

FAMILY BURDEN AMONG LONG TERM PSYCHIATRIC PATIENTS

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Subjective and objective burdens of the carers of schizophrenic and bipolar affective disorder patients were assessed. Burden was found to be higher among the carers of schizophrenic, young, male, low income and unemployed patients. This study shows a more comprehensive way of assessing family burden with due emphasis on positive mental health and coping resources of the carers.

INTRODUCTION

The behavior of relatives plays a significant role in the matter of patients' response in both schizophrenia (Vaughn & Leff, 1976) and depression (Hooley et al, 1986). All the relatives do not necessarily behave in the same manner and the nature of the burden placed on them may possibly lead some to resort to ineffective coping strategies. It has been observed that for a given amount of burden, the individual levels of distress show considerable variations (Platt, 1985). Barrowclough and Tarrier (1984) have noted that improvement in the way families try to cope with the burden of looking after schizophrenics at home has a beneficial effect on the course of schizophrenia.

Kavanagh (1992) in a review of recent literature has commented that family intervention may prove to be the most significant treatment breakthrough in schizophrenia since the discovery of neuroleptic medication. Marks (1992) has observed that in cases of serious mental illness, patients as well as relatives preferred community to hospital care, in spite of the fact that community care did not always have any appreciable impact. This proves that the family is seldom hesitant to shoulder burden.

Fadden et al (1987) in a review of studies on the family burden of psychiatric patients have observed that the families of schizophrenic patients constituted the only group which have been consistently studied, although there was evidence that the families of other patient groups were also seriously affected. They further note that the families often tolerate considerable burden without complaint. Indian studies on this topic are not many (Pai & Kapur, 1981; Gautam & Nijhawan, 1984; Ali & Bhatt, 1988). Kuruvilla (1993) identifies family burden as an important research area for a developing country like India. From the available literature, it appears that so far studies on family burden have been more concerned with the assessment of psychiatric morbidity among the family members of the patients,

and that no significant effort has been made to study their subjective well-being in terms of positive mental health or coping resources.

The present study was planned with the aim of assessing both the subjective and the objective burdens of the carers of two major psychiatric diagnostic categories, namely schizophrenia and bipolar affective disorder, with special emphasis on their positive mental health and coping resources. It may be mentioned here that the concept of burden, as observed by Fadden et al (1987) is characteristically associated with that of social performance.

Poor social performance of one member reciprocally affects the performance of any other member of the family, who has to compensate the deficiencies, experiencing burden. This led to the differentiation of burden into subjective and objective (Hoening & Hamilton, 1966). The objective burden refers to the changes in financial state, health, leisure etc. of the family members whereas the subjective burden represents the feeling of the family members for actually carrying a burden.

MATERIALS AND METHODS

The subject families were randomly drawn from the Psychiatry OPD of an urban teaching psychiatric hospital between November 1992 and April 1993. The identified primary carer of the patient was the family member who spent most of the time in direct care of the patient. The inclusion criteria were:

1. Diagnosis of schizophrenia and bipolar affective disorder as per ICD-10.
2. Duration of illness three to four years at the time of the examination for both schizophrenia and bipolar affective disorder.
3. In the case of bipolar affective disorder, at least three episodes of illness or persistence of symptoms for more than 50% of the time since the onset of illness.
4. Age between 20 and 55 years.

The exclusion criteria were:

1. Acute phase of the illness at the time of interview.
2. Patient being absent from home for a period of six months or more for any reason.
3. Presence of mental subnormality.

The objective burden was measured by the Interview Schedule developed by Pai & Kapur (1981). For the assessment of subjective burden, Subjective Well-being Inventory (SUBI) by Sell and Nagpal (1992) has been used. This inventory was evolved through a process of stepwise ethnographic exploration starting from unstructured interviews, followed by concept identification, concept clarification and concept itemization with ultimate quantitative concept validation and evaluation of the instrument. The questionnaire was administered in places like Delhi, Bangalore and Jodhpur.

The data from the respondents were subjected to factor analysis with varimax rotation. The resulting factors or concerns for a profile of well-being and ill-being have shown an extraordinary robustness over various samples, languages and various stages of reduction in the number of items from the original 130 to 40. The way of interpretation and the norms for the adult Indian population have been mentioned in the manual.

SUBI contains two sets of items: positive and negative. According to the authors, the positive items are more stable over time and are more influenced by personality traits. The negative items on the other hand, are more influenced by present life circumstances. The authors further noted that SUBI may help in the quantification of positive mental health in terms of the ecological model of health, i.e. the capability to maintain stability in the face of various changes and adversities. Moreover, these positive feelings about life can be considered as intra-personal coping resources.

Initially the primary carers were informed about the purpose and utility of the present study and all of them wholeheartedly agreed to participate. Subsequently the interview schedule and the inventory were administered. Regarding the income of the primary carers, the total family income was considered. An arbitrary division of low income family, i.e. a family with a total income of less than Rs. 2000/- per month and high income family, i.e. a family with a total income of more than Rs. 2000/- per month was made.

RESULTS

Initially, fifty six patients were included in the study. Among their primary carers, two could not come to the hospital due to physical illness and hence the final sample consisted of fifty four patients. Among them 30 (56.56%) were suffering from schizophrenia and 24 (44.44%) from bipolar affective disorder. Among the primary carers, 22 (40.74%) were wives, 8 (14.82%) husbands, 12 (22.24%) mothers, 8 (14.82%) fathers, 2 (3.7%) sons and 2 (3.7%) brothers.

Table 1
Sociodemographic Variables

Variable	Number	Percentage
Marital Status		
a) Married	36	66.67
b) Unmarried	18	33.33
Sex		
a) Male	34	62.96
b) Female	20	37.04
Age		
a) Less than 35 years	24	44.44
b) More than 35 years	30	55.56
Occupation		
a) Working	32	59.26
b) Non-working	22	40.74
Income		
a) Low	30	55.56
b) High	24	44.44

Table 1 shows the socio-demographic variables. Table 2 shows comparison of objective burden scores, SUBI positive items scores and SUBI negative item scores for different groups. A consistent pattern has emerged among the three sets of scores after statistical evaluation. Compared with the carers of bipolar affective disorder patients, carers of schizophrenic patients showed increased severity of burden in all three sets of scores, though statistical significance was reached only in SUBI negative item scores. The variation of burden in relation to the variables like age, sex, income and occupation are depicted in Table 2. Though increased burden was observed for the variables in all three sets, statistical significance was reached in only a few places. No such consistent pattern emerged for the scores in relation to marital status.

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Table 2

Statistical analysis of scores of Objective Burden Schedule, SUBI positive and SUBI negative items as obtained among different variables.

Measures	OBS.	SUBI (+)	SUBI (-)
I. Diagnosis			
a) Schizophrenia	4.70 ± 2.36	42.00 ± 7.99	45.07 ± 10.15
b) Bipolar Disorder	4.21 ± 2.55	38.33 ± 8.25	50.58 ± 7.35*
II. Marital status			
a) Married	4.24 ± 2.12	39.17 ± 9.29	42.73 ± 4.82
b) Unmarried	4.98 ± 2.97	47.72 ± 10.01**	47.11 ± 8.18**
III. Sex			
a) Male	5.01 ± 2.48	42.47 ± 8.29	44.35 ± 9.31
b) Female	3.60 ± 2.19	36.80 ± 6.91	52.90 ± 6.61
IV. Age			
a) Below 35 years	4.96 ± 2.13	42.33 ± 8.22	44.75 ± 10.77
b) Above 35 years	4.50 ± 2.56	38.80 ± 8.05	49.73 ± 7.55*
V. Employment			
a) Working	3.92 ± 1.93	38.25 ± 9.39	49.19 ± 9.75
b) Non-working	5.42 ± 3.18	43.45 ± 4.82	45.19 ± 8.44
VI. Income			
a) High Income	3.88 ± 2.05	38.83 ± 10.21	50.08 ± 9.65
b) Low Income	4.96 ± 2.65	41.53 ± 6.10	44.94 ± 8.23**

* p < .01; ** p < .001 (t test)

Table 3

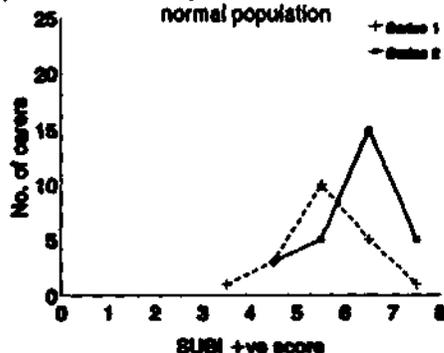
Coefficient of correlation between measures of objective burden score and SUBI in two groups classified according to diagnostic category.

Group	Schizophrenia		BAD	
	r.	df.	r.	df.
OBS and SUBI (+)	0.23	28	.025	22
OBS and SUBI (-)	0.822**	28	.949**	22

Table 3 shows the correlation (Pearson Product Moment Correlation) among the objective burden, SUBI positive item scores and SUBI negative item scores of the carers of schizophrenic and bipolar affective disorder patients. Though very high correlation was observed between objective burden and SUBI negative item scores (p < 0.01), no significant correlation was noted between objective burden scores and SUBI positive item scores.

Figure 1

Comparison of SUBI positive item-scores of carers of patients with schizophrenia and BAD with that of the normal population

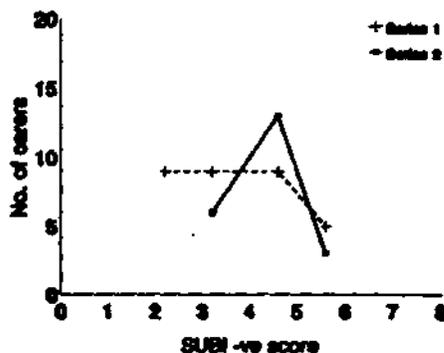


Mean SD 40.37 ± 8.16

Series 1 = Scores of carers of BAD patients
Series 2 = Scores of carers of Schiz. patients

Figure 2

Comparison of SUBI negative item-scores of carers of patients with schizophrenia and BAD with that of the normal population



Mean SD 47.91 ± 9.2

Series 1 = Scores of carers of Schiz. patients
Series 2 = Scores of carers of BAD patients

Figures 1 and 2 show the comparison of SUBI positive item scores and SUBI negative item scores of the carers of schizophrenic and bipolar affective disorder patients with that of the normal population (as obtained by Sell & Nagpal, 1992). Among the

carers of schizophrenic patients, 66.67% scored within the normal range of SUBI positive item scores. For SUBI negative item scores this figure was 53.33%. Similarly, for the carers of bipolar affective disorder patients, 66.66% of them scored within the normal range of SUBI positive item scores. This figure was 83.33% for SUBI negative item scores.

DISCUSSION

It has been observed in the present study that, compared with the carers of bipolar affective disorder patients, burden is more for the carers of schizophrenic patients. It has already been mentioned that Fadden et al (1987a), in their review, pointed out that studies in the area of family burden were confined mainly to schizophrenia. Although in another study, Fadden et al (1987b) found burden to be less among bipolar patients when compared to other varieties of depressive disorders, no ready reference is available regarding the comparison as shown in the present study. However, it is understandable that the chronic unremitting course of schizophrenia along with the personality disintegration which it produces, places considerable burden on the carers. Comparatively more burden was observed among carers of young and male patients. This finding corroborates with that of Martyns-Yellow's (1992) Nigerian study.

Nigeria is a developing country and their problems are more or less similar to those in India. Young age and male sex are considered to be the most productive segment of the society and any problem affecting this group will have a definite adverse effect on the carers. Similarly, the condition of the carers of patients who are unemployed or who come from low income families are under profound stress. Findings obtained regarding carers of married and unmarried patients do not follow a consistent pattern as the earlier ones and hence are difficult to comment upon.

Hoening and Hamilton (1966) found an interesting discrepancy between objective and subjective burden of the carers. Though not readily understandable, such findings were noted in subsequent studies (Fadden et al, 1987a). In the present study, it has been observed that the objective burden scores correlate highly with the SUBI negative item scores but not with SUBI positive item scores. The high correlation between the objective burden scores and SUBI negative item scores, which are more influenced by the present life circumstances indicates

that the carers' subjective experiences were considerably consistent with the magnitude of the problems caused by the illness of their relatives. However, it has been found that the majority of the carers lie within the normal range of SUBI scores. This shows that, in spite of having a high amount of objective burden, the majority of carers were enjoying subjective well-being, i.e. positive mental health and thereby possessing considerable coping resources. This helps in explaining the rather paradoxical findings of earlier studies as to how a large number of relatives could tolerate such a high objective burden without complaint.

Though the sample size of the present study is small, a consistent pattern has emerged from the findings of the different groups of data. However, inclusion of the assessment of the family environment, personality and other characteristics of the carers would have further improved the present study. Hence, to detect the vulnerable group estimation of objective burden is not enough. The inclusion of subjective well-being in terms of positive mental health and coping resources will add a new dimension to the study of this area and will help in formulating family intervention programs.

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