

# A Comparative Study of Quality of Life in Caregivers of Patients with Schizophrenia and Mood Disorder at a Tertiary Care Psychiatric Hospital at Visakhapatnam

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## ABSTRACT

### BACKGROUND

Caregivers play a significant role in psychosocial management of mentally ill patients, as a result of an increasing shift of psychiatric care to the community. Nowadays, caregiver's role becomes vital as psychiatric patients are receiving relatively short inpatient care, and early discharge from hospital. Caregivers of patients with major psychiatric disorders have diminished quality of life as these disorders are long-lasting. The purpose of this study was to compare the quality of life in caregivers of patients with schizophrenia and mood disorder.

### METHODS

This is a cross-sectional study. Sample consists of 60 caregivers of patients with schizophrenia and mood disorder, who are attending a government hospital for mental care. Data was collected and quality of life was assessed using world health organisation QOL - BREF (WHOQOL - BREF) questionnaire. Mean quality of life score of caregivers of patients with schizophrenia and mood disorder was compared. Higher the score, better the quality of life.

### RESULTS

Sample consists of 34 females and 26 males. Mean quality of life score of caregivers of patients with schizophrenia and mood disorder was 79.3 and 82.3, respectively. There is a significant difference between the mean quality of life score of caregivers of schizophrenia and mood disorder group with a P - value 0.013 (< 0.05). Quality of life is better in caregivers of patients with mood disorder compared to schizophrenia, maybe due to the nature of the illness, i.e. continuous in schizophrenia and episodic type in mood disorder.

### CONCLUSIONS

Measuring quality of life among caregivers can help initiate early intervention among vulnerable caregivers. By providing better health services and psychoeducation, caregivers quality of life can be improved, which improves the level of caregiving and also helps in enhancing the quality of life in mentally ill patients.

### KEYWORDS

Caregivers, Quality of Life, Schizophrenia, Mood Disorder

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*DOI: 10.18410/jebmh/2021/361*

*How to Cite This Article:*

*Rudraraju RKR, Molli S. A comparative study of quality of life in caregivers of patients with schizophrenia and mood disorder at a tertiary care psychiatric hospital at Visakhapatnam. J Evid Based Med Healthc 2021;8(23):1922-1926. DOI: 10.18410/jebmh/2021/361*

*Submission 28-12-2020,*

*Peer Review 06-01-2021,*

*Acceptance 19-04-2021,*

*Published 07-06-2021.*

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## BACKGROUND

Schizophrenia is a serious mental disorder with prevalence rates of 2 - 3 per 1000 patients reported from India.<sup>1</sup> The impact of schizophrenia on patients, their families and the wider society are no different from what has been observed in the rest of the world.<sup>1</sup> However, resource constraints, poverty, lack of education and inadequate access to health care facilities for patients makes the problem of providing care particularly daunting in India.<sup>1</sup> A comprehensive assessment of the patient and his/her caregiver needs to be carried out. Assessments of caregivers may focus on areas such as their knowledge and understanding of the illness, their attitudes and beliefs regarding treatment, the impact of the illness on them and their personal and social resources.<sup>1</sup>

Bipolar disorder (BPAD) is a serious mental disorder characterized by episodes of depression, hypomania/mania and mixed episodes, with inter episodic recovery.<sup>2</sup> However, many patients with BPAD continue to exhibit residual symptoms in the inter episodic period. Patients with BPAD encounter educational difficulties, job related problems, interpersonal difficulties, psychosocial dysfunction, disability, marital problems, multiple suicidal attempts, completed suicide and medication side effects. The illness usually starts in adolescence or early adulthood and has significant negative impact on the life of the sufferer and their caregivers.<sup>2</sup> As a result of an increasing shift of psychiatric care to the community, caregivers gained more significant role in the management of psychiatric illness. Deinstitutionalization and increasing psychiatric care to the community have led to an increase in the role of caregivers of mentally ill patients.<sup>3</sup>

In today's world, caregiver's play a vital role as psychiatric patients receive relatively short inpatient care and early discharge from the hospital. In India, where rehabilitation services are almost non-existent, and there is no social security system, the part the family becomes more important.<sup>4</sup> In India, studies show that the majority of people with schizophrenia or depression stay with their families.<sup>5</sup> On one hand, this family environment has led to immense progress for the patient. Still, on the other hand, there will be enormous physical, social, emotional, and financial burden on caregivers.

A caregiver has been defined as a family member who has been living with the patient and has been closely involved in his/her activities of daily living, health care, and social interaction for more than a year.<sup>6</sup> The world health organization (WHO) states caregiver burden as "the emotional, physical, financial demands, and responsibilities of an individual's illness that are placed on the family members, friends, or other individuals involved with the individual outside the health care system."<sup>4</sup> Relatives of patients with major psychiatric disorders feel burdened, as these disorders are unpredictable and long-lasting.

Previous studies have found that burden is experienced in the form of disruption of family life, family interactions, well-being, health, and financial burden affecting their quality of life (QOL).<sup>7</sup> The World Federation of Mental Health has issued a report supporting that caring for those with a

chronic psychiatric illness like schizophrenia, depression requires tireless effort, energy, and empathy and dramatically impacts caregiver's daily life.

WHO defines QOL as an individual's perception of their position in life in the context of the culture and value systems in which they live and about their goals, expectations, standards, and concerns.<sup>8</sup> QOL encompasses several important dimensions, including psychological status, functional abilities, personal well-being, social interaction, economic status, vocational status, and physical health.<sup>9</sup>

In caregiving burden, most of the caregivers suffer from poor psychological health and the same progress to developmental illness and have higher rates of depression than the general population.<sup>10</sup> Caregivers had a 63% higher risk of mortality than noncaregivers.<sup>11</sup> Almost two-thirds of all caregiver's report difficulty in their employment.<sup>12</sup>

Most of the studies have evaluated the QOL of mentally ill patients, but there are only a few that have evaluated QOL of apparently healthy caregivers of mentally ill patients. This study aimed to explore the QOL and its associations with certain psychological and sociodemographic factors among caregivers of mentally ill patients in a tertiary care hospital in urban India.

## Objectives

- To study the quality of life in caregivers of patients with schizophrenia and mood disorder.
- To study the quality of life in caregivers of patients with schizophrenia.
- To study the quality of life in caregivers of patients with mood disorder.
- To compare quality of life in caregivers of patients with schizophrenia and mood disorder.

## METHODS

This cross-sectional study was conducted on 60 caregivers of patients with schizophrenia and mood disorder who were attending the psychiatric outpatient department (OPD) of a tertiary care Government hospital for Mental Care, Visakhapatnam in urban India for six months from July 2019 to December 2019. Institutional ethics committee approval was obtained before the onset of the study. (IEC NO. 426 / 2019).

## Inclusion Criteria

The study population was caregivers of patients with schizophrenia and mood disorders (diagnoses were based on International Classification of Diseases -10) attending outpatient services in a tertiary care hospital who were more than 18 years of age and who fulfilled both the major criteria and one of the minor criteria. A total sample of 60 caregivers who fulfilled the above criteria was taken into the study.

- Both males and females who are caregivers of the patient were taken into the study.
- Major criteria were living with the patient, at least 3 days in a week for at least 6 months during the previous year

and closely involving in activities of daily living of the patients.

- Minor criteria were financial or business assistance, giving emotional support, daily supervision and personal care, the arrangement of doctor's appointment (making calls/transportation/explanations/translations), or involved in medical management.

### Exclusion Criteria

- Individuals with any illness that affect the quality of life.
- Substance dependence.

### Study Tool

After taking their informed consent, data was collected. Quality of life was assessed by using self-administered/ interviewer assisted (in case of insufficient ability) WHOQOL-BREF questionnaire. Quality of life questionnaire (WHOQOL-BREF) measured the primary study outcome.

### WHOQOL-BREF Scale

Physical, psychological, social, and environmental are the four main domains derived from the 26 items in this questionnaire. These physical, psychological, social and environmental domains were shown to be valid measures of overall quality of life and health. This WHOQOL-BREF scale is cross culturally sensitive and has good, excellent reliability and validity. The higher score meant a better quality of life. In this study, the Telugu version of WHOQOL-BREF was used. The following facets incorporated in each domain.

### Physical Health Facets

Daily living activities, medical substances and medical aids dependence, energy fatigue, mobility, pain and discomfort, sleep and rest, working capacity.

### Psychological Facets

Appearance and bodily image, negative and positive feelings, self-esteem, spirituality, religion or personal beliefs, thinking, learning, memory and concentration.

### Environment Facets

Financial resources, freedom, physical security and safety, health and social care: accessibility and quality, home environment, physical environment, transport, participation in and opportunities for recreational and leisure activities.

### Social Relationships Facets

Personal relationships, social support, sexual activity.

### Statistical Analysis

Statistical package for social sciences (SPSS) version 23 was used for data analysis. Independent sample t-test was used

to compare the mean quality of life scores of 2 groups. Analysis of variance (ANOVA) test was used to see the effect of caregiving years and relation with the patient on quality of life.

## RESULTS

Of total sample 60 (N), 50 % (30) were caregivers of schizophrenia and 50 % (30) were caregivers of mood disorders. Of total sample (60), 56.7 % (34) were females, 43.3 % (26) were males. Of total sample, 10 % (6) were of the age group 20 – 30 year, 43.3 % (26) were of the age group 31 – 40 year, 30 % (18) were of the age group 41 – 50 year, 16.6 % (10) were of the age group 51 – 60 year.

The mean age of the study population was  $43.80 \pm 5.39$  (range: 20 – 60). Of total sample (60), 45 % (27) were parents, 35 % (21) were spouse and others 20 % (12). Of total sample (60), 71.7 % (43) were employed and 28.3 % (17) were unemployed. Of total sample (60), 61.7 % (37) were literate and 38.3 % (23) were illiterate. Of total sample (60), 88.3 % (53) were married and 11.7 % (7) were unmarried.

Of total sample (60), 10 % (6) of the caregivers were providing care for less than 1 year, 56.7 % (34) of the caregivers were providing care for 1 – 5 years, 26.7 % (16) of the caregivers providing care for 6 – 10 year, 6.6 % (4) of the caregivers were providing care for more than 10 years. [Table 1]

	Characteristics	Number (N = 60)	Percent (%)
Age	20 – 30 years	6	10
	31 – 40 years	26	43.3
	41 – 50 years	18	30
	51 – 60 years	10	16.6
Sex	Male	26	43.3
	Female	34	56.7
Relation with patient	Parents	27	45
	Spouse	21	35
	Others	12	20
Education	Illiterate	23	38.3
	Literate	37	61.7
Working status	Unemployed	17	28.3
	Employed	43	71.7
Marital status	Married	53	88.3
	Unmarried	7	11.7
Caregiving years	< 1 year	6	10
	1 – 5 years	34	56.7
	6 – 10 years	16	26.7
	> 10 years	4	6.6
Diagnosis	Schizophrenia	30	50
	Mood disorder	30	50
Region	Rural	36	60
	Urban	22	36.7
	Tribal	2	3.3
Socioeconomic status	Lower	5	8.3
	Upper lower	14	23.3
	Lower middle	28	46.7
	Upper middle	11	18.4
	Upper	2	3.3

**Table 1. Characteristics of Caregivers of Patients with Schizophrenia and Mood Disorder**

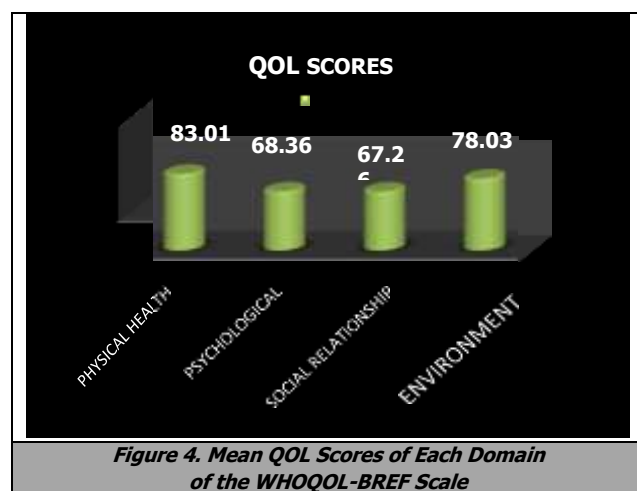
**Table 1. Characteristics of Caregivers of Patients with Schizophrenia and Mood Disorder**

Patient Diagnosis	No.	Mean $\pm$ SD	T - Value [95 % CI]	P - Value
Schizophrenia	30	79.31 $\pm$ 3.43	0.0432	0.013*
Mood disorders	30	82.33 $\pm$ 5.46	0.0663	

**Table 2. Mean Quality of Life Score of Caregivers of Patients with Schizophrenia and Mood Disorder**

\*indicates statistically significant difference

Mean quality of life score of caregivers of patients with schizophrenia and mood disorder was 79.3 and 82.3, respectively. (Table 2). There is a significant difference between the mean quality of life score of caregivers of schizophrenia and mood disorder groups with  $P$  - value 0.013 ( $< 0.05$ ). There is no significant difference in the mean quality of scores among individuals concerning caregiving years and relationship with the patient. The caregiver's age was inversely proportional to QOL. Caregiver with higher education status has better QOL. Of four domains, quality of life decreased more in psychological and social relationship domains. (Figure 4)



## DISCUSSION

If caregivers are unable to cope with the stress associated with the process of caregiving, they may have a poor quality of life (QOL) and may experience considerable amount of distress among themselves. Accordingly, the coping strategies used by the caregivers of schizophrenia are to be evaluated and understood well. The present study was done to measure and compare quality of life in caregivers of patients with schizophrenia and mood disorder who are attending Government hospital for mental care, Visakhapatnam. Understanding of quality of life in caregivers of patients with schizophrenia and mood disorder helps in improving the quality of life of caregivers which helps in management of patients effectively.

Quality of life as a measurement helps in identifying groups with physical or mental health problems and provide a follow up evaluation and guide to intervention. In this study, the caregivers experienced lower quality of life levels, where the most affected was the psychological domain, and the least was the physical domain. Caregiver's elderly age significantly affected most of the domains of WHOQOL. Caregiver's kinship, patient diagnosis, average caregiving hours, and caregiving years were other factors that affected the QOL. In this study, mean quality of life score of caregivers of patients with schizophrenia and mood disorder was 79.3 and 82.3, respectively. We found a statistically significant difference in the mean WHOQOL scores according to the patient's diagnosis, i.e. quality of life was better in

caregivers of patients with mood disorder compared to schizophrenia.

The high mean quality of life for the physical domain in our study was similar to a study conducted by Gholami A et al.<sup>13</sup> Physical domain implied that our study population had good activities of daily living, adequate energy and mobility, less pain and discomfort, sufficient sleep and rest, and good work capacity. A low psychological domain score in our study reflected a negative attitude toward life and reduced self-esteem. This might be due to the social stigma associated with mental health disorders. Our results confirm a previous study conducted by Lin JD et al.<sup>14</sup> It is interesting to note from earlier studies that family caregivers of patients with psychotic illness perceived poor quality of life compared to the general population. In a study done by KATE N et al. Caregiving burden, especially tension is associated with use of maladaptive coping strategies, poor quality of life and higher level of psychological morbidity in caregivers.<sup>4</sup> In a study done by Thara et al. it was found that Indian women with schizophrenia and broken marriages were disabled and stigmatised not only by the psychiatric illness, but by the social attitudes to divorce and marital separation. Most families in India, expressed intense distress and were especially concerned about the security of these women and their long-term future. Care of the children of these women was an additional problem, in the face of total lack of any financial support from the husbands.<sup>5</sup>

In a study done by Zendjidian X et al. it was found that, of all other caregivers in a family, mothers were generally the primary caregivers and reported a lower quality of life than other types of informal caregivers. As mothers are responsible for most aspects of the patient's daily care, they may experience a higher burden. It was found that caregiver's age was inversely proportional to quality of life, which might be attributed to their age-related morbidities and financial dependence. At the expense of their health and other comorbidities, older caregivers have to provide emotional support, assist them with daily living, and advocate for various services. The results were similar to several studies that found older caregivers having a higher care burden hence poorer quality of life. Caregiver with higher education status had better quality of life because of better knowledge about their relative's psychiatric illness and better-coping strategies.

## CONCLUSIONS

There are studies which measured quality of life in patients with mental illness. But studies measuring quality of life in caregivers of patients with mental illness are very less. In this study, the quality of life of caregivers of patients with schizophrenia and mood disorder was measured and compared. In this study, the caregivers experienced lower quality of life levels, where the most affected was the psychological domain, and the least was the physical domain. In this study it was found that the quality of life in caregivers of mood disorder was better than that of caregivers of schizophrenia. It was found that quality of life is poor in elderly caregivers than young adults. Caregivers

with higher education status had better quality of life compared to caregivers of low educational status.

Caregivers of mentally ill patients had diminished quality of life levels. Caregivers form an integral part of the psychosocial management of mentally ill patients. Studies which measure the quality of life among caregivers can help to initiate early intervention among caregivers who are vulnerable. By reducing the patient's symptomatology, increasing relatives' coping capacities, and decreasing the number of contact hours, caregiving tasks and problems may be diminished and related distress lowered. If distress is reduced, relatives may use less psychotropic medication and may visit their general practitioner less often.<sup>7</sup>

These studies also help the mental health professionals to identify those caregivers, who are at a high risk for physical and emotional problems. The professional health care workers can be more sensitive to the stress and burden experienced by the families by increasing the awareness among them. With the help of culturally integrated rehabilitation programs/day-care centres, health workers can provide better health services and better psychoeducation to the caregivers. Mental health professionals should create awareness to caregivers about illness, its treatment and prognosis and also coping strategies. This can improve their quality of life, which would enhance the level of caregiving and thereby improving the quality of life of mentally ill patients.

### Strengths of the Study

- Very few studies have been done on quality of life of caregivers of patients with mental illness in India. The present study focused on the quality of life in caregivers of patients with schizophrenia and mood disorder.
- Scale with excellent psychometric properties in terms of validity and reliability has been used for the study.

### Limitations

- The study has a small sample size.
- This is a cross-sectional study.
- As the study was carried out in a hospital setting, it cannot be generalized to a community.

### Recommendations for Future Work

- Studies with larger sample size can help in getting a more accurate representation of the general population and help in understanding the quality of life in caregivers of patients with schizophrenia and mood disorder.
- Studies have to be done to understand the coping strategies of the caregivers of patients with mental illness as different coping mechanisms are associated with various caregiving related outcomes among the caregivers like burden, caregiving experience, expressed emotion, illness perception, quality of life and psychological morbidity.

Data sharing statement provided by the authors is available with the full text of this article at jebmh.com.

Financial or other competing interests: None.

Disclosure forms provided by the authors are available with the full text of this article at jebmh.com.

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