CHAPTER VI

BURDEN ON THE FAMILIES OF

SCHIZOPHRENIC PATIENTS
Family potentials are increasingly focussed upon by the modern trends in mental health. During the last decade or so there has been an increasing trend all over the world towards treating mentally ill patients in their family setting and in their own community, rather than in mental hospitals. Even when the patient needs to be treated in the hospital in the acute phase of his illness, the tendency today is to discharge him into the community as soon as possible (Pai and Kapoor 1981).

While the policy of treating mental patients at home, reduces the load on hospitals, and may help early recovery and prevent chronic handicap (Tooth and Brooke, 1961), it perhaps increases the burden on the family and community. However, most countries have launched large scale community mental health programmes without assessing the burden, families may have to face and the possible damage to family members. In this context Carstairs (1968) has aptly pointed out that objective evaluations of the effectiveness of new procedures have seldom, if ever preceded their gaining currency in psychiatric practice.

So far very few systematic attempts, have been made to assess the type and degree of burden placed on the families of patients treated at home. Earlier workers,
studying the discharge of chronic patients into the community, attempted to assess social burden by readmission of the patient or relapse in his symptoms. Mandelbrote & Folkard (1961a; b) and Wing et al (1964) pointed out that the stress caused to families by patients' disturbing behaviour was an important factor in determining the patients' acceptance by the families, or alternatively their readmission to mental hospital. Subsequent workers such as Grad and Sainsbury (1963) and Hoenig and Hamilton (1966) tried to assess this aspect in greater detail. Grad and Sainsbury (1963) made headway in assessing the burden felt by patients' families on a three-point scale. They tested the scale for reliability and reported 75 per cent agreement between three interviewers. Hoenig and Hamilton (1966) added another dimension to this assessment by trying to differentiate between the objective and subjective burdens felt by family members.

No such work has been reported in an Indian setting. The economic and cultural conditions in India being vastly different from those of the Western world, the areas of family burden and the pattern of accepting or rejecting patients may be entirely different.

In the present study an attempt has been made to assess the burden on the families of 200 schizophrenic patients, using the standardized interview schedule prepared by Pai and Kapoor (1981).
TABLE NO. 59
BURDEN OF MENTAL ILLNESS ON THE FAMILIES OF THE PATIENTS

<table>
<thead>
<tr>
<th>Sl. No.</th>
<th>Burden of Mental Illness</th>
<th>Score</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Financial Burden</td>
<td>1055</td>
<td>5.275</td>
</tr>
<tr>
<td>2.</td>
<td>Disruption of Other Family Members Activities</td>
<td>1001</td>
<td>5.005</td>
</tr>
<tr>
<td>3.</td>
<td>Disruption of Family Leisure Time Activities</td>
<td>509</td>
<td>2.545</td>
</tr>
<tr>
<td>4.</td>
<td>Disruption in Family Interaction</td>
<td>883</td>
<td>4.415</td>
</tr>
<tr>
<td>5.</td>
<td>Effect on Physical Health of Others</td>
<td>144</td>
<td>0.72</td>
</tr>
<tr>
<td>6.</td>
<td>Effect on Mental Health of Others</td>
<td>24</td>
<td>0.12</td>
</tr>
</tbody>
</table>

Total Burden 3616 18.08

As seen in the table the total score as well as the mean score of each of the burden, the highest level of burden is experienced in respect of financial aspect. Next to this comes the burden arising out of disruption in other family members activities. The third burden experienced is in relation to disruption in family interaction. The disruption of family leisure time activities is found to be one of the burdens of the family members. It is also important to note that the physical and mental health of other family members are considerably affected by the schizophrenic individuals.
A. Financial Burden

The financial burden of these families is due to the following six aspects

(1) Loss of patient's income:

Many a time the patient loses his job because of his schizophrenic illness. He or she stops doing the work which they were doing earlier. If he were the only breadwinner, the family would be totally deprived of their income and economic security. This is more so in case of poor families where they have no other income. The sudden loss of income serves as a severe blow to the family and other family members are unable to cope with this situation. This in turn produces a chain reaction of stress and strain on other family members specially on children.

(2) Loss of income of other members of the family due to patients' illness

If a schizophrenic patient needs to be admitted to a hospital, other family members have to put lot of efforts. In this way the patient's spouse or siblings or grown up children or other relatives would not be able to go for work. Either they stay at home, to look after the patient's needs or lose their pay and their jobs. In this way the family finances are greatly affected by the loss of income of other family members in addition to the loss of patients income.
(3) **Expenditure incurred due to patients' illness and treatment**

In certain phases of illness the patient spends excessively or loses the money irrationally. For various reasons this becomes an uncontrollable phenomenon. Though other family members are aware of such wastage by the patients, they are helpless. In addition to these losses, money has to be spent on treatment, medicines, transport, accommodation away from home and so on. As has been discussed earlier most of the patients spend on other treatments, such as temples and native healers. This they tend to do with the fond hope of getting some help for their patients. They do their best to mobilize the meagre resources, loans from friends and relatives, mortgaging their lands and houses and other such means. By all these methods, the family finances are affected in such a way that they are unable to cope with the ordinary demands of daily living.

(4) **Expenditure incurred due to extra arrangements:**

Specially in smaller families when they are unable to manage the patients themselves, they seek other relatives help to come and stay with the patient or to look after the children. Sometimes they engage servants to manage the household work. These in turn affect the family finances.
The text is provided as follows:

(5) **Loans taken or savings spent:**

Because of sudden crises situations the family members depend on large amounts of loan. In fact at that time they do not think of any realistic ways of paying it back. In some families these are all the moments when they spend from their meagre savings. In this way not only the present living becomes miserable but their future too become bleak.

(6) **Postponement of certain planned activities because of the financial pressure of the patient's illness**

It is not uncommon to see family members postponing the marriage, a journey or religious rites because of the financial constraints mainly arising out of the patient's illness. In such circumstances chances of losing their other supports are high. In this way the family's financial difficulties affect the day to day living.

**B. Disruption of routine family activities:**

This is seen as a burden at least in the following five aspects:

(1) **Patient not going to work, school, college etc.**

As the illness progresses, the patient stops doing his routine responsibilities which in turn induces lot of agony in others' minds. Such losses need to be compensated in some way or other subsequently.
(2) Patient not helping in the household work:

The household work which used to be shared by the family members becomes unshared, undone, or inadequately completed. These are the problems felt by families depending on agriculture, handicrafts, and allied occupations.

(3) Disruption of activities of other members of the family:

As the patient becomes unco-operative, aggressive, assaultive and unmanageable, other members of the family or other relatives need to intervene and spend their full time with the patient either at home or in the hospital. Such practices make the members abandon the routine activities, thus causing innumerable problems.

(4) Patients behaviour disrupting activities:

The violent behaviour, destructive behaviour, impulsive activities, inability to sleep or not allowing others to sleep, all these behaviours are embarrassing to the family members and disrupt the family harmony and activities.

(5) Neglect of the rest of the family due to patient's illness:

Because of the preoccupation with the patient other members in the family including children are grossly neglected. Sometimes the anger and frustration are displaced
on the innocent children. As a result they miss either the school or meals.

C. Disruption of family leisure:

This is seen in the following four aspects:

(1) Stopping of normal recreational activities:

Anticipating patient's interference and irritable behaviour, the family members either completely or partially stop their normal recreational activities. The family members may become frustrated and agitated about such lapses.

(2) Patient's illness using up another person's holiday and leisure time:

The holidays and leisure time activities of the other members of the family are unduly affected by the patient's activities. The family members become helpless in this regard.

(3) Patient's lack of attention to other members of the family:

When mother or father is affected with schizophrenia, they hardly take care of the children's needs. They are affected adversely. When the process continues, the prolonged deprivation results in other deviations and disturbances.
Leisure activity being abandoned owing to patient's illness:

Whether it is a pleasure trip, picnic or family gathering all need to be abandoned due to embarrassing activities of the patient. Moreover as there is a need for somebody to look after the patient's needs, other family members are not in a position to leave him alone in the house.

D. Disruption of family interaction:

Family interaction of the patients are affected in the following five ways:

1. Ill-effect on the general atmosphere in the house:

   Suddenly the family becomes dull and quiet. There emerges lot of misunderstandings and quarrels on account of the patient. Each one accuses the other as the cause of patient's illness. They start exploring the family trees of each other to find out which family had mental illness. Accordingly they are abused, accused at the cost of the family harmony.

2. Other members getting into arguments:

   Heated arguments are held over the issues like how the patient should be treated, who should do the work, who is
to blame etc. These arguments more often than not lead to other serious difficulties and conflicts.

(3) Relatives or neighbours stopped visiting the families:

The stigma attached to mental illness, the fears and anxiety about the mental illness and other misconceptions make the neighbours and friends reduce the frequency of their visits or dealings with the family. In this way the families of schizophrenic patients are isolated gradually. Such isolation process per se induces a lot of complications to the course of the illness as well as problems for the family members.

(4) Family's avoidance of others:

Considering the stigma, many family members of the schizophrenic patients seclude themselves and avoid mixing with others because of shame of fear of being misunderstood. Such seclusion intensified by others' rejection becomes the source of infinite problems.

(5) Relationship difficulties:

The illness induces separation of spouses, quarrels between two families, property feuds, police intervention, embarrassment for family members and other problems. When the female members get this illness, such problems become very much intensified.
E. **Effect on physical health of others:**

This is seen as a burden in the following two ways:

1. **New Health Problems in others:**

   The patient's disturbing behaviour causes physical illhealth, injuries or increased proneness to diseases in other family members.

2. **Adverse effect on the health of others:**

   In case of the sick members of the family effects are seen very significantly. Either the existing illness is exacerbated or someone loses weight or other such deterioration in health status occurs due to the illness behaviour of the patient.

F. **Effect on mental health of others:**

Other family members seeking help for psychological problems - Problems like patient's impulsive suicidal attempt or utter disobedient behaviour or worries about future make other people psychologically affected. They seek the services of counsellors for solving their own problems.

1. **Increased mental health risk for others:**

   Other members of the family lose sleep, become depressed or weepy, express suicidal wishes, become excessively irritable and feel meaninglessness in living.
Unless they are given proper attention and care, they are likely to get into serious psychological and psychiatric problems.

**TABLE NO. 60**

**SUBJECTIVE BURDEN AS EXPERIENCED BY FAMILY MEMBERS DUE TO PATIENTS' ILLNESS**

<table>
<thead>
<tr>
<th>Sl.No</th>
<th>Level of Burden</th>
<th>Number of Families</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>No Burden = 0</td>
<td>5</td>
<td>2.5%</td>
</tr>
<tr>
<td>2.</td>
<td>Moderate = 1</td>
<td>102</td>
<td>51.0%</td>
</tr>
<tr>
<td>3.</td>
<td>Severe = 2</td>
<td>93</td>
<td>46.5%</td>
</tr>
<tr>
<td></td>
<td><strong>Total Burden</strong></td>
<td><strong>200</strong></td>
<td><strong>100.00%</strong></td>
</tr>
</tbody>
</table>

This table gives information about the subjective burden on the family. This is assessed by asking the following standard questions and scoring the relatives' answer: how much would you say, you have suffered owing to the patients' illness - severely, a little or not at all.

Five families (2.5%) have expressed that they are not at all facing any burden. This is contributed by many factors like signs and symptoms of patients' illness characterized by non-disturbing behaviour, presence of adequate number of members in the family to share the responsibility, adequate outside social support and allied reasons.
51% of the families are facing moderate burden due to the patient's illness whereas 46.5% of the families experience severe burden because of the patient's illness. Thus it is seen that almost all the families face either moderate or severe burden due to the patient's illness.

Such burdens need to be individualized by the professionals and in collaboration with the family members, suitable help need to be extended. In fact the reduction in family burden is the indicator of the effectiveness of the intervention programmes. While medicines and drugs could reduce the problem behaviour of patients to some extent, the casework, group work and community organisation services would be helpful in helping the patients and the family members to help themselves. In studies related to cost effectiveness, the family burden is given much priority and professional support.

Conclusion:

In this study it is found that most of the families of schizophrenic patients experience various types of burden due to the illness of the patient. It is evident from this study that highest burden is experienced by the families with regard to the financial aspect. Other burdens experienced by the family members are disruption of other family members' activities, disruption of family leisure time activities, disruption of family interaction and effect on physical and mental health of other members of the family.