

Research Paper

## Quality of Life and Burden of Care among Caregivers of Treatment Adherent and Non-Adherent Patients with Schizophrenia

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### ABSTRACT

**Background-** Schizophrenia is a chronic mental illness with an early onset and severe symptomatology. It negatively affects the lives of patients and requires years of caregiving. Non-adherence is a significant problem in schizophrenia and can result in increased psychiatric hospitalization, decreased quality of life, and increased caregiver burden therefore it must be assessed to provide relevant interventions. This study explores the impact of non-adherence on caregivers' quality of life and burden of care. **Aim-** To assess and compare quality of life and burden of care among caregivers of treatment adherent and non-adherent patients with schizophrenia. **Material and methods-** The study was done at a tertiary care hospital to assess and compare Quality of life and burden of care among caregivers of treatment adherent and non-adherent patients with schizophrenia. The study had a cross-sectional design and involved 30 caregivers each of treatment adherent patients with schizophrenia and treatment non-adherent patients with schizophrenia. The sample size was estimated after reviewing the last year hospital trend of patients with relevant diagnosis. Patients and their caregivers meeting inclusion and exclusion criteria and consenting were included in the study. The data on socio-demographic profile was collected via a proforma, adherence was assessed using Brief adherence rating scale, Quality of life among caregivers was assessed using WHO QOL-BREF and Burden of care was assessed using Burden assessment schedule of SCARF. **Results-** The overall quality of life gave a mean score of 82.90 with a standard deviation of 12.71 in the treatment adherent group and 75.80 with a standard deviation of 14.03 in the treatment non-adherent group. A p-value of 0.045 depicts statistical significance. The burden score was found to be higher in all the domains among the caregivers of treatment non-adherent patients, except in the domain of patient's support, where burden score was higher among the caregivers of treatment adherent patients. **Conclusion-** The study suggests that the caregivers of patients in treatment non-adherent group have overall poorer quality of life as assessed by WHO-QoL-BREF. Also, the burden of care is higher among the caregivers of treatment non-adherent group.

**Keywords:** Schizophrenia, Adherence, QOL, Burden of Care

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Schizophrenia is a chronic mental illness with an early onset and severe symptomatology. It negatively affects the lives of patients and requires years of caregiving<sup>1</sup>. The burden of caregiving for people with schizophrenia includes physical work, emotional pressure, social restrictions, and economic demands. Caregivers also face social stigma and prejudice from society<sup>2</sup>. The quality of life of caregivers is related to their burden of caregiving, lack of social support, and family relationship issues and hence experience a poor outcome in this domain<sup>3</sup>. With the increase in the incidence of mental illness, it is essential to evaluate the quality of life and burden of care among caregivers to provide necessary support and help to improve their overall wellbeing.

Non-adherence is a significant problem in schizophrenia due to factors such as lack of illness awareness, the direct impact of symptoms, social isolation, comorbid substance misuse, and stigma. This issue can result in increased psychiatric hospitalization, decreased quality of life, and increased caregiver burden. The impact of non-adherence on caregivers' quality of life and burden of care must be assessed to provide relevant interventions<sup>4</sup>.

In India, the shortage of trained professionals and infrastructure has resulted in an inadequate development of mental health services, leading to increased burden of care among family members of those with mental illnesses. Several studies have shown that caregiver burden is moderate to high, with male caregivers suffering significantly more burden.

Valenstein et al<sup>5</sup> found that 18% of schizophrenia patients were consistently nonadherent over a 4-year period, while Liu-Seifert et al<sup>6</sup> found that higher levels of perceived medication benefit were associated with reduced risk of early treatment discontinuation. Studies conducted by Adeosun and Adelufosi<sup>7</sup> found that female caregivers, unemployed caregivers, and poor social support were associated with higher burden scores, while studies by Gulseren et al<sup>8</sup> and Magliano et al<sup>9</sup> identified various factors associated with caregiver burden. Finally, a study by Angermeyer et al<sup>10</sup> found that the quality of life of spouses of mentally ill people was lower in domains such as psychological well-being and social relationships compared to the general population.

### **MATERIALS AND METHOD**

#### ***Research design and setting-***

A cross-sectional study is conducted. Standards described in the consolidated standards of reporting trials (CONSORT) were followed, using CONSORT checklist and CONSORT flow diagram. The study was carried out in the Department of Psychiatry, Pt.B.D. Sharma, PGIMS, Rohtak.

#### ***Sample size and collection-***

Participants were recruited using purposive sampling with total 60 participants from the outpatient department of Psychiatry, Institute of Mental Health, Pt. B. D. Sharma, University of Health Sciences, Rohtak. The data collection lasted from September 2021 to June 2022. The caregivers of patients diagnosed with schizophrenia according to ICD-10 criteria and those who fulfilled the study criteria were selected for the study.

#### ***Procedure and participants***

The present study was done at the Department of Psychiatry, Pt. B.D. Sharma PGIMS, Rohtak, a tertiary care hospital of North India. The aim of the study was to compare Quality

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of life and burden of care among caregivers of treatment adherent and non-adherent patients with schizophrenia. The study had a cross-sectional design and involved 30 caregivers each of treatment adherent patients with schizophrenia and treatment non-adherent patients with schizophrenia. The sample size was estimated after reviewing the last year hospital trend of patients diagnosed with schizophrenia visiting the Department of Psychiatry, Pt. B.D. Sharma PGIMS, Rohtak. The study was conducted with patients and their caregivers attending the psychiatry OPD. Caregivers of the diagnosed cases of schizophrenia were included in the study. The patients diagnosed with schizophrenia, coming for follow up in the psychiatry OPD with their caregiver, who fulfilled inclusion and exclusion criteria were selected and included in the study.

<b>Inclusion criteria for patient</b>	<b>Inclusion criteria for caregiver</b>
Patients diagnosed with schizophrenia (F-20 according to ICD 10)	Caregiver of age above 18 years
Patient age group between 18-65	Staying with patient during last 1 year prior to assessment
Total duration of illness more than 2 year	Subjects who are willing to give written consent.
Who are on oral medication only	

<b>Exclusion criteria for patient</b>	<b>Exclusion criteria for caregiver</b>
Patients with other physical or psychiatric co-morbidity	Caregiver with Mental retardation
Patients with Mental retardation	Caregiver taking care of more than one patient

The data on socio-demographic profile was collected via a proforma, adherence was assessed using Brief adherence rating scale, Quality of life among caregivers was assessed using WHO QOL-BREF and Burden of care was assessed using Burden assessment schedule of SCARF.

**WHO QOL-BREF (HINDI VERSION)<sup>11</sup>:** Hindi version of the WHO-QoL-BREF was used for assessing the quality of life of the caregivers. It is a 26-item instrument, which measures four domains of Quality of Life- physical health, psychological, social and environmental.

**BURDEN ASSESSMENT SCHEDULE OF SCARF<sup>12</sup>:** It is developed at SCARF with the support of the WHO SEARO and is based on an integrative framework encompassing subjective and objective components of burden. The instrument comprised 40-items with kappa value of 0.8.

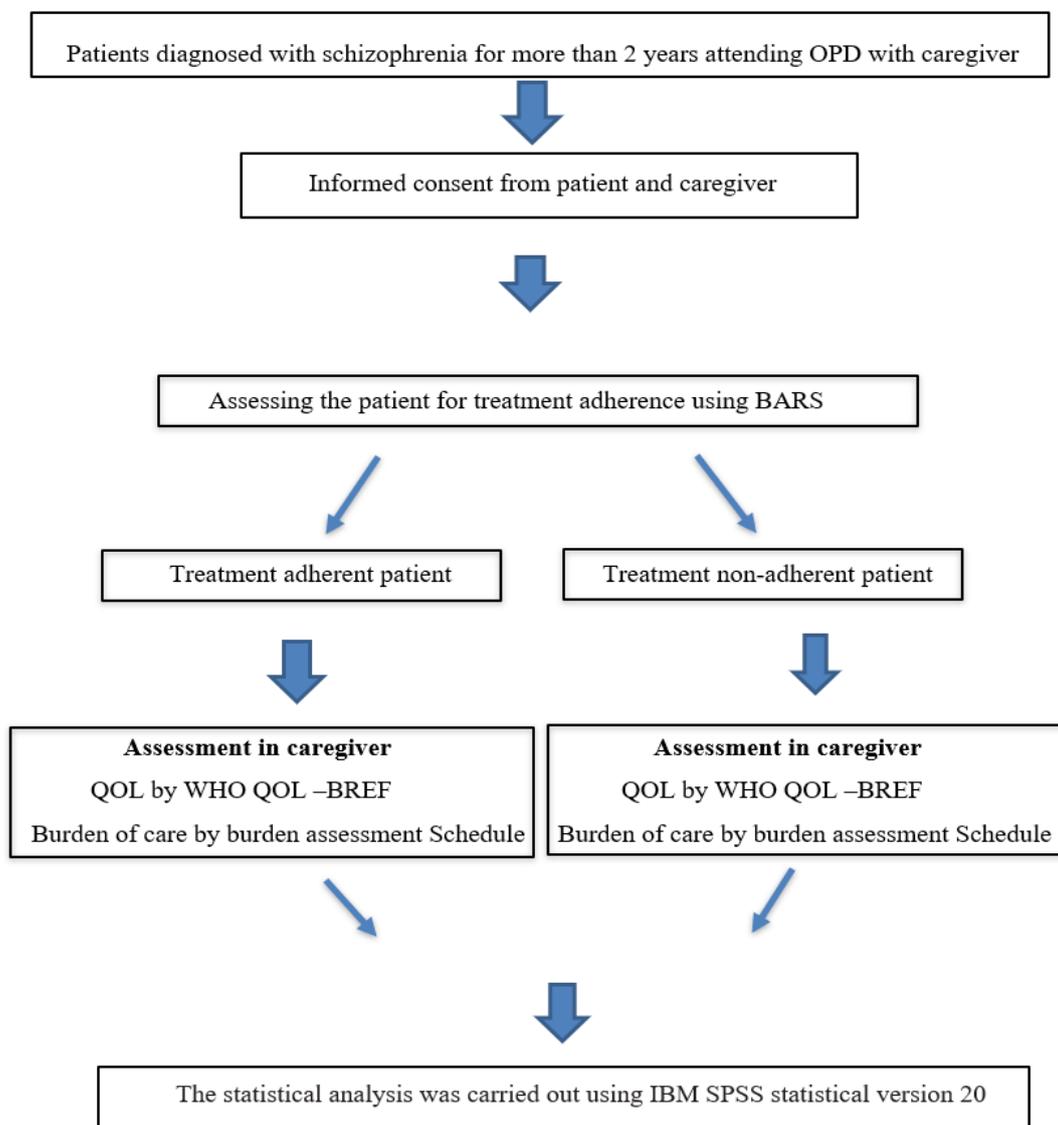
**BREIF ADHERENCE RATING SCALE (BARS)<sup>13</sup>:** The BARS is a clinician-administered adherence assessment tool consisting of three questions (adapted with permission from a questionnaire used in the CATIE trial about the patient's knowledge of their own medication regimen and episodes of missed medication taking

**Statistical analysis-** The statistical analysis was carried out using IBM SPSS (Statistical Package for Social Sciences) statistical version 20. The analysis includes frequency table, association of variables based on Chi-square test. All quantitative variables were estimated

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using measures of central location (mean and median) and measures of dispersion (standard deviation). All statistical tests were seen at two-tailed level of significance ( $p \leq 0.01$  and  $p \leq 0.05$ ).

### Flow Chart of the procedure



## RESULTS

The detailed information was collected from the care-givers of patients with Schizophrenia, presented in the outpatient facility of Department of Psychiatry from May 2021 to May 2022. 30 subjects each of treatment adherent and non-adherent patients with Schizophrenia were included in the final analysis. They were evaluated and assessed according to routine procedure followed in OPD/IPD as well as according to patient proforma. Quality of Life as well as Burden Assessment Schedule score were calculated and were used for statistical analysis, upon which following observations were made.

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**Demographic profile of treatment adherent (N=30) and non- adherent (N=30) patients with schizophrenia**

Demographic parameters	Study group		P value
	Adherent (N=30)	Non-Adherent (N=30)	
<b>Age group</b>			
18 to 25 years	2 (6.7%)	3 (10.0%)	0.940
26 to 35	9 (30.0%)	7 (23.3%)	
36 to 45	7 (23.3%)	9 (30.0%)	
46 to 55	6 (20.0%)	6 (20.0%)	
56 to 65	6 (20.0%)	5 (16.7%)	
<b>Gender</b>			
Male	17 (56.7%)	18 (60.0%)	0.793
Female	13 (43.3%)	12 (40.0%)	
<b>Education</b>			
Illiterate	7 (23.3%)	6 (20.0%)	0.113
Primary	8 (26.7%)	12 (40.0%)	
Matriculation	8 (26.7%)	3 (10.0%)	
Higher Secondary	2 (6.7%)	7 (23.3%)	
Graduation	2 (6.7%)	2 (6.7%)	
Post Graduation	3 (10.0%)	0 (0.0%)	
<b>Occupation</b>			
Employed	14 (46.7%)	7 (23.3%)	0.133
Unemployed	8 (26.7%)	14 (46.7%)	
Housewife	8 (26.7%)	9 (30.0%)	
<b>Marital status</b>			
Single	14 (46.7%)	9 (30.0%)	0.453
Married	15 (50.0%)	19 (63.3%)	
Widowed	1 (3.3%)	2 (6.7%)	
<b>Background</b>			
Rural	14 (46.7%)	24 (80.0%)	0.007
Urban	16 (53.3%)	6 (20.0%)	
<b>Family type</b>			
Nuclear Family	23 (76.7%)	25 (83.3%)	0.885
Joint Family	5 (16.7%)	3 (10.0%)	
Extended Nuclear Family	2 (6.7%)	2 (6.7%)	

Among both the groups, majority of the patients i.e., 53% were of middle age (25-45 years old). Among the treatment adherent group 12 (40 %) participants were aged above 45 years while among treatment non-adherent group 11 (36 %) were above 45 years of age. Among both the groups, majority of the participants were male, 56.7% in treatment adherent group and 60% in non-adherent group were male (Figure 1). Among the treatment adherent group 7 (23.3%) and 6 (20%) in non-adherent group had no formal education. Majority of the participants in treatment non-adherent group i.e., 12 (40%) had only primary level education. In treatment adherent group 3 (10%) of the participants were post-graduate while none of the participants in non-adherent group had done post-graduation. Among the treatment adherent group, majority i.e., 14 (46.70%) participants were employed, while among treatment non-adherent group, majority i.e., 14 (46.70%) participants were

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unemployed (Figure 2). Among both the groups majority of participants were married. Among the treatment adherent group, majority i.e., 16 (53.30%) participants were living in urban area and among the treatment non-adherent group, 24 (80.00%) participants were living in rural area (Figure 3). Among treatment adherent group, majority i.e., 23 (76.70%) participants were living in nuclear family, and similarly among the treatment non-adherent group, majority i.e., 25 (83.30%) participants were living in nuclear family.

### Comparison of WHO-QOL-Bref scores between caregivers of treatment adherent (N=30) and non-adherent (N=30) patients with schizophrenia.

Parameter	Study group		P value	Inference
	Adherent (N=30) (Mean $\pm$ SD)	Non-Adherent (N=30) (Mean $\pm$ SD)		
DOM1	13.92 $\pm$ 2.36	12.82 $\pm$ 2.64	0.090	<i>Insignificant</i>
DOM2	12.96 $\pm$ 1.94	11.67 $\pm$ 2.76	0.069	<i>Insignificant</i>
DOM3	11.20 $\pm$ 3.02	10.09 $\pm$ 3.13	0.167	<i>Insignificant</i>
DOM4	11.88 $\pm$ 2.21	10.97 $\pm$ 1.87	0.084	<i>Insignificant</i>
<b>Total score</b>	82.90 $\pm$ 12.71	75.80 $\pm$ 14.03	0.045*	<b>Significant</b>

\*P value < 0.05 (statistically significant)

The difference in mean of DOM1, DOM2, DOM3, DOM4 between two groups was statistically insignificant. The mean total score of treatment adherent group was 82.90  $\pm$  12.71 and treatment non-adherent group was 75.80  $\pm$  14.03, the difference between two groups was statistically significant (P value 0.045).

### Comparison of mean score for each domain of BAS scale among care givers of treatment adherent (N=30) and non-adherent (N=30) patients with schizophrenia.

Domains of burden scale	Study group		P value (Mann Whitney U test)	Inference
	Adherent	Non-Adherent		
Spouse related	5.63 $\pm$ 2.71	6.17 $\pm$ 2.49	0.301	<i>Insignificant</i>
Physical and mental health score	10.40 $\pm$ 3.02	11.73 $\pm$ 3.36	0.164	<i>Insignificant</i>
External support score	7.40 $\pm$ 1.65	8.07 $\pm$ 2.07	0.319	<i>Insignificant</i>
Care-Giver routine	6.13 $\pm$ 1.55	7.20 $\pm$ 1.16	0.004*	<b>Significant</b>
Support of patient	5.70 $\pm$ 1.21	5.67 $\pm$ 0.96	0.640	<i>Insignificant</i>
Taking responsibility	10.40 $\pm$ 2.27	12.73 $\pm$ 1.86	<0.001*	<b>Significant</b>
Other Relations	5.13 $\pm$ 1.53	6.00 $\pm$ 1.44	0.026*	<b>Significant</b>
Patient behaviours	8.07 $\pm$ 2.13	9.20 $\pm$ 3.13	0.179	<i>Insignificant</i>
Care-givers strategy	7.43 $\pm$ 1.77	8.20 $\pm$ 1.24	0.074	<i>Insignificant</i>

\*P value < 0.05 (statistically significant)

Among the treatment adherent group, the mean physical and mental health was 10.40  $\pm$  3.02 and it was 11.73  $\pm$  3.36 in treatment non-adherent group. The difference in the physical and mental health between study group was not statistically significant (P Value 0.164). Among the treatment adherent group, the mean care-giver routine score was 6.13  $\pm$  1.55 and it was 7.20  $\pm$  1.16 in treatment non-adherent group. The difference in the care-giver routine score between study group was statistically significant (P Value 0.004). Among the participants in treatment adherent group, the mean taking responsibility score was 10.40  $\pm$  2.27 and it was 12.73  $\pm$  1.86 in participants of treatment non-adherent group. The difference in the taking responsibility score between study group was statistically significant (P Value <0.001).

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Among the people in treatment adherent group, the mean of other relations score was  $5.13 \pm 1.53$  and it was  $6.00 \pm 1.44$  in treatment non-adherent group. The difference in the other relations score between study group was statistically significant (P Value 0.026). Among the people in treatment adherent group, the mean of patient behaviours score was  $8.07 \pm 2.13$  and it was  $9.20 \pm 3.13$  in treatment non-adherent group. The difference in the patient behaviours score between study group was statistically not significant (P Value 0.179). Among the people in treatment adherent group, the mean care-givers strategy score was  $7.43 \pm 1.77$  and it was  $8.20 \pm 1.24$  in treatment non-adherent group. The difference in the care-givers strategy score between study group was statistically not significant (P Value 0.074).

To summarize Quality of Life was measured using the WHO-QoL-BREF and compared between the two groups of caregivers. The overall quality of life was found to be significantly affected in caregivers of treatment non-adherent group with low total mean score as compared to treatment adherent group.

When the comparison is made between various domains of burden using the BAS, there is a statistically significant difference between the two study groups in the domains of- 1) caregiver routine ( $p=0.004$ ), 2) taking responsibility ( $p<0.001$ ), 3) other relations ( $p=0.026$ ). In these domains burden was found to be more in caregivers of treatment non-adherent group.

### DISCUSSION

The present study is based on the clinical concern that in the cases of severe mental disorders like that of schizophrenia, the caregivers experience a considerable amount of burden, which in turn affects their quality of life in all domains, which needs to be studied as it not just affects the course and treatment of the persons implicated, but also increase the burden of the disease and vice versa. Nonadherence to treatment also lowers the quality of life and increases the burden of care in caregivers of patient with schizophrenia. Decreased QOL may be associated with caregivers' burden, lack of social support, course of the disease and family relationships problems. In the light of the recent developments in the field of psychiatry, in terms of better accessibility, infrastructure, human resources and treatment options, the dynamics of relationship between the disease, patient and the caregiver has evolved significantly, and needs to be studied and understood.

#### *Comparison of Quality of Life*

The overall quality of life gave a mean score of 82.90 with a standard deviation of 12.71 in the treatment adherent group and 75.80 with a standard deviation of 14.03 in the treatment non-adherent group. A p-value of 0.045 depicts statistical significance. This suggest that the caregivers of patients in treatment non-adherent group have overall poorer quality of life as assessed by WHO-QoL-BREF.

The fact that the caregivers of patients with severe mental illnesses have a decline in their quality of life has been established by various studies [Foldemo et al<sup>14</sup> (2005), Li et al<sup>15</sup> (2007)], and that decline is particularly severe in case of caregivers of patients with schizophrenia, was underlined by the landmark study of Roychaudhuri et al<sup>16</sup> (1995). It was found in the present study that the quality of life was poor in caregivers of treatment non-adherent patients when compared with treatment adherent group. Although many previous studies have shown that treatment non-adherence is related to poor quality of life in patients but similar comparison studies on quality of life of caregivers is still lacking and more research is required to support these findings.

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### *Comparison of Burden of Care*

In this study, the burden score was found to be higher in all the domains among the caregivers of treatment non-adherent patients, except in the domain of patient's support, where burden score was higher among the caregivers of treatment adherent patients. The high burden score implies more burden in most of the domains for caregivers of treatment non-adherent patients. However, when compared statistically, more burden was found among the caregivers of treatment non-adherent patients only in the domains of care-giver routine, taking responsibility and other relations. Roychaudhuri et al<sup>16</sup> (1995), reported similar findings in his study as he found the burden to be higher among the caregivers of schizophrenic, young, male, low income and unemployed patients. These findings are partially in line with the findings of Kumar and Mohanty<sup>17</sup> (2007), who have reported significant burden only in the domains of external support, support of patient and patient's behavior apart from caregiver-routine and caregiver strategy. Chadda et al<sup>18</sup> (2007), on the other hand, have reported high scores specifically on two of the burden factors only: physical and mental health, and taking responsibility. As from the current study as well as previous studies it can be clearly concluded that there is higher burden of care among caregivers of patients with schizophrenia but the research comparing the effect of treatment adherence on burden of care is lacking. Hence, more research focusing on role of treatment adherence in quality of life and burden of care in caregivers of patients with mental illness is required.

### *Limitations of the Study*

- The study is hospital-based, and hence the findings cannot be generalized for the whole population.
- The sampling technique used was convenient sampling.
- Coping strategies of the caregivers which are known to mediate in the perception of the burden of care and quality of life have not been assessed in the study.
- There were no assessments of the level of patient's functioning, which is an important variable affecting the caregiver burden.

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### **Conflict of Interest**

The author(s) declared no conflict of interest.

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