

A Comparative Study on Assessment of Burden and Quality of Life Among Caregivers of Bipolar Disorder and Tuberculosis Patients

Dr Anubha¹, Dr Debasish Padhi², Dr Nasir Mahmood³, Dr Madhukar Katiyar⁴, Dr Akansha Arora⁵

¹Junior Resident, ²Assistant Professor, ³Professor, ⁴Professor and Head of Deptt. of Psychiatry,

⁵Junior Resident, Rama Medical College, Hospital and Research Centre, Kanpur.

Corresponding Author: Dr Anubha¹ (anubhasingh1903@gamil.com)

ABSTRACT

Background

In the healthcare domain, the indispensable role of caregivers in patient support is utmost. The family plays a crucial role in the care of a mentally and chronically ill patient. As these conditions can significantly impact the lives of patients, they also exert a profound influence on those who provide care, affecting their burden and quality of life.

Aim

This study aimed to evaluate the burden and Quality of Life among caregivers of Bipolar Disorder and Tuberculosis Patients.

Methods

This cross-sectional study involved primary caregivers of patients diagnosed with Bipolar Affective Disorder according to ICD-10 guidelines and of chronic medical conditions such as Refractory tuberculosis, and Drug-Resistant Tuberculosis. The study took place at the Department of Psychiatry, Rama Medical College, Hospital, and Research Centre, Kanpur. The sample was calculated using scientific statistical tools. The patient's caregivers were recruited from the Department of Psychiatry and the Department of TB & Chest till the required sample size was met and were categorized into two groups: Group 1 comprised 40 caregivers of bipolar patients, and Group 2 included caregivers of tuberculosis. Sociodemographic information was obtained through a semi-structured questionnaire. The Montgomery Borgatta Caregiver Burden Scale and Quality

of Life WHOQOL-BREF were administered to both groups to assess the burden and their Quality of life.

Results and discussion

According to the burden scale caregivers of Group 1 face more burden compared to Group 2 caregivers and their Quality of Life is also more affected in all the four domains. The result is statistically significant in all the dimensions.

Conclusion

Our study concluded that caregivers in both groups experience significant burden that adversely affect their quality of life. Therefore, strategies should be developed to support and psychoeducating caregivers to help them cope better and enhance their Quality of life.

Keywords: Burden, QoL, Caregiver, Bipolar, Tuberculosis.

Introduction

In the healthcare domain, the indispensable role of caregivers in patient support is utmost. Due to de-institutionalization and the growing trend of providing psychiatric care within the community, the significance of family caregivers has increased. Nowadays, following their brief stays in inpatient care, most Bipolar patients are discharged to their homes, often returning to the care of their families. ^[1] In India, the first-ever concept of including a family caregiver in treatment of the patient was introduced by Dr. Vidyasagar Rao in the 1950s. ^[2]

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.” ^[3] The family plays a crucial role in the care of a mentally and chronically ill patient such as Bipolar disorder and Tuberculosis. As these conditions can significantly impact the lives of patients, they also exert a profound influence on those who provide care, affecting their burden and quality of life. The burden of caregiving encompasses various physical, emotional, and financial challenges experienced by caregivers as they attend to the needs of their loved ones.

In India, where rehabilitation services are nearly non-existent and there is no social security system, the role of the family becomes increasingly crucial ^[4] and it plays a vital role in the management and well-being of individuals with chronic illnesses. Caregivers frequently sacrifice

their desires and endure considerable stress, which is often overlooked. The demands of caregiving can deplete one's emotional well-being, leading to a higher incidence of depression compared to the general population.^[5] The concept was first introduced by Treudley^[6] in 1946 as the negative impact of caregiving on a caregiver's mental health and quality of life.

The WHO defined caregiver burden as “the emotional, physical and financial demands and responsibilities of an individual's illness that are placed on family members, friends or other individuals involved with the individual outside the health care system.”^[7] Several studies conducted earlier on primary caregivers of patients with Bipolar disorder have shown that these caregivers experience a moderate to severe level of burden.^[8-12] The burden experienced by caregivers of patients with Bipolar disorder is a critical area of study that significantly impacts their quality of life.

The 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 in relation to their goals, expectations, standards, and concerns.^[13] Previous studies have found that heavier caregiver burden leads to poorer QoL among caregivers of Bipolar disorders.^[12,14-16] Caregivers of individuals with Bipolar disorder face substantial challenges, including high levels of distress, anxiety, and depressive symptoms due to the demanding nature of caregiving.

Research has shown that caregivers often feel forgotten, with healthcare systems focusing primarily on the patient's needs rather than theirs. The cyclical and unpredictable nature of Bipolar disorder further complicates the caregiving experience, leading to frequent changes in stressors that affect caregivers' overall well-being.

In contrast, Tuberculosis caregivers confront challenges related to infection control, medication adherence, and addressing social stigma associated with the disease. The prolonged treatment duration, potential for drug resistance, and the need for isolation during the infectious period can compound the burden on caregivers, impacting their quality of life and emotional well-being. In 2018, around 1.5 million people died from Tuberculosis. The WHO aims to eliminate Tuberculosis-related death, disease, and suffering by 2035 through the 'End TB Strategy' and to ensure that no family is burdened with catastrophic expenses due to tuberculosis (World Health Organisation, 2019).

However, the emergence of Drug-Resistant Tuberculosis (DR-TB) poses a significant threat and hinders the vision to end TB. The prolonged, toxic, and expensive treatment puts a heavy burden on families. Numerous studies have shown that caregivers of individuals with multidrug-resistant Tuberculosis (MDR-TB) face multiple challenges which include balancing caregiving responsibilities with full-time employment and sourcing funds for medical expenses and household needs. [17-19]

Though several studies have been done earlier, on caregiver burden and quality of life in the caregivers. However, there is less or no data comparing caregiver burden and quality of life in caregivers of patients afflicted by Bipolar Disorder and Tuberculosis patients. The study aims to compare and evaluate the caregiver burden and quality of life in primary caregivers of Bipolar Disorder patients and Tuberculosis patients.

Materials and Methods

This cross-sectional study involved primary caregivers of patients diagnosed with Bipolar Affective Disorder according to ICD-10 guidelines.^[20] The study took place at the Department of Psychiatry, Rama Medical College, Hospital, and Research Centre, Kanpur from March to May 2023. Caregivers of patients with chronic medical conditions such as Refractory tuberculosis, and Drug-Resistant Tuberculosis were recruited from the Tuberculosis & Chest department.

Institutional ethical committee approval was obtained for the study. Patients and their caregivers attending both the hospital outpatient and inpatient sections and willing to provide consent were included. The sample was calculated using scientific statistical tools. The patient's caregivers were recruited from the Department of Psychiatry and the Department of Tuberculosis till the required sample size was met. Caregivers were categorized into two groups: Group 1 comprised 40 caregivers of bipolar patients, and Group 2 included caregivers of patients with tuberculosis.

Inclusion and Exclusion Criteria

Caregivers aged over 20 years, residing with the patient for at least 12 months, providing care, having the most frequent contact with the patient, and offering financial support were included. Caregivers under 20 years old and those not related by blood to the patients were excluded. Spouses were included regardless of blood relation.

Assessment Tools

Sociodemographic data were collected through a semi-structured questionnaire.

The Montgomery Borgatta Caregiver Burden Scale ^[21] - consisting of 14 items, each with 5 possible responses, each response was given a score from 1 to 5. The questionnaire assessed Objective Burden (OB), Subjective stress Burden (SB), and Demand Burden (DB). For participants, the questionnaire was administered through interviews in their native language.

Quality of life WHOQOL-BREF ^[22,23] - This is the short version of the WHOQOL 100 consisting of 26 items across 4 QOL domains: physical health (7 items), psychological health (6 items), social relationships (3 items), and environment (8 items). Items are rated on a 5-point Likert scale (a low score of 1 to a high score of 5) to determine a raw item score. The mean score for each domain is then calculated, resulting in a mean score per domain between 4 and 20. Finally, this mean domain score is then multiplied by 4 to transform the domain score into a scaled score, with a higher score indicating a higher QOL. When transformed by multiplying 4, each domain score is then comparable with the scores used in the original WHOQOL-100.

Statistical Analysis

Participants were assured of the anonymity and confidentiality of their information to prevent reporting bias. Sociodemographic and individual characteristics were presented as numbers and percentages. Data were tabulated and analyzed using descriptive statistics, and an unpaired t-test to determine a P-value. All analysis was conducted using IBM SPSS version 28.0.1.0 for Windows.

Result

In this study, the two groups consisted mainly of family members as caregivers for bipolar patients (N=40) and for Tuberculosis patients(N=40). The sociodemographic characteristics are shown in Table 1. In terms of age distribution, both groups primarily consist of caregivers aged between 30 to 39 and 40 to 49, with Group 2 showing a slightly higher representation in the latter age bracket. Most of the caregivers in both groups are married, although Group 2 demonstrates a slightly higher proportion of married caregivers and spouses emerge as the primary caregivers in both groups, followed by offspring and parents. Regarding the duration, most caregivers in both groups have

been providing care for longer duration but Group 1 exhibits a higher percentage of caregivers who have been providing care for over 10 years compared to Group 2.

Caregiver burden

Table 2 represents the Montgomery Borgatta Caregiver Burden scale which compares the burden experienced by caregivers of bipolar patients and tuberculosis patients across objective, subjective, and demand burden dimensions. The scores in caregivers of Bipolar patients were significantly higher compared to Tuberculosis patients

Objective Burden: Caregivers of bipolar patients report a higher mean objective burden score compared to caregivers of tuberculosis patients with a p-value less than 0.0001, indicating a statistically significant difference.

Subjective burden: In this also caregivers of bipolar patients report a mean score of 14.20, whereas caregivers of tuberculosis patients report a lower mean score of 12.50. The p-value <0.001 shows a statistically significant difference between the two groups.

Demand Burden: Bipolar patients demonstrate a significantly higher mean of 13.35 compared to Tuberculosis patients with a mean score of 8.90, indicating a highly statistically significant difference ($p < 0.0001$). This implies that caregivers of bipolar exhibit a greater burden.

Overall, caregivers of bipolar patients consistently report higher levels of objective, subjective, and demand burden compared to caregivers of tuberculosis patients, as evidenced by the significant differences in mean scores and p-values across all dimensions.

Table 1: Description of socio-demographic variables of caregivers

Variables		Group 1		Group 2	
		N	%	N	%
Age (Years)	20-29	10	25	09	22.5
	30-39	14	35	12	30
	40-49	08	20	14	35
	50-59	06	15	04	10
	≥ 60	02	05	01	2.5
Gender	Male	22	55	19	47.5
	Female	18	45	21	52.5
Education	Illiterate	16	40	14	35
	Primary	14	35	16	40

	Secondary	08	20	07	17.5
	Graduation	02	05	03	7.5
Marital Status	Single	15	37.5	14	35
	Married	22	55	26	65
	Divorced	03	7.5	00	00
Relationship of Caregivers	Spouse	18	45	16	40
	Offspring	08	20	07	17.5
	Parent	10	25	11	27.5
	Sibling	04	10	06	15
Duration of care	1-5 years	10	25	26	65
	6-10 years	19	47.5	08	20
	> 10 years	11	27.5	06	15

Table 2: Comparison of means of various caregiver burden in Bipolar and Tuberculosis patients

Burden	Bipolar Mean \pm S.D	Tuberculosis Mean \pm S.D	t value	P value
Objective Burden	21.45 \pm 2.99	15.90 \pm 3.65	7.434	< 0.0001
Subjective Burden	14.20 \pm 2.64	12.50 \pm 2.06	3.207	< 0.001
Demand Burden	13.35 \pm 2.23	8.90 \pm 1.91	9.550	< 0.0001

Table 3: Quality Of Life domain in caregivers of patients with bipolar disorder and Tuberculosis patients.

QOL domain	Bipolar Mean \pm SD	Tuberculosis Mean \pm SD	t value	P value
Physical Domain	48.05 \pm 6.13	55.73 \pm 7.80	4.891	< 0.0001
Psychological Domain	46.55 \pm 6.91	53.75 \pm 8.04	4.294	< 0.0001
Social Domain	49.73 \pm 5.99	54.80 \pm 7.53	3.332	0.001
Environmental Domain	50.00 \pm 5.60	52.98 \pm 6.46	2.199	0.030

This table compares the quality of life (QOL) domains in caregivers of patients with bipolar disorder and tuberculosis patients across four dimensions: physical, psychological, social, and

environmental. Overall, caregivers of tuberculosis patients consistently report higher quality of life scores across all domains compared to caregivers of bipolar patients, as indicated by the statistically significant differences in mean scores and low p-values across all dimensions.

Caregivers of bipolar patients report the lowest mean score in the psychological domain followed by the physical and social domain whereas caregivers of Tuberculosis scored the lowest mean in the environmental domain. Tuberculosis patients' caregivers also suffer lower mean scores in the psychological domain which is later followed by the social and physical domain.

Discussion

Both bipolar disorder and tuberculosis are chronic conditions that directly, and profoundly affect the families of those affected. While providing care for individuals, family members also endure a substantial burden, resulting in a significant decline in their quality of life due to the stress inherent in the caregiving role. This study aimed to investigate the burden and quality of life experienced by caregivers of individuals with bipolar disorder and tuberculosis. The findings revealed that caregivers of these diseases bear a significant burden.

Caregivers who take the major responsibility of caregiving for mentally and medically ill patients have to undergo undesirable levels of severe burden.^[24] Caregiver burden is categorized in terms of objective burden (OB), subjective burden (SB), and demand burden (DB). OB is defined as “the extent of disruptions or changes in various aspects of the caregivers’ life and household. It measures the disruption of the caregiver's life”. SB is defined as “the caregivers’ attitude or emotional reactions to the caregiving experience. It measures the emotional impact of caregiving on the caregiver”. DB measures “the extent to which the caregiver feels the responsibilities are overly demanding”.^[25] Objective burden was assessed by mean scores on the Montgomery Borgatta burden scale was on the higher side which indicated that caregivers were encountering substantial challenges in caring for their ill relatives. This finding aligns with prior research conducted by Nageshwar Rao et al.^[12]

In a country like India, where psychiatric illnesses are often perceived as taboo or cursed, the stigma surrounding mental health issues persists within our society. Caregivers have to exert additional physical strength, as the patient relies on them, and sometimes have to deal with the patient's reluctance to cooperate in severe cases. The study findings imply a high burden on

caregivers of bipolar patients which is consistent with a previous study conducted by Ampalam P et al. ^[25] in a government hospital for mental care among 100 caregivers comparing psychiatric illness and chronic medical illness. Other similar studies conducted by Mital et al. ^[26], Yılmaz et al. ^[8], and Gania et al. ^[27] found that caregivers of patients with bipolar disorder had a nearly moderate level of burden. As can be seen in Tables 2 and 3, caregivers of patients with Bipolar have a higher burden of care and are likely to have depression, anxiety, and poor quality of life. The achieved results indicate that care burden influenced QoL in all domains, Similar results were found in previous studies. ^[14,16, 28]

While the circumstances may differ slightly for chronically ill patients as these patients are mentally sound, still caregivers face significant challenges. In the case of tuberculosis, caregivers encounter social isolation due to fear of contracting the disease and additionally, the financial strain of treatment costs. Our results show that caregivers of patients with tuberculosis are likely to experience a significant burden of care and impact QoL. Other studies also showed similar results ^[18,19, 29] shows family caregivers of these patients suffer from mental distress.

Our study indicates that caregivers of tuberculosis patients often experience a poor quality of life with the burden of care can be predicted by the environmental domain of quality of life as seen in Tables 2 and 3. This could be attributed to the multitude of challenges faced by caregivers when a family member is diagnosed with tuberculosis, particularly if they are the sole wage earners. Financial strain can one of be the major issues and other factors like isolation, disturbance in daily routines, and duties can lead to poor quality of life among caregivers. Similar results were found in other studies. ^[17,30]

Conclusion

This study highlights the pivotal role of caregivers in providing support to individuals with bipolar disorder and tuberculosis. It emphasizes the significance of addressing the needs of caregivers to enhance patient outcomes and promote their own well-being. By recognizing and attending to the challenges faced by caregivers, the healthcare system can cultivate a more supportive and inclusive environment for both patients and their caregivers. Attending professionals can do psychoeducation, motivate the caregivers, and counsel them about coping methods to improve their QoL.

Limitations

While this study provides valuable insights, it has some limitations that need to be taken into account. The cross-sectional design prevents establishing causality. The study sample also included few caregivers who were not educated and the burden scale had to be translated into the local language which could be a confounding factor. Moreover, the study's small sample size and hospital-based nature further limit its generalizability.

Financial support and sponsorship – Nil.

Conflicts of interest- There are no conflicts of interest.

References

1. Kaushik P, Bhatia MS. Burden and quality of life in spouses of patients with schizophrenia and bipolar disorder. *Delhi Psychiatry Journal*. 2013; 16:83–9.
2. Chadda RK. Caring for the family caregivers of persons with mental illness. *Indian J Psychiatry*. 2014; 56:221–7.
3. Ravi S, Goud BR, Archana M, Pius TM, Pal A, John V, et al. Burden among caregivers of mentally ill patients: A rural community – Based study community medicine. *Int J Res Dev Health*. 2013; 1:29–34.
4. Kate N, Grover S, Kulhara P, Nehra R. Relationship of caregiver burden with coping strategies, social support, psychological morbidity, and quality of life in the caregivers of schizophrenia. *Asian J Psychiatr*. 2013; 6:380–8.
5. Pratima B, Jena S. Caregiver burden in severe mental illness, review article. *Delhi Psychiatry J*. 2011; 14:211–9.
6. Treudley MB. Mental illness and family routines. *Ment Hyg*. 1946; 30:235–49.
7. Geneva: WHO; 2005. WHO. A Glossary of Terms for Community Health Care and Services. WHO Centre for Health Development.

8. Yılmaz, S. Perceived Care Burden and Related Factors in Primary Caregivers of Patients Diagnosed with Bipolar Disorder. *J. Psychiatr. Nurs.* 2020, 12, 9–17.
9. Perlick DA, Rosenheck RA, Miklowitz DJ, Chessick C, Wolff N, Kaczynski R, et al; STEP-BD Family Experience Collaborative Study Group. Prevalence and correlates of burden among caregivers of patients with bipolar disorder enrolled in the Systematic Treatment Enhancement Program for Bipolar Disorder. *Bipolar Disord* 2007; 9:262–73.
10. ERTEN E, OZDEMIR A, FISTIKCI N, ALPMAN N The effect of period and course characteristics on caregiver burden in patients with bipolar disorder. *Turkish Journal of Psychiatry.* 2014; 25(2): 114 – 123.
11. Swaroopachary. R.S, Ivaturi. S.C, Kalasapati. L & Reddy. C.M (2019). Caregiver Burden in Bipolar Affective Disorder. *International Journal of Indian Psychology*, 7(1), 130-136.
12. Nageswar Rao Nallapaneni, Prabhakar Yendluri, Chandra Bhanu Gupta Paritala, Bhupal Naidu Racharla. “A Study of Caregiver Burden in Bipolar Affective Disorder”. *Journal of Evolution of Medical and Dental Sciences* 2015; Vol. 4, Issue 49, June 18; Page: 8499-8515
13. Group TW. The World Health Organization quality of life assessment (WHOQOL): Development and general psychometric properties. *Soc Sci Med* 1998; 46:1569-85.
14. Mohamed, Afaf & Mohsen, Nesreen & Morkos, Bishoy & Naguib, Rehab. (2022). Quality of life among caregivers of patients with bipolar 1 disorder. *Egyptian Journal of Psychiatry.*
15. Ukpong D, Ibigbami O. Correlates of quality of life in caregivers of patients with schizophrenia and bipolar affective disorder: A study from southwestern Nigeria. *Turk Psikiyatri Derg.* 2021;32(1):26–32.
16. Cheng, WL., Chang, CC., Griffiths, M.D. et al. Quality of life and care burden among family caregivers of people with severe mental illness: mediating effects of self-esteem and

- psychological distress. *BMC Psychiatry* 22, 672 (2022).
17. Thanduxolo Elford Fana & Lizo Sotana | (2021) Exploring the experiences of family caregivers with people with drug-resistant tuberculosis, *Cogent Social Sciences*, 7:1,1906494.
 18. Sukumani, J. T., Lebese, R. T., Khoza, L. B., & Risenga, P. R. (2012). Experiences of family members caring for tuberculosis patients at home in Vhembe district of the Limpopo Province. *Curations*, 35, 1–9.
 19. Wu S, Zhang H, Wang Y, Wang J, Zhang P, Asakawa T, Lin Y. Call for special attention to the caregiver burden of patients with drug-resistant tuberculosis in low- and middle-income countries. *Biosci Trends*. 2023 Nov 18;17(5):405-408.
 20. World Health Organization. (1992). The ICD-10 classification of mental and behavior disorders: clinical descriptions and diagnostic guidelines. World Health Organization.
 21. Montgomery, Rhonda. (2006). Using and Interpreting the Montgomery Borgatta Caregiving Burden Scale.
 22. World Health Organization. (2004). The World Health Organization Quality of life (WHOQOL) - BREF, 2012 revision. World Health Organization.
 23. World Health Organization. WHOQOL-BREF: introduction, administration, scoring and generic version of the assessment: field trial version, December 1996. No. WHOQOL-BREF. Geneva: World Health Organization, 1996.
 24. Walke SC, Chandrasekaran V, Mayya SS. Caregiver Burden among Caregivers of Mentally Ill Individuals and Their Coping Mechanisms. *J Neurosci Rural Pract*. 2018 Apr-Jun;9(2):180-185.
 25. Ampalam P, Gunturu S, Padma V. A comparative study of caregiver burden in psychiatric illness and chronic medical illness. *Indian J Psychiatry*. 2012 Jul;54(3):239-43.

26. Mital AK, Sabnis SG, Kulkarni VV. Caregiver Burden in Medical versus Psychiatric Patients: A Cross-sectional Comparative Study. *Indian J Psychol Med.* 2017 Nov-Dec;39(6):777-784.
27. Gania, Ab. Majid et al. "Caregiver burden in the families of the patients suffering from bipolar affective disorder." (2019).
28. Patil A, Kale SS. Quality of life in family members of patients of Schizophrenia and Bipolar Mood Disorder: Cross sectional study in a sample of the Indian population. *NJNS.* 2023;20(2):40-48.
29. Mohebzi Z, Dehbozorgi R, Setoode G, Momennasb M, Heydari N, Shaygan M. Lived Experience of Iranian Family Caregivers of Tubercular Patients: A Qualitative Study. *Invest. Educ. Enferm.* 2022; 40(3):e02.
30. Adamu, H.I., Osoba, T.A., White, C.R. and Abdullahi, Y.G. (2018) Relationship between Caregiver's Quality of Life and Childhood Tuberculosis in Bauchi State, Northeastern Nigeria.