 and 60 were classified as moderate to severe burden; and scores of 61 or above indicated severe burden<sup>15</sup>. Stress levels were measured using the Perceived Stress Scale. Scores between 0 and 13 were classified as low stress, indicating minimal levels of perceived stress. Scores ranging from 14 to 26 were categorized as moderate stress, reflecting the level of stress individuals experienced. Scores between 27 and 40 were considered high perceived stress, suggesting a significant level of stress experienced by individuals<sup>16</sup>.

SPSS version 26 was used to analyze the data. Means, standard deviations, and ranges were calculated for continuous variables, including age, duration of illness, and caregiving period. At the same time, frequencies and percentages were used for categorical variables like gender, diagnosis, stress levels, and belief systems. The reliability of the Zarit Burden Interview and the Perceived Stress Scale was assessed using Cronbach's alpha, yielding 76.3% and 71.6%, respectively. Burden and stress scores were categorized according to standard cutoffs to determine the distribution among caregivers. Chi-square tests were applied to examine associations between demographic or clinical characteristics and levels of burden and stress. A p-value of  $\leq 0.05$  was considered statistically significant for inferential comparisons.

## RESULTS

This study included a total of 363 participants. Descriptive statistics of patient and caregiver demographics and burden and stress scores are shown in **Table I**. The mean age of patients was  $39.06 \pm 13.59$  years, ranging from 19 to 73 years. The majority of patients were male (54.5%), and 60.6% had depression, followed by anxiety (30%) and psychosis (9.4%). The duration of psychiatric illness in patients averaged  $7.27 \pm 3.73$  years, ranging from 2 to 20 years. Caregivers were predominantly females (59%), with a mean age of  $44.06 \pm 16.64$  years, ranging from 18 to 80 years. The average duration of caregiving was  $6.31 \pm 3.62$  years, ranging from 1 to 18 years. Regarding clinical scores, the mean burden score among patients was  $40.54 \pm 17.90$  (range: 0 to 88), while the mean perceived stress score was  $21.44 \pm 7.07$  (range: 0 to 40).

**Table I: Descriptive statistics of patients and caregiver demographics and burden and stress score (n=363)**

Variables	Frequency	Percent
Age of Patients (years)*	39.06±13.59	
Gender of Patients	Male	198 54.5%
	Female	165 45.5%
Type of Psychiatric Illness	Depression	220 60.6%
	Anxiety	109 30.0%
	Psychosis	34 9.4%
Duration of Psychiatric Illness (years)*	7.27±3.73	
Age of Caregivers (years)*	44.06±16.64	
Gender of Caregivers	Male	149 41.0%
	Female	214 59.0%
Relationship with the Patient	Parent	89 24.5%
	Spouse	91 25.1%
	Child	49 13.5%
	Sibling	115 31.7%
	Friend	4 1.1%
	Cousin	15 4.1%
Duration of caregiving (years)*	6.31±3.62	
Total Burden score*	40.54±17.90	
Total Stress score*	21.44±7.07	

\*= mean ± standard deviation was given

The severity of caregiver burden showed notable variation: 51% experienced moderate to severe burden, 15.7% reported no to mild burden, and 9.9% reported severe burden. Regarding perceived stress,

**Table II: Distribution of Caregiver Burden, Perceived Stress Levels, and Belief Systems among Participants (n=363)**

Variable	Category	Frequency	Per-cent%
Severity of Burden	No to mild burden (0–21)	57	15.7
	Mild to moderate burden (22–40)	85	23.4
	Moderate to severe burden (41–60)	185	51.0
	Severe burden (>60)	36	9.9
Stress	Low score (0–13)	46	12.7
	Moderate stress (14–26)	235	64.7
	High perceived stress (27–40)	82	22.6
Beliefs	Religious	Patient has gone for treatment as a result of this disease Yes	167 46.0
		No	196 54.0
	Overvalued Ideas	belief that you consider more important than others Yes	192 52.9
		No	171 47.1
	Nazar	Patient got this disease as a result of Nazar Yes	207 57.0
		No	156 43.0
	Jadu	Patient got this disease as a result of Jadu Yes	214 59.0
		No	149 41.0

64.7% of caregivers reported moderate stress, 22.6% reported high stress, and 12.7% reported low stress. Regarding belief systems, 46% of patients had sought 'Dum' (spiritual healing) as a form of treatment.

**Table III: Comparison of Caregiver Burden across Demographic and Clinical Characteristics (n=363)**

Variable	Category	Caregiver burden				p-value
		No to mild	Mild to moderate	Moderate to severe	Severe	
Gender (Patient)	Male	30 (52.6%)	43 (50.6%)	104 (56.2%)	21 (58.3%)	0.792
	Female	27 (47.4%)	42 (49.4%)	81 (43.8%)	15 (41.7%)	
Psychiatric Illness (Patient)	Depression	29 (50.9%)	46 (54.1%)	117 (63.2%)	28 (77.8%)	<0.001
	Anxiety	28 (49.1%)	31 (36.5%)	44 (23.8%)	6 (16.7%)	
	Psychosis	0 (0%)	8 (9.4%)	24 (13.0%)	2 (5.6%)	
Relationship with the patient	Parent	12 (21.1%)	21 (24.7%)	46 (24.9%)	10 (27.8%)	0.761
	Spouse	15 (26.3%)	22 (25.9%)	47 (25.4%)	7 (19.4%)	
	Child	6 (10.5%)	9 (10.6%)	26 (14.1%)	8 (22.2%)	
	Sibling	21 (36.8%)	27 (31.8%)	58 (31.4%)	9 (25.0%)	
	Friend	0 (0%)	0 (0%)	3 (1.6%)	1 (2.8%)	
	Cousin	3 (5.3%)	6 (7.1%)	5 (2.7%)	1 (2.8%)	
Gender (Caregiver)	Male	24 (42.1%)	41 (48.2%)	68 (36.8%)	16 (44.4%)	0.331
	Female	33 (57.9%)	44 (51.8%)	117 (63.2%)	20 (55.6%)	

A chi-square test was applied, and  $p \leq 0.05$  was considered significant.

**Table IV: Comparison of Caregiver Stress across Demographic and Clinical Characteristics (n=363)**

Variable	Category	Stress			p-value
		Low	Moderate	High	
Gender (Patient)	Male	22 (47.8%)	126 (53.6%)	50 (61.0%)	0.319
	Female	24 (52.2%)	109 (46.4%)	32 (39.0%)	
Psychiatric Illness (Patient)	Depression	18 (39.1%)	151 (64.3%)	51 (62.2%)	<0.001
	Anxiety	28 (60.9%)	59 (25.1%)	22 (26.8%)	
	Psychosis	0 (0%)	25 (10.6%)	9 (11.0%)	
Relationship with the patient	Parent	11 (23.9%)	58 (24.7%)	20 (24.4%)	0.645
	Spouse	9 (19.6%)	63 (26.8%)	19 (23.2%)	
	Child	5 (10.9%)	28 (11.9%)	16 (19.5%)	
	Sibling	18 (39.1%)	72 (30.6%)	25 (30.5%)	
	Friend	0 (0%)	3 (1.3%)	1 (1.2%)	
	Cousin	3 (6.5%)	11 (4.7%)	1 (1.2%)	
Gender (Caregiver)	Male	22 (47.8%)	94 (40.0%)	33 (40.2%)	0.606
	Female	24 (52.2%)	141 (60.0%)	49 (59.8%)	

A chi-square test was applied, and  $p \leq 0.05$  was considered significant.

Additionally, 52.9% of caregivers endorsed overvalued ideas, 57% believed the illness was caused by 'Nazar' (evil eye), and 59% attributed it to 'Jadu' (witchcraft), as shown in **Table II**.

When examining the association of caregiver burden with demographic and clinical characteristics, no significant differences were found based on the gender of the patient ( $p = 0.792$ ), relationship to the patient ( $p = 0.761$ ), or caregiver gender ( $p = 0.331$ ). However, a significant relationship was observed between psychiatric illness type and caregiver burden ( $p < 0.001$ ), with caregivers of patients with depression reporting the highest burden, as explained in **Table III**. In the case of caregiver stress, no significant difference was found based on patient gender ( $p = 0.319$ ), relationship to the patient ( $p = 0.645$ ), or caregiver gender ( $p = 0.606$ ). Nevertheless, caregiver stress was significantly higher for caregivers of patients with depression ( $p < 0.001$ ), where 62.2% of caregivers reported high stress, as shown in **Table IV**.

## DISCUSSION

This study explored the burden and stress experienced by caregivers of individuals with psychiatric illnesses, along with their belief systems. We used standardized instruments, such as the Zarit Burden Interview and the Perceived Stress Scale, to quantify the extent of burden and stress in this population. The findings revealed that a significant proportion of caregivers had a caregiver burden. In our study, 51% of caregivers experienced moderate to severe burden, 15.7% reported no or mild burden, and 9.9% reported severe burden. These results align with existing literature indicating that psychiatric caregiving poses a significant burden on individuals, affecting their mental, emotional, and physical well-

being<sup>2,5,8,17,18</sup>. Naik G 2023<sup>18</sup> reported that caregiver burden was mild in 24%, moderate in 31%, and severe in 45% of caregivers. In another study, little to no burden was found in 17.8%, mild to moderate burden in 35.1%, moderate to severe burden in 32.5%, and severe burden in 14.6% of caregivers of psychiatric patients<sup>13</sup>. Rahmani F 2022<sup>19</sup> documented that little to no burden was reported in 12.9%, mild to moderate in 19.4%, moderate to severe in 29.4%, and severe burden in 38.3% of caregivers of patients with schizophrenia. The difference in burden severity is attributed to the difference in sample composition, as our study included caregivers of individuals with varying psychiatric diagnoses.

Our study observed no significant difference in caregiver burden and stress between genders ( $p=0.331$ ). However, previous studies have shown that female caregivers tend to experience a greater burden than male caregivers ( $p<0.05$ )<sup>5,18</sup>. The lack of significant gender differences in our study could be due to cultural and social factors that differ from those in previous studies. Interestingly, the type of psychiatric illness appeared to influence caregiver burden and stress. Caregivers of patients with depression reported significantly higher burden and stress compared to those caring for individuals with anxiety or psychosis, with  $p<0.05$  each. This may be due to the chronic and relapsing nature of depressive disorders and the emotional toll they impose.

The prevalence of moderate to high stress among caregivers, with nearly 87.3% scoring in the moderate or high-stress categories, indicates the challenging nature of caregiving roles. Similarly, a recent Pakistani study revealed that almost 50% of caregivers experienced mild to severe depression, while approximately 46% reported facing anxiety<sup>20</sup>. A Nepali

study also reported that most of the caregivers (86%) experienced moderate stress, followed by 14% with severe stress<sup>21</sup>. A more recent study reported that the overall level of secondary traumatic stress among caregivers was higher than the established scale midpoint, with a mean score of  $43.80 \pm 10.46$ <sup>22</sup>. Similarly, a study conducted in Bangladesh using the Perceived Stress Scale reported that 21.63% of caregivers experienced low stress, 76.60% had moderate stress, and only 1.75% reported high perceived stress<sup>23</sup>. Psychiatric illnesses often require long-term commitment, continuous monitoring, and emotional resilience, which explains the elevated stress levels among attendants. The unpredictable nature of psychiatric symptoms, social stigma, and a lack of structured support systems for caregivers in many regions, including Pakistan may compound stress<sup>20</sup>.

Belief in supernatural causes often coexists with formal psychiatric care in South Asian societies and hinders timely access to evidence-based treatment<sup>24-26</sup>. This study also examined the belief systems of caregivers and uncovered a strong reliance on cultural and spiritual explanations for psychiatric conditions. A considerable proportion of caregivers reported belief in supernatural causes such as Nazar (evil eye) (57%) and Jadu (witchcraft) (59%), with many patients seeking "Dum" (46%). These beliefs may influence the caregiving experience in multiple ways, from delaying psychiatric treatment to reinforcing stigma and isolation of both patients and caregivers. Addressing these belief systems through culturally sensitive psychoeducation is essential to improving patient and caregiver outcomes.

The study highlights the need for better mental health education and awareness among caregivers. Informing caregivers about the biological and psychological causes of psychiatric illnesses can reduce stigma, raise empathy, and improve caregiving practices. Furthermore, recognizing caregiver needs and providing psychological support, counseling, and relief care is vital in minimizing caregiver stress and preventing the development of secondary mental health issues in caregivers themselves.

The study had several limitations. Firstly, the small sample size and cross-sectional design restricted the generalizability of the findings. Important confounding variables such as caregiver personality traits, presence of comorbid physical illnesses, levels of expressed emotion, and intra-family conflicts were not explored. Additionally, the cross-sectional approach limited the ability to draw causal relationships. A longitudinal design would have provided more profound insights into the progression and extent of caregiver burden over time.

## CONCLUSION

Caregivers of psychiatric patients experience significant levels of burden and stress, particularly when dealing with depressive disorders. Belief in

supernatural causes remains widespread and may influence perceptions and practices of caregiving. There is an urgent need for culturally tailored support systems, psychoeducation, and policy-level interventions to support the mental health and well-being of caregivers.

**Ethical permission:** PNS Shifa, Karachi, Pakistan, ERC letter No. ERC/2023/PSY/71.

**Conflict of Interest:** No conflicts of interest, as stated by the authors.

**Financial Disclosure / Grant Approval:** No Funding agency was involved in the research

**Data Sharing Statement:** The corresponding author can provide the data proving the findings of this study on request. Privacy or ethical restrictions bound us from sharing the data publicly.

## AUTHOR CONTRIBUTION

Memon RZ: Idea conception, study design, data collection, results and interpretation, manuscript writing and proofreading

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Iqbal H: Idea conception, study design, data collection, results and interpretation, manuscript writing.

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