

Research Article

Assessment of Family Burden of Patients Suffering from Schizophrenia-Need of the Hour

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A B S T R A C T

Background: Schizophrenia is a debilitating, persistent disorder that requires continuous care and support. Families of Schizophrenic patient provide proper help, care and support to these people.

Objectives: 1) To assess the burden on the families of patients suffering from schizophrenia. 2) To find out the relationship of family burden with social functioning, psychosocial dysfunction and the severity of illness.

Material and Methods: It was a hospital based, cross-sectional study for the duration of 6 months. Purposive sampling was used to select 100 study participants. Out of the total, 50 study subjects were diagnosed cases of schizophrenia and 50 subjects were diabetic patients taken as controls. These patients had either spouse or other first degree relative as their caregivers. Two pre-tested, semi-structured questionnaire was used for data collection. The clinical symptomatology of the patients was assessed by Positive and Negative Syndrome Scale (PANSS). Dysfunction was assessed by Dysfunction Analysis Questionnaire (D.A.Q.). The Family Burden Interview schedule was used to assess the family burden. Quantitative data was expressed in the form of mean, standard deviation and using Student's T-test. Qualitative variables were expressed as percentages and proportions and chi-square test. Statistically significant findings were considered when p value < 0.05. Correlation was also seen between various socio-demographic variables.

Result: All the caregivers of schizophrenic patients experienced moderate to severe burden in all the areas. Total burden among caregivers of schizophrenic patients was much higher as compared to diabetic patients which was statistically significant also. **Conclusion-**Families of schizophrenic patients carry a significant burden as compared to diabetes in terms of social, vocational, personal, familial and cognitive areas. Psychosocial intervention program should be instituted on the basis of proper assessment of key caregivers regarding their coping styles, communication skills and community resources.

Keywords: Schizophrenia, Diabetes, Caregivers, Families, Psychosocial Burden, Psychiatric Disorder

Introduction

Globally, schizophrenia is a debilitating, persistent psychiatric disorder that affects approximately 3 to 6 patients per 1000 persons.¹ The World Health Organization² estimated that there are more than 21 million people suffering from schizophrenia worldwide. It has been listed as the 8th leading cause of disability-adjusted life years in the 15 to 44 age group³ and has extolled significant costs to the patients, the family and the society at large.⁴ Schizophrenic patients are dependent on their family members for their livelihood. In current era, mode of delivery of psychiatric care is also shifted from hospital-based to community or, family based thus the ultimate burden of patients is on families.

In western countries, about 25% to 50% of schizophrenia patients depend on families, while in Asian countries, about 70% patients are cared for by their families.⁵⁻⁷ In addition, over 80% of individuals with a schizophrenic family member have been documented to suffer from tremendous burden in various aspects including economy, social activities, physical and mental health.⁸ India ranks at the upper stages as per the prevalence rate of Schizophrenia is concerned. Amongst the epidemiological studies in India, Study of Functional Psychosis in Urban Community (SOFPU) in Madras is the most confounding multistage census survey,⁹ the prevalence rate of Schizophrenia was estimated at 2.62/1000.

There is very limited research on the relationship of burden with the severity of illness and degree of burden faced by the families. Therefore, the present study was planned to assess the family burden of schizophrenia and its relationship with the severity of illness and degree of psychological dysfunction in a group of chronic schizophrenic patients.

Material & Methods

Study Place and Study Duration: The present study was conducted in Psychiatry OPD and Diabetic clinic of a tertiary care Hospital of New Delhi.

Study Duration: The study was conducted for a period of 6 months.

Study Design: It was a hospital based, cross-sectional comparative study.

Sampling and Sample Technique: Purposive sampling was used to select 100 study participants in which 50 care givers of schizophrenia and 50 care givers of diabetes taken as comparative group. They were either spouse or other first degree relative of patients.

Eligibility Criteria

Inclusion criteria: Care givers of patients who fulfilled the ICD-10 DCR (Diagnostic Criterion for Research) for Schizophrenia. They were first degree relatives or spouse available for interview, who had stayed with the patient for

at least the last six months. Their patients were on a stable antipsychotic dose for the last 3 months.

Exclusion criteria: A) Care givers of schizophrenic patients who had presence of accompanying chronic physical illnesses like diabetes mellitus, hypertension, chronic respiratory illness, epilepsy etc. B) Care givers who themselves or their patients had physical disability including sensory deficit. C) Care givers of patients who had presence of active psychotic symptoms like delusions, hallucinations and disorganized behavior needing active intervention.

Study Tool

Two pre-tested, semi-structured questionnaire (see Appendix) were used for data collection in which first part was covered with socio-demographic variables like age, sex, marital status, education, occupation, family type, income and locality and second part comprised of various assessment scales. The clinical symptomatology of the patients was assessed by Positive and Negative Syndrome Scale.¹⁰ Dysfunction was assessed by Dysfunction Analysis Questionnaire (D.A.Q.).¹¹ Family burden Interview schedule was used to assess the family burden.¹²

The details of these scales are as follows:

1. Family Burden Interview Schedule¹²

This is a semi-structured interview schedule comprising twenty-four items grouped under six areas:

- Financial burden
- Disruption of family routine activities
- Disruption of family leisure
- Disruption of family interaction
- Effect on physical health of others
- Effect on mental health of others

Rating of burden is done on a three-point scale for each item and a standard questionnaire to assess the 'subjective' burden is also included in the schedule. This scale has been developed keeping in mind the socio-economic and cultural condition in India which are different from West. The inter-rater reliability for all items was reported to be more than 0.78 by the authors of the schedule. Validity of the schedule was assessed by correlating objective burden ratings with subjective as reported by the relatives. The correlation was found to be 0.72, which was considered significant.

2. Dysfunction Analysis Questionnaire (DAQ)¹¹

DAQ has fifty items grouped into five areas namely, 1) Social, 2) Vocation, 3) Personal, 4) Family and 5) Cognitive. The items are rated on a five point scale and a total attenuated percentage score is calculated to measure the amount of dysfunction Higher the score, more is the dysfunction.

3. Positive and Negative Syndrome (PANSS)¹⁰

The PANSS measurement derives from behavioral information

plus a four phase 35-45 minutes clinical interview. This is followed by seven-point ratings on 30 symptoms; with severity defined. The ratings provide summary score on seven item positive scale and seven item negative scale. 16 item general psychopathology scale and a composite (positive minus negative) index. Excellent inter-rater and test retest reliabilities have been demonstrated. In addition, it has been carefully validated against other instruments.

Data Entry and Analysis

Data was entered in MS-Excel and data analysis was done using SPSS version 22.0. Quantitative data was expressed in the form of mean, standard deviation and using Student's t-test. Qualitative variables were expressed as percentages and proportions and chi-square test. Statistically significant findings were considered as p -value < 0.05 . The correlation was also assessed between various socio-demographic variables.

Ethical Consideration

Written informed consent was taken from the patients and family members mentioning that the information being

collected is to be used for scientific purpose only. Proper confidentiality was ensured during data collection. Ethical approval was taken from the institutional ethical committee.

Result

For the present study, two groups of patients were taken that is schizophrenics and diabetics. Each group consisted of 50 patients.

Table 1, demonstrates that there were more male subjects with schizophrenia (54%) as compared to females (46%), whereas in diabetic group half of them were males and half females. In both the groups the majority of them were married (52% and 94% respectively) but statistically higher numbers were in diabetics ($p < 0.05$). In diabetes group subjects were significantly older age group as compared to schizophrenia ($p < 0.004$). The majority of the study population in both the groups were educated up to primary or, below matric (74%). Nearly half of the schizophrenic patients reside in nuclear family (52%) and in rural area (50%), whereas in diabetic group majority of them were joint families (64%) and but half of subjects resided in rural areas (54%).

Table 1. Socio-demographic profile of study subjects

S. No.	Socio-demographic Variables	Schizophrenia Number (%)	Diabetes Number (%)	p-value
1.	Gender			
	Male	27 (54)	25 (50)	P=0.68
	Female	23 (46)	25 (50)	
2.	Age (in completed years)			
	15-25	11 (22)	4 (8)	P=0.004*
	26-35	20 (40)	10 (20)	
	36-45	12 (24)	17 (34)	
	>45	7 (14)	19 (38)	
3.	Marital status			
	Single	19 (38)	2 (4)	p-value=0.0001
	Marital	26 (52)	47 (94)	
	Others (divorced, widowed or separated)	5 (10)	1 (2)	
4.	Educational status			
	Up to primary	18 (36)	25 (50)	p-value=0.141
	Matric	20 (40)	11 (22)	
	Above matric	12 (24)	14 (28)	
5.	Area of residence			
	Rural	25 (50)	27 (54)	p-value=0.107
	Urban	25 (50)	23 (46)	
6.	Family type			
	Nuclear	26 (52)	18 (36)	p-value=0.107
	Joint	24 (48)	32 (64)	
Total		50 (100)	50 (100)	

Table 2. Socio-demographic profile of care givers/relatives of study subjects

S. No.	Variables	Relatives of Schizophrenic patients No. (%)	Relatives of diabetic patients No. (%)	p-value
1.	Sex			
	Male	34 (68)	29 (58)	0.3
	Female	16 (32)	21 (42)	
2.	Age in groups			
	15-25	02 (04)	04 (08)	0.05
	26-35	05 (10)	10 (20)	
	36-45	16 (32)	17 (34)	
	>45	27 (54)	19 (38)	
3.	Marital status			
	Married	49 (98)	48 (96)	1.0(Fisher exact test)
	Others	1 (02)	2 (04)	
4.	Education			
	Primary	18 (36)	25 (50)	0.89
	Matric	14 (28)	11 (22)	
	Above matric	18 (36)	14 (28)	
5.	Duration of relatives stay with the patients (in years)			
	5-10	02 (04)	06 (12)	0.056
	11-15	05 (10)	10 (20)	
	16-20	15 (30)	06 (12)	
	>20	28 (56)	28 (56)	
6.	Relationship of family members with the patient			
	Husband	12 (24)	21 (42)	0.003
	Wife	10 (20)	19 (38)	
	Father	18 (36)	02 (04)	
	Others	10 (20)	08 (16)	

Table 2, reveals that in both the groups, the majority of the relatives were males (68%) and married (98%) in Schizophrenic group, most of the relatives were studied up to or below matric (64%) and in diabetic group 77% were studied less than or up to matric level. Most of the relatives of schizophrenic were above 35 years of age (86%) and 44% of the relatives were living with the patient for 20 years or less. In Diabetic group, the primary care givers were husbands (42%) followed by wives (38%) while in schizophrenic group it was father (36%) followed by husband (24%) who were primary caregivers.

Table 3, reveals that all caregivers of schizophrenic patients experienced moderate to severe level of burden in all

the areas of burden. Total burden among caregivers of schizophrenic patients were very much higher as compared to diabetic patients and the results were also statistically significant.

Table 4, shows that on inter-group comparison, significant differences were found between dysfunction in individual areas in schizophrenia and diabetes.

In schizophrenia, there was significant correlation between positive score symptomology and burden whereas there was high correlation between negative score and family burden. Similarly statistically significant correlation was seen between general psychopathology and total burden (Table 5).

Table 3. Distribution of study population showing the differences in the family burden between both the groups

Burden in individual area	Schizophrenia (n=50)		Diabetes (n=50)		't'-value	'p'-value
	Mean	S.D.	Mean	S.D.		
A. Financial	5.44	3.05	1.92	2.13	6.67	<0.05
B. Routine family activities	5.66	3.21	0.86	1.68	9.36	<0.05
C. Disruption of family leisure	3.46	2.31	0.96	1.56	6.32	<0.05
D. Disruption of family interaction	4.54	2.90	0.30	0.76	9.99	<0.05
E. Effect on physical health of others	2.26	1.21	0.20	0.53	11.02	<0.05
F. Effect on mental health	1.86	1.28	0.76	0.92	4.94	<0.05
Burden total	23.2	11.08	4.20	5.38	10.91	<0.05

Table 4. Distribution of study subjects by using dysfunctional analysis questionnaire (D.A.Q.) values

Dysfunction sub-scale	Schizophrenia (n=50)		Diabetes (n=50)		't'-value	'p'-value
	Mean	S.D.	Mean	S.D.		
Social	69.74	20.62	43.00	8.61	8.46	<0.001
Vocational	75.40	23.32	45.84	11.37	8.06	<0.001
Personal	61.60	16.00	42.26	10.82	7.08	<0.001
Family	70.00	19.26	42.20	9.05	9.23	<0.001
Cognitive	56.88	14.81	41.16	3.66	7.28	<0.001

Table 5. PANSS scale distribution in schizophrenia and its correlation with total burden (N=50)

PANSS Score	Mean	S.D.	'r' value	'p' value
Negative score	18.04	7.71	0.73	<0.001
Positive score	10.24	4.08	0.34	<0.05
General Psychopathology	37.82	13.80	0.64	<0.01
Total score	23.2	11.08		

Discussion

In the present study, family burden showed significant differences between schizophrenia and diabetic groups. All the six areas of burden namely; financial, disruption of family routine activities, disruption of family interaction, effects on physical health of others and effect on mental health of others were severely affected. This confirmed the view that relatives of schizophrenia experienced severe burden as compared to chronic medical illness like diabetes.

It is evident from the present study that regarding socio-demographic profile of schizophrenia, there were male preponderance. The present study reported higher number of males with schizophrenia, which is in accordance with the previous findings.^{13,14-16} Many (86%) young patients i.e. upto 45 yrs. were present in schizophrenic group and this difference was statistically significant. Most of the patients with schizophrenia were under the age group 21-40 years of age (83.4%). Similar finding was also observed in other study.¹⁷ Most (74%) of study population in both the groups

were educated up to or, below matric. Nearly half of the schizophrenic patients reside in nuclear family and from rural area.

The present paper reflected that males, married relatives were more in both the groups i.e. schizophrenics and diabetic group. This finding was in contradiction with a study conducted by Disha et al.¹⁸ Most of the relatives were studied upto or below matric in Schizophrenic group (64%) and diabetic (77%) group. Most (79%) of the relatives of schizophrenic patients were above 35 years of age and 44% of the relatives were living with the patient for 20 years or less. In Diabetics, primary care givers were husbands (42%) followed by wives (38%) while in schizophrenic groups, it was fathers (36%) followed by husbands (24%), who took care of the patients.

In the present study, it was found that all caregivers of schizophrenic patients experienced moderate to severe level of burden in all the areas of burden. Total burden among caregivers of schizophrenic patients were very

much higher as compared to diabetic patients which was statistically significant also. On inter-group comparison, significant differences were found between dysfunction in individual areas in schizophrenia and diabetes. In schizophrenia, there was significant correlation between positive score symptomology and burden whereas there was high correlation between negative score and family burden. Similarly, statistically significant correlation was seen between general psychopathology and total burden.

Similar finding was also observed by Vasudeva et al¹⁹ that the caregivers of schizophrenia group had significantly higher total burden score as compared to caregivers of bipolar disorder. Caregivers of Schizophrenia experienced significantly higher burden in area of external support, caregivers routine, and other relations. Also supported by Koujalgi SR et al²⁰ where caregivers of schizophrenic patients in comparison to depressive disorder have significantly high family burden except the effect on physical health of other family members and in Lorenza Magliano et al¹⁸ study that caregivers of schizophrenic patients having both objective and subjective burden were significantly higher.

Limitation

The informants were mainly key relatives. Further studies are needed to know whether the burden of the primary caregivers differ from relatives staying in the same house or by other at different places. Another limitation is the cross-sectional design of the study making it impossible to make an accurate assessment of the family burden during caregiving, which is an evolving and dynamic process. Future studies are needed to find any relation between coping strategies adopted by the caregivers and family burden faced by the caregivers.

Conclusion

Care givers/ relatives of schizophrenic patients carry a huge burden in terms of social, vocational, personal, familial and cognitive areas. They are also potentially a higher risk group for mental disorder. The exploration of burden of family caregivers gives baseline data necessary for decisions taking, further research and generation of coping styles and tools to promote rehabilitative caring. Psychosocial intervention program must be planned on the bases of proper assessment of caregivers coping styles, communication skills and community resources of key caregivers.

Conflict of Interest: None

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Appendix

पहले से पहले कमी आ गई है
अच्छा जैसा ही मामूली काफी बहुत अधिक

SA बीमारी से पहले की

तुलना में आजकल

1. लोगों से मिलना-जुलना
2. घूमना-फिरना, सिनेमा आदि जाना
3. शादी-ब्याह में जाना
4. त्यौहार में भाग लेना
5. दोस्तों, रिश्तेदारों या पड़ोसियों को घर दावत (निमन्त्रण) पर बुलाना
6. सभाओं, मजलसों आदि में भाग लेना (तजगां, कीर्तन, सत्संग आदि)
7. नए लोगों में मेलजोल बढ़ाना या पहल करना
8. दोस्तों/रिश्तेदारों के घर जाना
9. कोई घर आए तो खुश होना
10. लोगों के साथ मिलजुल कर काम करना

पहले से पहले कमी आ गई है
अच्छा जैसा ही मामूली काफी बहुत अधिक

VA बीमारी के पहले की तुलना में आजकल

11. काम-काज में मन लगना
12. काम का ठीक तरह से होना
13. साथियों के साथ मिलजूल कर काम करना
14. उच्च अधिकारियों के साथ मिलजुल कर रहना
15. हाथ में लिए हुए काम को पूरा करना
16. आमदनी या वेतन आदि
17. उच्च अधिकारियों द्वारा आपके कार्य की प्रशंसा करना
18. कार्य में प्रमोशन का अवसर
19. पूरे घण्टे काम करना
20. ठीक समय पर काम कर लेना

पहले से	पहले	कमी आ गई है
अच्छा	जैसा ही	भाग्यही काफी बहुत अधिक

PA बीमारी के पहले की तुलना में आजकल

21. शारीरिक (जिस्मानी) स्वास्थ्य
22. मानसिक (दिमागी) स्वास्थ्य
23. काम-वास्तना में रुचि लेना
24. खाने पीने का ख्याल रखना
25. समय पर सोना जागना
26. नहाना कपड़े बदलना और अपनी सफाई का ध्यान रखना
27. अपना काम/जिम्मेदारियां ठीक से निभाना
28. जिन कामों में शौक रखते हो वे काम करना
29. गुस्ता आने पर अपने आपको काबू में रखना
30. आदते

पहले से पहले बनी आ गई है
अच्छा जैसा ही माफूसी करनी बहुत अधिक

FA बीमारी के पहले की तुलना में आजकल

31. परिवार के सभी सदस्यों के साथ मिलचुल कर रहना
32. पारिवारिक कार्यों (जैसे शादी-ब्याह, त्यौहार आदि) में भाग लेना/हाथ बटाना)
33. खाली समय घरवालों के साथ बिताना
34. घरेलू मामलों में सबके साथ सलाह-मशवरा करना
35. बच्चों के साथ खेलना या बाजार आदि में जाना
36. पति/पत्नी के साथ समय बिताना
37. घर के बड़े-बूढ़ों का ख्याल रखना
38. परिवार में सबके साथ खुश रहना
39. परिवार के प्रति अपनी जिम्मेदारियां निभाना
40. परिवार के सब लोगों के साथ अच्छा व्यवहार करना

पहले से पहले कमी आ गई है
अपना जैसा ही मामूली काफी बहुत अधिक

CA बीमारी के पहले की तुलना में आजकल

41. काम पर ध्यान लगाना
42. वाददायित ठीक रहना
43. समय पर सोच समझकर फैसला करना
44. सचेत/होशियार रहना ताकि पता रहे कि आसपास क्या हा रहा है
45. समय, दिन और तारीख का ज्ञान रहना
46. रास्तों और जगहों की सही पहचान कर लेना
47. व्यक्तियों की शकल/नाम याद रखना
48. छोटी-छोटी बातों पर नाराज न होना
49. जल्दी से किसी बात को समझ लेना
50. फायदे और नुकसान की बात को जल्दी भांप लेना/समझ लेना

Remarks : मरीज के बारे में कुछ और बताना हो तो आप नीचे दिए हुए खाली जगह पर लिख दें।