ORIGINAL ARTICLE

Family Burden among Caregivers of Mentally ill Patients Residing in an Urban Community of Delhi: A Cross-Sectional Study

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ABSTRACT

Background: Family plays a pivotal role in the care of mentally ill patients. Family burden refers to the stress and strain that family members or friends experience when they take care of someone who is ill. This burden can include emotional, physical, and financial challenges. **Aim & Objective**: To assess the family burden among caregivers of mentally ill patients residing at Kalyanpuri, East Delhi. **Settings and Design**: Community based Cross-Sectional Study Design **Methods and Material**: A primary caregiver of mentally ill patients, who were residing at Kalyanpuri area and attending the psychiatric clinic of Lal Bahadur Shastri Hospital and Urban Health Centre Kalyanpuri, run by the Department of Community Medicine, Lady Hardinge Medical College, were interviewed using Family Burden Interview Schedule (FBIS) and Family burden among the study participants was assessed. **Statistical analysis used**: Data were appropriately coded and entered into the freely available SPSS version for analysis. **Results**: A total of 250 primary caregivers were interviewed and family burden was found in them. Nearly half (49.6%) and one third (34.4%) of the participants experienced moderate and mild level of burden respectively, with the lowest (16.0%) number of participants experiencing the severe level of burden. In different domains disruption of routine family activities had highest mean weighted score (1.13 ± 0.39). The level of burden in caregivers was significantly associated with gender of caregivers, duration of illness of the patient and time spent on caregiving ($p < 0.05$). **Conclusions**: Most of the caregivers were suffering from a moderate level, followed by mild and severe level burden.

KEYWORDS

Caregivers; Mentally Ill Patients; Family Burden Interview Schedule

INTRODUCTION

Mental disorders lead to significant disturbances in thinking, emotional regulation, or behaviour in the patients. Mental health disorders are one of the highest prevalent health issues affecting nearly 970 million people worldwide.(1) For proper caregiving of mentally ill, patient's family plays a major role. 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. Caregiver burden is the emotional, physical and 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.(2) The unpredictable nature of mental health conditions, associated with the stigma related to mental illness, can leave caregivers feeling isolated. They may struggle with managing the care recipient's symptoms, handling crises, or ensuring compliance with treatment plans. This constant responsibility often leads to fatigue, sleep disturbances, and a decline in the caregiver's physical and mental health. Caregivers may also experience financial strain due to medical expenses or reduced work hours, as well as social withdrawal as their time and energy are consumed by caregiving. Feelings of frustration, guilt, or resentment are common, especially when support systems are lacking. Addressing caregiver burden requires access to resources, support networks, and mental health services to ensure both caregivers and patients can thrive. There is dearth of literature on community-based study in this field.

Aim & Objective: To assess the Family Burden among caregivers of the mentally ill patients residing at Kalyanpuri, East Delhi.

MATERIAL & METHODS

Study design: Community based Cross-Sectional Study

Study duration: Study was conducted between November 2022 to February 2024.

Study setting: The study was conducted at Kalyanpuri East Delhi, an Urban Field Practice area of Department of Community Medicine, Lady Hardinge Medical College, New Delhi.

Study population: Primary caregivers of mentally ill patients who are 18 year and more and residing at Kalyanpuri, Delhi

Sample size calculation: Estimated sample size was 250. Sample size was calculated on the basis of prevalence of severe caregiver burden (3) (40.9%), 95% confidence interval and 15% relative error.

Inclusion Criteria: Primary Caregivers those who were primarily involved in caregiving and living with the diagnosed mentally ill patients in the same environment, for past 1 year.

Exclusion Criteria: Caregivers who are hired paid for providing the caregiving services like Nurse, Maid, Ayah etc

Methodology: Primary caregivers of the mentally ill patients attending the Psychiatric clinic of Lal Bahadur Shastri Hospital and Urban Health Centre Kalyanpuri were enlisted for study. Prior permission from ethical committee of Lal Bahadur Shastri Hospital was taken. The details of the patients including the address were noted from the Psychiatry clinic which is functional daily in Lal Bahadur Shastri Hospital and weekly in Urban Health Centre, Kalyanpuri and later home visits were made and the caregivers were interviewed in depth in community setting.

Data collection tools: A standardised scale and Semi-structured self-designed pre-tested questionnaire were used to assess Family Burden among caregivers and Socio-demographic profile(4)and details of caregivers.

Family Burden Interview Schedule (FBIS)(5) was used for assessing Family Burden. The interview schedule was developed by Pai and Kapur (1981) to assess caregiver burden. The scale consists of 24 items grouped under six areas. (i) Financial Burden (6 items), (ii) Disruption of Family Routine Activities (5 items), (iii) Disruption of Family Leisure (4 items), (iv) Disruption of Interaction (5 items), (v) Effect on Physical Health of others (2 items), (vi) Effect on Mental Health of the others (2 items). Each item is rated on a 3-point scale- 0= No Burden, 1=Moderate Burden and 2=Severe Burden. The reliability and validity are more than 0.87 and 0.72, respectively. FBIS score between 0-16 was considered as mild level of burden, 17-32 as moderate level of burden and score 33-48 as severe level of burden.

RESULTS

A total of 250 caregivers of mentally ill patients were interviewed. The study had a higher proportion of females (60.8%) compared to males (39.2%), with a mean age of 40.34±11.75 years. The largest age group was 40-49 years (30.8%), followed by 30-39 years (27.6%). Among males, the 40-49 years group was the most prevalent (41.8%), while females were most represented in the 30-39 years group (25.7%). More than half (51.2%) of participants belonged to the upper lower class as shown in Table 1.

Table 1 Socio-demographic details of Caregivers and patients with mental illness. (N=250)

Age of caregivers in completed years	**Gender of caregivers (%)**		**Total (%)**
	Male No. (%)	Female No. (%)	
18-29	5(5.1)	38(25.0)	43(17.2)
30-39	30(30.7)	39(25.6)	69(27.6)
40-49	41(41.8)	36(23.7)	77(30.8)
50-59	16(16.3)	26(17.1)	42(16.8)
>60	6(6.1)	13(8.6)	19(7.6)
Total	98(100)	152(100)	250(100)
Mean± Standard deviation	41.00±10.51	39.00±12.44	40.34±11.75
Range	19-70	19-67	19-70
Socio Economic status of Caregivers as per Modified Kuppuswamy scale	Number (%)		
Upper middle	22(8.8)		

Lower middle	65(26.0)
Upper lower	128(51.2)
Lower	35(14.0)
Total	250(100)
Type of family	Number (%)
Joint	122(48.8)
Nuclear	128(51.2)
Total	250(100)

Over half of the participants (56.8%) were spouses of mentally ill patients, followed by parents (20%). The average duration of illness was 4.66±4.86 years, with the majority of patients (58.4%) having experienced mental illness for 1-3 years at the time of the interview, and 11.6% for more than 10 years. Caregivers spent an average of 13.94±5.99 hours per day caring for patients. Half of the caregivers (50%) dedicated 9-16 hours daily, while 24% spent more than 16 hours per day with their patient's details were shown in Table 2.

Table 2 Details of Relationship of caregivers with mentally ill patient, Duration of Mental Illness and hours spent in caregiving. (N=250)

Relationship of caregivers with mentally ill patient	**Number (%)**
Spouse	142(56.8)
Parents	50(20.0)
Son/Daughter	42(16.8)
Sibling	6(2.4)
Daughter in law	4(1.6)
Grandparents	3(1.2)
Sister-in-law	3(1.2)
Total	250(100)
Duration of Mental illness (completed years)	**Number (%)**
1-3	146(58.4)
4-6	53(21.2)
7-10	22(8.8)
>10	29(11.6)
Total	250(100)
Time spent in caregiving per day (Hours)	**Number (%)**
1-8	65(26.0)
9-16	125(50.0)
>16	60(24.0)
Total	250(100)

The Family Burden Interview Schedule (FBIS) assessed the burden experienced by caregivers of patients with mental illness. About half of the participants (124, 49.6%) reported a moderate level of burden, while one-third (86, 34.4%) reported mild burden, and 40 (16.0%) reported severe burden. The overall mean score was 20.55 ± 8.56, indicating a moderate burden. Among different domains, Disruption of Routine Family Activities had the highest mean score (1.13 ± 0.39), followed by Disruption of Family Leisure (0.96 ± 0.39) and Financial Burden (0.83 ± 0.48), suggesting these areas contributed most to the caregivers' burden, as shown in Table 3, 4.

Table 3 Level of Burden based on Family Burden interview schedule among caregivers(N=250)

Level of burden (score range)	**Number (%)**
Mild (0-16)	86(34.4)
Moderate (17-32)	124(49.6)
Severe (33-48)	40(16.0)
Total	250(100)

Table 4 Magnitude of Family burden among caregivers based on various domains of Family Burden Interview Schedule (N=250)

Domains of family burden interview schedule	**Score Range**	**Mean score ± SD**	**Weighted mean score, Mean± SD**	**Median score**
Financial Burden	1-12	4.98±2.87	0.83±0.48	4
Disruption of Routine family activities	1-10	5.66±1.97	1.13±0.39	5
Disruption of family leisure	0-8	3.82±1.57	0.96±0.39	4
Disruption of family interaction	0-10	3.78±2.68	0.76±0.54	3
Effect on the physical health of others	0-4	1.42±0.91	0.71±0.46	1
Effect of the mental health of others	0-3	0.98±0.77	0.49±0.38	1
Overall family burden	0-40	20.55±8.56	0.86±0.36	19

Caregiver burden varied significantly across different mental illnesses. Substance Abuse patient's caregivers reported the highest burden, with 75% facing severe burden. Intellectual Disability patient's caregivers experienced a mix of moderate (60%) and severe (40%) burden. OCD patient's caregivers experienced moderate (75%) to severe (25%) burden. Schizophrenia caregivers mostly faced moderate (72.3%) to severe (14.9%) burden. Bipolar Disorder caregivers had moderate (78.6%) and severe (14.3%) burdens, while Anxiety caregivers had 54.5% reporting moderate burden. For Depressive Disorder, 78.2% of caregivers reported mild burden, with no severe burden This indicates that the level of caregiver burden is highly dependent on the specific mental illness (Table 5).

Female participants experienced a higher level of caregiver burden compared to males, with a statistically significant association ($p < 0.001$) between burden levels and gender. As the duration of mental illness increased, the number of caregivers reporting severe burden also rose, with a significant difference ($p < 0.001$). Additionally, longer hours spent by caregivers with patients were linked to higher levels of burden, with a statistically significant difference ($p = 0.028$). Overall, significant associations were found between caregiver burden and gender, duration of mental illness, and time spent with patients. (Table 6)

Table 5 Level of burden among caregivers with different types of mental illness in patients (N=250)

Mental illness in patients	Level of Burden in caregiver			Total (%)
	Mild	Moderate	Severe	
Depressive Disorder (n = 78)	61(78.2)	17(21.8)	0(0)	78(100)
Schizophrenia (n= 47)	6(12.8)	34(72.3)	7(14.9)	47(100)
Anxiety (n= 33)	15(45.5)	18(54.5)	0(0)	33(100)
Obsessive-Compulsive Disorder(n= 24)	0	18(75.0)	6(25.0)	24(100)
Substance Abuse (n = 28)	0(0)	7(25.0)	21(75.0)	28(100)
Bipolar disorder (n = 28)	2(7.1)	22(78.6)	4(14.3)	28(100)
Intellectual disability (n = 5)	0(0)	3(60.0)	2(40.0)	5(100)
Anxiety with Depressive Disorder (n = 2)	1(50.0)	1(50.0)	0(0)	2(100)
Depressive disorder with OCD (n = 2)	0(0)	2(100)	0(0)	2(100)
Schizophrenia with OCD (n= 2)	1(50.0)	1(50.0)	0(0)	2(100)
Schizophrenia with Bipolar disorder (n = 1)	0(0)	1(100)	0(0)	1(100)
Total	86(34.4)	124(49.6)	40(16.0)	250(100)

Table 6 Association of Family burden with Socio-demographic profile of Caregivers and Socio-clinical status of mentally ill patients (N=250)

Socio-demographic profile of caregivers		Number (n)	Burden Mean± SD	Test statistics	p value
Gender	Male	98(39.2)	16.66±8.27	6.182*	<0.001
	Female	152(60.8)	23.06±7.80		
Marital status	Married	219(87.6)	20.52±8.78	0.084#	0.969
	Unmarried	20(8.0)	20.50±7.27		
	Widowed	8(3.2)	20.75±5.37		
	Divorced	3(1.2)	23.00±11.00		
Type of family	Joint	122(48.8)	20.57±8.83	0.039*	0.969
	Nuclear	128(51.2)	20.53±8.33		
Socio-clinical status of patients					
Gender	Male	119(47.6)	26.26±7.73	13.00*	<0.001
	Female	131(52.4)	15.37±5.41		
Duration of Mental Illness (Completed Years)	1-3	146(58.4)	17.40±6.89	21.56#	<0.001
	4-6	53(21.2)	23.43±7.73		
	7-10	22(8.8)	25.45±8.92		
	>10	29(11.6)	27.45±9.99		
Time Spent (Hours)	1-8	65(26.0)	19.31±7.82	3.62#	0.028
	9-16	125(50.0)	19.99±8.35		
	>16	60(24.0)	23.07±9.37		

**= t value (Independent T test was applied); # = F value (ANOVA test was applied)*

Figure 1 Distribution of caregivers based on level of burden as per Family Burden Interview Schedule

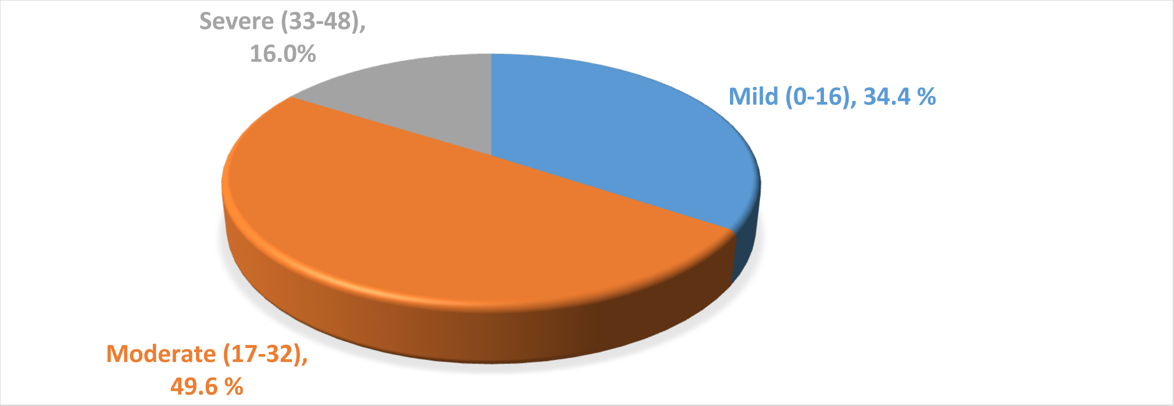
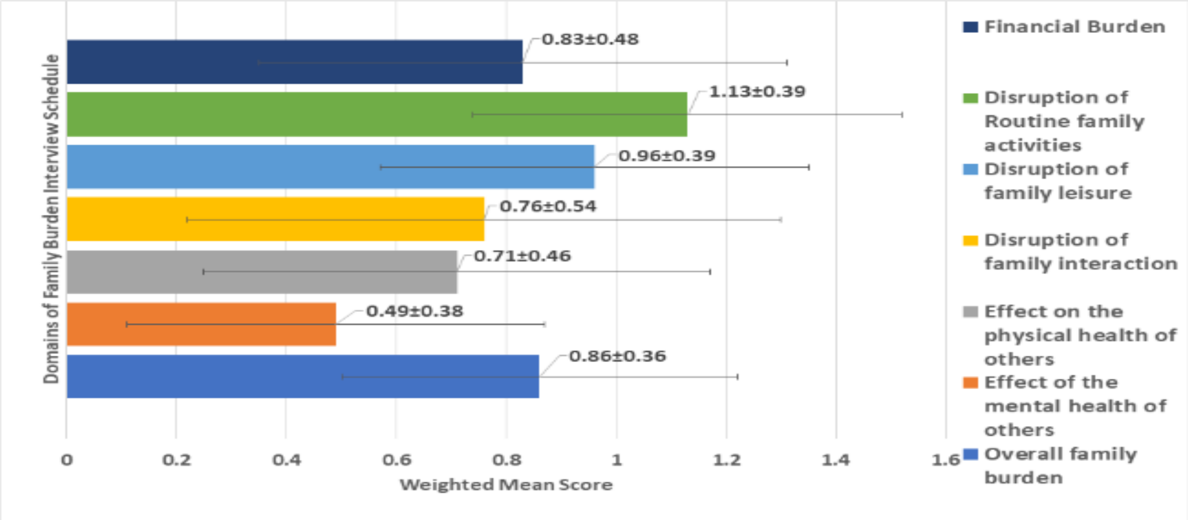


Figure 2 Weighted Mean score and standard deviation of various domain of Family Burden Interview



DISCUSSION

In our study, the majority of relatives of patients were spouses, accounting for 56.4%, which closely aligns with findings from Subbu R et al.(6) However, this proportion was lower in studies conducted by Mehra A et al.(7) and Singh A et al.(8), where the focus was on caregivers of patients with schizophrenia and affective disorders, who were predominantly unmarried. The distribution of family burden levels, as assessed by the Family Burden Interview Schedule, indicates that 49.6% of participants experienced a moderate level of burden, followed by 34.4% with mild burden, and 16.0% with severe burden which is similar to study conducted by Thakur V et al.(9). The total mean score of the Family Burden Interview Schedule (FBIS) in our study was 20.55±8.56, closely resembling the findings of Ayalew M et al.(10). However, our mean score was lower compared to studies by Mehra A et al.(7) and Chien WT et al.(11). Notably, these studies primarily focused on patients with schizophrenia or affective disorders, both of which typically impose a higher burden on family caregivers. In our study the female caregivers were found to be significant associated with burden (p-value <0.001), aligning with findings from studies by Ebrahim OS et al.(12), Benallel K et al.(13), Walke SC et al.(2) and Kumar R et al.(14), Naik K. et al.(15). The consistent pattern across these studies suggest that gender may indeed be a crucial factor influencing the burden experienced by caregivers of patients with mental illness. However, there is no association found in between Marital status and level of burden among caregivers similar to Benallel K et al.(13), Kumar R et al.(14), Naik K et al.(15). The duration of illness was also found to be associated significantly with the level of burden among caregivers (p-value < 0.001) in our study which was consistent with findings from studies by Walke SC et al.(2), Pant S et al.(16), and Naik K et al.(15). However, our results were contrary to the study by Benallel K et al.(13), which focused solely on caregivers of schizophrenia patients, representing negligible proportion in our study. There is no significant association found between level of burden and type of family alike studies by Subbu R et al.(6), Naik K et al.(15).

CONCLUSION

More than half (56.8%) of the caregivers were spouse of the patients followed by parents 20.0%. Patients with Depressive Disorder in our study were 31.2% followed by schizophrenia 18.8%. Mean time spent by caregivers was 13.94±5.99 hours with range 8-24 hours. Around half (49.6%) of the participants were suffering from moderate level of burden followed by mild (34.4%) and severe (16.0%) according to Family Burden Interview Schedule. In different domains of FBIS, Disruption of routine family activities had higher mean weighted score. Among all the participants, caregivers of substance abuse patients suffered from more severe level of burden (75%) as compared to moderate level (25%). Among caregivers of Depressive Disorder patients (78.2%), most of them suffered from mild level of burden as compared to moderate (21.8%). A statistically significant association (p-value < 0.05) was observed between the level of burden in caregivers and the gender of caregivers, duration of illness of the patient, and time spent for caregiving.

RECOMMENDATION

Understanding the burden experienced by caregivers of mentally ill patients would help in developing comprehensive management plans which would in turn increase the quality of life of mentally ill patients and their caregiver. It is also crucial to incorporate family caregiver support and interventions into national mental health care strategies.

LIMITATION OF THE STUDY

Due to its cross-sectional design, the current study may not capture the evolving trends of family burden over an extended period of time, limiting a comprehensive understanding of their dynamic nature.

RELEVANCE OF THE STUDY

Mental illness places a significant burden on caregivers, affecting their physical, emotional, and financial well-being. Therefore, it's essential to investigate the challenges faced by these caregivers to better understand their needs and improve treatment outcomes.

AUTHORS CONTRIBUTION

All authors have contributed equally.

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Nil

CONFLICT OF INTEREST

There are no conflicts of interest.

DECLARATION OF GENERATIVE AI AND AI ASSISTED TECHNOLOGIES IN THE WRITING PROCESS

The authors haven't used any generative AI/AI assisted technologies in the writing process.

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