Original Article

Caregiver Burden and Quality of Life in Primary Caregivers of Schizophrenia Patients: A Cross-sectional Study from a Tertiary Care Hospital

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Abstract

Background: With a shift in treatment and care of schizophrenia over the years, with more and more patients being treated on an outpatient basis and cared in community, caregivers experience distress in psychological and emotional health, have reduced social contact, have financial difficulties, have low life satisfaction, and have poor mental and physical health. **Aims:** The aim is to understand the quality of life (QoL) and the extent of burden perceived by caregivers while caregiving a family member with a diagnosis of schizophrenia. **Materials and Methods:** This was a cross-sectional study. A total of 75 schizophrenia patients and their caregivers were included in this study. Standardized instruments were administered to patients as well as to caregivers to collect data regarding symptomatology in patients and perceived burden and QoL in their caregivers. **Results:** The mean age of caregivers was 40.49 ± 12.65 years, and of patients was 37.45 ± 9.55. The mean score on the Schizophrenia Caregiver Quality of Life (S-CGQoL) questionnaire was 44.8 ± 8.67. 76% of caregivers had a score <50. QoL was significantly correlated with burden on caregivers ($r = -0.478$; $P = 0.0001$) and duration of illness of patients ($r = 0.243$; $P = 0.014$). The mean score on Zarit Burden Interview (ZBI) was 38.28% ±11.19. 64% of caregivers perceived mild-to-moderate burden. Caregivers burden was correlated with manifestation of negative symptoms in patients ($r = 0.287$; $P = 0.013$). Negative symptom scores significantly predicted the burden perceived by caregivers. **Conclusion:** Caregivers of schizophrenia patients experience a considerable level of burden which with significant correlations between negative symptoms in patients and scores on ZBI. Negative symptoms in patients were the only predictor of the burden on caregivers. Low QoL with a score of <50 on S-CGQoL was present in two-thirds of caregivers. QoL was related positively to the duration of illness and negatively to the burden on caregivers.

Keywords: Burden, caregiver, quality of life, schizophrenia

INTRODUCTION

Schizophrenia, a severe mental disorder, typically begins in late adolescence or early adulthood and is characterized by profound disruptions in thinking, affecting language, perception, and the sense of self, and it often includes psychotic experiences, such as hallucinations or delusions.[1] The World Health Organization while providing the facts of this disorder mentions that it affects >21 million people worldwide, is a treatable disorder, one in two people living with schizophrenia does not receive care for the condition, and care of persons with schizophrenia can be provided at the community level, with an active family and community involvement.[2] There has been a shift in treatment and care of schizophrenia over the years, with more and more patients being treated on an outpatient basis and cared in community.[3] It is estimated that about 70% of people with schizophrenia in Asian countries live with their families or friends.[4] Caregivers are the persons who have significant responsibility for the well-being of a person diagnosed with schizophrenia. In developing countries, the structure of families and economic difficulties resist the use of paid caregivers for patients with schizophrenia.[5] The burden

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of caring for these patients is further increased by challenges in the health system, such as inadequate health personnel and poor infrastructure.[5] As a result of caregiving, they experience distress in psychological and emotional health, have reduced social contact, have financial difficulties, have low life satisfaction, and have poor mental and physical health.[6] To understand the quality of life (QoL) and extent of burden perceived by caregivers while caregiving a family member with a diagnosis of schizophrenia, we framed this study as in our state, till now, no such study has been conducted.

MATERIALS AND METHODS

This was a cross-sectional study conducted in a tertiary care hospital from June 2019 to September 2019. This study was approved by the institute's ethics committee. The study population included schizophrenia patients undergoing treatment as outpatients and their caregivers. All the diagnoses were reviewed using DSM-5 criteria. Those who were not willing to participate were excluded. Schizophrenia patients not accompanied by primary caregiver or caregivers who came without patients to collect medications were also excluded. Written informed consent was obtained from the patients as well as their caregivers. The Positive and Negative Syndrome Scale (PANSS) was administered to the patients. To assess QoL in caregivers, the Schizophrenia Caregiver Quality of Life questionnaire (S-CGQoL) was administered to them. The perceived burden in caregivers was assessed by administering Zarit Burden Interview (ZBI) in them.

PANSS is a 30-item scale in which there are three component scales in its, i.e., a seven items positive Scale, a seven items Negative Scale and a sixteen items General Psychopathology Scale. According to the severity of symptoms, each item is rated from 1 to 7, with one for absent to seven for extreme.[7]

S-CGQoL, developed by Richieri *et al*., is a multidimensional self-administered instrument. There are 25 items in it with options from Never to Always, describing seven dimensions (Psychological and Physical Well-Being; Psychological Burden and Daily Life; Relationships with Spouse; Relationships with Psychiatric Team; Relationships with Family; Relationships with Friends; and Material Burden). Each item was rated from 0 to 4 with 0 representing the worst response and 4 representing the best possible response. Accordingly, all dimension scores were transformed into a 0–100 scale with 0 score for worst QoL and 100 score for best QoL.[8]

ZBI by Zarit *et al*. is a 22 item self-report, used to assess the perceived burden of rendering care. Response options in each item range from 0 to 4. Accordingly, the cumulative score ranges from 0 to 88. The score is interpreted as 0–21: Little or no burden, 21–40: Mild-to-moderate burden, 41–60: Moderate-to-severe burden, 61–88: Severe burden.[9]

SPSS version 16 (Statistical Package for the Social Sciences; IBM Software, Armonk, NY, USA) was used for the data analysis. Mean scores on SCQoL and ZBI were compared among sociodemographic variables of patients and caregivers using independent samples *t*-test and analysis of variance. To examine the relationship among various key variables and also with sociodemographic factors, Pearson's correlation coefficient was obtained. Multiple regression analysis was used to identify predictor variables that have an influence on the manifestation of burden on caregivers.

RESULTS

The mean age of caregivers was 40.49 ± 12.65 years. A majority of them were men (70.7%). Around 2/3rd (64%) of them were from a rural background, with a majority of them married (84%). With regard to occupation, 18.7% were employed, whereas 30.7% were skilled workers, 50.6% were unskilled workers with 80% of them having a monthly income of >5000 RS. Educational background was low only around 6% of them being graduate or above. The majority of them had a family size between 5 and 10 (76%).

The mean age of patients was 37.45 ± 9.55 years. Majority of them were men (69.3%). Around 2/3rd (64%) of them were from a rural background. With regard to occupation, most of the patients were unemployed (65.3%). Only 5.3% were employed and had an income of >5000. About 84% of our patients had no income of their own. As with caregivers, the educational background was low in patients with only around 4% of them being graduate or above. Above 53.3% were unmarried and 14.7% were divorced. Around 70% had a duration of illness 5 years or more. Table 1 shows the distribution of three domains of PANSS in patients.

Quality of life profile of caregivers

All dimension scores in the S-CGQoL questionnaire were linearly transformed to a 0–100 scale, with 100 indicating the best possible level of QoL and 0 the worst. The mean score on the S-CGQoL questionnaire was 44.8 ± 8.67, with a range of 28–63. 76% of caregivers had a score <50. Table 2 shows a comparison of mean scores on S-CQoL among various sociodemographic variables of patients and caregivers.

Burden profile of caregivers

The mean score on ZBI was 38.28 ± 11.19, with a range of 19–63. 64% of caregivers perceived mild-to-moderate burden, whereas 30.7% of them perceived moderate-to-severe burden. Little or no burden was present only in one caregiver and severe burden was present in three caregivers. Table 3 shows a comparison of mean scores on ZBI among various sociodemograhic variables of patients and caregivers, respectively.

Table 4 depicts the correlation between various variables. As can be seen in this table, there is a significant negative correlation between QoL and the burden on caregivers ($r = -0.478$; $P = 0.0001$). QoL was also significantly correlated with duration of illness of patients ($r = 0.243$; $P = 0.014$). There was no significant correlation between QoL and other

Table 1: Distribution of positive and negative syndrome scale sub-scale score among schizophrenia patients

Score	Positive symptoms, *n* (%)	Negative symptoms, *n* (%)	General psychopathology, *n* (%)
10-19	40 (53.3)	11 (14.7)	-
20-29	34 (45.4)	30 (40.0)	-
30-39	1 (1.3)	31 (41.3)	26 (34.7)
40-49	-	3 (4.0)	41 (54.6)
50-59	-	-	8 (10.7)
Total	75	75	75
Mean	19.75	28.39	42.11
SD	5.76	6.79	5.83
Range	11-30	19-42	31-54

SD: Standard deviation

Table 2: Comparison of caregiver quality of life among sociodemographic variables

Sociodemographic variable	*n*	S-CGQoL Mean score±SD	*t*/*F*; *P*
Gender of patient			
Males	52	44.29±8.67	*t*=0.76; *P*=0.45
Females	23	45.96±8.73	
Marital status of patient			
Married	24	48.04±9.09	*F*=2.92; *P*=0.06
Unmarried	40	43.78±8.34	
Divorced	11	41.45±7.25	
Gender of caregiver			
Males	53	44.23±8.89	*t*=0.89; *P*=0.38
Females	22	46.18±8.16	
Marital status of caregiver			
Married	63	45.22±8.56	*t*=0.97; *P*=0.38
Unmarried	12	42.58±9.29	
Residence			
Rural	48	43.80±8.03	*t*=1.23; *P*=0.22
Urban	27	46.30±9.07	
Family size (members)			
<5	16	43.69±9.77	*F*=0.18; *P*=0.84
5-10	57	45.07±8.56	
>10	2	46.00±0.0	

S-CGQOL: Schizophrenia Caregiver Quality of Life questionnaire, SD: Standard deviation

variables. Caregivers burden was also significantly and positively correlated with manifestation of negative symptoms in patients ($r = 0.287$; $P = 0.013$), but with other variables, it had a nonsignificant correlation. General psychopathology in patients was correlated positively with manifestation of both positive symptoms ($r = -0.419$; $P = 0.001$) and negative symptoms ($r = -0.319$; $P = 0.005$).

Predictors of caregiving burden

A multiple linear regression method was used to see if the scores on subscales of PANSS and the duration of illness predicted the extent of burden perceived by the caregivers, i.e., the total score on ZBI. Accordingly, the dependent variable was the score on ZBI for the caregivers, whereas independent variables were the scores on three subscales of PANSS and duration of illness. Using the enter method, we found the extent of burden perceived by caregivers was not explained by the total PANSS score with a variance of 3.6% ($F = 2.97$; $R^2 = 0.039$, R^2 adjusted $= 0.036$, $P = 0.09$). Table 4 depicts subscales of PANSS predicting the burden perceived by the caregivers [Table 5]. However, the score on the negative symptom scale significantly predicted the burden perceived by caregivers.

Discussion

Our study found that on PANSS, positive symptoms, negative symptoms, and general psychopathology were highly prevalent among schizophrenia patients. On correlating these three subscales of PANSS with scores on S-CQoL and ZBI, we found there was no significant correlation except for a significant positive correlation of negative symptoms and burden on caregivers. Like our study, Stanley *et al*. did not found any significant relationship between the three subscales of the PANSS and caregiver burden but found caregiver QoL negatively correlated with the general psychopathology subscale.[10] However, there have been studies previously which have found a positive correlation between PANSS score and burden on caregivers.[11] However, there has been a concern that mere improvement in clinical symptoms in not sufficient to alleviate burden on caregivers and improve their QoL.[12] In our study, most of caregivers perceived mild-to-moderate or moderate-to-severe burden while caregiving an individual with schizophrenia. This is in concordance with many studies from India as well as from the west, which have found high levels of perceived burden in caregivers of patients with schizophrenia.[13-19] We found a mean score of 38.38 while assessing caregiver burden on ZBI. Those studies which have previously looked for caregiver burden using the same instrument of ZBI have found a wide variation in scores of caregiver burden.[20,21] This can be attributed to the differences in methodology, cultural differences in these countries, and differences in sociodemographic characteristics of caregivers.[20] Further, studies have demonstrated that caregivers of schizophrenia patients bear other types of psychological and social burdens that are not easily quantified.[5,22] Sociodemographic characteristics of patients and caregivers like residence, marital status, family size, and durations of illness did not have a significant influence on burden perceived by caregivers. However, in caring female patients, caregivers perceived significantly more burden in comparison to caregiving a male patient. Our results are in concordance with many studies, in which sociodemographic variables were found to have no influence on the burden perceived by caregivers.[10,15] However, with regard to gender, there are some studies which have found more burden perceived by male caregivers and some studies which have found more burden perceived by female caregivers but an earlier study from India did not found any significant difference in burden perceived by caregivers based on the gender of patients.[23-25] Caregiver burden was significantly and positively correlated with negative symptoms in patients, whereas other two subscales of PANSS did not show any significant correlation. There are many studies which have shown a positive correlation between PANSS scores and caregiver burden.[11,19] However, some studies have not found any significant correlation between PANSS scores and caregiver burden.[10,26] More symptomatic a patient more will be impairment in his functioning, which ultimately will result in a greater degree of responsibility on their caregivers and thus increasing their caring burden. Therefore to address caregiver burden, it is very important to effectively treat schizophrenia patients. In our study, through regression analysis, the total PANSS score did not predict burden on caregivers. This is in contradiction with previous studies that have shown higher PANSS scores predicting higher burden on caregivers in several domains.[19] However, in subscales of PANSS, negative symptom scale significantly predicted burden on caregivers. This is in accordance with many studies from India as well as outside India which have found psychopathology in schizophrenia patients predicting caregiver burden.[18-20,23,27] Stanley *et al*. and Aydin *et al*. did not found any PANSS subscale as a predictor of the burden on caregivers.[10,26] Most of the caregivers had low QoL in various dimensions on the S-CGQoL scale. This is in agreement with most of the earlier studies from India as well as outside India.[5,19,28-31] It has been reported earlier that caregivers of patients with schizophrenia are ten times more likely to remain isolated with poor QoL in comparison to normal matched controls.[32] However, when comparing mean scores of SCGQoL among sociodemographic characteristics of patients and their caregivers, there was no significant influence of these characteristics on caregivers QoL. In literature, most of the studies have found low QoL in caregivers of schizophrenia patients who are young, female, with low educational level, unemployed, and are parents of the patients.[33-35] However, there are many studies as well, including studies from India which have found no differences in QoL of caregivers in relation to sociodemographic characteristics.[10,25,36] There was a significant positive correlation between caregivers' QoL and duration of illness, indicating the chronic nature of this disorder does have an impact on caregivers. This is consistent with previous studies that have shown patient characteristics such as duration of illness, positive symptoms, and negative symptoms significantly correlated with caregivers QoL.[10,15,19,37] However, in our study, scores on subscales of PANSS were not significantly correlated with QoL. In a recent study, clinical improvement in schizophrenia patients was not found to have any significant effect on the QoL of caregivers.[12] However, previously, it has been found that negative symptoms and general psychopathology contribute significantly to low QoL in caregivers of schizophrenia.[38] Conversely, with improvement in QoL of caregivers, psychotic symptoms in

Table 3: Comparison of burden on caregivers among sociodemographic variables

Sociodemographic variable	*n*	ZBI Mean score±SD	*t*/*F*; *P*
Gender of patient			
Males	52	36.52±10.86	*t*=2.09; *P*=0.04*
Females	23	38.86±11.30	
Gender of caregiver			
Males	53	38.04±11.25	*t*=0.23; *P*=0.77
Females	22	38.86±11.30	
Marital status of patient			
Married	24	37.63±11.96	*F*=0.11; *P*=0.897
Unmarried	40	38.33±11.17	
Divorced	11	39.55±10.42	
Marital status of caregiver			
Married	63	36.70±11.14	*t*=2.95; *P*=0.004*
Unmarried	12	46.58±7.37	
Residence			
Rural	48	36.81±10.20	*t*=1.53; *P*=0.13
Urban	27	40.89±12.56	
Family size (members)			
<5	16	38.63±11.43	*F*=0.015; *P*=0.99
5-10	57	38.16±11.42	
>10	2	39.00±0.0	

*Statistically significant. ZBI: Zarit Burden Interview, SD: Standard deviation

Table 4: Correlation between various variables

	Family size	DOI	Positive	Negative	General	SCQoL	ZBI
Family size	1						
DOI	0.173	1					
Positive	−0.095	−0.151	1				
Negative	0.076	−0.018	0.216	1			
General	0.074	0.002	0.419*	0.319*	1		
SCQoL	0.069	0.243*	0.038	0.152	−0.017	1	
ZBI	−0.011	0.004	0.060	0.287*	0.062	−0.478*	1

*Statistically significant. QoL: Quality of life, ZBI: Zarit Burden Interview, DOI: Duration of illness

Table 5: Regression analysis of positive and negative syndrome scale sub-scale scores and the duration of illness with caregiver burden

Independent variable	Dependent variable (score on ZBI)		
	β	*t*	*P*
Score on positive scale	0.014	0.108	0.924
Score on negative scale	0.296	2.44	0.017*
Score on general psychopathology scale	−0.038	−0.292	0.771
Duration of illness	0.011	0.011	0.914

*Statistically significant. ZBI: Zarit Burden Interview

patients may improve, which indirectly will have an impact on QoL of patients.[37] We found a significant correlation between low QoL and high burden in caregivers. A recent study from India did not report this correlation, but in literature, it has been shown that low QoL and high burden in caregivers are positively correlated.[10,15,36,39]

Limitations

Our study was cross-sectional in nature, which limits our ability to capture the changing dynamics of caregiving as experienced by caregivers at different points of time. The caregiver burden is multidimensional, but we took it as a one-dimensional variable; thus, it does not give us an insight into various areas where they experience more burden. The adverse mental health consequences of caregiving an individual with schizophrenia have been reported in many previous studies, but we omitted this important aspect of caregivers in our study.[40-42] It has also been demonstrated that coping strategies used by caregivers do have an influence on the burden perceived by them and this also was ignored in our study.[30] Cultural variations may also limit wider generalizations of our results. Lack of a control group in our study limits the specificity of our results to schizophrenia caregivers.

CONCLUSION

To conclude findings of our study, caregivers of schizophrenia patients experience considerable level of burden. To a large extent, the burden on caregivers was not related to sociodemographic variables of patients and caregivers and the clinical profile, except for significant correlations between negative symptoms in patients and score on ZBI. In addition, negative symptoms in patients were the only predictor of burden on caregivers in our study. We found a score of <50 on S-CGQoL in around two-third of our participants. Like caregivers burden, QoL was not related to sociodemographic variables of patients and caregivers and to the clinical profile of patients. However, QoL was related positively to the duration of illness and negatively to burden on caregivers. High perceived burden and low QoL in caregivers of schizophrenia patients need an address. They should be provided adequate financial, educational, and psychosocial support. In addition, family interventions such as psychoeducation and provision of support groups for caregivers of schizophrenia patients need to be started to reduce their burden and increase their QoL.

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Conflicts of interest

There are no conflicts of interest.

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