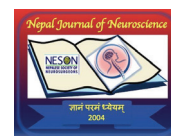


Quality of life in family members of patients of Schizophrenia and Bipolar Mood Disorder: A cross-sectional study in a sample of the Indian population



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Abstract

Introduction: Schizophrenia and bipolar disorder are chronic mental diseases with far-reaching effects on those who suffer from them and people who care for them. Family members suffer physical and tremendous emotional distress, often reflected in daily activities and functioning. The quality of life deals with how well a person can do their daily tasks. We have tried to assess the quality of life of family members of people with schizophrenia and bipolar disorder. **Materials and Methods:** A cross-sectional analysis was performed at a Tertiary Care Centre located in Maharashtra. The research was conducted over the course of six months. After gaining consent, 70 family members of patients diagnosed with schizophrenia as well as bipolar illness were chosen. Sociodemographic data were collected from participants and the quality-of-life instrument (WHO-QoL-BREF) was administered to them. Statistical analysis: SPSS-PC -25 version was used for data analysis. The Shapiro-Wilk test was used to investigate normal distribution. The difference in means between the groups was investigated using student t-test or Mann-Whitney U-test. Statistical differences between supplied proportions was calculated by the chi-square/exact Fisher's test. Multivariate linear regression analysis was done to see the factors associated with quality of life. Statistics were deemed significant at a $P < 0.05$.

Results: In all four dimensions of the WHO-QoL-BREF, those caring for patients with schizophrenia fared worse than those caring for patients with BMD, most noticeably in the physical category ($p=0.001$).

Conclusions: Interventions in the form of psychoeducation and provision of psychosocial support may enhance the welfare of caregivers.

Key words: Schizophrenia, quality of life (QoL), Bipolar mood disorder, caregivers, family members

Introduction

Both bipolar disorder and schizophrenia are long-term mental health conditions which are debilitating as well as negatively impact the patients. They are classified as serious mental illnesses (SMI) because they meet the

criteria for non-organic psychosis with a long duration of illness or treatment and are often associated with disability.^{1,2}

Schizophrenia has a long and tortuous course with severe psychotic signs such as hallucinations, delusions, and disorganized behaviour and speech. In addition, it often impairs the patient's cognitive functioning, which is linked with significant impairment and distress for the patient and family members.^{3,4,5}

Bipolar disorder is characterized by mood episodes, i.e., mood elevation and increased goal-directed activity on some occasions and low mood and decreased activity on others.⁶ Due to the recurrent nature of the bipolar disorder, each episode, as well as the fear of future episodes, exposes the family members to stressful situations.^{7,8}

Prevalence of schizophrenia is 0.4 per cent current and 1.4 per cent for a lifetime experience and bipolar affective disorder is 0.3 per cent current and 0.5 per cent for a lifetime experience in the Indian population as per the survey conducted by NMHS in the year 2015 to 2016.⁹

The increasing prevalence of these psychiatric illnesses and the recent deinstitutionalization of patients indirectly reflect the burden and responsibility that

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caregivers must shoulder in recent times.¹ In developing countries, caregivers are the backbone of community health care.² Patients with chronic mental problems benefit greatly from the greater prevalence of family caregiving that is common in Asian nations due to the region's strong cultural and familial values.^{10,11,12} However, delivering care for a patient who has a persistent mental illness may be demanding and have a detrimental influence on the caregivers' QOL.

The WHO describes "quality of life" (QOL) as one's perception of the actual position in their life in context to objectives, norms, expectations, and worries, along with the value systems and culture in which one currently living.^{13,14,15,16}

Stressors related to finances, difficulties in dealing with patient's uncontrollable emotions^{10,17} and behaviors, a lack of personal/social life^{10,18}, and the stigma and isolation^{10,19} they face affect their overall lifestyle and mental health.

In this research, we will examine the QOL of family members of patients with long-term mental illnesses such as schizophrenia along with bipolar mood illness and their association with various aspects of caregivers' lives.

Material and Methods

This research was cross-sectionally carried out in the outpatient as well as inpatient settings of a Tertiary Care Centre over 6 months. In addition, the research was approved by the Institutional ethics committee.

Relatives who met the criteria for inclusion were enrolled in research after obtaining an electronic or written informed agreement. Although, all had the right to leave at any time during the study without affecting their patient's treatment.

Inclusion Criteria

The research comprised people who fit the following requirements: Caregivers (spouses or first-degree relatives), who care for the daily needs of patients detected with schizophrenia along with bipolar mood illness (diagnosed as per the ICD 11 criteria, 2019/2021), with a minimum duration of 2 years, in the acute or maintenance phase of treatment. A duration of 2 years was selected, to address duration of untreated psychosis in acute patients and to maintain congruence of diagnosis for those in their maintenance phase. Male and female caregivers between the ages of 18 and 60 years, caring for the patients for 2 years or more were included in the study.

Exclusion criteria

Caregivers who refused to consent and those who had psychiatric disorders (diagnosed as per the ICD 11 criteria, 2019/2021) or comorbid medical conditions.

Data collection

Data collected included:

Sociodemographic profile of caregivers: (a) Age, (b) gender, (c) relationship with the patient, (d) education level, (e) employment status, (f) marital status, in addition to whether they live in a household with the patient

Instruments used:

1] The self-administered instrument WHOQOL-BREF with 26 items consists of 4 areas: mental health, physical health, environmental health, and social relationships with 6 items, 7 items, 8 items, and 3 items respectively.; it also includes items on QoL and general health. A response scale of 1-5, or a five-point ordinal scale, is used to rate each item of the WHOQOL-BREF. The totals are then linearly converted into a 0 to 100 scale.^{20,21,22}

Data and statistical analysis:

The gathered information was transformed into variables, coded, and put into Microsoft Excel. The SPSS-PC -25 version was used to examine and statistically assess the data.

The Shapiro-Wilk normality test was performed to determine if the various parameters had a normal distribution. The mean±standard deviation was used to express quantitative data. The statistical significance of the mean differences between the groups was assessed using Student t tests and Mann-Winey U tests. Frequency and percentages were utilised to represent qualitative data, and Fisher's exact or the chi-square test was used to evaluate whether statistically significant variations in proportions existed. Multivariate linear regression analysis was done to address confounding factors and assess which factors were associated strongly with quality of life. A $P < 0.05$ was considered statistically significant.

Results

Sociodemographic profile of patients and participants

The two groups consisted mainly of family members caring for BMD (n=35) and schizophrenia patients (n=35)

The sociodemographic features of the patients along with the participants are brief in Tables 1 and 2 and shown in Figures 1 and 2.

The mean age of BMD patients was 37.31±11.68 years, with the majority being male (57%), whereas the mean age of schizophrenia patients was 37.40±11.37 years, with the majority being female (65.7%).

Among caregivers, the mean age of BMD caregivers was 41.86±12.13 years, while the mean age of schizophrenia caregivers was 49.6±11.77 years, indicating that schizophrenia caregivers were significantly older than their BMD counterparts ($p < 0.01$)

Although no significant difference in illness duration and its impact on the quality of life was discovered between the 2 groups, schizophrenia patients were found to have longer illness duration than Bipolar Mood Disorder (BMD). This is summarized in Table 3

Most of the caregivers caring for schizophrenia patients were illiterate compared to caregivers for patients of BMD who had a high school degree, but despite this, the employment status of both groups was the same, and most of them were married.

Women predominated in both groups, suggesting that it was mostly women in the family who acted as primary caregivers for patients in both groups, although no statistical significance was noted between the two groups of caregivers.

For BMD patients, the primary caregivers were the patients' spouses, whereas for patients with schizophrenia, mainly the parents were the primary caregivers.

All caregivers reported living with the patient they were caring for.

Quality of life of caregivers

Overall, the QOL(quality of life) of the caregivers caring for patients with schizophrenia was lower than the

QOL of the caregivers of BMD patients in all domains, as shown in Figure 3.

Although the overall scores for the psychological domain were lower compared to other domains for both groups, the physical domain was significantly impaired in those caring for patients with schizophrenia compared to BMD patients (p-value = 0.001), followed by the social relationship's domain (p< 0.01), the psychological domain (p = 0.02), and finally the environmental domain (p = 0.03), summarized in Table 4 and shown in Figure 3.

Multivariate linear regression analysis for factors affecting the quality of life domains

Multivariate linear regression analysis was done where it was found that overall, the group of caregivers for the schizophrenia patients showed an inverse relationship with the physical, social relationships and the environmental domain of quality of life.

Also the higher educational status of both the groups showed a direct relationship with the environmental, physical and the psychological domain of life.

The age of the caregiver was shown to affect the environmental domain of quality of life.

This has been summarized in Table 5.

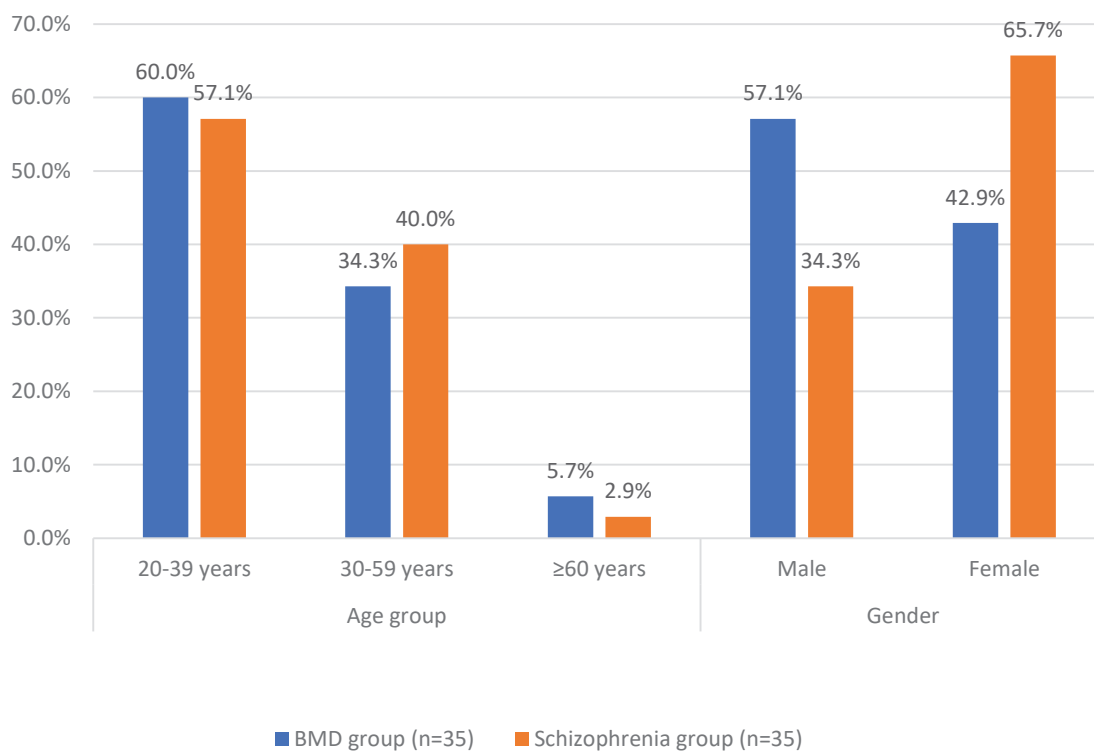


Figure 1: Demographic profile of patients

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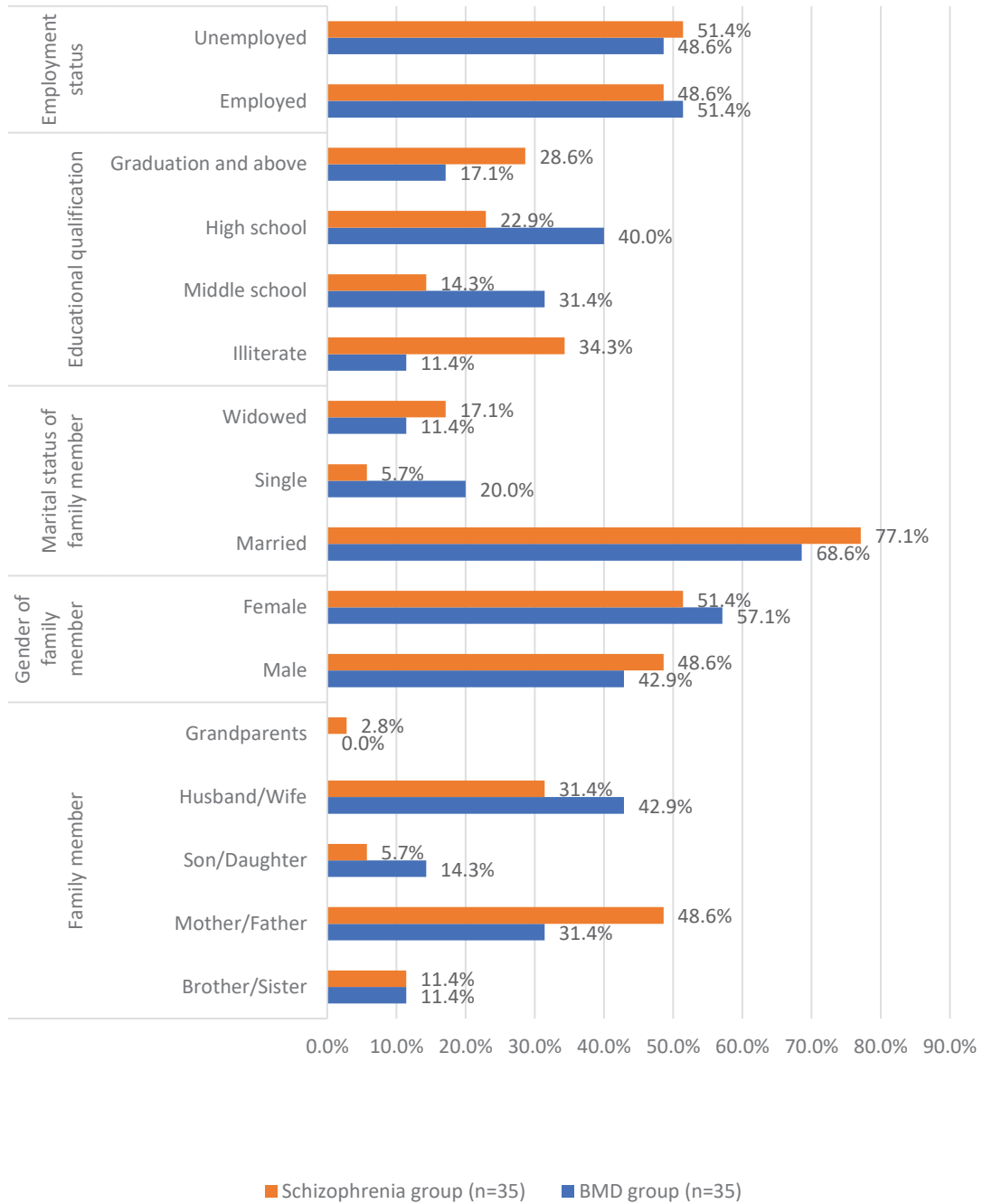


Figure 2: Sociodemographic profile of family members of patients

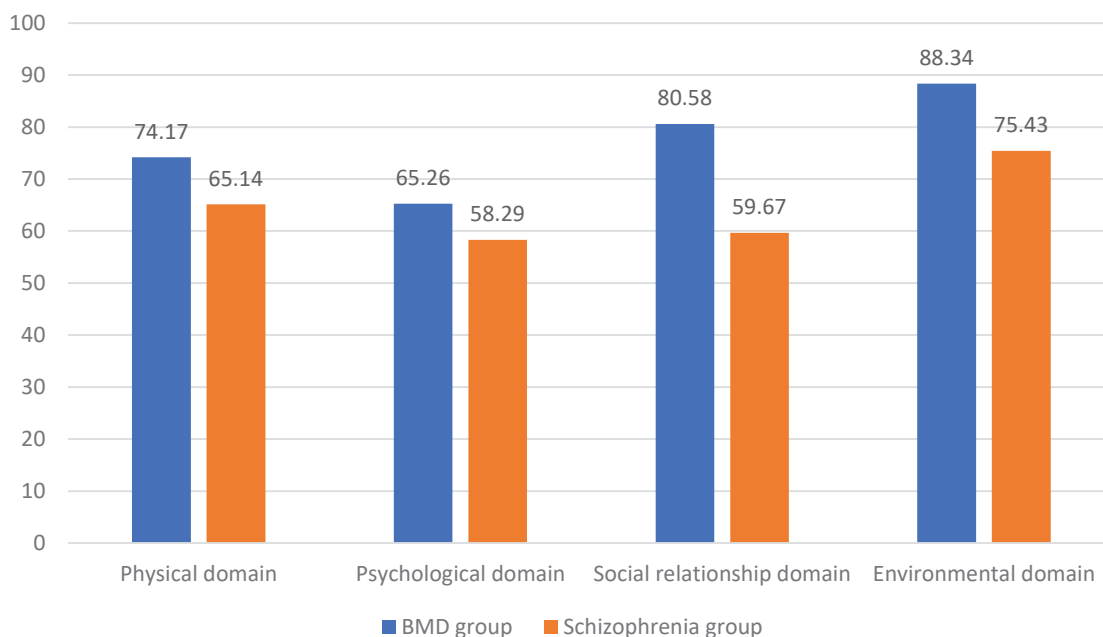


Figure 3: Quality of life in family members of patients with Bipolar mood disorder and Schizophrenia

	BMD group (n=35)	Schizophrenia group (n=35)	p value
Age group			
20-39 years	21 (60%)	20 (57.1%)	0.77
30-59 years	12 (34.3%)	14 (40%)	
≥60 years	2 (5.7%)	1 (2.9%)	
Mean age in years	37.31±11.68	37.40±11.37	0.97
Gender			
Male	20 (57.1%)	12 (34.3%)	0.05*
Female	15 (42.9%)	23 (65.7%)	

Table 1 : Demographic profile of patients

*Significant at 0.05. BMD- Bipolar Mood Disorder

	BMD group	Schizophrenia group	p value
Mean age of family member	41.86±12.13	49.6±11.77	<0.01
Family member			
Brother/Sister	4 (11.4%)	4 (11.4%)	0.38
Mother/Father	11 (31.4%)	17 (48.6%)	
Son/Daughter	5 (14.3%)	2 (5.7%)	
Husband/Wife	15 (42.9%)	11 (31.4%)	
Grandparents	0	1 (2.8%)	
Gender of family member			
Male	15 (42.9%)	17 (48.6%)	0.63
Female	20 (57.1%)	18 (51.4%)	
Marital status of family member			
Married	24 (68.6%)	27 (77.1%)	0.18
Single	7 (20%)	2 (5.7%)	
Widowed	4 (11.4%)	6 (17.1%)	

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Educational qualification			
Illiterate	4 (11.4%)	12 (34.3%)	0.03*
Middle school	11 (31.4%)	5 (14.3%)	
High school	14 (40%)	8 (22.9%)	
Graduation and above	6 (17.1%)	10 (28.6%)	
Employment status			
Employed	18 (51.4%)	17 (48.6%)	0.81
Unemployed	17 (48.6%)	18 (51.4%)	

Table 2: Sociodemographic profile of family member of patients

*Significant at 0.05, BMD-Bipolar Mood Disorder.

	BMD group	Schizophrenia group	p value
Duration of illness	9.66±6.13	10.06±7.22	0.95
Sharing a home with patients	35 (100%)	35 (100%)	-

Table 3: Duration of illness among the patients of BMD and Schizophrenia.

QOL domain	BMD group	Schizophrenia group	p value
Physical domain	74.17±8.58	65.14±13.53	0.001*
Psychological domain	65.26±13.61	58.29±13.17	0.02*
Social relationship domain	80.58±14.34	59.67±13.08	<0.01*
Environmental domain	88.34±20.92	75.43±23.72	0.03*

Table 4 : Quality Of Life domain in family members of patients with Bipolar Mood disorder and Schizophrenia.

*Significant at 0.05 level, QOL- Quality of life, BMD-Bipolar Mood Disorder

	Factors	B	p value	95.0% Confidence Interval for B	
				Lower Bound	Upper Bound
Physical Domain of Quality of life	Age of Family member	0.21	0.06	-.010	.440
	Gender of Patient	-0.73	0.78	-6.004	4.545
	Schizophrenia Group	-10.18	<0.001	-15.694	-4.673
	Higher Educational Status	3.94	0.002	1.478	6.418
Psychological Domain of Quality Life	Age of Family member	0.112	0.413	-.159	.382
	Gender of Patient	-1.765	0.581	-8.115	4.585
	Schizophrenia Group	-7.507	0.027	-14.141	-.873
	Higher Educational Status	4.268	0.006	1.294	7.241
Social Relationships Domain of Quality of Life	Age of Family member	.087	0.233	-.057	.231
	Gender of Patient	1.142	0.502	-2.238	4.522
	Schizophrenia Group	-7.171	<0.001	-10.703	-3.640
	Higher Educational Status	1.227	0.126	-.356	2.810
		B	p value	95.0% Confidence Interval for B	
Environmental Domain of Quality of life	Age of Family member	.579	0.001	0.231	0.928
	Gender of Patient	-1.942	.637	-10.129	6.245
	Schizophrenia Group	-15.379	0.001	-23.932	-6.825
	Higher Educational Status	14.376	<.0001	10.542	18.209

Table 5 : Multivariate linear regression analysis for factors affecting the different domains of quality of life.

Discussion

Our research set out to determine how those close to patients with bipolar illness and schizophrenia coped in terms of QOL.

We found that family members of people with schizophrenia had a poorer QOL than those caring for patients with Bipolar Mood Disorder (BMD) and were found to affect all four domains of quality of life, especially the physical and social relationships domain of quality of life. Observation of the sample of caregivers of schizophrenia patients revealed that they were significantly older compared with caregivers of BMD patients, which most likely may contribute to lower quality of life. This was also found in similar studies conducted by Ukpong D et al.2021 and others in the past^{23,24,25,26}

Advanced age was found to be related to lower quality of life after multiple regression analysis was done, especially in the environmental domain of life which often includes factors like indulging in activities for recreational purposes, accessibility to healthcare and social services and financial as well as physical safety.²⁷ Older individuals tend to have inhibitions in the form of mobility and accessibility which could show significant effect on their health and in turn may affect their environmental domain of quality of life.²⁸ Advanced age was also associated with poor quality of life in another study by Ukpong D et al,2021.

Prolonged illness duration may also be a contributing factor to the poor QOL of schizophrenia caregivers but in our study there wasn't a significant difference noted between the two groups. Caregivers caring for the chronically ill are often overworked and may experience burnout due to the constant need for care and commitment to patients suffering from schizophrenia. This constant commitment of time and energy to patient care may leave caregivers with no time for social contact or inhibit/limit their social life and interactions compared to their BMD colleagues. In addition, long-term care may also predispose caregivers to psychological manifestations.

Multiple regression analysis found that the gender of the patient was did not significantly affect the domains of quality of life in both groups. However, Women are the primary caregivers in both patient groups, which may be due to sociocultural upbringing and expectations that society in our country has for women to traditionally assume the role of caregiver.^[29] Traditional gender roles also place a burden on women who are at the forefront of caring for people with chronic mental disorders, especially in India.²⁹

Most of the primary caregivers for people with schizophrenia in our study are the patient's parents, though no significant association could be drawn between the two groups. But earlier research findings have shown

that parents are often the caregivers for schizophrenia patients as compared to BMD and can have an effect on the QOL.^{29,30} Because schizophrenia is a lifelong condition, parents are frequently the primary caretakers for their children from a young age, providing them with both social support and structure. This can strain both their physical and social relationships, as parents also seem to age as the illness progresses, and caregiving becomes tedious and exhausting for them as the years go by. All these factors can exhaust and emotionally strain them, which can have harmful psychological consequences in the long run. This can affect their QOL, especially in physical/social relations, as patients with chronic mental illnesses are known to cause disruptions in their home environment and therefore need to be treated with the utmost care and attention by caregivers, which can also have long-term psychological effects.³¹

The Educational qualification of the caregivers showed a significant association as well as had a direct effect on the environmental, psychological as well as physical domain of the quality of life in the family members of the patients. Individuals with a higher educational status have better job prospects which leads to better financial opportunities which is required for long term care of patients with psychiatric illness, better understanding which may help in compliance with treatment and facilitate in long term satisfaction and less behavioural complications in the patient.³² Education is found to be predictor for one's health status which in turn can have effects on the quality of life of the individuals.^{33,34,35}

Limitations

The study's sample size was small, which resulted in certain limitations. Also, associated factors such as caregiver burden, level of expressed emotion, degree of disability, or co-existing depression and anxiety among participants were not considered in the study. Relatives of individuals suffering from other chronic mental illnesses were not included in this study.

Certain groups of schizophrenia patients were cared for by their grandparents or parents due to most of them being unmarried, this could be one of the reasons why the mean age of caregivers for schizophrenia could be higher. Due to these limitations, The results of this study cannot be extrapolated to another group of caregivers and these limitations should be addressed in future studies.

Conclusion

The overall Quality of life (QOL) was lesser for carers of people with schizophrenia compared to those of people with a bipolar mood disorder.

Factor contributing to poor QoL in caregivers were

mainly older age, especially affecting the environmental domain. Whereas higher educational status among the caregivers showed a positive effect in physical, psychological and environmental domain of quality of life.

Caregiving often involves physical and psychological stress and affects social relationships, financial circumstances, and employment status. Family caregivers' emotional as well as physical health is negatively impacted by unexpected behavioral abnormalities in patients with persistent mental disorders.^{36,37}

The QOL of family caregivers can be improved by various psychosocial interventions, such as providing education to family members in brief about the nature of the disorder, its course and treatment and managing their long-term expectations. Support groups can also be offered for caregivers to share their experiences and suggestions for the patient's care.

It may also be helpful to suggest that the primary caregiver take frequent breaks from caregiving or ask other family members for support.³⁸

In addition, family members with poor quality of life can be screened for co-morbid depression, and early intervention and appropriate treatment can help improve the caregiver's QOL.

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