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Sultana Yesmin
Tutor, College of Nursing, Asia
Heart Foundation, Kolkata,
West Bengal, India

Madhusri Manna
Vice Principal, College of
Nursing, Asia Heart
Foundation, Kolkata, West
Bengal, India

Kasturi Mandal
Principal, College of Nursing,
Asia Heart Foundation,
Kolkata, West Bengal, India

Kathika Pattanayak
Professor, College of Nursing,
Asia Heart Foundation,
Kolkata, West Bengal, India

Sritama Nath Chowdhury
Clinical Instructor,
International Institute of
Nursing and Research,
Kalyani, West Bengal, India

Assessment of family burden and it's co-relates among the caregivers of mentally ill patients in a OPD of selected mental hospital, West Bengal

Sultana Yesmin, Madhusri Manna, Kasturi Mandal, Kathika Pattanayak and Sritama Nath Chowdhury

Abstract
Background and Purpose: History of mental health showed that mentally ill have been tremendously stigmatized in most parts of the world. It is currently being recognized that all mental illness is characterized by some disruption of normal social and interpersonal relationship. The family forms one of the most important parts of the multidimensional care system for the mentally ill, of course many patient with serious mental illness becomes detached from the families. But even when the families want to participate in the patient care, they often feel excluded. With the trend towards deinstitutionalization, family are often primary care givers, confidentially laws designed to protect the privacy of consumers, or often used as barriers to provide families with basic information for family care giving. This study was conducted to assess the family burden and to find out the associated factors of family burden among caregivers of mentally ill patients in a OPD of selected mental hospital, Kolkata.
Methods: Hundred family members were selected by purposive sampling technique. A quantitative non-experimental survey approach is selected for the present study to assess family burden and correlates among the caregivers of mentally ill patients. The family burden was assessed by the tool Interview Schedule on Caregiver Burden Scale by Zarit *et al.* 1980 Gerontologist,20(6),649-55 through interviewing and the co-relates are find out by using the tools Interview Schedule on demographic characteristics and associated factors. Associated factors refers to perceived stress, daily living activities, faced financial problem etc.
Results: Out of hundred family members, 56% family members had moderate family burden, 31% had mild family burden, 8% had severe family burden and 5% had no or minimal burden. It is also assessed that there is a significant association of family burden with financial problem faced to bear treatment expenses, which was statistically significant as evident from the chi square value i.e 14.117 and difficulty faced in self routine adjustment, the chi square value is 6.338. Out of hundred family members 90% had moderate stress and only 3% family members had low stress. And there is positive co-relation between family burden and perceived stress of caregivers which was statistically significant as evident from 'r' value (0.362). And there is negative co-relation between family burden and independence in activities of daily living which was statistically significant as evident from 'r' value (-0.29,-0.39,-0.34).
Conclusion: Our study was conducted to assess the family burden and identity its co-relates among caregivers of mentally ill patients. The following conclusions are based on the study findings of the study. In this study, 56% caregivers had moderate family burden, 31% had mild family burden, 8% caregivers had severe family burden and 5% caregivers face no or minimal family burden. The study could be implicated in different areas of nursing practice and nursing research with recommendation. This study can be done in large sample.

Keywords: Family burden, Co-relates, Caregivers, Mentally ill patients.

Introduction

Mental illness is a leading cause of global burden of disease [1]. The burden arises from the distressing nature of mental illness, not only for affected people but also for their family members [2]. In the latter half of the twentieth century the process of deinstitutionalization shifted the treatment of the mentally ill patient in people from state institution to community care center [3]. This shift had an impact on the mental health system and families of people with mental illness as family members are inadequately prepared to be caregiver for their ill relatives [4]. Family burden is viewed as the non-mediated effect on family living with and caring for a relative affected by mental illness [5].

Corresponding Author:
Madhusri Manna
Vice Principal, College of
Nursing, Asia Heart
Foundation, Kolkata, West
Bengal, India

There are two defined types of burden: Objective burden, which refers to the observable cost to the family that results from the disease and Subjective burden, which includes the individual's perception of the situation as burdensome [6].

The impact of mental illness on the overall quality of life has been hardly explored. While there are studies to show the stress and burden experienced by the familiar question remain as to how family's global quality of life gets affected when challenged by care giving responsibilities to a mentally ill relative [7].

Burden of family care givers leads to negative consequences not only for themselves but also for patients, other family members and health care system. For care givers, burden negatively affects care giver's physical, emotional and economic status. therefore, their negative quality of life have imported on poor caring, mistreatment on behaving violently to the patients which can cause patients relapse. Therefore, this review paper will include theoretical foundation of burden, in particular when caring for persons with mental disease and related factors [8].

Vaughn CE, Leff JP explain that family members play a role in the patient adaptation or maladaptation of illness. Family members can either increase or decrease the stress the patient experiences at home. Family members want information regarding patient symptomatology. Families sought financial relief, someone to talk to, who understands the disorder and respite care for brief periods [9].

There are approximately 450 million people across the world dealing with mental illness [10].

A study conducted in Andhra Pradesh in 2012 had suggested that the burden on a care giver is more in case of patient with psychiatric illness other than chronic medical illness [11].

H.N Swati, K.G Kiran, Kumar Nanjesh, Uday Kiran conducted study among caretaker of patient with psychiatric illness study results showed that 85% of subjects accept being frustrated about show improvement of the patients and mean burden score was 69.94 [12].

David J Kavanagh, studied on 65 relatives of patients with Schizophrenia who were attending a public mental health outpatient services in the province of Africa, Chile were assessed on Spanish version of the Zarit Caregiver Burden Scale. Average level of burden were very high, particularly for mothers, and care of patients with more hospitalizations in the previous three years [13].

The burden perceived by caregivers of patients with psychiatric illness is a fundamental prognostic aspect in the history of the disease at caregiver burden is repeatedly a critical determinant for negative caregiving outcomes. The most common mental health consequences identified are depression, anxiety and burnout [14].

An individual needs a worm accepting environment to live mentally healthy. Methany RV, Topalis M, described that regardless of the pattern of behavior disorder that characterized a patient's mental illness, there are certain general principles that apply to the care of all who show behavior disorders. An individual needs a supporting environment, with a reasonable degree of security and self-confidence. Acceptance is an active process, a series of positive behavior designed to convey to the patient to respect for him as an individual who possess worth and dignity [15].

Caregiver is the responsible for the care of someone who has poor mental health, is impaired by sickness or old age. The role they have taken provides for the followings task: Take care of someone who has chronic disease or illness; Managing medications or taking to the doctors or nurses on someone's behalf; disabled; (Grunfeld, *et al.* 2004) Take care of household chores, meals, or bills for someone who cannot do these things alone (Levine & Barry) [16].

The family is major source of support of mentally ill patients. Family is not only provide practical help and personal care such as bathing eating taking drugs but also give emotional support to their relative with a mental disorder in the face of insufficient knowledge, skill to provide care, immediate social support include mental health facilities. Caregiving is associated with all the features of a chronic stress experiences and challenges. These challengeable task, chronic stress, daily hassles and negative caregiver perception being profound objectives and/or subjective burden that involves psychosocial, physical and financial impact on caregiver of individuals [17].

Materials and Methods
A quantitative non-experimental survey research design was conducted from 17.06.2019 to 29.06.2019 at Out Patient Department (OPD) of Antaragram Psychiatric Hospital and Rehabilitation centre. Institutional Ethical committee permission was sought. Administrative permission was taken from Antaragram Psychiatric Hospital and Rehabilitation centre. Anonymity and confidentiality were maintained. Informed consent was obtained from each participants in this study.

The Objectives of the study were
a. Primary objective:
▪ To assess the family burden.
▪ To find out the co-relates of family burden.
b. Secondary objective:
▪ To find out the associated factors of family burden.

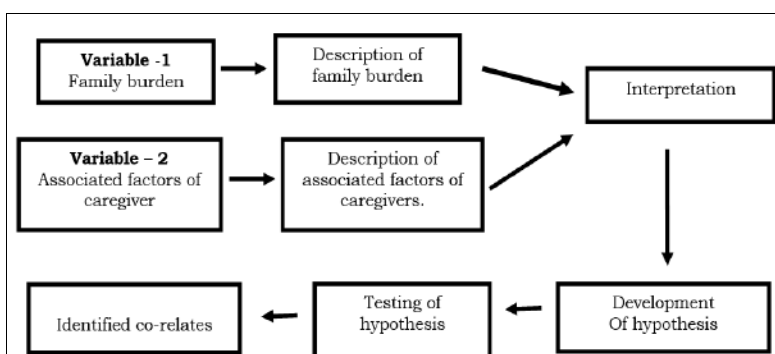**Research Design**: The quantitative non-experimental survey research design was adopted.

Fig 1: Schematic representation of research design.

Sample and sampling technique: Hundred samples were selected by purposive sampling technique. Sample refers to the family members who are giving care and living with the patients more than one year.

Inclusion criteria for selection of the participants were –
- Primary care giver who are family member.
- More than 18 years.
- Family members who are living with the patient more than one year and closely associated with patient's daily activity.
- Willing to participate.
- Available during date collection period.
- Able to understand and speak Bengali or English.

Exclusion criteria were
- First time OPD attendance.
- Family members who are not staying with the patients.

Data collection tools and techniques
Background information was collected by demographic proforma, which consisted of demographic data of family members. It was validated by five experts. The reliability was to be established by test-retest methods and 'r' was calculated by percentage of agreement. The calculated value is 0.6 to 1.

Family burden were assessed by Zarit's Caregiver Burden Scale, which had 22 items. The copyright permission was taken for this standardized tool. The reliability was established by internal consistency by Cronbach's alpha and calculated value alpha=0.91.

Associated factors are assessed by Interview Schedule on associated factors, which consisted of 13 items. It was validated by five experts, There was 100% agreement for 9 items, 80% agreement on 2 items.. The reliability was to be established by test-retest methods and 'r' was calculated by percentage of agreement and calculated value is 0.5 to 1.

Associated factors are assessed also by Perceived Stress Scale by Sheldon Cohen, which consist of 10 items. The copyright permission was taken for this standardized tool. The reliability was established by internal consistency by Cronbach's alpha and calculated value alpha=0.708.

Associated factors are assessed also by Katz Index of Independence in Activity of Daily Living on activities of daily living, which had 6 items. The copyright permission was taken for this standardized tool. The reliability was to be established by test-retest methods and 'r' was calculated by percentage of agreement and the calculated value is 0.9 to 1. Associated factors are assessed also by Lawton Brody Instrumental Activities of Daily Living on activities of daily

living, which had 8 items. The copyright permission was taken for this standardized tool. The reliability was to be established by test-retest methods and r was calculated by Pearson's correlation coefficient and the calculated value is r=0.84.

Results

Table 1: Frequency distribution of participants in terms of demographic characteristics of caregivers. N=100

Characteristics	Frequency
Age	
18-28 yr	24
29-39yr	19
40-50yr	27
51-61yr	20
≥62yr	10
Gender	
Male	54
Female	46
Educational Status	
No formal education	17
Just literate	3
Class I-IV	21
Class V-VIII	25
Class IX-XII	20
H.S and Above H.S	14
Unemployed	18
Agriculture	10
Service	14
Business	8
Self employed	17
Others	33
Occupation	
Per capita income (In Rs.)	
<700	18
700-1899	46
1900-3099	20
3100-4299	7
4300 and above	9

Table 1 reveals that highest family members i.e 27 was in the age group of 40-50 years and most are male family members. Majority of the family members were belongs to Class V-VIII level of educational status i.e 25 and most of them are from different occupational status i.e 33. It also indicates that majority of their per capita per month income belongs to the range Rs 700-1899 group i.e 46.

Table 2: Frequency distribution of caregivers in terms of associated factors of family burden N=100

Characteristics	Frequency
Residence	
Rural	86
Urban	14
Marital Status	
Married	86
Unmarried	11
Widower	3
Family Type	
Joint	18
Nuclear	80
Extended	2
Family Member Present	
2-5 members	69

6-9 members	23
10-13 members	8
Relationship of patient with caregiver	
Parent	11
Spouse	25
Sibling	15
Children	44
Others	5

Table no.2 reveals that majority of the family members are living in rural area i.e 86 and it also indicates that most of them are married i.e 86 and were living in a nuclear family i.e 80. Majority of no. of family members are in range of 2-5 members i.e 69 and majority of their their relationship of patient with caregiver were their children i.e 44.
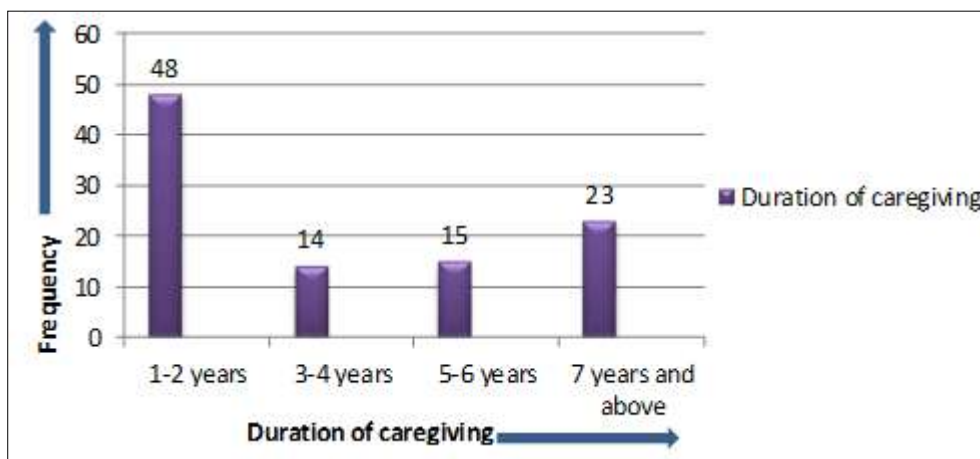

Fig 2: Frequency distribution of participants in terms of duration of care giving of mentally ill patients. N=100

Fig.no 2 indicates that majority i.e. 48 caregivers' duration of caregiving of mentally ill patients 1-2years whereas only 14 caregivers duration of caregiving is 3-4 years.

Table 3: Frequency distribution of caregivers in terms of hobby, source of financial support, intervals for follow up, total visiting time and time taken for travel from home to clinic. N=100

Characteristics	Frequency
Hobby	
Gardening	4
Cooking	30
Travelling	16
Others	50
Source of financial support for caring your relative	
Son	7
Father	10
Husband	22
Others	61
Days interval comes for follow up	
1-4 week	52
5-8 week	28
9 week and above	20
Total visiting times	
2-6 times	48
7-11 times	19
12-16 times	10
17 & above	23
Time taken for travel from home to clinic	
<1 hr	12
1-2 hr	51
Above 2 hr	37

Table no. 3 reveals that majority of family members i.e 50 had others hobby and their majority i.e 61 taken source of financial support for caring were from others source. Majority of their intervals comes for follow up i.e 52 were 1-4 weeks and their total visiting times majority i.e 48 were 2-6 times and majority of their i.e 51 takes time for travel from home to clinic were 1-2 hours.
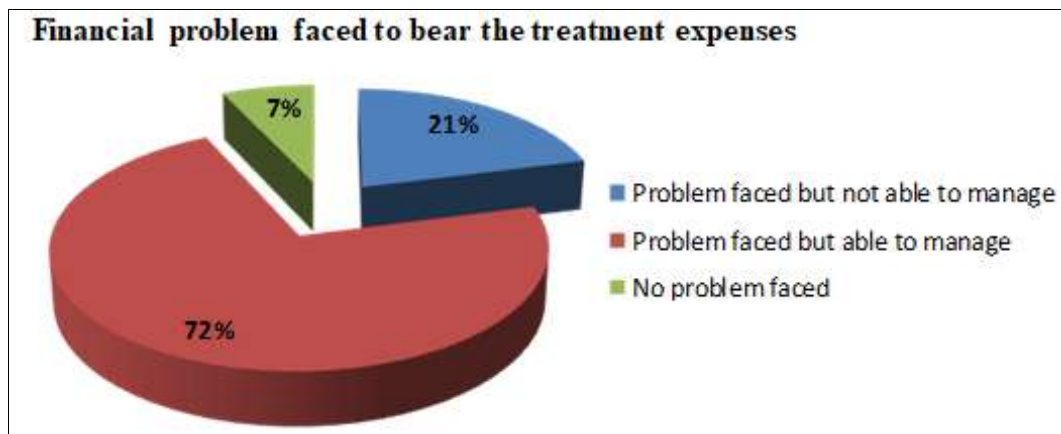
Fig 3: Frequency and percentage distribution of caregivers in terms of financial problem faced by the family members for bearing treatment expenses of mentally ill patients. N=100

Figure shows that most of the caregivers i.e 72 face problem to bear treatment expenses but they were able to manage and only 7 caregivers not face any problem to bear treatment expenses.
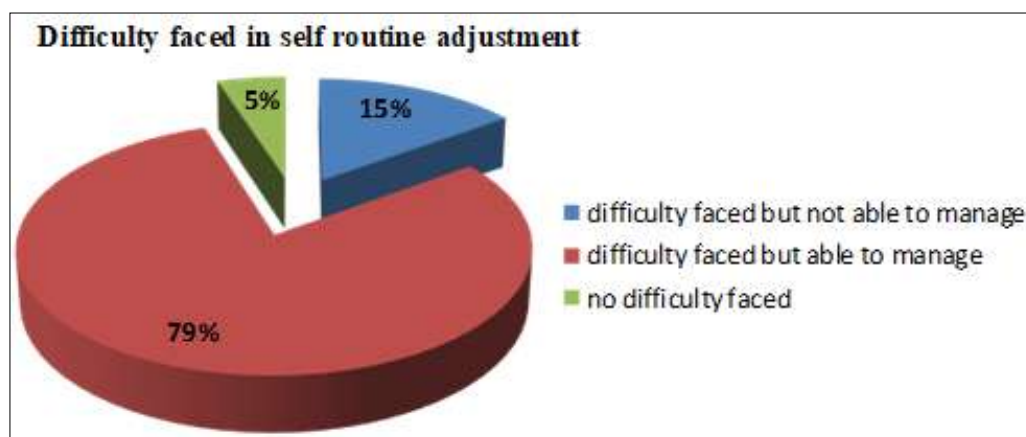

Fig 4: Frequency and percentage distribution of caregivers in terms of difficulty faced by the family members in self routine adjustment. N=100

Figure shows that most of the caregivers i.e 79 face difficulty but able to manage and only 5 caregivers not face any difficulty.
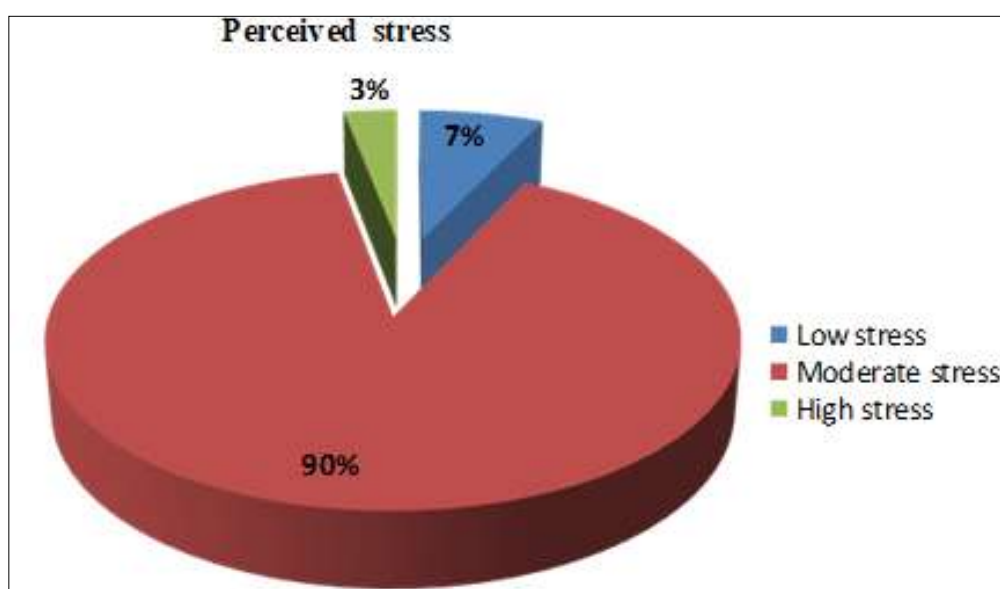

Fig 5: Frequency and percentage distribution of caregivers in terms of perceived stress among caregivers of mentally ill patients. N=100.

This figure shows that maximum caregivers i.e 90 had moderate stress where as only 3 caregivers had low stress.
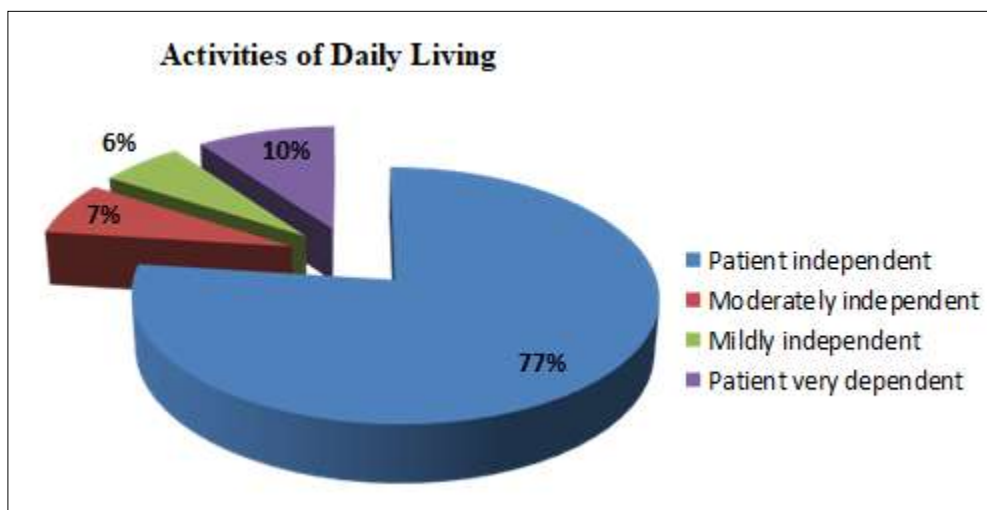
Fig 6: Frequency and percentage distribution in terms of independence of activities of daily living (Bathing, dressing, toileting, transferring, continence and feeding) of mentally ill patients. N=100

This figure shows that most of the mentally ill patients i.e 77 are independent in performing activities of daily living and only 6 mentally ill patients are mildly independent.
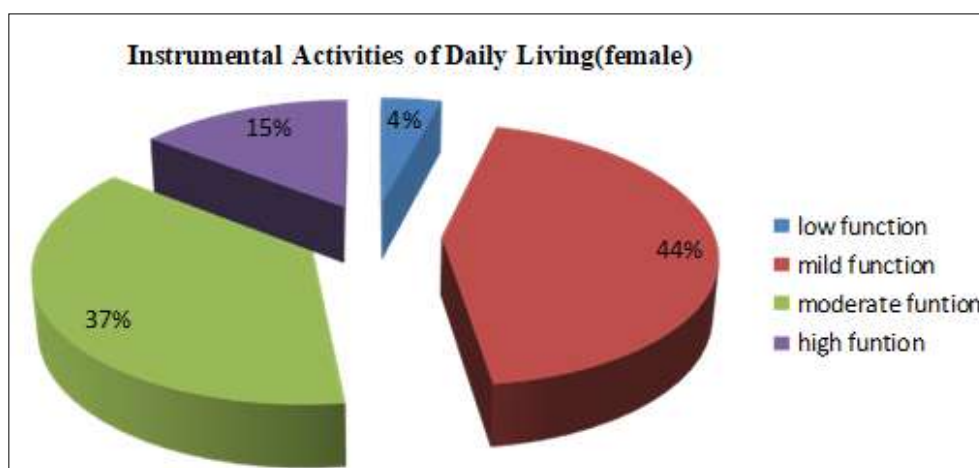

Fig 7: Frequency and percentage distribution in terms of instrumental activities of daily living. $n_1 = 48$

This figure shows 21 (44%) mentally ill patients (female) are having low function, dependent and only 2(4%) mentally ill patients are having high function, independent.
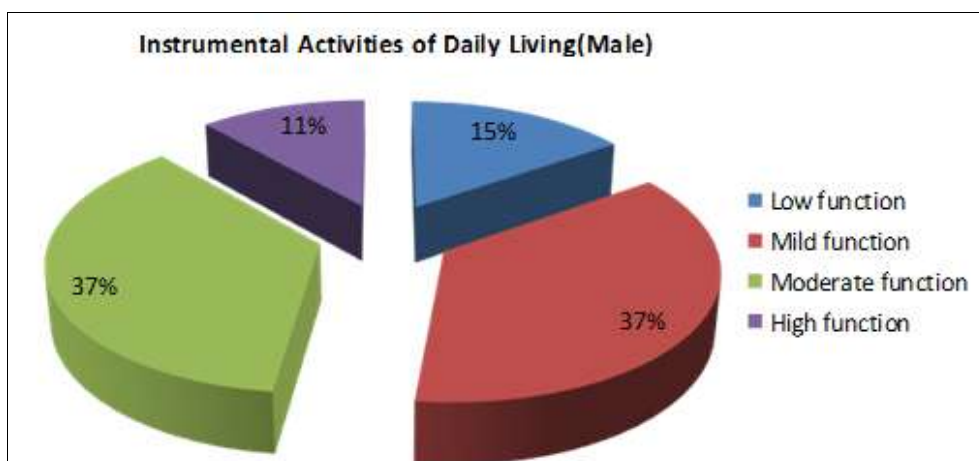

Fig 8: Frequency and percentage distribution in terms of instrumental activities of daily living(ability to use telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility of own medications & ability to handle finances) $n_2 = 52$

This figure shows 19 (37%) mentally ill patients (male) are having mild and moderate function and only 6(11%) mentally ill patients are having high function.
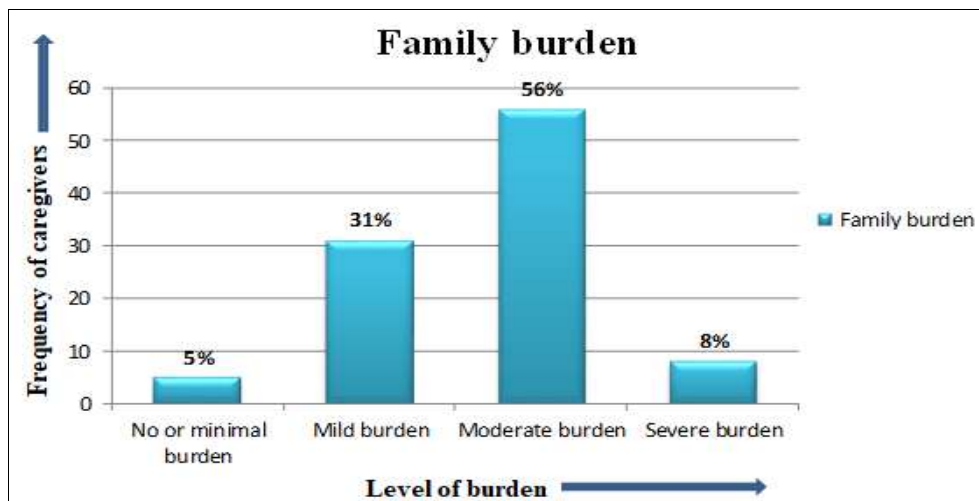
Fig 9: Frequency and percentage distribution of the caregivers in terms of family burden. N=100

The figure shows that most of the family member's i.e 56 had moderate family burden and only 5 family members were facing no or minimal burden.

Table 4: Chi-square value of demographic characteristics (association between family burden demographic characteristics like age, gender, occupation and per capita monthly income). N=100

Sl no.	Probable factors	X^2	Df	α value	Table value
01.	Age	0.3088	2	0.05	5.99
02.	Gender	0.0017	1	0.05	3.84
03.	Occupation	4.789	5	0.05	11.07
04.	Per capita monthly income	6.5206	4	0.05	9.49

Table no 4 reveals that the obtained value is less than the table value showed family burden and demographic characteristics, had no significant association.

Table 5: Chi-square value shows association between associated factors and family burden. N=100

Sl no.	Probable factors	X^2	Df	α value	Table value
01.	Residence	0.793	1	0.05	3.84
02.	Family type	0.268	2	0.05	5.99
03.	Family members	0.2708	1	0.05	3.84
04.	Duration of care giving	0.0667	1	0.05	3.84
05.	Relationship of patient with caregiver	3.784	4	0.05	9.49
06.	Source of financial support	3.1972	3	0.05	7.82
07.	Interval of follow up	1.7219	2	0.05	5.99
08.	No. of visit	1.88	2	0.05	5.99
09.	Travelling time	3.90	2	0.05	5.99
10.	Financial problem faced to bear treatment expenses	14.117*	2	0.05	5.99
11.	Difficulty in self routine adjustment	6.338*	2	0.05	5.99

$P<0.05*$ highly significant

The table 5 shows that there was association between family burden and financial problem faced to bear treatment expenses and difficulty faced in self routine adjustment as evident from chi-square value i.e 14.117 and 6.338 which was more than the table at 0.05 level of significance.

Table 6: Correlation and coefficient value shows relation of perceived stress of family members of mentally ill patients and activities of daily living of mentally ill patients with family burden among the family members. N=100

Sl no.	Components	'r'	df	't'	α level	Table value
1.	**Relationship with perceived stress**					
2.	**Relationship with activities of daily living**					
	• Independence in activities of daily living	0.362043	98	3.84*	0.05	1.98
	• Instrumental activities of daily living scale(I.A.D.L)	-0.28992	98	2.99*	0.05	1.98
	❖ Female	-0.39758	46	2.99*	0.05	2.02
	❖ Male	-0.34898	50	2.64*	0.05	2.02

$t_{98}*<0.05, t_{46}*<0.05, t_{50}*<0.05$

The table 6 shows that the co-relation coefficient value (r) of family burden with perceived stress was 0.362 which lies between 0 and + 1 (0<0.362<1). Thus it signifies weakly positive correlations and is statistically significant (t $_{98}$ =3.84, p< 0.05).

It also shows that the co-relation coefficient value (r) of family burden with Independence in activities of daily living was -0.289 which lies between -1 and 0 (-1<-0.289<0). Thus it signifies weakly negative correlation and is statistically significant (t $_{98}$ = 2.99, p<0.05).

It also shows that the co-relation coefficient value (r) of family burden with Instrumental activities of daily living scale (I.A.D.L) for female was -0.397 which lies between -1 and 0 (-1<-0.397<0). Thus it signifies weakly negative correlation and statistically significant (t $_{46}$ =2.99, p<0.05).

It also shows that the co-relation coefficient value (r) of family burden with Instrumental activities of daily living scale (I.A.D.L) for male was -0.348 which lies between -1 and 0 (-1<-0.348<0). Thus it signifies weakly negative correlation and statistically significant (t $_{50}$ = 2.64, p<0.05).

Discussion

In the present study, the family burden of mentally ill patients among the family members, 56% family members had moderate family burden, 31% had mild family burden, 8% family members had severe family burden and 5% family members face no or minimal family burden.

The findings of the present study consistent with other study conducted by Bhandari A. R, Marahatta K, Rana M, Ojha S.P, Rejmi M.P suggested a study on caregiving burden among family members of people with mental illness. This is a descriptive cross sectional study in a sample of 56 family caregivers of people with mental illness. Sample was selected using purposive sampling method and their caregiving experience was assessed by using Burden Assessment Schedule. The result found that 56 caregivers, 48.2% had moderate level of burden and 32.1% had severe level of burden. Highly significant was found among married and spouse caregivers.

The present study findings revealed that, Chi square test shows that there is significant association between financial problem faced to bear treatment expenses and family burden (X^2 =14.117). And there is significant association between difficulty in self routine adjustment and family burden(X^2 =6.338).This is supported by the study conducted by Andren and Elmstahl(2007)in Sweden examined the relationship between income, subjective health and caregiver's burden in people with dementia. Finding showed that low income was associated with higher degree of burden on caregiver. In addition Caregiver Burden Score was negatively co-related with their income, family with lower socioeconomic status experienced a higher level of burden.

In the present study we found that 90 caregivers of mentally ill patients had moderate stress level and only 3 caregivers had low stress level. This is supported by the study conducted by Kamala Darlami, Reshmi Ponnose, Pradap Jose was conducted a study on caregivers stress of psychiatric patients and coping to assess the caregivers stress.50 caregivers of psychiatric patients were selected through purposive sampling technique. The results related to stress level of respondents (86%) were at moderate stress followed by 14% severe stress.68% respondent used active coping mechanism where as 32% adopted passive coping method. The majority of the respondent use social support,

positive re-interpretation and religious coping strategies to overcome the stress.

Conclusion

The caregivers of mentally ill patients has moderate family burden and there was significant association between family burden and difficulty faced by the caregivers in self routine adjustments. There was also significant association between family burden and financial problem face to bear treatment expenses of mentally ill patients.

The identified co-relates of family burden are perceived stress, activities of daily living, financial problem faced to bear treatment expenses and difficulty in self routine adjustment.

Author's contribution

Manna Madhusri conceived the study, designed methodology, organize & contributed in data analysis, guiding treatment administration, supervise the research work & correction of manuscript.

Yesmin Sutana wrote proposal, plan and executed the experimentation. She also had done data collection, data management and reporting. She constructed the manuscript.

Mandal K did substantive contribution in constructing the idea, planning research design, took responsibilities in logical interpretation and presentation of results, finalization of research.

Pattanayak Kathika contributed towards sampling process, tool development, research design and development of treatment.

All authors provided critical feedback and helped shaping the research, analysis and manuscript.

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