

# Emotional burden and psychological distress in caregivers of patients with obsessive compulsive disorder

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## ABSTRACT

**Objectives:** To seek the association and prevalence of emotional burden of caregivers of OCD patients with their emotional states of anxiety, depression and stress.

**Methods:** Descriptive study design was used. Present study was established in indoor and outdoor of Department of Psychiatry, Nishtar Medical University and hospital, Multan, Districts Head Quarters Hospital, Khanewal and D.G Khan Teaching Hospital from June, 2022 to November, 2022. Participants were 220 caregivers of OCD patients (Male=89, Female=131) approached through consecutive sampling technique. The Zarit Burden Interview (ZBI), and Depression anxiety stress scale (DASS) was utilize on participants along with demographics variable sheet. The data was analyzed using descriptive and inferential statistics by using SPSS-22.


**Results:** Pearson correlation showed significant positive association between emotional burden and three emotional states comprising of stress, anxiety and depression in caregivers of OCD patients. Descriptive statistics showed emotional burden was severe in (74.5%) caregivers of OCD patients. Emotional states was measured on three subscales with the following findings as level of stress was on mild level (48.1%), anxiety was severe (55.9%) in most of the caregivers and frequency of depression was on moderate (57.7%) level in Caregivers of OCD. Findings showed female caregivers perceived more burden as compared to male caregivers. Therefore, level of stress was also higher in female caregivers as compared to male caregivers.

**Conclusion:** It was concluded that psychiatric disorders, particularly OCD, impose a significant burden on caregivers, leading to psychological distress, including stress, anxiety, and depressive symptoms.

**Keywords:** Obsessive-Compulsive Disorder (MeSH); Caregiver Burden (MeSH); Depression (MeSH); Anxiety (MeSH); Stress (MeSH); Stress Disorder (MeSH).

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forgotten; physicians and clinicians may neglect to ask caregivers about their own mental and physical well-being throughout the disease course of the respective partner.<sup>4</sup>

Families of OCD patients face a lot of burden due to less social and financial. Caregiver of OCD patient might experience the emotional burden which causes anxiety, stress and depression. Caregivers of patients often experience symptoms of depression, such as persistent sadness, loss of interest, feeling of hopelessness and changes in appetite or sleep patterns. Due to uncertainty and responsibility caregivers also experienced anxiety. They may worry about wellbeing of the person they care for. Anxiety symptoms can include restlessness, irritability, difficulty concentrating and physical symptoms. Caregiving is stressful, as it involves managing complex medical needs, coordinating appointments, administering medication and providing emotional support. Stress is defined by overwhelmed, fatigued and over thinking.<sup>5</sup>

Numerous studies have been conducted to evaluate the emotional burden in family members of the patients with OCD. It was estimated that emotional burden in caregivers were similar or even greater than affective and schizophrenic disorders.<sup>6,7</sup> Caregivers of individuals with psychiatric disorder such as OCD

## INTRODUCTION

Mental illness can have a significant impact on family dynamics and relationships. Family members may experience increased level of stress, anxiety and depression as they try to cope with and support their loved ones with mental illness. Specifically, severity in obsessive compulsive symptoms is directly associated with family distress.<sup>1</sup> Therefore family members experienced feelings of hopeless and helplessness, frustration, anger, guilt, fatigue and other associated symptoms. Mental illness leads significant impact on

both patients and family members.<sup>2</sup> Caregiver burden is a multifaceted concept, as individuals can experience both objective and subjective types of burden.<sup>3</sup> The manner in which the family members of Obsessive compulsive disorder OCD patients facilitate, reassure and modify their routine and activities due to patient's obsessions and compulsions which may cause burden and psychological distress in family members. Caregiver burden has been largely overlooked by clinicians and in interventions. Informal caregivers have been called "the invisible patient" as they are often

experience significant emotional burden and psychological distress due to demands and challenges associated with caregiving. Inadequate sources and lack of trainings to deal with such situations can worsen in the condition of patient.<sup>8</sup> In earlier study, moderate level of emotional burden was assessed which was associated with the severity of disorder among family members of patient with OCD.<sup>9,10</sup>

Existing literature has explored various aspects of caregiver burden in the context of chronic physical illnesses<sup>11</sup> and some psychiatric conditions, but there is a notable gap in research specifically addressing the experiences of caregivers for patients with OCD.<sup>12</sup> This gap is particularly concerning given that caregivers are often deeply affected by the demands of caring for a loved one with OCD, experiencing high levels of stress, anxiety, and depression.<sup>13</sup>

Caregivers of individuals with obsessive compulsive disorder often experience significant emotional burden and distress due to demands and challenges associated with caregiving. Current study was conducted to explore the relationship and intensity of emotional burden and psychological distress in caregivers of OCD patients. Although there are limited studies on the unique experience of the caregivers in Pakistani perspective. Therefore, this study is intended to assess how family members of OCD patients experience caregiver burden and distress such anxiety, stress, and depression. Present study conducted on caregivers of OCD patients is essential for understanding the broader context of OCD treatment and providing caregivers with the support they need to fulfil their critical role in the care and recovery of their loved ones. This research will be helpful in leading to better outcomes for both the person with OCD and their caregivers.

### Objectives of the study

1. To assess the relationship of emotional burden and emotional states of anxiety, depression and stress in caregivers of OCD patients
2. To assess the prevalence and intensity of emotional burden and emotional states of anxiety, depression and stress in caregivers of OCD patients

## METHODS

The present study was held in Department of Psychiatry and Behavioral Sciences, Nishtar Medical University and hospital Multan, District Headquarter Hospital Khanewal and Teaching Hospital D.G Khan. Ethical approval letter was obtained from the Institutional Review board of the University, Order no: 1166 dated: 22-7-2022. Patients and caregivers were approached from in-patient and outpatient treatment services. Time period of the study was from July to December, 2022. Caregivers of OCD patients (N=220) were selected through consecutive sampling method in the study, (Males=89, Females=131) with age range of 18-60 years. Inclusion criteria: Patients included in the study had to meet the diagnostic criteria for OCD as outlined in the DSM-5. Caregivers were selected based on the indication by the OCD patients, identifying family members actively involved in their care. Caregivers must have been involved in the care of the OCD patient for a minimum of one year. Caregivers participating in the study were required to have the ability to understand the content of the questionnaires. Exclusion criteria: Patients with psychiatric disorders comorbid with OCD were excluded from the study. Patients who did not meet the inclusion criteria were excluded. Patients who attended the study without a caregiver were also excluded.

Present study based on descriptive research design. Consecutive sampling technique was used to collect data. Informed consent was taken from the participant prior to the study. All information and raw data were recorded on booklet consisted of sociodemographic sheet, The Zarit Burden Interview and Depression Anxiety Stress Scale.<sup>11-13</sup> If required then assistance was provided to complete the performance. Confidentiality and patient clinical care was ensured to the participants.

For analysis descriptive and inferential statistics both were applied by using SPSS-21 to obtain frequency and percentage. Person correlation was used to determine the association

between variables. Independent sample test was used to assess gender differences. 0.05 was selected as Alpha level of significance.

## RESULTS

Table I of Sociodemographic profile showed the caregivers of OCD patients is shown in Table I. Frequency of male caregivers was 40.4% and frequency of female caregivers was 59.5%. Male caregivers having age group 18 to 40 years were 70.4% and female caregivers having age group from 31 to 55 years were 29.5%. Findings of the family system of caregivers showed 74.5% belonged to nuclear family system and 25.4% caregivers' belonged to joint family system. In this study 68.1% percent of participants were from urban areas, 31.8% were from rural areas. Demographics findings of our study also explored that most of the participants were belonged to low socioeconomic status.

Table II of Correlation matrix showed that caregiver burden showed no association with stress, but exhibits positive association with anxiety and depression  $p < 0.05$ .

Table IV showed frequency of care duration was also important as more affected duration of illness was more than 5 years or more 125 (56.8%)

Table III showed that frequency of mother caregiver, 127 (57.7%) was more as compared to other relationships of patients with OCD.

Table V showed level of emotional burden in caregivers was mild in 4.0% moderate in 21.3% and severe 74.5% in caregivers of OCD patients.

The Table VII shows the middle most value median and interquartile range for difference in scores of males and females. It indicates that there was difference on emotional burden among male and female caregivers of OCD patients. Female caregivers showed more burden as compared to males and median score indicates that male caregivers are more prone to psychological distress. The Interquartile Range (IQR) is represented with the lower quartile (LQR) first and the upper quartile (UQR) second for each variable and gender group.

**Table I: Demographic characteristics of the participants (n=220)**

Demographic Variables		Frequency	Percentage
Gender	Male	89	40.45
	Female	131	59.54
Family System	Joint	56	25.45
	Nuclear	164	74.54
Locality	Urban	150	68.18
	Rural	70	31.81
Age (Years)	18-40	155	70.45
	41-55	65	29.54
Monthly Income (PKR)	10000-20000	31	14.09
	21000-30000	15	6.81
	31000-40000	28	12.72
	41000-50000	28	12.72
	50000-1 lac	98	44.54
	Above- 1 lac	28	12.72

**Table II: Correlation matrix of emotional burden and psychological distress among caregivers of OCD patients (n=220)**

Variables	Caregiver Burden	Stress	Anxiety	Depression
Caregiver Burden	–	0.48	.380**	.340**
Stress		–	..773**	.560**
Anxiety			–	.807**
Depression				–

Note: P&lt;0.05\*, P&lt;0.01\*\*

**Table III: Caregivers of OCD patients (n=220)**

Caregivers	Frequency	Percentage
Mother	127	57.72
Father	15	6.81
Sibling	37	16.81
Spouse	41	18.63

## DISCUSSION

In this study, we aimed to evaluate the factors affecting the mental health in caregivers of patients with OCD. Sociodemographic profile of the caregivers of OCD patients is shown in Table I. Frequency of male caregivers was 40.4% and frequency of female caregivers was 59.5%. Demographics findings of our study are consistent with

another study<sup>8</sup>, in which 31% were male caregivers of OCD patients and female caregivers were 69%. Caregivers having age group 18 to 40 years were 70.4% and caregivers having age group from 31 to 55 years were 29.5%. A research<sup>16</sup> showed similar demographics findings that around 48% caregivers of OCD patients were young and their age ranged from 18 to 45. Family caregivers

were 44% with age range of 40 years and above and 69% of them were females. Findings of the family system of caregivers showed most of the participants belonged to nuclear family system. In the same way a study<sup>17</sup> also showed that 75% OCD patients and caregivers belonged to the nuclear family system and remaining 25% were from joint family system. In this study most of the participants were from urban areas than rural areas. Our demographic findings are also in accordance with another findings<sup>14</sup> that caregivers living in urban areas were 57% and 40% caregivers were living in rural areas.

Demographics findings of our study also explored that low to middle socioeconomic status, were high in percentage. Likewise findings of another study<sup>18</sup> also reported that 70% of the caregivers were employed in a paid job and were of middle socioeconomic status.

Table II of Correlation matrix showed that caregiver burden is positively associated with emotional states of stress, anxiety and depression. A previous research showed consistency with our findings that caregiver of OCD patients experienced the emotional burden with severity of Psychological distress such as anxiety, depression and stress.<sup>19</sup> Moreover another study showed a highly significant positive relationship between obsessive compulsive disorder in patients and its association with caregiver burden and psychological distress.<sup>20</sup>

Table III showed that frequency of mother caregivers was high as compared to other relations of OCD patients. As previous studies also supported our findings that half of the caregivers (50%) were parents, (46.8%) of them were spouse in the caregiver group, whereas siblings and others represented almost a quarter (22%).<sup>21</sup> Moreover, another research had also revealed the same findings as percentage of female caregivers was more (69%) as compared to male caregivers (31%) of OCD patients.<sup>22</sup>

Table IV showed most of the caregivers were providing care to their OCD patient for last 5 years of illness onset. In the same way a previous study also

**Table IV: Duration of care for OCD patients (n=220)**

Duration of Care ( Years)	Frequency	Percentage
1	14	6.36
2	29	13.18
3	20	9.09
4	18	8.18
5	125	56.81
9	14	6.36

**Table V: Intensity of emotional burden of caregivers of OCD (n=220)**

Severity Level	Caregiver Burden	
	Frequency	Percentage
No or Minimal Burden	–	–
Mild	9	4.09
Moderate	47	21.36
Severe Burden	164	74.54

**Table VI: Intensity of psychological distress among caregivers of OCD (n=220)**

Severity Level	Stress		Anxiety		Depression	
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage
Mild	106	48.18	11	5	25	11.36
Moderate	98	44.54	40	18.18	127	57.72
Severe	16	7.27	123	55.90	68	30.90
Extremely severe	–	–	46	20.90	–	–

**Table VII: Median and interquartile ranges for comparison on gender of caregiver burden and psychological distress (n = 220)**

Variables	Median (LQR-UQR=IQR)	Median (LQR-UQR=IQR)
	Male	Female
Caregiver Burden	73 (63-82=13)	73.50 (64-82=9)
Stress	12 (12-14=3)	12 (12-14=2)
Anxiety	11 (9-15=6)	10 (9-15=1)
Depression	13 (11-14=3)	12 (11-14=6)

n=number of caregivers; LQR=Lower Quartile, UQR= Upper Quartile, IQR=interquartile range

revealed that the longer care duration of OCD illness predicts depression and burden in the caregiver.<sup>23</sup> Another research findings showed consistency with our findings that caregivers (45.1%) were having duration of caring

experience for 5 to 9 years.<sup>20</sup> In addition to current findings a study showed longer course of OCD and poorer patient insight into OCD symptomatology are also predictive of heightened caregiver burden.<sup>7</sup>

Table V showed the intensity of caregiving amongst the caregivers 82% showed severe burden while only 18% exhibited moderate level of emotional burden. In a similar vein found that (40%) of caregivers in the current study reported a high burden level.<sup>24</sup>

Table VI showed that amongst the caregiver mild stress was reported high as compared to moderate and severe stress percentage. As subscale anxiety is concerned in caregivers, and similarly in depression subscale showed moderate level of severity of caregivers. In another study similar findings were observed where level of stress was 46.9%, while anxiety was 36.3%, and depression was 9.4%.<sup>25</sup>

The Table VII shows that there was significance difference on emotional burden among females ( $75.4 \pm 8.38$ ) and male ( $69.6 \pm 12.5$ )  $p < 0.05$ , caregivers of OCD patients. There was also significant difference on stress, level of stress was found to be more in female caregivers ( $12.3 \pm 3.50$ ) as compared to male caregivers ( $11.9 \pm 3.40$ )  $p < 0.05$ . Another study was aligned with our results concluding that female caregivers had a higher risk of developing depressive symptoms.<sup>26</sup>

## CONCLUSION

In conclusion, our findings suggest that multiple factors contribute to the emotional burden and psychological distress among caregivers of OCD patients. Existence of OCD patients in family was positively correlated with emotional burden and psychological distress in caregivers. Severe level of emotional burden was prevailing among caregivers of OCD. Stress was mild, anxiety was severe in caregivers as well as moderate level of depression was found in caregivers of OCD patients. While considering higher number of mothers as caregivers of OCD patients in the family, they required greater assistance to resolve psychological issues. These findings highlight the urgent need for mental health services to integrate caregiver support into the treatment plans for OCD patients. By providing comprehensive assistance to caregivers, particularly those who are mothers, healthcare systems can enhance the overall well-being of both



patients and their families, potentially improving treatment outcomes for OCD.

### Limitations of the study and future recommendations

There are a few limitations that we must acknowledge in this study. Study was focused to one psychiatric illness. Some patients came with secondary caregivers rather than primary it creates somehow barriers to assess actual caregiver burden and distress. Study should be extend to other mental disorders in future research. Some other factors such as Social and psychological features of worse mental health outcomes in caregivers should also be explored.

Future studies may focus on the increase awareness in family members of OCD patients. There is huge need to be taught about how to deal emotional burden and distress by using coping strategies and stress management methods. To manage caregiver burden and to reduce stress, family support system should be strong. In Pakistan, family is a main supporting source for the patients with physical and mental illness. Training and assistance must be provided to such family to alleviate their emotional burden and distress. Hospital facilitate in from of free or less cost medicines to the patients so that financial burden may decrease on families of the patients. Encouragement of such caregivers will helpful in reducing the negatives consequences of the handling patients with mental illness from a long period of time as well as their quality of life will also be better. Future research should explore targeted interventions designed to alleviate the psychological distress experienced by caregivers, with a focus on personalized support programs for caregivers. Longitudinal studies are also needed to assess the long-term impact of caregiving on mental health and to identify effective strategies for reducing the emotional burden over time.

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## AUTHORS' CONTRIBUTIONS

Following authors have made substantial contributions to the manuscript as under:

**HAS, KI & RR:** Conception and study design, acquisition of data, drafting the manuscript, approval of the final version to be published

**FR & AW:** Analysis and interpretation of data, critical review, approval of the final version to be published

**AJ:** Study design, acquisition of data, critical review, approval of the final version to be published

*Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.*

## CONFLICT OF INTEREST

Authors declared no conflict of interest, whether financial or otherwise, that could influence the integrity, objectivity, or validity of their research work.

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## DATA SHARING STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request



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