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Burden of care and quality of life in caregivers of patients presenting in manic episode of bipolar affective disorder

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Abstract

Background

Bipolar affective disorder is a chronic mood disorder characterized by manic, depressive, hypomanic, or mixed episodes, often leading to considerable caregiver burden. This study assesses the burden of care and quality of life (QOL) in caregivers of patients experiencing manic episodes.

Methodology

A cross-sectional descriptive study was conducted at the Mental Hospital, Lagankhel, involving 65 caregivers recruited through convenience sampling. Data were collected using a semi-structured proforma, WHO-QOL-BREF for QOL assessment, and BAS for burden evaluation. Sociodemographic and clinical associations with QOL and burden were analyzed using appropriate statistical tools.

Results

Significant differences in QOL scores were associated with caregiver age, sex, relationship with the patient, and education level. Multiple linear regression showed that patient's education, number of episodes, family history, caregiver's age, and occupation significantly influenced QOL. Higher burden scores were found among caregivers with lower education and socioeconomic status. A negative correlation was observed between burden and QOL scores.

Conclusion

Caregivers who were older, female, parents, or had lower education reported poorer QOL. Patient-related factors and caregiver demographics influenced QOL. Higher caregiver burden was linked to lower QOL, emphasizing the need for supportive interventions targeting at-risk caregiver populations.

Keywords

Bipolar affective disorder, mania, caregiver, quality of life, burden

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INTRODUCTION

Bipolar affective disorder is a chronic mood disorder characterized by manic, hypomanic, depressive, or mixed episodes.[1] The prevalence of bipolar disorder across the world varies from 0.3 to 1.2% by country. Globally, an estimated 46 million people had bipolar disorder in 2017, with 52 and 48 % being male and female respectively.[2] Bipolar disorder is the sixth leading cause of Disability Adjusted Life Years (DALYs) among people aged 10 to 24 years worldwide.[3]

WHO defines quality of life (QOL) as "individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".[4] Bipolar disorders having multiple recurrence of illness, hospitalization and increased severity of symptoms; are associated with poor QOL of caregivers and higher caregiver burden.[5,6] In a study by Perlick et al., 93% of caregivers reported moderate or higher degree of caregiving strain when their relative was admitted in a psychiatric facility, and 70% reported moderate or higher burden 15 months later.[7]

Assessment of caregiver burden and QOL can help to assess the gravity of the situation and necessary interventions can be developed and implemented to reduce the caregiver strain and improve QOL of caregivers of patients with bipolar affective disorder.

MATERIALS AND METHODS

This cross-sectional study was conducted at Mental Hospital, Lagankhel, from Magh 2078 to Asar 2079. It involved caregivers of inpatients diagnosed with BPAD mania, aged 18 years or older, who had been caregiving for at least six months. Ethical approval was obtained from the IRB of NAMS, Bir Hospital (Ref No: 14701207879). Caregivers with chronic medical, surgical, or mental illness, physical disability, or illiteracy were excluded.

Non-probability convenience sampling was used. Based on hospital records of BPAD mania admissions from Baisakh to Chaitra 2077 (N = 184), the sample size was calculated using the Modified Cochran's formula for small populations.

Using a prevalence (p) of 93.0% from Perlick et al.7 (2001), Z = 1.96 (95% confidence), and a 5% margin of error:
$n_0 = Z^2p(1-p)/e^2$
$n_0 \approx 100$
Adjusted sample size:
$n = n_0 / [1 + ((n_0 - 1)/N)]$
$n = 100 / [1 + ((99)/184)] \approx 65$
Thus, the final sample size was 65.

Data were collected using a semi-structured format covering patients' socio-demographics (age, sex, address, province, education, marital status, occupation, religion, socioeconomic status, duration of illness, number of episodes, age of onset, family history of psychosis, YMRS score at admission, psychotic symptoms, and substance use excluding nicotine) and caregivers' details (age, sex, relationship, education, marital status, occupation, religion, caregiving duration).

The WHOQOL-BREF8, a 26-item tool, assessed caregivers' quality of life, while the 40-item Burden Assessment Schedule (BAS)9 measured objective and subjective burden. Written informed consent was obtained, and the nature of study and procedure were explained to the participants. The Nepali version of WHOQOL-BREF validated by Giri et al.10 was used. With forward and back translation following Wild et al. (2005)11, translated BAS was self-administered. Statistical analysis was conducted using GraphPad Prism and R. Mann-Whitney U test and Kruskal-Wallis test were used for non-parametric group comparisons. Variables with $p < 0.2$ were included in multiple linear regression. BAS items specific to spouses were excluded for total score comparability. Spearman's correlation was used for correlation analysis.

RESULTS

Sociodemographic Profile of Patients and caregivers (Table 1)

Among the patients, the majority were female (n=42), urban residents (n=41), and from Bagmati province (n=35). Most were educated (n=43), with primary education (n=27). The mean age was 33.7 ± 11.27 years, with the highest proportion (n=23) in the 25–34 age group. Most were employed prior to the episode (n=38) and married (n=44).

Most caregivers were female (n=44), with primary education (n=31), employed (n=53), and married (n=46). Mean age was 37.2 ± 13.2 years, and most (n=31) were from the upper-lower socioeconomic class. Mean caregiving duration was 5.85 ± 7.67 years.

Illness related variables (Table 2)

The mean illness duration was 12.10 ± 10.52 years, with 30 patients ill for over 10 years. Mean number of episodes was 4.74 ± 6.19, with most (n=44) having 2–4 episodes. Mean age at onset was 21.7 ± 6.5 years. A majority (n=33) had no family history of psychosis. Mean YMRS score at admission was 33.8 ± 7.8, with most (n=30) presenting with moderate mania (YMRS 26–37).

Correlation between QOL and different variables of study WHOQOL-BREF Analyses

Male caregivers had significantly higher physical domain scores (64.69 ± 13.59 vs. 57.14 ± 14.77, p=0.0402) and total scores (59.27 ± 11.41 vs. 53.16 ± 13.35, p=0.04) compared to females (Figure 1). Caregivers with education above primary level had better QOL.

Caregivers aged 40+ had lower physical (57.15 ± 14.1 vs. 67.51 ± 12.71, p=0.02), social (54.29 ± 17.69 vs. 63.03 ± 19.17, p=0.049), and total QOL scores (53.35 ± 12.2 vs. 61.35 ± 11.22, p=0.01). Parent caregivers had significantly lower overall QOL (2.07 ± 0.88 vs. 3.00 ± 1, p=0.045) and total scores (50.12 ± 13.26 vs. 62.23 ± 11.74, p=0.045) than children.

Marital status, psychotic symptoms, caregivers' occupation, illness duration, and caregiving duration did not impact QOL. However, environmental domain and total QOL were significantly lower in lower vs. upper socioeconomic groups (49.21 ± 11.27 vs. 61.81 ± 10.56; 2.41 ± 0.81 vs. 3.21 ± 0.89; both p<0.05) (Figure 2).

BAS Analysis

Caregivers with primary education or less had higher burden scores (76.85 ± 10.82 vs. 70.23 ± 8.89, $p<0.05$). Caregivers of patients from lower socioeconomic class also had higher scores (77.84 ± 10.2 vs. 70 ± 9.48, $p<0.05$) (Figure 3).

Multiple Linear Regression

Patient education, number of episodes, family history, caregiver age, marital status, and occupation influenced QOL. Higher patient education decreased QOL: primary (11.1 times, $p<0.05$), secondary (12.5 times, $p<0.01$), and higher secondary (27 times, $p<0.0001$). More episodes reduced QOL (1.1 times per episode, $p<0.001$), while family history increased it (6.4 times, $p<0.05$). Caregiver age and being single decreased QOL by (0.7 times per year, $p<0.001$) and (16.8 times, $p<0.01$) respectively. Being unemployed increased QOL vs. business-employed (11.4 times, $p<0.05$).

Correlation Analysis

Significant correlations: BAS and QOL total ($r=-0.54$, $p<0.0001$), age at onset and QOL ($r=0.35$, $p<0.005$), caregiver age and QOL ($r=-0.31$, $p<0.05$), YMRS and illness duration ($r=-0.28$, $p<0.05$), number of episodes and illness duration ($r=0.66$, $p<0.001$), patient age and illness duration ($r=0.68$, $p<0.001$), patient age and episodes ($r=0.44$, $p<0.001$), and patient age and age at onset ($r=0.52$, $p<0.001$).

DISCUSSION

This study aimed to assess the quality of life (QOL) and caregiver burden among caregivers of inpatients with BPAD mania. The findings highlight significant associations between caregiver characteristics, patient-related variables, and QOL or burden scores.

The mean age of participants in this study was 33.7±11.27 years, and caregivers was 37.2±13.2 years which is comparable to previous studies[12, 13] The majority of caregivers were women, consistent with previous literature emphasizing that caregiving roles are traditionally assumed by females.[12,14] Most were employed, yet those who were unemployed reported better QOL. This could reflect fewer role conflicts, greater flexibility, and more time available for caregiving responsibilities. Employed caregivers may face additional stress from job demands and financial pressures, affecting their overall well-being.[13]

Educational status also played a crucial role. Caregivers with education above primary level showed better QOL, potentially due to better coping skills, understanding of illness, and access to resources15.17. Interestingly, patients' higher education was associated with decreased caregiver QOL. This unexpected finding might be due to increased expectations, disappointment with the patient's illness trajectory, or challenges in managing behaviors in educated patients.

Age significantly influenced QOL. Caregivers aged 40 and above had lower scores in physical and social domains and overall QOL, possibly due to cumulative physical strain and social isolation from long-term caregiving.[12, 16, 17, 18, 19] Similarly, parent caregivers experienced lower QOL than children caregivers. This might be related to emotional stress, physical health decline with age, or prolonged caregiving responsibility as reported by studies from India and France.[20,21]

Socioeconomic status significantly impacted QOL and caregiver burden. Lower SES caregivers had poorer environmental domain scores and higher burden scores, likely due to limited access to health services, financial stress, and fewer coping resources. These findings align with existing evidence that socioeconomic disadvantage amplifies caregiving stress and reduces QOL.[17]

The mean burden score of the caregivers in BAS in this study was 73.66±10.38 (calculated after omitting items 17, 18, 19, 20 as they contain spouse related questions only) which is slightly lower than similar study done in India22 (BAS score 76.7 (SD±12.3).

The burden of care, as measured by BAS, was higher in caregivers with lower education and those caring for patients from lower socioeconomic backgrounds. These groups may have less access to support systems and fewer coping mechanisms, leading to increased perceived burden as indicated by similar studies.[17]

Regression analysis revealed that caregiver age, marital status, and occupation were significant predictors of QOL. Older caregivers and unmarried individuals had lower QOL scores. Caregiving without spousal support and advancing age may intensify stress and isolation. Unemployed caregivers, however, reported better QOL, likely due to fewer competing demands.

Patient-related variables such as the number of episodes and absence of family history of illness also influenced caregiver QOL. More episodes were associated with lower caregiver QOL, likely due to the cumulative emotional and physical toll.[17,24] Interestingly, having a family history of mental illness was associated with better QOL. This could be due to better understanding and preparedness in managing psychiatric conditions.

Spearman correlation further supported these associations. There were significant negative correlations between caregiver burden and QOL[13,18,19,21], caregiver age and QOL, and YMRS scores and illness duration. Positive correlations were found between patient age and illness duration, and number of episodes, suggesting a progressive nature of the illness with advancing age.

This study has several strengths and limitations. We used WHOQOL-BREF, a globally validated tool for assessing health-related QOL. However, being a single-center study, the findings may not be generalizable across Nepal. Lack of blinding and selection of available caregivers who may not have been the primary caregivers could also introduce bias.

CONCLUSION

Overall, the study underscores the complex interplay between sociodemographic, clinical, and psychosocial factors in shaping the experiences of caregivers. The findings stress the need for targeted interventions, such as psychological support, educational programs, and social services, particularly for older caregivers, those with limited education, and those from lower socioeconomic backgrounds.

Table:1 Sociodemographic profile of patients

Characteristics		Patients		Caregivers	
		Number (n)	Percentage (%)	Number (n)	Percentage (%)
Age in years	18-24	14	21.5	15	23.1
	25-34	23	35.4	13	20.0
	35-44	17	26.2	19	29.2
	45 and above	11	16.9	18	27.7
Sex	Male	23	35.4	21	32.3
	Female	42	64.6	44	67.7
Residence	Urban	41	63.1	41	63.1
	Rural	24	36.9	24	36.9
Education	No formal education	12	18.5	2	3.1
	Primary or below	27	41.5	31	47.7
	Secondary	15	23.1	11	16.9
	Higher secondary and above	11	16.9	21	32.3
Marital status	Married	44	67.7	46	70.8
	Single/Separated/divorced/widowed	21	32.3	19	29.2
Socioeconomic status	Upper lower	31	47.7	31	47.7
	Lower middle	20	30.8	20	30.8
	Upper middle	14	21.5	14	21.5
Socioeconomic status	Less than 1 year			15	23.1
	1-5 years			30	46.2
	6 or more years			20	30.7

Table 2: Illness related variables

Illness related variables		Number (n)	Percentage (%)
Total duration of illness	1-5 years	21	32.3
	6-10 years	14	21.5
	More than 10 years	30	46.2
Number of episodes	2-4	44	67.7
	5 and above	21	32.3
Age of onset of illness	10-19	27	41.6
	20-29	30	46.2
	30 and above	8	12.3
Family history of psychotic illness	Yes	32	49.2
	No	33	50.8
YMRS Score at admission	20-25	12	18.5
	26-37	30	46.1
	38-60	23	35.4

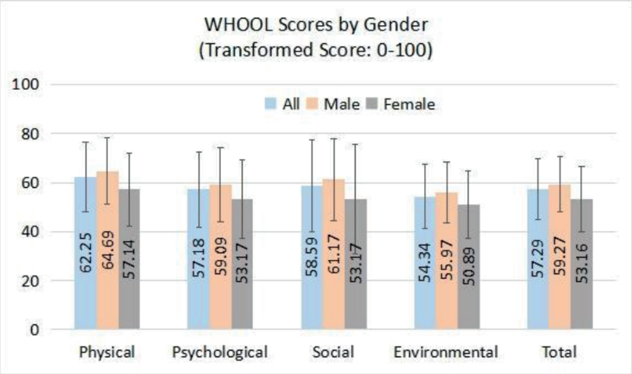
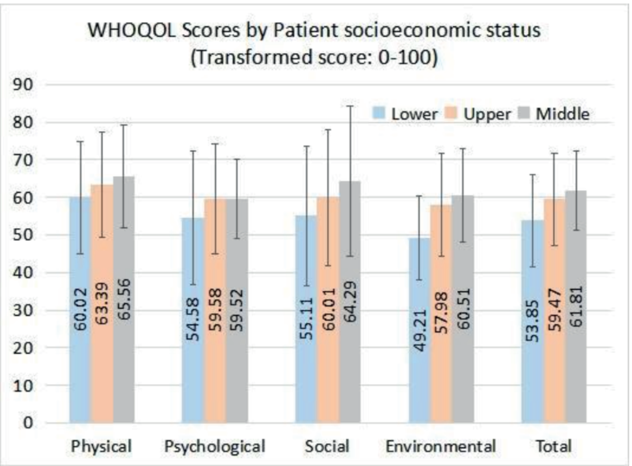


Figure 1: Figure showing mean scores in different domains of WHOQOL in care givers in different genders. Error bars show standard deviations.



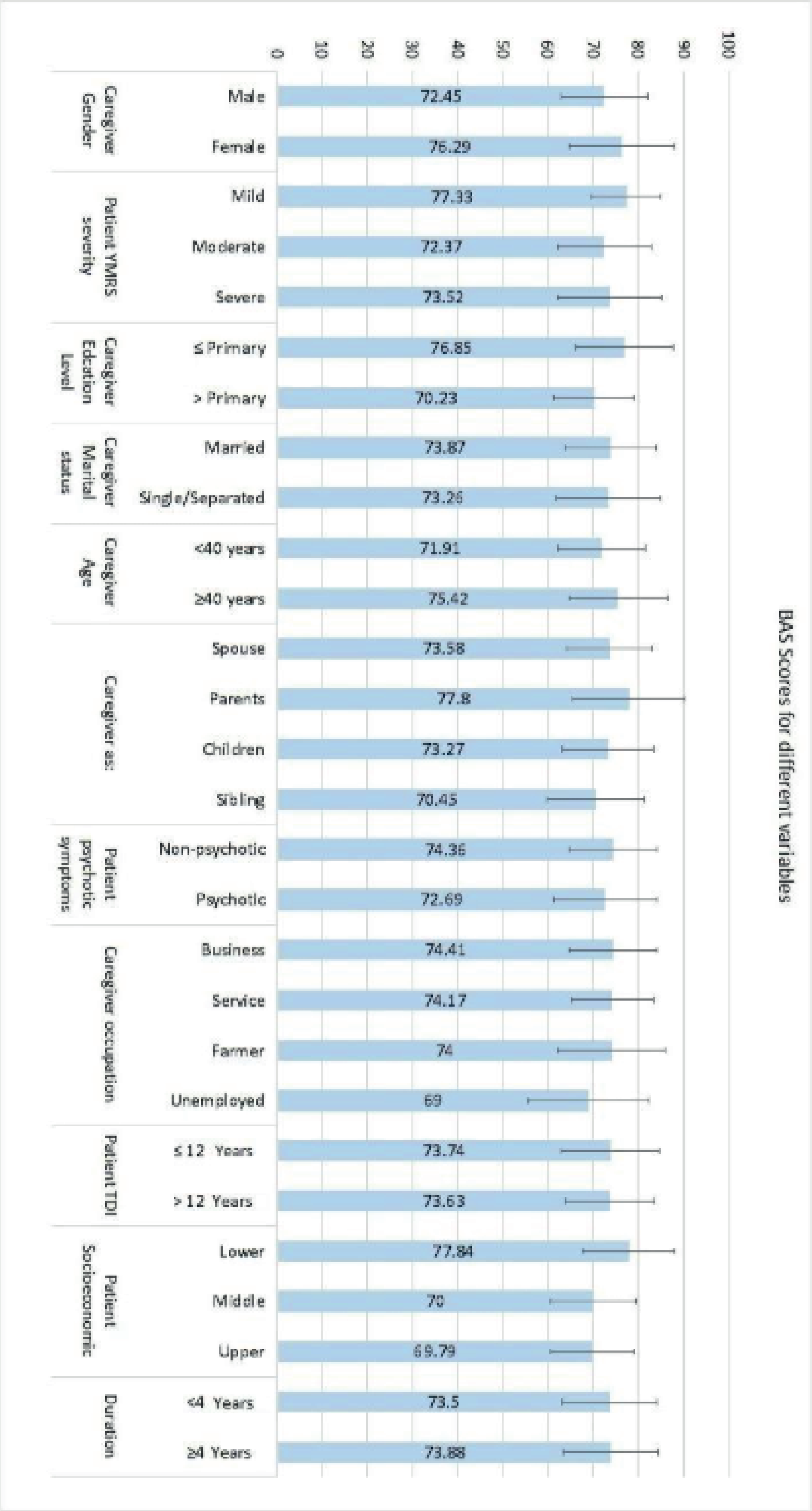


Figure 3: Figure showing mean BAS scores in different variables. Error bar show standard deviations.

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