

# Impact and Burden on the Quality of Life of Primary Caregivers of Schizophrenic Patients Presented in Lahore General Hospital

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## ABSTRACT

**Background:** Schizophrenia is a psychiatric disorder that incapacitates & overpowers the way a person conceives, perceives, conjectures and executes his internal thoughts and reciprocates with the external world. It can also be defined as a persistent deficit in cognition with the negative and positive symptoms, which typically starts in young age. Schizophrenia is characterized by social and functional disabilities not only of the affected patient, but also for the society and the family. Therefore, the current research focused on the impact and burden on quality of life of the primary caregivers of schizophrenic patients.

**Aims & Objective:** To determine the quality of life, predictors of QOL and caregiver burden among primary caretakers of patients having schizophrenia.

**Methods:** The cross-sectional research design was used in the present study and was conducted in Lahore General Hospital from January 2022 to June 2022. Using purposive sampling technique, 150 patients who attended the Psychiatry outpatient department of the hospital were recruited for this study.

**Results:** It shows that out of total 150 people, 98 (65.3%) males and 52 (34.7%) females were present in this study. Mostly parents 101(67.4%) were primary caregivers in the present population along with spouses 13(8.7%) and 26(17.4%) were real brothers/sisters. The frequency and percentage of son/daughter 3(2.2%) and 7 (4.3%) caregivers were with other relationships. Most of the caregivers 121(80.4%) were married, and 13(8.7%) were single. It also shows that the mean age of the male patients was 43.50 (14.73) years and mean age of the female was 48.91 (16.50). Family Burden Schedule interview identifies that financial burden has highest mean and effect on physical health of others has lowest mean. In WHOQOL-BREF physical, psychological and social health subscales has highest mean than environmental one. And that significant inverse relationship of financial burden has been found with social relationships, physical health and environment of caregivers. As financial burden increases environmental conditions, physical health and social relationships of caretakers decreases.

**Conclusion:** Caregiver burden is found to be negatively linked to QOL of the caregivers of individuals having schizophrenia. Moreover, caregiver burden is found to be a significant negative predictor of QOL of individuals taking care of people having schizophrenia.

**Keywords:** Schizophrenia, Quality of Life, Caregivers, Patient Welfare, Burden of Life

## INTRODUCTION

Schizophrenia is a psychiatric disorder that incapacitates and overpowers the way a person conceives, perceives, conjectures and executes his internal thoughts and reciprocates with the external world<sup>1</sup>. It can also be defined as a persistent deficit in cognition with the negative and positive symptoms, which typically starts in young age<sup>2,3</sup>. The clinical picture depends on the phase of life of the patient and includes Positive and Negative symptoms (hallucination, delusion, conceptual disorganization) and (blunt effect, lack of spontaneity, cognitive deficits, social & emotional withdrawal) respectively<sup>4,5,6</sup>. However, these symptoms vary drastically from one person to another. The cognitive deficit experienced by patients with schizophrenia serves as a predictor of occupational functioning and adherence to treatment<sup>7</sup>. The warning signs of schizophrenia include hostility or suspiciousness, inability to cry or express happiness, oversleeping or insomnia, expressionless gaze<sup>8</sup>, lack of awareness of personal hygiene, odd or irrational statements, inappropriate laughter or crying, forgetfulness, severe reaction to disapproval and failure to concentrate<sup>9,10</sup>.

According to ICD 10, schizophrenia is further differentiated into disorganized, paranoid, residual, catatonic, and undifferentiated types majorly depending upon the clinical presentation<sup>11</sup>. When the main etiological links are explored, the schizophrenia is found to be caused by a combination of environmental and genetic factors<sup>12,13,14</sup>.

Schizophrenia is characterized by social and functional disabilities not only of the affected patient, but also for the society and the family. Over the decades, the care of schizophrenic patients has been moved from the hospitals to community, where family members provide the greater part of concern to these patients<sup>15,16</sup>. In Pakistani culture, family is incorporated for the

treatment of patient, living with them. When schizophrenic patient is admitted to hospital and is also suicidal or disturbed, family members were anticipated to perform the patient's part and bear expenditure of the treatment, manage and treat the patient and involve the patient in significant rehabilitating activities. All these experiences put a significant amount of burden on caregivers and affect their quality of life. Research suggested that most of the primary caregivers experienced psychological morbidity due to their role of providing care. Therefore, the current research focussed on the burden and quality of life of the primary caregivers of schizophrenic patients.

## PATIENT & METHODS

**Research Design:** The cross-sectional research design was used in the present study.

**Sampling Strategy:** Purposive sampling strategy was used. This sampling strategy was used because of characteristics of caregivers who were coming with patients with schizophrenia in Psychiatry department indoor/outdoor facilities at Lahore General Hospital.

**Sample:** The sample size of the current study was determined with the help of formula of sample size in proportion. Determined sample size was 96 rounded off to 100 with  $\alpha = 0.5$  and  $\beta = 0.95$  with medium effect size. In the current study a total of 150 caregivers (98 men, 52 women) were taken from Lahore General Hospital Lahore to minimize the representative sample.

### Inclusion Criteria

- Caregivers of patients with diagnosed psychiatric illness of schizophrenia, according to ICD 10 Criteria.
- Caregivers of patients with schizophrenia who were above 18 to 60 years of age.

- Primary caregivers (spouse in case of married person or caretaker sharing same house).

**Exclusion Criteria**

- A caregiver who was related to the patient other than parent, spouse, sibling or close relative in case of no parent, spouse or sibling alive or unable to take care.
- Caregivers of patients with co morbid disorders (i.e. Substance dependence apart from nicotine, intellectual disability, depressive disorder, anxiety disorder, obsessive compulsive disorder, psychosis etc.).

**RESULTS**

The present study explored the burden & effect QOL of caregivers and the correlation of caregiver burden with quality of life in primary caregivers of individuals having schizophrenia.

The results of the study (Table 1) shows that 98 (65.3%) males and 52 (34.7%) females were present in this study. Mostly parents 101(67.4%) were primary caregivers in the present population along with spouses 13(8.7%) and 26(17.4%) were real brothers/sisters. The frequency and percentage of son/daughter 3(2.2%) and 7 (4.3%) caregivers were with other relationships. Most of the caregivers 121(80.4%) were married, and 13(8.7%) were single. The divorced were 3 (2.2 %) and the widows were 13 (8.7%). 55 (55%) of the caregivers were educated up till primary and 39(26.1%) had no formal education. The caregivers with matric qualification were 20(13%) and above matric qualified caregivers were 36(23.9%). While 137 (91.3%) caregivers had a joint family system and 10(6.5%) of the caregivers of the patients with schizophrenia were living in an extended family system. 78 (52%) of the patient’s caregivers were Jobless whereas, 33 (21.7%) of caregivers were employed, and 39 (26.1%) of the caregivers were self-employed.

Table 2: Identified that the mean age of the male patients was 43.50 (14.73) years and mean age of the female was 48.91 (16.50). Table 2 also identifies that in Family Burden Schedule interview, financial burden has highest mean and effect on physical health of others has lowest mean. In WHOQOL-BREF physical, psychological and social health subscales has highest mean than environmental one.

Table 3: Hypothesis we stated that there is a relationship between caregiver burden and Quality of Life of caretakers of people with schizophrenia. For testing this hypothesis, Pearson’s Product Moment Correlation was used.

Table 3, shows that significant inverse relationship of financial burden has been found with social relationships, physical health and environment of caregivers. As financial burden increases environmental conditions, physical health and social relationships of caretakers decreases.

Disruption of routine family activities had significant inverse relationship with physical health of caregiver which indicating that family activities of caregivers increase and physical health of caregivers decreases. Disruption of family leisure had significant negative relationship with physical health and social relationships

of care giver.

This shows that as disruption of family leisure increases physical health and social relationships of caregiver decreases. Disruption of family interaction had significant inverse relationship with social relationship, physical health and environment of caregiver. Effect on mental and physical health of others had significant increase relationship with social relationships and environment of caregiver. This indicates that as effect of burden on mental and physical health of others increases, social relationships and environment of caregiver decreases.

Table 1: Frequency and Percentages of Demographic Variables of Caregivers of Patients with Schizophrenia.

Variables	F	%
Gender		
Male	98	65.3
Female	52	34.7
Relationship with patient		
Spouse	13	8.7
Real Brother/Sister	26	17.4
Parents	101	67.4
Son/Daughter	3	2.2
Others	7	4.3
Marital Status		
Married	121	80.4
Single	13	8.7
Divorced	3	2.2
Widowed	13	8.7
Occupation		
Jobless	78	52.2
Employed	33	21.7
Self Employed	39	26.1
Education		
No Formal Education	39	26.1
Primary	55	37.0
Matric	20	13.0
Above Matric	36	23.9
Family System		
Joint	137	91.3
Extended	10	6.5
Not Responded	3	2.2

Note: N=150, M=Mean, SD=Standard Deviations, f=Frequency, %=Percentage

Table 2: Mean and Standard deviation of Age, Number of Episodes, Score on Family Burden Interview Schedule and WHO QOL-BREF

Assessment Measures	M	SD
Age		
Male	43.50	14.73
Female	48.91	16.50
Family Burden Interview Schedule	49.03	12.05
Financial burden	12.90	3.34
Disruption of family activity	9.97	2.76
Disruption of family leisure	8.23	2.66
Disruption of family interaction	9.67	3.19
Effect on physical health of others	3.09	1.23
Effect on mental health of others	5.17	2.05
WHOQOL-BREF	3.09	.66
Physical health	3.37	.75
Psychological	3.09	.75
Social relationships	3.33	.86
Environment	2.81	.78

Note N=112. M= Mean, SD = Standard Deviation

Table 3: Intercorrelations, Means, and Standard Deviations for Scores of Family Burden Interview Schedule and WHOQOL-BREF

	1	2	3	4	5	6	7	8	9	10	11	12
Financial Burden												
Disruption of Family Activity	.57**											
Disruption of Family Leisure	.45**	.63**										
Disruption of Family Interaction	.45**	.67**	.66**									
Effect on Physical health of others	.36**	.42**	.42**	.66**								
Effect on Mental Health of others	.36**	.60**	.53**	.57**	.61**							
Physical health	-.32**	-.24**	-.16*	-.25**	-.13	-.15						
Psychological	.00	-.02	.05	-.11	.06	.02	.67**					
Social relationships	-.45**	-.48	-.26**	-.47**	-.26**	-.43**	.54**	.44**				
Environment	-.25**	-.14	-.04	-.28**	-.19*	-.17*	.69**	.75**	.48**			
Family Burden Interview Schedule	.73**	.85**	.80**	.85**	.67**	.74**	-.29**	-.01	-.52**	-.23**		
WHOQOL-BREF	-.31**	-.25**	-.13	-.34**	-.18*	-.21**	.88**	.85**	.66**	.90**	-.32**	-

Note, N= 150 \* <.05, \*\* <.01, \*\*\* <.001

**DISCUSSION**

The findings of the researches conducted by different researchers have a strong negative association between caregiver burden and

QOL of caregivers of individuals having schizophrenia<sup>17, 18, 19, 20</sup>. Results of the current research are consistent with the findings of the previous researches conducted on primary caregiver burden

and QOL. In the present study it was found that 91.3% participants lived in joint family system where everyone is very much concerned about the health of one another and been greatly affected by the illness of even a single family member. Furthermore, 86% of the caregivers were spouses, parents, siblings living with the patient and taking care of the patient along with their other responsibilities, hence increasing their family burden<sup>21,22</sup>. The finding of the present study is in line with the findings of the previous researches exploring this phenomenon.

Results of the research further showed that financial burden is negatively linked with quality of life (social relationships, physical health and environment). In the present study, 53% of the caregivers were jobless which make it more difficult to manage the financial burden of the family along with the expenses of medication and hospitalization for the patient with schizophrenia.

As social interaction, socialization, uniformity and continuity in daily routine life and leisure time activities have a strong contribution in enhancing QOL of people, any disturbance in them result in a decrease in quality of life. In the case of high levels of caregiver burden, quality of life decrease as caregivers fail to manage their daily life and leisure time activities and are always preoccupied with the care and needs of the patient with schizophrenia requiring loose supervision. Results of the research are in line with the previous researches conducted by<sup>23,24,25,26</sup>.

Findings of the present research are in line with the findings of the previous researches conducted by<sup>27,28,29</sup>. They explored the predictive relationship between caregiver burden and QOL and found caregiver burden as significant negative predictor of QOL of people taking care of individuals suffering with schizophrenia.

## CONCLUSION

Caregiver burden is found to be negatively linked to QOL of the caregivers of individuals having schizophrenia. Moreover, caregiver burden is found to be a significant negative predictor of QOL of individuals taking care of people having schizophrenia.

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