

A Cross-sectional Study of Burden and Psychiatric Morbidity in Caregivers of Psychosis Patients in a Rural Tertiary Teaching Hospital

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ABSTRACT

Introduction: Global Burden of Disease Study 2017 reports around 20 million people suffering from schizophrenia and other psychoses. Family members are the primary caregivers for the majority of persons with mental illness. Looking after their physical and financial needs causes caregivers to experience a burden which in turn leads to psychiatric morbidities. The present study aims to assess the caregiver burden and associated psychiatric morbidities in caregivers of patients with psychosis attending a rural tertiary teaching hospital.

Methodology: This was an observational cross-sectional study conducted on 60 primary caregivers of patients with psychosis who are aged 18 years and above and providing care for at least 1 year. Burden Assessment Schedule (BAS) was used to assess caregiver burden and Mini International Neuropsychiatric Interview (MINI) was used to screen for psychiatric morbidities.

Results: Among the caregivers, most were females (61.67%), illiterates (48.33%), belonged to lower socio-economic class (53.33%), and spouses of the patient (70%). Around 63.3% of the caregivers experienced moderate to severe burden. The mean BAS score was 66.65 ± 25.28 . Around 40% of the caregivers experienced depressive disorders. Higher Burden assessment scores were significantly associated with the presence of psychiatric morbidities ($p < 0.001$). In addition, longer duration of caregiving was also significantly associated with the presence of psychiatric morbidities ($p < 0.01$). Elder age was also found to be significantly associated with higher burden. ($p < 0.05$).

Conclusion: This study has revealed a significant burden in the caregivers of psychosis patients and a higher prevalence of psychiatric morbidities among them. This emphasizes the need to strategize interventions and coping strategies for the caregivers.

Keywords: Caregiver Burden, Psychosis, Psychiatric morbidities, Burden Assessment Schedule

(Paper received – 20th February 2024, Peer review completed – 11th March 2024, Accepted – 8th April 2024)

INTRODUCTION

Global Burden of Disease (GBD) study 2017 reports that around 13 percent of the world population i.e., 970 million, have been suffering from mental illnesses of which 20 million are suffering from Schizophrenia and other psychoses [1]. Mental illness is characterized by disturbance in cognition, emotional regulation, and behavioural functioning resulting in enormous social and economic burden to the affected individuals, their families, and communities [2].

An integral part of the care system for people with chronic mental illnesses is family [3]. In India, the family support system plays a significant role in caring for people with mental illnesses as professional services are not adequately developed in public and private sectors due to a shortage of skilled human resources and infrastructure [4]. 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 [5].”

The caregivers often play multiple roles in caring for persons with mental illness, including taking day-to-day care, supervising their medications, taking the patient to the hospital, and looking after the financial needs thus experiencing considerable burden and stress and hence need help to cope with it. The caregiver burden is a universal phenomenon. Studies show that almost 80% of caregivers experience a burden in their caregiving role [6].

In the case of caregivers who provide long-term care for individuals with chronic mental illness, psychological or economic difficulties can be seen. These difficulties can lead to emotional disturbances such as burden, depression, anxiety, burnout, impaired physical health, social isolation and economic difficulties [7]. Goldstein, Miklowitz, and Richards reported that 44% of caregivers of individuals with chronic mental illness have anxiety disorders [8]. Steele, Maruyama, and Galynker reported in a systematic review that depression occurred in 46% of caregivers of persons with mental illness [9].

The present study aimed to explore the burden experienced by the caregivers of patients with psychosis, assess the psychiatric morbidity of caregivers, and explore the association between caregivers' burden and psychiatric morbidity in a rural setting.

METHODOLOGY

This is a comparative cross-sectional study done on primary caregivers of clinically diagnosed patients with psychosis attending the psychiatry department at a tertiary care teaching hospital located in a rural area after taking written informed consent. The Institutional ethical review committee approved this study. Data was collected over 18 months from January 2019 to June 2020. The sample size was calculated based on a recent study [10].

A minimum Sample size of 47 was deemed adequate. However, at least 60 subjects each were considered for evaluation keeping attrition in view. Criteria for inclusion were caregivers of patients with psychosis living with the patients and caring for them for at least 1 year after diagnosis and aged above 18 years, at the time of study. Caregivers of patients with psychosis secondary to chronic medical illnesses or substance abuse disorders and caregivers of patients with schizoaffective disorders were excluded.

All the caregivers were given a specially prepared proforma which contained information about socio-demographic details like age, gender, education, occupation, monthly income, type of family, relationship to patient, duration of caregiving, and patient illness.

Burden Assessment Schedule (BAS) [11], developed by Thara and others was used to assess both the objective and subjective burden experienced by the caregivers of mentally ill patients. BAS has been reported to have good inter-rater reliability (κ 0.80) and satisfactory face validity in terms of the relevance of the items in measuring caregiver burden.

Mini International Neuropsychiatric Interview (MINI) [12] was used to assess psychiatric morbidity. MINI is a short structured diagnostic interview, developed jointly by psychiatrists and clinicians in the United States and Europe, for DSM-IV and ICD-10 psychiatric disorders and comprises modules for 17 psychiatric diagnoses.

Statistical Analysis: The data was entered into the Microsoft Excel 2007 version and further analysed using Statistical Package for the Social Sciences (SPSS) v. 20 applying the chi-square test and Fisher-Freeman-Halton test and a P value of < 0.05 was statistically significant.

RESULTS

A total of 60 caregivers have been assessed. Many the caregivers (30%) were in the age group of 31-40 years followed by 41-50 years (26.67%). Most of the caregivers (61.67%) were females. Most of the caregivers were illiterate (48.33%). Among the caregivers, a large number were skilled workers (36.67%) followed by unskilled workers (28.33%). Most of them belonged to lower socio-economic class (53.33%). A vast majority of the caregivers (70%) were spouses of the patients. (Table 1)

The duration of caregiving varied among the caregivers. More caregivers (36.67%) were providing the care for about 5-7 years. Most of the patients (73.33%) were suffering from paranoid schizophrenia followed by undifferentiated schizophrenia (15%). The burden assessment scores were found to be mild in 36.67% of the caregivers followed by moderate (31.67%) and severe (31.67%). (Table 2)

Around half of the caregivers (50%) have not experienced any psychiatric morbidities. Among the other half, a majority (26.67%) have experienced Major depressive disorder followed by dysthymia (13.33%), alcohol use disorders (8.33%), and panic and anxiety disorders (1.67%). (Table 3)

Table 1: Socio-demographic distribution of Caregivers

Sociodemographic variable		Frequency	Percentage
Age in years	18 – 30	11	18.33%
	31 – 40	18	30%
	41 – 50	16	26.67%
	51 – 60	9	15%
	>60	6	10%
Gender	Female	37	61.67%
	Male	23	38.33%
Education level	Illiterate	29	48.33%
	Primary school	15	25%
	High school	12	20%
	Intermediate	4	6.67%
Occupation	Unemployed/ Housewife	16	26.67%
	Unskilled worker	17	28.33%
	Semiskilled worker	5	8.33%
	Skilled worker	22	36.67%
Socio-economic status	Lower	32	53.33%
	Upper lower	13	21.67%
	Lower middle	10	16.67%
	Upper	5	8.33%
Relationship to patient	Father	5	8.33%
	Husband	18	30%
	Mother	13	21.67%
	Wife	24	40%

Table 2: Frequency Distribution of Other Parameters and Burden Assessment Scores

Other Parameters		Frequency	Percentage
Duration of Caregiving in years	2-4	13	21.67%
	5-7	22	36.67%
	8-10	17	28.33%
	>10	8	13.33%
Illness of patient	Paranoid Schizophrenia	44	73.33%
	Residual Schizophrenia	5	8.33%
	Undifferentiated Schizophrenia	9	15%
	Psychosis not otherwise specified (NOS)	1	1.67%
	Delusional disorder	1	1.67%
Burden Assessment Scores	Mild (0-40)	22	36.67%
	Moderate (41-80)	19	31.67%
	Severe (81-120)	19	31.67%

Among the caregivers, 90.91% (n=20) of the caregivers with mild BAS scores did not have any psychiatric morbidities. Thirty-seven percent (n=7) of the caregivers with moderate BAS scores screened for dysthymia and 78.95% (n=15) of the caregivers with severe BAS scores screened for MDD. This shows that the severity

of the burden was significantly associated with the psychiatric morbidities in the psychosis group ($p=0.000$). (Table 4)

Table 3: Frequency Distribution of Psychiatric Morbidities in Caregivers

Psychiatric Morbidities	Frequency	Percentage
None	30	50%
Panic disorder	1	1.67%
Alcohol use disorders	5	8.33%
Dysthymia	8	13.33%
Major Depressive Disorder (MDD)	16	26.67%

Table 4: Association of Burden Assessment scores with psychiatric morbidities

BAS Scores	Psychiatric Morbidities					P value
	None	Panic Disorder	Alcohol Use Disorders	Dysthymia	MDD	
Mild	20 (90.91%)	-----	1 (4.55%)	1 (4.55%)	-----	0.000*
Moderate	10 (52.63%)	-----	1 (5.26%)	7 (36.84%)	1 (5.26%)	
Severe	-----	1 (5.26%)	3 (15.79%)	-----	15 (78.95%)	
Total	30 (50.00%)	1 (1.67%)	5 (8.33%)	8 (13.33%)	16 (26.67%)	

Table 5: Association of Duration of caregiving with Psychiatric morbidities

Duration of caregiving in years	Psychiatric Morbidities					P value
	None	Panic Disorder	Alcohol Use Disorders	Dysthymia	MDD	
2-4	11 (84.62%)	-----	1 (7.69%)	1 (7.69%)	-----	0.002*
5-7	13 (59.09%)	1 (4.55%)	1 (4.55%)	5 (22.73%)	2 (9.09%)	
8-10	6 (35.29%)	-----	1 (5.88%)	2 (11.76%)	8 (47.06%)	
>10	-----	-----	2 (25.00%)	-----	6 (75.00%)	
Total	30 (50.00%)	1 (1.67%)	5 (8.33%)	8 (13.33%)	16 (26.67%)	

Duration of caregiving was also found to be significantly associated with psychiatric morbidities ($p=0.002$) with 84.62% of the caregivers providing care for 2-4 years did not screen for any psychiatric morbidities whereas 47.06% of the caregivers providing care for 8 - 10 years and 75% of those providing care for more than 10 years screened for MDD respectively. (Table 5)

Table 6: Association of Age and Burden Assessment scores

Age in years	B.A.S. scores			P value
	Mild	Moderate	Severe	
18 – 30	7 (63.64%)	4 (36.36%)	-----	0.011*
31 – 40	6 (33.33%)	9 (50.00%)	3 (16.67%)	
41 – 50	4 (25.00%)	5 (31.25%)	7 (43.75%)	
51 – 60	4 (44.44%)	1 (11.11%)	4 (44.44%)	
>60	1 (16.67%)	-----	5 (83.33%)	
Total	22 (36.67%)	19 (31.67%)	19 (31.67%)	

Higher burden scores were associated with increasing age. Eighty-three percent of the caregivers above 60 years had severe B.A.S. scores. Age was significantly associated with B.A.S. scores ($p=0.011$). (Table 6)

DISCUSSION

Caregiver burden is a universal phenomenon. Research defining caregiver burden began in the 1960s. Grad and Sainsbury measured burden as any cost to the family. Zarit, Reever, and Bach-Peterson conclude it is the characteristics of the caregiving situation and availability of resources, rather than the condition of the recipient, that have a direct relationship to the well-being of the caregiver. George and Gwyther reinforced Zarit's definition they found that physical, psychological, emotional, social, and financial problems are all related to caregiver burden [13].

Caregiving has been identified as a chronic stressor that places caregivers at risk for physical and emotional problems [14]. The negative impact of caregiving on the caregivers' mental health is widely substantiated in the literature. Approximately 30% of caregivers reported that caregiving has affected their well-being and that they were often worried or depressed in data collected by the Australian Bureau of Statistics (ABS) [15]. A review of 41 studies published between 1990 and 1995 focused on the effects on caregivers of people with dementia. This review reported increased levels of psychiatric morbidity and higher levels of depression among caregivers [16].

In the present study, we have assessed 60 caregivers of patients with psychosis for caregiver burden and associated psychiatric morbidities. The mean BAS score of the caregivers was 66.65 ± 25.28 . This is similar to the study done by Rammohan, Rao, and Subbakrishna who have identified the mean BAS scores to be 65.50 ± 8.61 in parents and 70.00 ± 8.74 in spouses of schizophrenic patients [17]. Similar results have also been observed by Vasudeva, Sekhar, and Rao who conducted a comparative study between caregivers of schizophrenia and bipolar patients which showed mean BAS scores of 68.75 ± 8.76 and 64.45 ± 10.14 respectively in caregivers of schizophrenia and bipolar patients [18].

In the present study, we have observed that half of the caregivers did not suffer from any psychiatric morbidities. But the remaining half have screened for psychiatric morbidities. Among them, 26.67% have screened for major depressive disorder and 13.33% for dysthymia which in total account for around 40% of the caregivers being screened for depressive disorders. This was like the findings reported by Rodrigo and others who found that 37.5% of the caregivers screened positive for depression [19].

Kumar, Babu, and Kumar found that 39% of the caregivers of schizophrenic patients have experienced depressive episodes which was like the findings of our study [20]. Magaña, Ramírez García, Hernández, and Cortez also found that 40% of the caregivers of schizophrenic patients screened for depression as in our study [21].

Around 91% of the caregivers with mild burden did not screen for any psychiatric morbidities. Whereas 47% of the caregivers suffering moderate burden and all the caregivers (100%) experiencing severe burden have screened positive for psychiatric morbidities. The present study also reveals a significant association ($p < 0.001$) between the burden and psychiatric morbidities among the caregivers. Similar findings have been observed in other studies assessing the burden of care among the relatives of schizophrenic patients [22-23]. In addition to the above findings, we have also observed that the duration of caregiving was significantly ($p < 0.05$) associated with the presence of psychiatric morbidities. Around 84% of the caregivers providing care for 2-4 years have not developed any psychiatric morbidities whereas all the caregivers (100%) providing care for more than 10 years have been screened positive for psychiatric morbidities. Around 56% of caregivers providing care for 8 years or more have screened positive for major depressive disorder. We have also observed higher burden scores were associated with increasing age and that age was significantly associated with burden scores ($P < 0.05$). Similar findings were also observed in studies [24-25].

CONCLUSION

This study has revealed a significant burden among the caregivers of patients with psychosis and also a higher prevalence of psychiatric morbidities among them. There was also a significant association found between burden and psychiatric morbidities. These findings emphasize the need for the identification of burden on the caregivers of patients with psychosis so that they are not adversely affected by it. This also stresses the need to strategize interventions focusing not only on the patients but also involving the caregivers which are feasible with the available infrastructure and resources. The present study has certain limitations. The sample size was modest and the study was done in a hospital setting hence the results cannot be generalized to a wider population. Rater bias could not be completely excluded as the examiners who applied BAS and MINI were not blind to the diagnosis.

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Acknowledgements – Nil

Conflict of Interest – Nil

Funding – Nil