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Original Research Article

Descriptive Observational Study on Quality of Life and Caregiver Burden Among Caregivers of People with Severe Mental Illness

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Abstract:

Background: Severe mental illnesses (SMI) such as schizophrenia, bipolar affective disorder (BPAD), severe depression, and severe obsessive-compulsive disorder (OCD) significantly impact not only patients but also their caregivers. Caregivers often experience considerable burden and reduced quality of life (QOL), which in turn affects patient care.

Aim: To assess and compare the caregiver burden and quality of life among caregivers of patients with different severe mental illnesses.

Methods: A cross-sectional observational study was conducted at a tertiary care center on 120 caregivers of patients diagnosed with schizophrenia, BPAD, severe depression, and severe OCD (30 in each group). Caregivers above 18 years, living with the patient for more than a year, were included. Tools used were Zarit Burden Interview (ZBI) for burden assessment and WHOQOL-BREF for quality of life evaluation. Data were analyzed using t-test and ANOVA.

Results: The majority of caregivers were male (85.8%), married (89.2%), from rural backgrounds (51.7%), and primarily spouses or parents (69.2%). The mean Zarit burden scores were highest for schizophrenia (56.8), followed by BPAD (49.07), severe OCD (46.87), and severe depression (36.03), showing statistically significant differences (p=0.001). WHOQOL-BREF scores were lowest among caregivers of schizophrenia patients across physical, psychological, and environmental domains (p=0.001), whereas caregivers of severe depression patients had better QOL. Social relationship domain differences were not significant.

Conclusion: Caregivers of individuals with severe mental illnesses experience substantial burden and poor QOL, with the greatest impact seen in caregivers of schizophrenia patients. Early identification and psychosocial support for caregivers are essential to improve both caregiver well-being and patient outcomes.

Keywords: Severe Mental Illness, Caregiver Burden, Quality of Life, Schizophrenia, Bipolar Disorder, Depression, OCD.

Introduction

There are around 970 million individuals with mental illnesses globally, with anxiety and depressive disorders being the most prevalent [1,2]. According to the WHO schizophrenia, bipolar disorder, depression, and alcohol use disorders are important causes for years lived with disability [3].

As per NIMH (National Institute of mental health) severe mental illness is defined as a mental, behavioural, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities [4]. Severe mental illness also affects the quality of life of the patient and caregiver. WHO defines the quality of life (QOL) as an individual's awareness of their situation in life according to the conditions of the social and cultural systems in which they reside and in relation to their aims, environment, social relations, and other associated factors [5].

A caregiver has been defined as "a family member, who has been staying with the patient for more than a year and has been closely related with the patient's daily living activities, discussions, and care of health" [6].

Burden may be defined as the problems, difficulties, and negative life events influencing the

life of family members concerned with a loved one with a mental illness [6]. It has been observed that >90% of patients with chronic mental illness live with their families and continue to take care of basic necessities [7].

This study assesses the QOL and caregiver burden which can help in initiating early intervention among the vulnerable caregivers. Also, this will help to enhance the level of caregiving and thereby improving the QOL of mentally ill patients.

Methods and Methodology

The current study is a cross-sectional Observational study that was conducted at the tertiary health-care center. The study was started after clearance from Research Review Board and Ethical Committee. The aim of the study was to assess quality of life and burden in caregivers of people with severe mental illness. Other objectives were to compare the quality of life and caregiver burden among subgroups of caregivers of people with different disorders under severe mental illnesses.

Sample of 120 cases is calculated at 95% confidence and 80% power. Inclusion criteria were caregivers of patient with diagnosis of Schizophrenia, Bipolar disorder, severe depression and severe OCD, primary care giver including first-degree relatives; parents, siblings, or offspring and spouses of the index patients, care giver literate and understandable, more than 18 years of age, either sex, living with patient with more than a year and closely associated with patient's daily activities. Exclusion criteria were home nurses, non-availability of primary caregivers, caregivers with IDD, Dementia, Severe Medical Illness, Substance abuse and caregivers not giving written informed consent.

Clinical Performa was prepared to collect the sociodemographic data and other clinical information. Other scale including BPRS, YMRS, YBOCS and HAM-D was applied to assess severity. Zarit Burden Interview, DASS-21 and WHOQOL-BREF were applied to assess burden, and quality of life in study population.

To investigate the association between participants, characteristics and their QOL, unpaired t-test was used. The descriptive variables from demography were tested using mean, standard deviation. T-test and ANOVA were used to test the relationship between burden types and demographical characteristics.

Results

Table 1: Shows the sociodemographic profile of caregivers

Variables	N	Frequency	Percent
Age group in years	18-30	24	20
	31-50	52	43.3
	51-60	28	23.3
	Above 60	16	13.3
Sex	Female	17	14.2
	Male	103	85.8
Marital status	Unmarried	12	10
	Married	108	89.2
	Widow	0	8
	Divorced	0	0
	Separated	0	0
Qualification	Primary	42	35
	Secondary	12	10
	Higher Secondary	24	20
	Graduate	32	26.7
	Postgraduate	10	8.3
Occupation	Unemployed	5	4.2
	Unskilled	64	53.3
	Semiskilled	16	13.3
	Skilled	8	6.7
	Professional	21	17.5
	Businessman	6	5
Locality	Urban	58	48.3
	Rural	62	51.7
Family type	Nuclear	63	52.5
	Joint	43	35.8
	Extended	14	11.7

Monthly family income (INR)	Below 5000	11	9.2
	5000-10000	32	26.7
	Above 10000	77	64.2
Socioeconomic status	LSES	59	49.2
	MSES	32	26.7
	HSES	29	24.2
Relationship with patient	Spouse	42	35
	Offspring	17	14.2
	Parent	41	34.2
	Sibling	17	14.2
	Others	3	2.5
Duration of care group in years	1-5	41	14.2
	6-10	55	45.8
	Above 10	24	20

Table no.1 is shows that the caregivers of patients with severe mental illness are taken and age of the caregivers divided in to four age groups. Out of a total of 120 caregivers, the number of caregivers between the ages of 31 to 50 years is the highest.

Out of the caregivers taken, maximum number of caregivers are married, educated up to primary school, came under the category of unskilled worker and majority number of caregivers comes under spouse and parent's category.

Table 2: Shows comparison of sociodemographic profile of caregivers of patient with schizophrenia, BPAD, severe OCD and severe depression

Diagnosis →	Schizophrenia	BPAD	Severe OCD	Severe Depression	P Value
Variables	**Mean ± Standard Deviation**				
Age in years	46.33±15.988	48.07±11.721	42.27±12.998	44.93±12.109	.388
Sex	1.93±.254	1.87±.346	1.83±.379	1.80±.407	.503
Marital status	1.90±.305	1.93±.254	1.83±.379	1.93±.254	.412
Qualification	2.37±1.564	2.50±1.333	2.60±1.404	3.07±1.285	.242
Occupation	2.77±1.331	2.87±1.332	3.23±1.675	2.93±1.202	.603
Locality	1.70±.466	1.50±.509	1.43±.504	1.43±.504	.127
Family type	1.63±.718	1.47±.730	1.70±.702	1.57±.626	.607
Socioeconomic status	1.73±.868	1.60±.770	1.90±.885	1.77±.774	.573
Duration of care in years	10.30±5.61	7.96±5.94	7.46±5.10	6.70±3.92	.051

BPAD: Bipolar affective disorder, OCD: obsessive compulsive disorder

Table number 2 showing that there is no statistically significant difference was found among these groups of severe mental illness in term of sociodemographic profile of caregivers. However, there was no significant difference between caregivers' type of family and occupation between four groups of severe mental illness.

Table 3: Shows the burden and its comparison of caregivers of the patients with schizophrenia, BPAD, severe OCD and Severe depression

Scale	Types of severe mental illness	N	Mean	Standard Deviation	P Value
Zarit Burden Score	Schizophrenia	30	56.80	10.210	0.001
	BPAD	30	49.07	12.619	
	Severe OCD	30	46.87	12.114	
	Severe Depression	30	36.03	9.072	
	Total	120	47.19	13.251	

Table no.3 shows the mean score of caregiver burden where for schizophrenia 56.80, for BPAD 49.07, for Severe OCD 46.87 and for severe depression 36.03. Highest the zarit burden having the maximum caregiver burden. There was statistically significant difference between the four groups in term of zarit burden, where majority of caregiver burden was found in caregiver of patient with schizophrenia followed by BPAD, severe OCD and severe depression.

Table number 5 showing the severity of depression, anxiety and stress in caregivers of patients with different group of severe mental illness.

Table 4: shows the WHOQOL and its comparison of caregivers of the patients with schizophrenia, BPAD, severe OCD and Severe depression					
WHOQOL Domains	**Diagnosis**	**N**	**Mean**	**Standard Deviation**	**P Value**
Physical Domain	Schizophrenia	30	36.13	19.702	0.001
	BPAD	30	40.20	14.048	
	Severe OCD	30	42.80	15.821	
	Severe Depression	30	53.47	11.752	
	Total	120	43.15	16.698	
Psychological Domain	Schizophrenia	30	30.30	16.543	0.001
	BPAD	30	37.60	17.057	
	Severe OCD	30	39.70	19.768	
	Severe Depression	30	53.10	14.967	
	Total	120	40.17	18.864	
Social Relationship Domain	Schizophrenia	30	28.10	18.449	0.143
	BPAD	30	28.20	21.145	
	Severe OCD	30	35.50	21.787	
	Severe Depression	30	37.70	18.443	
	Total	120	32.38	20.226	
Environment Domain	Schizophrenia	30	31.50	11.032	0.001
	BPAD	30	32.73	15.386	
	Severe OCD	30	41.20	16.709	
	Severe Depression	30	51.40	14.871	
	Total	120	39.21	16.509	

Table no.4 shows that there is statistically significant difference in quality of life of caregivers in three domains; physical domain, psychological domain and environment domain. There is no statistically difference in social relationship domain of quality of life of caregivers. The mean score of caregiver quality of life where the score in physical domain of quality of life for schizophrenia 36.13, for BPAD 40.20, for severe OCD 42.80 and for severe depression 53.47. In psychological and environment domain of quality of life the score for schizophrenia is 30.30 and 31.50, for BPAD 37.60 and 32.73, for severe OCD 39.70 and 41.20 and for severe depression 53.10 and 51.40 respectively. Table shows that the quality of life of caregivers of patients with schizophrenia having the poor quality of life in comparison of BPAD, severe OCD and severe depression. Caregivers of severe depression patients have better quality of life in comparison of other severe mental illness.

Discussion

Severe mental illness is more disabling for the patient and caregivers. As per NIMH definition, schizophrenia, bipolar affective disorder, severe depression and severe obsessive-compulsive disorder being considered as severe mental illness.

Caregivers, who take the major responsibility of caregiving for a mentally ill individual, have to undergo undesirable levels of severe burden. The caregivers are in need of support and understanding. Furthermore, the mentally ill patient can dominate them; due to this, there may be a rise in distress and it may affect their ability to handle the crisis. [8] Negative quality of life faced by the caregivers can lead to poor quality of caregiving for those under their care as well as deterioration of their own quality of life.

The purpose of the current study was to compare the quality of life and caregiver burden among subgroups of carers of people with various disorders under severe mental illnesses, as well as to evaluate the quality of life and caregiver burden among caregivers of people with severe mental illness. This study found that poor quality of life and highly prevalent burden among in caregivers of schizophrenic patients followed by BPAD, severe OCD and severe depression.

These 120 patients were recruited in set of 30 patient with schizophrenia, 30 patients with bipolar disorder, 30 patients with severe OCD and rest 30 with severe depression. All the 4 groups were matched in terms of sociodemographic profile. There was no statistically significant difference in terms of age, sex and other demographic factors.

Mostly caregivers were between the age of 31 to 50 years (43.3%). Mostly caregivers were male (85.8%), married (89.2%), had lower education (primary education, 35%), were in unskilled job (53.3%), more were from rural area (63%) and nuclear family (52.5%). Most of the caregivers were from lower socio-economic status (59%) and were their spouse (42%).

Most of the patient were in 18-30 age group (35.8%). Mostly patient in the sample were male (57.5%), married (65.8%), had primary education (20.8%), having unskilled job (50%), from rural area (51.7%), nuclear family (52.5%), and from lower socio-economic status (49.2%).

WHOQOL-BREF scale was applied to assess the quality of life of caregivers of patient with severe mental illness. Zarit burden scale was applied to assess the burden in caregivers of patient with severe mental illness.

The majority of the caregivers were male in between 31 to 50 years of age group, married, belongs to nuclear family, Hindu of rural background belonging to lower socioeconomic class. Majority of caregivers were spouse and parents.

No statistically significant difference was found among these groups of severe mental illness in term of sociodemographic profile of caregivers. However, there was no significant difference between caregivers' type of family and occupation between four groups of severe mental illness [9]. 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.

Caregivers of patient with schizophrenia scored mean 56.80 on zarit burden scale. The score comes at moderate to severe burden. 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 [10,11]. This can be attributed to the differences in methodology, cultural differences in these countries, and differences in sociodemographic characteristics of caregivers [10].

Further, studies have demonstrated that caregivers of schizophrenia patients bear other types of psychological and social burdens that are not easily quantified [12,13]. Sociodemographic characteristics of caregivers like residence, marital status, family size, and durations of illness did not have a significant influence on burden perceived by caregivers. Our results are in concordance with many studies, in which sociodemographic variables were found to have no influence on the burden perceived by caregivers [9,14].

As the schizophrenia is most disabling and chronic disease and causes significant socio-occupational dysfunction. It reduces the quality of life of patient. As the patient develops socio-occupational dysfunction, poor self-care and economically weak, it affects the primary caregiver the most. In severe mental illness caregiver with schizophrenia develops most burden as compared to bipolar, OCD and depression. In our study, most of caregivers perceived moderate-to-severe burden while caregiving an individual with schizophrenia. However, This is in difference 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 [14–16].

Caregiver of patient with bipolar disorder scored 49.07 mean at Zarit burden scale which is also falls at moderate to severe burden category. This caregiver has moderate to severe burden but less than caregiver of patient with schizophrenia and the difference is statistically significant. Patient with bipolar disorder mostly has complete inter-episodic recovery which makes the patient functional and would be less dependent on caregivers.

Caregivers of patient with severe OCD scored 46.87 mean on Zarit burden scale which comes under moderate to severe burden category. Although the burden is less than schizophrenia and bipolar disorder and the difference is statistically significant.

Caregivers of patient with severe depression scored 36.03 mean score on Zarit burden scale which falls under mild to moderate burden. In depression patient has more subjective distress than affecting the caregivers.

QOL as a measurement can identify groups with physical or mental health problems and provide a guide to intervention and follow-up evaluation [17]. In our study Quality of life of caregivers was assessed in 4 domains, first physical domains in which Caregivers of patient with schizophrenia has least score (36.13 mean), then caregivers of patient with bipolar disorder (mean score 40.20), then severe OCD (mean score 42.80) and caregivers of patient with severe depression had better score (Mean score 53.47). The difference in all 4 severe mental illness was statistically significant (P=0.001).

In domain of psychological quality of life, caregivers of patient with schizophrenia had worst as compare to other severe mental illnesses. The difference is statistically significant (P=0.001). Caregivers of patient with severe depression has better psychological quality of life as compare to other severe mental illness and the difference is statistically significant.

All 4 severe mental illnesses are not different statistically in terms of social relationship domain of quality of life (P=0.143).

Caregivers of patient with schizophrenia also has worst environment domain of quality of life with mean score 31.5 and it is statistically significant (P=0.001). Caregivers of patient with bipolar, severe OCD and severe depression has better quality of life in the same order.

On comparison of caregiver burden in different age groups, it was found that there is no statistically significant difference in different age groups (P=0.457). Age of the patient also do not affect caregiver burden (P=0.94).

Caregiver burden was found more in males as compared to females and there was statistically significant difference (P=0.023). Sex of the patient doesn't affect the caregiver burden (P=0.998). 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 find any significant difference in burden perceived by caregivers based on the gender of patients [18–20].Caregiver burden was more in caregivers who were married as compared to unmarried (P=0.045). It is also do no depend on marital status of the patient. Caregiver burden was same in all categories of socio-economical groups and there was no statistically significant difference (P=0.133). Caregiver burden has direct correlation with the duration of care and it was statistically significant (P=0.001). locality of patient does not affect the burden of caregiver.

Physical and psychological Quality of life was more in caregiver if the age of the patient was more than 60 years. It was statistically significant only for physical quality of life. There was no role of age in social and environmental quality of life. The results are similar to several studies that found older caregivers having a higher care burden hence poorer QOL [21,22]. A low psychological domain score in our study reflected negative attitude toward life and reduced self-esteem. This might be due to the social stigma associated with the mental health disorders. Our results confirm to a previous study conducted in Taiwan [23]. 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 [24–26]. 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 [9,20,27]. 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.

The high mean Quality of life in caregivers of patients with schizophrenia for the physical domain in our study was similar to a study conducted in Iran [17]. Most of the caregivers of patients with schizophrenia had low QOL in various domain on the WHOQOL-BREF tool. This is as per the most of the earlier studies from India as well as outside India [12,28–31].

25 caregivers of patient with severe mental illness had mild depression, 27 had mild anxiety and 30 had mild stress.

30 out of 120 caregivers of patient with severe mental illness had moderate depression, 21 had moderate anxiety, 24 had moderate stress. 36 caregivers had severe level of depression, 39 had severe level of anxiety and 41 had severe level of stress. 16 caregivers had extreme level of depression, 19 had extreme anxiety and 7 caregivers had extreme stress. 45 caregivers were normal in terms of depression, anxiety and stress.

Overall mean score of DASS for depression is 18.98, for anxiety is 13.75 and for stress is 22.73. According to individual severe mental illness, majority of the carers of patients with schizophrenia and BPAD perceived severe depression, anxiety and stress. Caregivers of Severe OCD perceived moderate depression, anxiety and stress. Caregivers of severe depression perceived moderate depression, anxiety and mild stress. According to overall mean score maximum of caregivers perceived moderate depression, anxiety and stress.

Conclusion

Caregivers of patient with severe mental illness has significant caregiver burden and poor quality of life. Caregiver of patient with schizophrenia has maximum burden and worst quality of life in severe mental illness. Caregiver of patient with severe depression has better quality of life and less burden as compare to other severe mental illness.

Limitation and future directions: The selection of the sample from a hospital- based population and the cross-sectional design limit the findings from this study to be generalized. This study had also less sample size so it is limited in terms of generalizing the finding. There was no healthy control arm. Future study with large sample size is required to generalize the results.

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