COMPARISON OF THE EXTENT AND PATTERN OF FAMILY BURDEN IN AFFECTIVE DISORDERS AND SCHIZOPHRENIA

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This study sought to compare the extent and pattern of burden experienced by relatives of two different patient groups, one with affective disorders and the other with schizophrenia. Cross-sectional assessment of family burden using the Pai and Kapur's Interview Schedule was done in 78 patients with either bipolar disorder or recurrent major depression and 60 patients with schizophrenia diagnosed according to DSM-III. The inter-rater reliability of the interview schedule for burden was also undertaken prior to the assessment of burden in the main study sample. Both groups were similar with regard to sociodemographic variables, duration of illness and dysfunction of patient except for lower mean age and greater number of single patients in schizophrenia group. The extent of both objective and subjective burden was significantly more in relatives of schizophrenics. The pattern of burden was, however, almost similar in both the groups. Burden was principally felt in the areas of family routine, family leisure, family interaction and finances. The emotional health of the family was relatively untouched and the impact on physical health of the caring relatives due to burden of care was almost negligible. Various sociodemographic and clinical variables related to burden as well as the implication of the findings of the study are discussed.

Key words: schizophrenia, affective disorder, burden, family burden.

INTRODUCTION

The family has always been recognized as an important factor both in the genesis and prognosis of mental illness. Initial studies generally focused on the possible etiologic role of the family, but the perspective has now changed to incorporate the family as a "reactor" to mental illness of a member (Kreisman & Joy, 1974). This has led to interest in various problems that arise from the patient's presence at home such as financial difficulties or marital disharmony. The sum total of these problems or difficulties which affect the significant others of a psychiatric patient is referred to as social or family burden (Piatt, 1985).

Studies spanning over about four decades and using diverse methodologies have consistently shown that families of psychotic patients experience substantial hardships in many areas of family life. The major part of this research has been devoted to evaluation of burden among families of schizophrenic patients though some studies have also examined other groups of patients (Grad & Sainsbury, 1963; Reynolds & Hoult, 1984). Recently, however, there has been a gradual broadening of interest to include families of patients with affective disorders especially major depression. Sufficient empirical work has been done to document burden perceived by relatives in these families during acute episodes as well as periods of remission (Keitner & Miller, 1990). Certain studies done on recurrent unipolar depression and bipolar depression have found an extent of burden almost similar to that prevalent in families of schizophrenic patients (Jacob et al, 1987; Fedden et al, 1987).

Apart from documenting the extent of family burden the other significant advance in this field has been the attempt of investigators to provide an idea of the pattern or typology of burden. Such information is of pragmatic use to the clinician who can then interview the relatives in a knowledgeable way and devise appropriate strategies to help them cope with various problems. Creer and Wing (1974) have provided this sort of typology of burden among relatives of schizophrenic patients and Jacob et al (1987) and Fedden et al (1987) have done similarly for patients with affective disorders.

Despite overwhelming evidence of the problems which people face when living with the psychiatrically ill, research data pertaining to family burden is rather limited, more so in the case of affective disorders. There is also a lack of studies which have actually compared the family burden among different groups of psychiatric patients. Therefore we, conducted the present study with the aim of comparing the extent and pattern of burden among families of schizophrenia and affective disorders patients.
MATERIAL AND METHODS

SAMPLE

The study was conducted in the Department of Psychiatry of Nehru Hospital, Postgraduate Institute of Medical Education and Research, Chandigarh, India. The sample was selected from a population of patients attending the psychiatric services of the Institute.

SELECTION CRITERIA

Patients of either sex in the age range of 15 to 50 years were included on meeting the following criteria:

1. DSM-III (American Psychiatric Association, 1980) diagnosis of schizophrenia, bipolar disorder or major depression recurrent episodes. The patients were independently diagnosed by two investigators (PK and AA).

2. Illness duration of more than one year.

3. Staying with a relative currently and for 3 years prior to the assessment with the same relative.

Relatives were included if they satisfied the following criteria:

1. Any healthy adult aged 18 years or more.

2. Staying with the patient currently and at least for 3 previous years.

The following were excluded from the study:

1. Patients with DSM-III diagnosis of bipolar disorder with only manic episodes and no history of depressive episodes.

2. Patients with any other chronic physical illness, personality disorder, organic brain disease or substance abuse.

3. Families with another family member (other than the patient) with a psychiatric or chronic physical illness.

STUDY GROUPS

The sample consisted of two study groups based on diagnoses:

1. Schizophrenia group included sixty patients with DSM III diagnosis of schizophrenia.

2. Affective disorder group included seventy eight patients with DSM III diagnosis of bipolar disorder or major depression recurrent episode.

TOOLS

1. **Family Burden Interview Schedule** of Pai and Kapur (1981).

   This is a semi-structured interview schedule comprising twenty four items grouped under six areas: i) financial burden, ii) disruption of family routine activities, iii) disruption of family leisure, iv) disruption of family interaction, v) effect on physical health of others and vi) effect on mental health of others.

   Rating of burden is done on a three point scale for each item and a standard question to assess the 'subjective' burden is also included in the schedule. This scale has been developed keeping in mind the socio-economic and cultural conditions in India which are different from the West. The validity and reliability of the scale have been shown to be satisfactory. 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 burden as reported by relatives. The correlation was found to be 0.72 which was considered significant.

   The scale though primarily devised for patients of schizophrenia has also been used in a number of Indian studies to evaluate burden among families of neurotic patients, patients with alcohol abuse, mental retardation and chronic physical illness.

2. **Dysfunction Analysis Questionnaire (DAQ)** of Pershad et al (1985).

   The DAQ has fifty items grouped into five areas namely social, vocational, personal, family and 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. **Comprehensive Psychopathological Rating Scale (CPRS)** of Asberg et al (1978).

   This well known scale was employed to assess manifest psychopathology of the patients.

4. **The Scale for the Assessment of Positive Symptoms (SAPS)** of Andreasen (1984).

5. **The Scale for the Assessment of Negative Symptoms (SANS)** of Andreasen (1984).

   These two well known instruments which are extensively used in schizophrenia research were utilized to assess positive and negative symptoms in the schizophrenic group.
RELIABILITY EXERCISE

Since the assessment of burden was done by two investigators (SC and LR) a separate inter-rater reliability exercise was carried out with the principal instrument of the study i.e. Family Burden Interview Schedule of Pai and Kapur (1981) to eliminate possible observer bias. For this an additional sample of 21 patients of either schizophrenia (n=12) or affective disorder (n=9), diagnosed as per DSM-III by two investigators (PK & AA), were rated independently on the schedule by both raters i.e. SC and LR. The inter-rater reliability for the total objective burden score was determined by using the Pearson's Product Moment Coefficient of Correlation.

The DAQ (Pershad et al, 1985) was developed and standardized in this very department and is also extensively used by us, therefore, conducting separate inter-rater reliability exercise for DAQ between SC and LR was not considered necessary and as such was not undertaken.

PROCEDURE

The relative experiencing the maximum burden was chosen from the informants accompanying the patient. Usually the closest relative experiencing the maximum burden was chosen, this being determined by interviewing the persons accompanying the patient. If such a relative was not available or did not give consent, the next most suitable relative was chosen. After obtaining information about sociodemographic factors the relative was interviewed regarding the family burden and the burden was rated on the schedule of Pai and Kapur (1981). Next the relative was asked to assess the dysfunction of the patient using DAQ (Pershad et al, 1985). All assessments were done only once at the time of initial contact. The treatment of the patients was neither controlled nor changed. A similar procedure was followed for the inter-rater reliability exercise, except that the DAQ was not administered.

STATISTICAL ANALYSES

Appropriate statistical tests both parametric and non-parametric were carried out wherever indicated. These included the $X^2$ test, Student 't' test and linear correlation analysis.

RESULTS

The total number of patients in the affective disorder group was 78 and the schizophrenia group had 60 patients.

Sociodemographic profile:

The mean age of patients with affective disorder was 35.72 (SD 7.37) years which was significantly higher than the mean age of 32.13 (SD 8.74) years of schizophrenic patients ($t=2.58, df=136, p<0.05$). Males constituted the majority (about 62% in the affective disorder group and 58% in schizophrenia). More patients in the affective disorder group were married (81%), whereas a major proportion of the schizophrenia group (55%) were not; this difference was also significant ($X^2=19.13, df=1, p<0.01$). Most patients had less than 10 years of formal education (73% in the affective disorder and 83% in the schizophrenic group). About two thirds of the patients in both groups were employed and were earning members of the family. More than half (53%) of the families in each group were of nuclear type and about 70% of them came from an urban background. Apart from age and marital status there were no significant differences between the two groups on other sociodemographic parameters. The sociodemographic information is shown in Table 1.

| Parameter                  | Affective disorder group (n=78) | Schizophrenia group (n=60) |
|----------------------------|---------------------------------|-----------------------------|
| **Age in years**           |                                 |                             |
| Mean                       | 35.72                           | 32.13                       |
| SD                         | 7.37                            | 8.74                        |
| Gender                     |                                 |                             |
| Males                      | 48                              | 35                          |
| Females                    | 30                              | 25                          |
| Marital status             |                                 |                             |
| Ever married               | 63                              | 27                          |
| Never married              | 15                              | 33                          |
| Formal education (years)   |                                 |                             |
| Up to 10                   | 57                              | 50                          |
| More than 10               | 21                              | 10                          |
| Family type                |                                 |                             |
| Nuclear                    | 41                              | 32                          |
| Non nuclear                | 37                              | 28                          |
| Place of residence         |                                 |                             |
| Urban                      | 54                              | 42                          |
| Rural                      | 24                              | 18                          |

$^1 t=2.58, df=136, p<0.05$.
$^{**} X^2=19.13, df=1, p<0.01$.

All other variables showed no significant difference.
Description of the relatives:

Of the 78 relatives in the affective disorder group, 49 were spouses, 18 parents and 11 siblings and children. The mean age of the relatives in this group was 39.77 (SD 13.01) years. Males (n=38) and females (n=40) were almost equally represented in the relatives group of affective disorder subjects. Most of the relatives (n=52) in this group had 10 years or more of formal education. As regards occupation, there were 39 housewives/students in this group. Three relatives were unemployed and the rest were engaged in meaningful jobs.

There were 60 relatives of patients with schizophrenia. This group comprised 20 spouses, 30 parents, 9 siblings and a grown-up child. The mean age of relatives in this group was 46.53 (SD 12.33) years. There were 47 male and 13 female relatives. Most of them (n=39) had 10 years or more of formal education. But for 5 relatives who had retired and 13 housewives, the rest of the relatives were employed.

Clinical variables and dysfunction:

The affective disorder group had a heterogeneous mix of patients and had 24 bipolar disorder-mania, 37 bipolar disorder-depressed and 17 major depression recurrent episodes as per DSM-III. Fifty patients belonging to affective disorder group were on lithium prophylaxis and the rest were either on antidepressants or neuroleptics. Most of the patients in the affective disorder group were in a stage of remission and 6 patients in this group had CPRS ratings as zero. The mean CPRS score of the other 72 patients in this group was about 7 (mean 6.93, SD 3.71).

The schizophrenic group had 30 "positive" schizophrenic patients with a mean SAPS score of 37.80 (SD 10.51) and 30 "negative" schizophrenics with a mean SANS score of 67.40 (SD 19.17). Every patient in this group was on neuroleptics.

The mean duration of illness in the affective disorder group was 10.35 (SD 6.43) years and that in schizophrenic patients was 8.33 (SD 6.73) years and comparison on this variable was not statistically significant (t=1.78, df=136). The amount of dysfunction rated on the DAQ (13) was, however, more in the schizophrenic group (mean 53.03, SD 11.24) compared to the affective to the disorder group (mean 49.81, SD 8.80), but this difference was also statistically not significant (t=1.85, df=136).

Inter-rater reliability of Pai and Kapur's schedule:

For this, the objective burden score of 21 patients rated independently by the two raters was subjected to correlation analysis. The mean scores of the 2 raters were 13.10 (SD 6.10) and 14.24 (SD 5.34) and the coefficient of correlation was of the order of r=0.85 (df=20, p<0.01). Similarly the correlation coefficients for each of the 6 subscales ranged from 0.76 to 0.88. The subscale of "effect on physical health of others" had the highest correlation coefficient and the subscale of "disruption of family interactions" the lowest. The schedule thus showed a satisfactory degree of inter-rater reliability. Moreover, these results compare well with those reported by Pai and Kapur (1981) themselves who found a reliability score of not less than 0.785 for any item of the scale.

| Type of burden | Affective disorder group | Schizophrenia group |
|----------------|--------------------------|---------------------|
| Objective burden scores | Mean 15.10 | 18.13 |
|               | SD 6.07 | 7.95 |
| Global objective burden | No burden 0 | 0 |
|                       | Moderate burden 53 | 32 |
|                       | Severe burden 25 | 28 |
| Subjective burden felt by relatives | No burden 18 | 4 |
|                           | Moderate burden 44 | 23 |
|                           | Severe burden 16 | 33 |

\[ t=2.49, df=136, p<0.01. \]
\[ X^2=19.53, df=2, p<0.01. \]

Extent of burden in the study groups:

Table 2 shows the extent of objective and subjective burden perceived by the relatives. The mean objective burden score in relatives of schizophrenic patients was significantly higher compared to the affective disorder group (t=2.49, df=136, p<0.05) but the global objective burden was similar in both study groups (X^2=3.06, df=1, not significant). A totally different picture emerged when the relatives were questioned regarding their perception of subjective burden due to the illness of the patient.
Compared to 23% of the relatives of affective disorder group who did not report experiencing subjective burden, only 7% of the relatives of schizophrenics did not report subjective burden. Moderate and severe subjective burden were also significantly more in relatives of schizophrenics compared to the relatives of affective disorder group ($X^2 = 19.53$, df=1, $p<0.01$).

**Pattern of burden in the study groups:**

The exploration of pattern of burden in the two study groups revealed certain subtle variability. Both study groups reported financial burden, disruption of family routine, family leisure, and family interactions. Burden in the area of mental and emotional health was considerably less and that in the area of physical health of the family members was almost negligible.

In the affective disorder group, maximum burden was experienced in the area of disruption of family routine followed by disruption of family leisure, financial burden and disruption of family interactions. Among the relatives of schizophrenics also, maximum burden was seen in the sphere of routine family activities. However, in contrast to affective disorder families, this was followed by burden in the area which in turn was more than the burden experienced in the areas of family leisure or family interactions. When the two groups were compared it was noted that the schizophrenic group had significantly more financial burden, disruption of family routine and disruption of family leisure. These results are displayed in Table 3.

An attempt was made to explore the relationship between burden of care and, DAQ, SAPS and SANS in the schizophrenic groups and burden scores and DAQ in the affective disorder group. In the positive schizophrenia group, the mean objective burden score was 18.3 (SD 7.8) and the mean subjective burden score was 1.5 (SD 0.74). In the negative schizophrenia group the respective mean scores for objective and subjective burden were 17.9 (SD 8.2) and 1.4 (SD 0.57). In the positive schizophrenia group there was no significant correlation between SAPS score and objective burden ($r=0.23$) but in the negative schizophrenia group there was significant correlation between SANS scores and burden ($r=0.65$, $p<0.01$). Similarly, it was seen that subjective burden and SAPS score did not have a significant relationship ($r=0.28$) but SANS and burden scores showed significant correlation ($r=0.81$, $p<0.01$).

**Table 3:** Sociodemographic profile of the sample

| Area of burden                  | Affective disorder group (n=78) | Schizophrenia group (n=60) |
|---------------------------------|---------------------------------|---------------------------|
| Financial                       | Mean 3.35                       | 4.50                      |
|                                 | SD 2.50                         | 2.83                      |
| Disruption of family routine    | Mean 4.49                       | 5.28                      |
|                                 | SD 2.35                         | 2.06                      |
| Disruption of family interactions| Mean 2.65                       | 3.67                      |
|                                 | SD 1.55                         | 2.45                      |
| Effect on physical health of relatives | Mean 0.03                       | 0.17                      |
|                                 | SD 0.22                         | 0.49                      |
| Effect on mental health of relatives | Mean 0.58                       | 0.65                      |
|                                 | SD 0.78                         | 0.60                      |

* $t=2.50$, df=136, $p<0.05$.
** $t=2.08$, df=136, $p<0.05$
*** $t=2.89$, df=136, $p<0.01$

As regards the relationship between dysfunction as measured on DAQ and burden, it was seen that in both positive and negative schizophrenic groups, there was significant positive correlation between DAQ scores and objective burden (for positive schizophrenia group, correlation between DAQ and objective burden $r=0.46$, $p<0.01$; and for negative schizophrenia group, correlation between DAQ and burden $r=0.52$, $p<0.01$). Similar was the case for subjective burden and DAQ scores (for positive schizophrenia DAQ: subjective burden $r=0.38$, $p<0.05$ and for negative schizophrenia DAQ: subjective burden $r=0.69$, $p<0.01$).

Exploration of relationship between DAQ scores and objective and subjective burden scores in affective disorders group yielded results similar to the ones obtained in positive and negative schizophrenia groups. The mean DAQ score for the group as a whole was 49.60 (SD 7.88) and its correlation with objective burden was significant ($r = 0.67$, $p<0.01$). Similar was the case for correlation between DAQ and subjective burden.
DISCUSSION

As mentioned earlier, studies of family burden have been mainly conducted with schizophrenic subjects, other conditions like affective disorders have been relatively neglected probably because of the notion that they do not entail chronicity or impairment. The present study arose from the concern that such notions may be false and that families with affective disorder patients also face considerable burden due to the ill members.

Our results show that families of patients with affective disorders as well as schizophrenia experience considerable burden. Despite this high prevalence of burden, relatives demonstrated a great deal of tolerance. This is reflected by the fact that nearly 16% of our study families did not perceive subjective burden in caring for the patient.

The extent of both objective and subjective burden in relatives of schizophrenia was, however, significantly more than that in families with affective disorders. The difference in burden cannot be attributed to sociodemographic parameters, as significant differences between the study groups in age and marital status are possibly a function of the illness. Neither could it be attributed to the duration of illness or the amount of dysfunction which were almost similar in both study groups.

One possible reason for the difference could be the fact that most affective disorder patients were in state of remission whereas most of the schizophrenic patients were either actively psychotic at the time of assessments or had considerable negative symptoms as evinced by SAPS SANS scores. However, since the assessment of burden was done on longitudinal basis (while psychopathology ratings were crosssectional), the influence of the current state of the patients is less likely to be of any great consequence in determining burden scores. The difference in the extent of burden thus reflects differences due to the nature of illness itself.

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One reason for greater burden among schizophrenics could be the chronic nature of the illness in contrast to discrete episodic nature of affective disorder. Giel et al (1983) have suggested that a chronic illness with severe loss of insight would significantly increase the extent of burden. Brown et al (1966) found that chronic course of schizophrenia had greater degree of burden compared to schizophrenia with an episodic course. On the other hand, coping of the spouses of affective disorders especially bipolar patients has been reported to be better by Fedden et al (1987) possibly due to discrete nature of the episodes; the ability of spouses to spot an oncoming episode early and the expectation that in between episodes the patient will return to normal level of functioning.

We have demonstrated that, despite differences in extent, the pattern of burden in both of the study groups was similar. The four principal areas of burden in both groups were similar. Disruption in family routine was the area in which burden was experienced the most in both the groups. Most families found patient's inability to work very distressing and inconvenient.

The two study groups differed slightly with regard to financial burden and disruption of family leisure; financial burden was more than restriction of leisure in the families of schizophrenics. The opposite was true for affective disorders. Financial burden was primarily a direct outcome of loss of patient's income and secondarily due to expenses of treatment. In many cases these included substantial amounts spent on indigenous treatment or on various rituals prescribed by local faith healers. Many relatives reported that the illness of their kin had severely denied their savings and some families were forced to take loans.

Disruption of family interactions was another significant aspect of burden. As a consequence of patient's illness, family members remained tense and irritable and had frequent misunderstandings among themselves about caring for the patient. However, relatively few caregivers reported reduced interaction with friends and neighbors and almost none felt the family to have become secluded due to the patient's illness. The emotional health of the caretakers was affected in a number of cases with many reporting loss of sleep or appetite and constant worrying. However, hardly anyone had ever considered consulting a psychiatrist or even telling the treating physician of his or her problems. Burden in this area as well as physical health of family members was negligible when compared with other areas.

The pattern of burden particularly in the areas of family routine, family leisure and family interactions as well as in financial sphere is not surprising. A similar pattern has been reported by others also. Creer et al (1982) have reported that the most common problems faced by the relatives were in caring for the patient and putting up with his/her socially embarrassing and difficult behavior.
Among affective disorder patients, Fadden et al (1987) found that social and leisure activities of the relatives suffered the most. Certain socio-cultural factors unique to the Indian setting could have contributed to the particular pattern of burden. For generations, life in India has revolved around the joint family system which acted as a buffer against stress and was suited to the agrarian pattern of Indian society. However, with rapid urbanization and industrialization leading to the fragmentation of this joint family system and now more and more nuclear families are emerging. Due to threats of new stressors, the nuclear families are more vulnerable (Sethi & Manchanda, 1978).

The entire study sample had an excess of nuclear families. Hence, the observation that disruption of family routine and leisure activities formed a significant part of burden is not entirely unexpected. Further, in India, families especially rural ones, have to travel long distances to reach a mental health facility largely because of the fact that such facilities are not abundant and access to such treatment units is often limited. Considerable reliance is placed on indigenous forms of treatment as these more readily available. Moreover, majority of the population has firm belief in the efficacy these modalities of treatment. Given these set of circumstances, it becomes clear why financial hardships formed a significant part of the burden and why expenses of treatment included money spent on travel and local faith healers.

Gautam & Nijhawan (1984) have reported similar pattern of burden including one study which had patients of schizophrenia and had also used the instrument of Pai and Kapur. In another study- a WHO Multicentric study reported by Giel et al (1983), the center from India reported that in families of patients with psychosis, burden was chiefly felt in financial and interpersonal spheres and it was also commented that certain socio-cultural factors contribute to a pattern of burden unique to the Indian milieu.

An interesting relationship between dysfunction and burden experienced by the relatives emerged. Whereas for affective disorders and negative schizophrenia as independent groups had significant correlation between dysfunction and burden, the same was not true for positive schizophrenia. We do not have any explanation for this finding.

Thus, the principal conclusion of this study is that, though the extent of burden among families of schizophrenic patients is more than that among affective disorders, there is a considerable burden even among the latter with a pattern almost identical to the former. This has important implications for management of patients with affective disorders, one being the adoption of family intervention strategies similar to those used in schizophrenia, a suggestion that has often been made. For clinicians dealing with such patients, an awareness of the nature of the problems faced by the family will help them in dealing more effectively with the patient and his family.

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