

ORIGINAL RESEARCH

Family burden in relatives of patients with schizophrenia-A hospital based study

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ABSTRACT

Introduction: Schizophrenia is a chronic mental illness. Care givers of these patients are usually family members who often experience high degree of burden, lack of social support and stigma. **Aims:** The aim of this study was to assess the family burden reported by caregivers of Patients with schizophrenia. **Materials and methods:** A cross sectional study was done in 100 family members of patients with schizophrenia attending a tertiary care hospital. Data was collected using semi structured questionnaire and family burden interview schedule (FBIS) and general health questionnaire (GHQ). **Results:** Most of the patients are males, single, illiterates and unemployed. Caregivers are females, married, literates and employed. Relationship of patient with caregivers are parents in most of the families. Based on GHQ score 32 caregivers experienced mild distress and 55 caregivers experienced severe distress. Financial burden, Disruption of family's routine activities and physical health of caregiver is increasing the burden on the family. Number of admissions in 1 year => >3, Caregiver's gender and Patients age were significant Predictors of family burden. **Conclusion:** There is a requirement for economic support and early intervention to reduce growing incidence of mental health problems in caregivers of schizophrenia patients.

Keywords: Schizophrenia, Caregivers, family burden interview schedule (FBIS) and general health questionnaire (GHQ).

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INTRODUCTION

In India there are few studies on this caregiver's suffering in the family members of schizophrenic patients. Effects on the household like financial loss; effects on health, children, family routine; and the abnormal behaviours shown by the patient constitute the objective burden and the extent to which relatives felt they carried a burden constitute subjective burden. As the disease progresses, it carries with it a tremendous increase of burden on the caregiver who does the caregiving. Schizophrenia is a chronic mental illness. Caregivers of these patients are usually the family members who often experience high degree of burden during the process.¹

Caregiver burden is used to describe the physical emotion and financial toll of providing care.

Primary caregiver is an adult relative, living with patient in the same environment for at least 12 months and was involved directly in giving care to patients and is most supportive either emotionally or

financially, i.e., felt more responsible for patients. (Rammohan et al, 1994; Sczufca et al., 1999)

According to World Health Organization more than 21 million people are suffering with schizophrenia worldwide. Schizophrenia has been listed as the 8th leading causes of disability-adjusted life years in the 15 to 44 age group. It has extolled significant costs to the patients, the family and the society at large.² In the last 5 decades there is a worldwide shift in psychiatric care from hospital-based to community-based leading to Deinstitutionalization of care with families providing the majority of care and shouldering the bulk of burden'. About 25% of schizophrenia patients depend on families in western countries, in comparison to Asian countries where it is as high as 70% and approximately 80% of these family member experience various aspects of caregiver burden in schizophrenia.^{4,5} The burden perceived by caregivers of patients with psychiatric illness is a fundamental prognostic aspect as the caregiver burden is reportedly a critical determinant for negative

caregiving outcomes. In addition, Indian families report a low level of formal support services compared with the Western countries. However, little research has been devoted to the identification and understanding of this phenomenon so we aim of this study was to determine the prevalence of the burden reported by family caregivers of schizophrenic patients.

MATERIALS AND METHODS

A cross sectional study was done on 100 family members of patients with Schizophrenia attending the tertiary care hospital at Visakhapatnam. Data was collected using semi structured interviews with the help of Family burden Interview Schedule (FBIS) and General Health Questionnaire (GHQ).

Inclusion criteria: Patients diagnosed according to the ICD-10 criteria for schizophrenia, Primary caregiver should be currently living with the patient and has taken the most responsibility of caring, with full understanding about the situation of both the patient and the family) Primary caregiver older than 18 years of age) Primary caregiver is able to understand and communicate well

Exclusion criteria: 1) Patients with comorbid medical or substance abuse disorder or other psychiatric illnesses 2) Patient living alone 3) Primary family caregivers with severe comorbid physical or mental disorders who are unable to communicate
Study tools

Family burden Interview Schedule

FBIS is a semi-structured interview instrument proposed by Pai and Kapoor (1981).⁵ It is composed of 25 items that are grouped into the following 6 scales.

Financial burden (items 1-5)

Disruption of family routine activities (items 6-12)

Disruption of family leisure activities (items 13-15)

Disruption of family interactions (items 16-20)

Effect on the physical health of others (items 21-22)

Effect on the mental health of others (items 23-25)

Each item was rated on a three-point scale, where 0 was no burden, 1 was a moderate burden, and 2 was a severe burden. The total scores range from 0 to 48 with 48 indicating the highest burden of care. Internal consistency was demonstrated by a significant Cronbach's α of between 0.62 and 0.82

FAMILY BURDEN INTERVIEW SCHEDULE SEMI-STRUCTURED INTERVIEW⁵

Scales	Items
Financial burden	1. Loss of patients income 2. Loss of income of other family members 3. Expenses of patient's illness 4. expenses due to other necessary changes in arrangements 5. Loans taken
Disruption of family routine activity	6. Any other planned activity needing finance, postponed 7. Patient nor attending work, school, etc 8. Patient unable to help in household duties 9. Disruption of activities due to patient's illness and care 10. Disruption of activities due to patients irrational demands 11. Other family members missing school, meals, etc. 12. Stoppage of normal recreationa activities
Disruption of family leisure	13. Absorption of another members holiday and leisure time 14. Lack of participation by patient in leisure activity 15. Planed leisure activity is abandoned
Disruption of family interactions	16. Effect on general family atmosphere 17. Other members arguing over the patient 18. Reduction or cessation of interaction with friends and neighbours 19. Family becoming secluded or withdrawn 20. Any other effect on family or neighbourhood relationships
Effect on physical health of others	21. Physical illness in any family member 22. Any other adverse effect on others
Effect on mental health of others	23. Any member seeking professional help for psychological illness 24. Any member becoming depressed, weepy, irritable 25. How you have suffered owing to patient's illness

Item 25 is to assess subjective burden, rest all Items from 1 to 24 to assess objective burden .

GENERAL HEALTH QUESTIONNAIRE⁶

The General Health Questionnaire (GHQ) is a screening device for identifying minor psychiatric disorders in the general population and within community or non-psychiatric clinical settings such as primary care or general medical out-patients. The (GHQ-12) (Goldberg & Williams, 1988)⁶ consists of 12 items, each one assessing the severity of a

psychological problem over the past few weeks; present and recent complaints) using a 4-point Likert-type scale (Better than usual/Same as usual/Less than usual/Very less than usual). The total score ranges from 0 to 36. The positive items are scored from 0 to 3 and the negative items are scored from 3 (always) to 0 (never). High scores indicate worse health

GHQ-ITEMS⁷

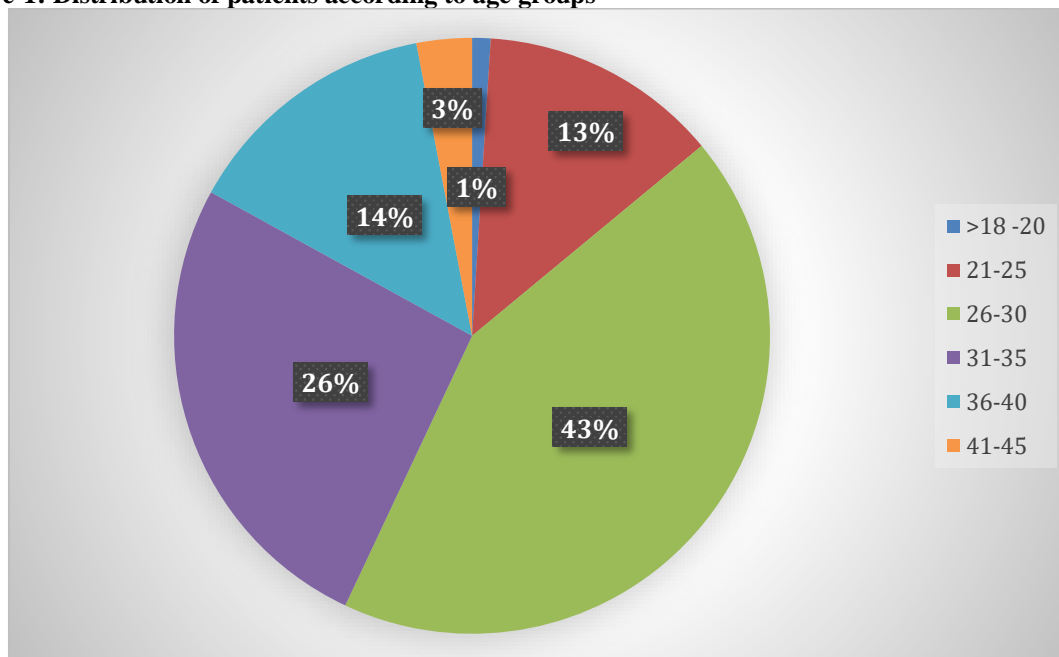
Question	Better than usual	Same as usual	Less than usual	Very less than usual
1. Able to concentrate	1	2	3	4
2. Loss of sleep over worry				
3. Playing a useful part				
4. Capable of making decisions				
5. Felt constantly under strain				
6. Couldn't overcome difficulties				
7. Able to enjoy day-to-day activities				
8. Able to face problems				
9. Feeling unhappy and depressed				
10. Losing confidence				
11. Thinking of self as worthless				
12. Feeling reasonably happy				

Results were analysed using SPSS v23, Microsoft excel and Google Data Sheets

RESULTS

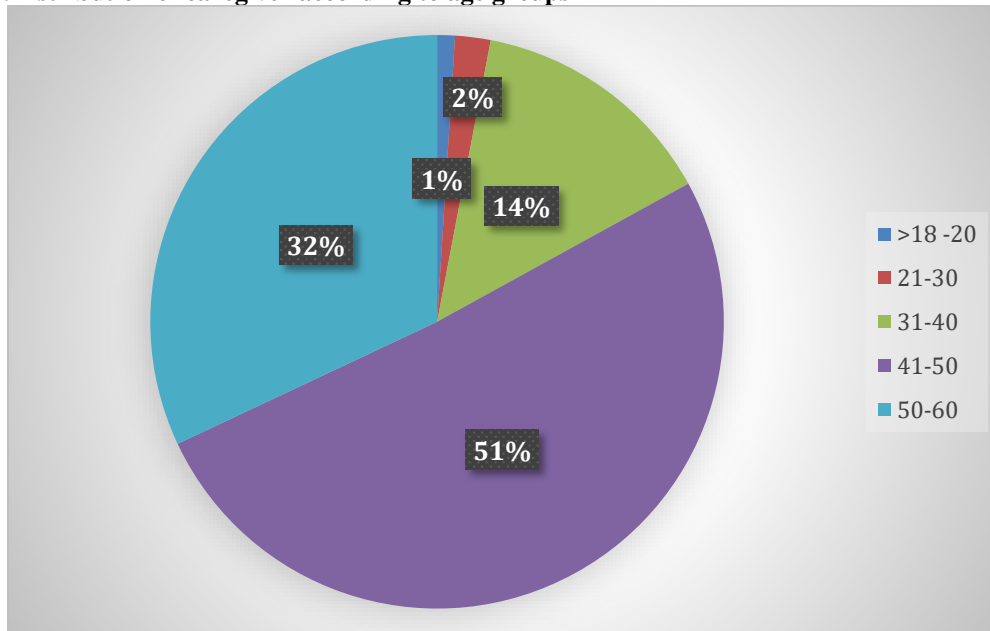
The study included 100 caregivers, in which mean age of patient 29.5 years. Minimum age of patient is 18 to maximum 45 years.

Figure-1: Distribution of patients according to age groups



Most of the patients in study belong to 26-30 years age group. Mean age of patients is 29.5

Figure-2: Distribution of caregiver according to age groups



Most of the caregiver in study belong to 41-50 years age group. Mean age of caregiver is 46.8

Table-1: Demographic details of patients and caregivers

	Number of patients	Number of Caregiver
Males	65	31
Female	35	69
Marital status		
Married	24	46
Single	41	33
Separated	27	14
Divorced	6	5
Widowed	2	2
Educational status		
Literate	33.6	59
Illiterate	66.4	41
Employment		
Unemployed	63	39
Employed	37	61

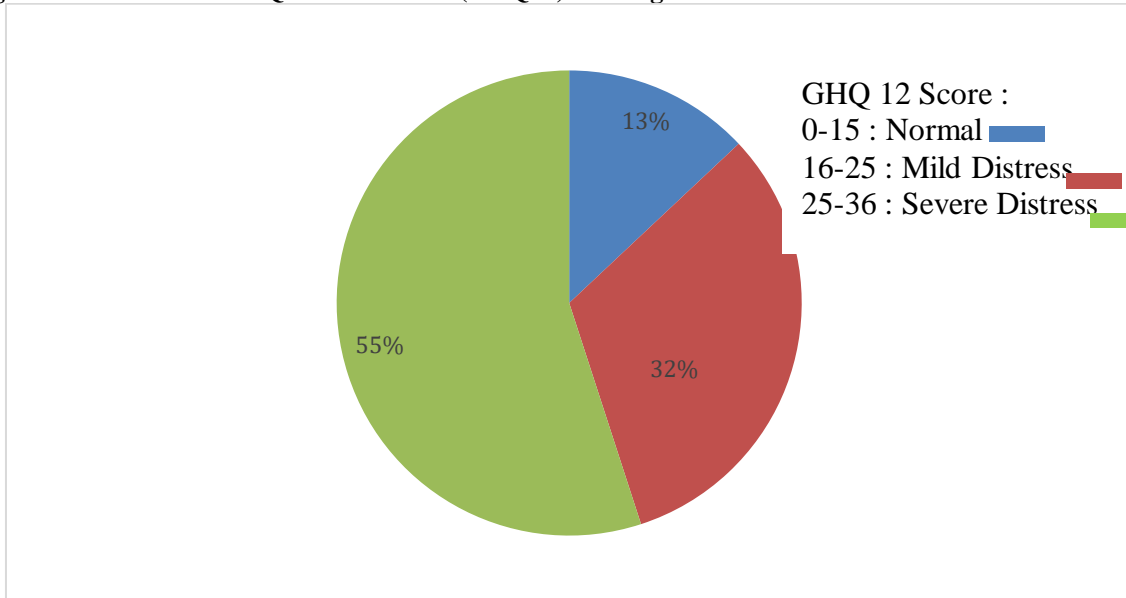
Most of the patients are males, single, illiterates and unemployed. Caregivers are females, married, literates and employed.

Table-2: Caregiver's relation with patient

Kinship	Frequency (%)
Either parent	69
Spouse	23
Other family members (siblings, etc.)	8

Relation of patient with caregivers are parents in most of the families.

Figure-1: General Health Questionnaire 12(GHQ12) of caregivers



32 caregivers showed mild distress and 55 caregivers reports severe distress

Table-3: Family history of illness and Multiple hospital admissions

Family history of illness in patients		Multiple admissions =>3 in a year	
YES	27%	Yes	43%
NO	73%	No	57%

Family history of illness is less in patients but there are multiple admissions =>3 in a year

Table-4: Family burden parameters

Items	Mean scores	Rank
Cat A:Financial burden	1.36	1
1. Loss of patient's income	1.40	7
2.Loss of income of other family members	1.54	2
3.Expenses of patient's illness	1.59	1
4.Expenses due to other necessary changes in arrangements	0.90	21
5. Loans taken	1.28	10
6.Any other planned activity needing finance, postponed	1.45	5
Cat B:Disruption of family's routine activities	1.24	3
7.Patient not attending work, school, etc.	1.50	3
8. Patient unable to help in household duties	1.30	9
9. Disruption of activities due to patient's illness and care	1.11	16
10.Disruption of activities due to patient's irrational demands	1.10	17
11.Other family members missing school, meals, etc.	1.22	11
Cat C: Disruption of family leisure activities	1.11	4
12.Stopping of normal recreational activities	1.22	11
13.Absorption of another member's holiday and leisure	1.12	15
14. Lack of participation by patient in leisure activity	1.20	13
15.Planned leisure activity abandoned	0.90	21
Cat D: Disruption of family interactions	1.04	5
16. Effect on general family atmosphere	1.33	8

17. Other members arguing over the patient	1.50	3
18. Reduction or cessation of interaction with friends and neighbours	0.98	18
19. Family becoming secluded or withdrawn	0.60	24
20. Any other effect on family or neighbourhood relationships	0.80	23
Cat E: Effects on physical health of others	0.97	6
21. Physical illness in any family member	0.97	20
22. Any other adverse effect on others	0.98	18
Cat F: Effects on mental health of others	1.31	2
23. Any member seeking professional help for psychological illness	1.42	6
24. Any member becoming depressed, weepy, irritable	1.20	13

Financial burden ie Expenses of patient's illness and Loss of income of other family members was more . Disruption of family's routine activities as Patient not attending work, school, etc was maximum.

Table-5: Logistic regression analysis - Predictors of family burden

Variables	P value
No of admissions in 1 year =>3	0.003* (Statistically significant)
Caregiver's gender	0.034* (Statistically significant)
Patients age	0.031* (Statistically significant)
Family history of illness	P value > 0.05(Statistically not significant)
Total duration of illness and drug compliance	P value > 0.05(Statistically not significant)
Patient's Education/ Marital/Employment status	P value > 0.05(Statistically not significant)
Caregiver's age/marriage/occupation	P value > 0.05(Statistically not significant)

No of admissions in 1 year =>3, Caregiver's gender and Patients age were significant Predictors of family burden.

DISCUSSION

The current medical strategy supports community-based care for people with schizophrenia and favours short-term hospital stays. In the community, family members provide the majority of support and are in charge of patient care. It is important to highlight the personal effects of schizophrenia as a chronic illness. Little prior research has been done on family caregivers of patients with schizophrenia, and what little that has been done has mostly been on the relationship between the caregiver's behaviour and the patient's progression of schizophrenia.

In this study, Most of the patients are males, single, illiterates and unemployed. Caregivers are females, married, literates and employed. Relationship of patient with caregivers are parents in most of the families. Caregivers are more likely to be women in many parts of the world. For example, in the United Kingdom, about 58% of the caregivers are women.⁸ Asian studies found that about 70% of family caregivers are females .⁹ The majority of family caregiving is usually provided by parents, spouses, or relatives. Studies found that most family caregivers of

adult clients with schizophrenia are their parents, and they are of older age. In Asian studies, it is also found that caregivers' burden score was positively correlated with their age .¹⁰ Our investigation clearly revealed that caregiver burden in older caregivers is higher. However, the result of this study differed from the Mexican Americans' study that caregivers with younger age experienced higher level of family burdens.¹¹ The differences could be related to the traditional Asian culture, which regards the older people in a family as the "heads of household" who have the major responsibility to take care of other family members and are responsible for their health condition.^{11,12}

32 caregivers experienced mild distress and 55 caregivers experienced severe distress. The results of this study revealed that the caregivers of patients with Schizophrenia experienced significant amount of burden just like most of the studies reported in the literature.^{13,14} [FarshidShamsaei](#) et al¹⁵ reported moderate burden and severe burden which is less when compared in there study. McDonnell et al.¹⁶ (2003) reported that family members providing care

to patients with schizophrenia experienced high rates of burden. The majority of studies on burden of caregivers of patients with schizophrenia conducted so far report significant burden of caregivers with over 90% of families, experiencing moderate to severe burden. The burden of care givers of patients with schizophrenia was large and multifaceted.

In our study Financial burden ie Expenses of patient's illness and Loss of income of other family members, Disruption of family's routine activities as Patient not attending work, school, etc , Effects on physical health of others as Effects on mental health of others was much more in caregiver. Lauber reported that threats, nuisances, time spent with the affected one, restricted social life and leisure activities are also predictors of burden.¹⁷ Data on such issues are essential in organizing services for the primary caregivers and mobilizing financial assistance.

Study shows significant caregiver burden and an overall burden on the family of schizophrenia patients. The most affected segment of the family is the financial component resulting in a high degree of financial burden. Multiple correlates have been identified during the study contributing to family burden. Large degree of family burden is borne by women[mothers and sisters] as they tend to be involved in the household work and caregiving aspects of the family. Patient's age is another significant factor determining the family burden score. Increasing age of the patient is associated with greater impact of caregiving contributing to overall increase in burden scores. Surprisingly, total duration of illness, and treatment compliance are not significantly associated with contributing to family burden, but multiple admissions as defined by more than 3 in a calendar year are associated with significant contribution to family burden. More than 50% of the caregivers have reported higher scores in GHQ12. This is in accordance with a study carried out by Montero. This finding suggests that caregivers are potential "high risk group" for mental disorders

CONCLUSION

Financial burden is the most significant burden affecting the family. Hence there is a requirement to offer economic support to the families of schizophrenia patients. Higher GHQ scores highlights the importance of early medical, psychological, and social intervention in order to reduce the growing incidence of mental health problems particularly depression and anxiety in these caregivers.

Information on positive predictors of family burden will help in targeted interventions in schizophrenia.

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