Determinants of the Caregiver's Appraisal in the Context of Caregiving

NASREEN BANU AND K. MAYURI

The article seeks to examine the factors affecting the caregiver's appraisal of caring for a mentally ill relative. Two hundred and ten caregivers attending to a family member with chronic mental illness were interviewed for the present study. The results of path analysis indicate burden experienced in the context of caregiving, patient's illness characteristics, and kinship support to be the most significant factors contributing to the caregiver's appraisal of the caregiving experience. Implications of the findings were summarised.

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INTRODUCTION

In the earliest family stress models (Hill, 1949 and 1958), the family's definition was focussed solely on the stressor event, what Lazarus (1966) has called 'primary appraisal'. In the Double ABCX Model (McCubbin and Patterson, 1982), the family's perception of the original stressor event was expanded to include the family's perception of other stressors and strains, plus their perceptions of family resources. This latter perception is what Lazarus (1966) called secondary appraisal, that is appraisal of capabilities. Another way that meanings (appraisals) were included in the Double ABCX Model was in terms of 'coping', which was defined to include both cognitive and behavioural strategies.

Taylor (1983) has provided a framework to consider how the cognitive strategies (appraisals) may facilitate successful adaptation in the process of adjusting to a stressful life situation. First, one is attributing a cause to the event. The attribution theory suggests that identifying a cause may be a part of the adaptive process. Second, establishing a sense of mastery or control over the situation, which may be a powerful factor in reducing the feeling of stress. Third, enhancing one's self-esteem, that is focussing on the positive attributes of the situation.

Huang (1991) developed the T-Double ABCX model, which considers the relationship between the stressors, resources, perceptions and the adaptation process. This model (Figure 1) identifies the family's appraisals, personal and social supports, and family coping strategies as mediating variables between demands/stressors and family adaptation.
It demonstrates how events affect a person’s morale and functioning and how individuals can react very differently to similar events. The model illustrates that the effects of environmental stressors are determined in part by the resources available for dealing with challenging events and in part by the ways that an individual appraises and copes with the demands of the stressors. Therefore, the resources, appraisal and coping responses, and the nature of the stressors all combine to determine an individual’s adaptation to a stressful situation. The model stresses that the adaptive capacity of the individual depends on the event/stressor characteristics, coping strategies, selected personality attributes and social support networks, and so on. Compared to the other models, the individual stress and adaptation model focuses on the factors that may impinge on the individual’s appraisal responses, which may further affect the individual’s adaptation process.

In developed countries/societies, caring for a mentally ill patient is in the domain of professional caregivers who, in most cases, are not related to the care recipient (patient). But in traditional societies like India, caring for a mentally ill relative is essentially within the realm of the family unit. More specifically, this responsibility defaults to either the parent or the spouse of the sick person.
The fact that caregiving in India essentially rests with the family members, who are not professionals, the caregiving experience would be different from that of a professional caregiver. This difference could be attributed to the fact that in most cases, the caregivers neither have adequate knowledge about the mental illness nor the symptoms associated with it. The problem is further compounded by the social stigma attached to the people suffering from mental illness, because of which there are delays in diagnosing the illness early.

The other determinants that could influence the caregiver's appraisal is the behavioural symptoms associated with the mental illness. Besides this there could be some personal and family factors such as age, education, occupation, marital status, personality traits, family environment, family support, and so on, that could contribute to the caregiver's appraisal. Given the diverse factors impinging on the caregiver's appraisal of caring for a mentally ill relative, the present research was undertaken to trace the most significant contributing factors and its directionality of the effect (direct and indirect) on the caregiver's appraisal of the situation in the context of the caregiving experience.

Within the family stress theory, one of the critical constructs that has been more difficult and elusive to conceptualise is the meaning attached to the stressful life situation. The present research makes an attempt to trace the factors contributing to the caregiver's appraisal of the situation in the context of attending to a family member with chronic mental illness.

METHOD

Procedure

Ex-post facto research design was used in the present investigation as the caregiver's appraisal of the stressful situation has already manifested. Data from the respondents was collected by a carefully constructed and pre-tested interview schedule, which included the measurement of all the variables under investigation.

A list of 25 nursing homes in the twin cities of Hyderabad and Secunderabad, providing care to the mentally ill, was sourced from mental health professionals, government mental hospitals, acquaintances and through the Internet. Out of the 25 nursing homes, only three were selected for the present study as these hospitals catered to more number of patients suffering from schizophrenia and bipolar disorder. Besides, the minimum period of stay in the nursing home was from 15 days to one month, which was convenient for conducting in depth interviews. Majority of the cases admitted were from middle class and lower-middle class families and whose caregivers were willing to share their caregiving experiences.
Purposive sampling method was used to select a sample size of 210, of which 105 were drawn from the government mental hospital; the remaining sample (105) were drawn from the two private nursing homes. Out of this, 105 caregivers attending to patients suffering from acute schizophrenia (35), chronic schizophrenia (35) and bipolar disorder since the last one year (minimum period) were selected. The sample was limited only to spouses/parents attending to a mentally ill relative as they were particularly vulnerable to the stress of the caregiving experience due to multiplicity of responsibilities.

**Measures**

The following standard measures were used for collecting information related to the variables assumed to be influencing the caregiver's perception/appraisal of the caregiving experience.

1. A general interview schedule was developed and used to collect the demographic profile of the caregiver and the care recipient.
2. Dysfunction Analysis Questionnaire (DAQ), developed by Pershad and others (1985), was used to find out the current psycho-social functioning of the patient. Psycho-social functioning is an important variable in a psychiatric condition. The DAQ Scale was developed exclusively to find out the extent of functioning, after being affected by the illness in psychiatric patients.
3. Burden Assessment Scale (BAS), developed by Thara and others (1989) was used to measure both the subjective and objective burden as perceived by the caregivers of chronic mentally ill patients. This Scale has been developed from the perspective of the chronically mentally ill and conceptualised to predict burn out in persons caring for a chronically mentally ill patient.
4. Caregiver's perception/appraisal of the situation was found out through self-reported checklist.
5. Social Support Scale (SSS), developed by the National Institute for Mentally Handicapped, was used to find out the social network of the caregiver.
6. Family Environment Scale (FES), developed by Bhatia and Chadha (1996), was used to find out the extent of its influence on the caregiver's appraisal.
7. Multi-dimensional Assessment of Personality (MAP) inventory was used to find out the relationship between the caregiver's appraisal and selected personality traits in the context of the caregiving experience.

**RESULTS**

The data collected from the selected sample was coded, scored, tabulated and analysed using the appropriate statistical procedure. Percentages were obtained for general information pertaining to the
caregiver's personal and family variables and the patient's personal and illness characteristics.

Caregiver's Profile and Family Characteristics

The significant findings under this section were:

- Majority of the caregivers were females (73 per cent) and were in the age group of 36-40 years.
- Compared to the female caregivers, male caregivers were relatively better educated (secondary education).
- Half of the female caregivers were homemakers (50 per cent).
- Majority of the caregivers were from the Hindu community (75 per cent).
- Most of the caregivers were living with their spouses (83 per cent).
- With regard to the relationship between the caregiver and the patient: caregiver as mother (35 per cent), as wife (35 per cent), and as husband (23 per cent).
- The monthly income of the family was Rupees 2500/-

Patient Profile and Illness Characteristics

The significant findings under this section were:

- More than half (66 per cent) of the patients were males; of these, 25 per cent were diagnosed as bipolar patients and 26 per cent chronic schizophrenics.
- 43 per cent of the patients were in the age group of 20-25 years, followed by 23 per cent in the age group of 36-40 years.
- 63 per cent of the patients were spouses, of which, 39 per cent were husbands and 24 per cent wives to the caregivers; 31 per cent of the patients were sons to the caregiver.
- The duration of the illness was above five years for 33 per cent of the patients.
- The frequency of hospitalisation of the patient was found to be more than four times in a year for 30 per cent of the cases.
- The health condition was found to be deteriorating for 39 per cent of the sample, and in 32 per cent of the cases, it was reported to be fluctuating.

Information Related to Other Independent Variables

Besides the general information, percentages were also calculated for other significant variables, that is psycho-social functioning of the patient, caregiver's burden with reference to the caregiving experience, caregiver's appraisal of the situation, social support, family environment, and personality traits of the caregiver. Based on caregiver's responses to the DAQ, it was found that the illness severely impacted the psycho-social functioning of the patient in all the five areas, that is social, vocational, personal, familial and cognitive areas.
The responses of the caregivers to the BAS (both objective and subjective burden) was found to be high (54 per cent). The objective burden was related to leisure time, financial strain, reduced social contacts, family frictions and conflicts with others. The subjective burden was related to worries and uncertainties about the future, psychological feelings of guilt, resentment, feeling of being trapped (role captivity), embarrassment and social stigma associated with having a mentally ill patient in the home.

With regard to the caregiver's appraisal of the situation, the concept of time dimension was used in the present situation in the context of the caregiving experience over a period of time: one is at time T1 when the illness was initially diagnosed and the other when the caregiver was interviewed, that is after one year — T2. The appraisal scores at T1 and T2 was found to be similar in the case of male caretakers. However, it was found to be different for female caretakers at T2:

- 13 per cent of the female caregivers perceived the situation as a threat,
- 44 per cent as a loss,
- 47 per cent as a challenge,
- 57 per cent as not controllable, and
- 73 per cent as expected.

Based on the research review, the caregiver's appraisals were categorised as threat, loss, challenge, controllable and acceptable (Lazarus and Folkman, 1984). Here the appraisal categories were being scored as 'yes' or 'no' with a score of one for 'yes' and a score of two for 'no'. There are both positive and negative markings for the same categories: for example, considering the situation not as loss, or a threat, but as challenge, controllable and expected are considered as positive appraisals.

The caregiver's responses to SSS showed that the level of social support was moderately high (71 per cent) from kinship, followed by support from in-laws/relations (55 per cent) and neighbours (52 per cent). Support from the above sources was received mostly in assisting the caretaker in household chores, attending to young children, sharing feelings, thoughts and emotions. Financial help was found only from kinship to some extent. Not much technical support (information related to patient's condition, management of behavioural symptoms, side effects of medication, and so on) was traced from the medical professionals.

Most of the caregiver's responses to the FES was found to be in the average category (72 per cent). The Scale consists of three important dimensions: (i) relationship, (ii) personal growth, and (iii) system maintenance. The first dimension reflects the degree of commitment and support from family members, which was found to be in the average category. The second dimension measures the decision-making capacity and the extent of participation of family members in social and recreational activities, which was also found to be average. The third
dimension includes structured planning of family responsibilities and degree of limit set in the family which was in low category (47 per cent).

The MAP inventory measures 20 personality dimensions of the caregivers. From the caregiver's responses, it was found that some of the personality scores (adaptability, achievement motivation, boldness, maturity, mental health, morality, sensitivity and social warmth) were in the average category, especially for the female caregivers. In the other areas of personality (competition, enthusiasm, guilt proneness, imagination, innovation, leadership, shrewdness and suspiciousness), the scores were in the low category. The scores indicate the dominance of that particular trait.

Relationship between Caregiver's Appraisal and Selected Independent Variables

Appraisals — whether loss, threat or challenge — may be influenced by the caregiver's personal (age, gender, occupation, education, marital status, relationship with the patient, burden experienced, personality traits) and family characteristics (type of family, number of dependents, size of the family, family income, family support, family environment), as well as the patient's personal (age, gender, working status, relationship with the caregiver) and illness characteristics (illness type, duration of illness, frequency of hospitalisation, current level of functioning). In order to find out the most significant relationships between the caregiver's appraisal in the context of the caregiving experience with other independent variables, correlation coefficients were computed. The results are presented in the following tables.

<table>
<thead>
<tr>
<th>Table 1: Relationship between Caregiver's Appraisal of the Situation and Caregiver's Personal and Family Variables (at T1)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregiver Variable</strong></td>
</tr>
<tr>
<td>------------------------</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Occupation</td>
</tr>
<tr>
<td>Relationship with patient</td>
</tr>
<tr>
<td>Family income</td>
</tr>
</tbody>
</table>

*Source: Significant (p<0.05), ** Significant (p<0.01)

*Note: Only significant values of the variables are presented in all the tables.

With regard to appraisal at T1, gender was positively correlated with loss and challenge categories of appraisal, which explains the fact that the female caretakers perceived the situation not as a loss, but as a challenge. Occupation of the sample was positively correlated at the 1 per cent level of significance showing that better the occupation level of the caretaker, the situation was perceived positively, that is not as a
loss but as a challenge. Relationship with the patient had negative rela-
tionship with caregiver’s appraisal at the 5 per cent level of signifi-
cance, that is when the caretaker’s relationship with the patient was
that of a husband (spouse), the situation was considered as challenge. If
the family income was better, the situation was perceived as controlla-
ble.

**TABLE 2: Relationship between Caregiver’s Appraisal of the Situation and Caregiver’s Personal and Family Variables (at T2)**

<table>
<thead>
<tr>
<th>Caretaker Variable</th>
<th>Threat</th>
<th>Loss</th>
<th>Challenge</th>
<th>Controllable</th>
<th>Expected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>-0.0023</td>
<td>-0.2762**</td>
<td>-0.1265</td>
<td>-0.0459</td>
<td>-0.0375</td>
</tr>
<tr>
<td>Age</td>
<td>0.1967*</td>
<td>-0.1554</td>
<td>-0.1441</td>
<td>-0.1622</td>
<td>-0.1462</td>
</tr>
<tr>
<td>Education</td>
<td>0.0150</td>
<td>-0.0121</td>
<td>0.0962</td>
<td>0.2502**</td>
<td>0.0428</td>
</tr>
<tr>
<td>Relationship</td>
<td>-0.1683</td>
<td>0.3501**</td>
<td>0.2849**</td>
<td>-1.607</td>
<td>0.0817</td>
</tr>
<tr>
<td>Marital status</td>
<td>0.1259</td>
<td>-0.1900*</td>
<td>-0.0128</td>
<td>0.0236</td>
<td>0.0274</td>
</tr>
<tr>
<td>Family life stage</td>
<td>0.2331*</td>
<td>-0.0503</td>
<td>-0.1850*</td>
<td>-0.2229</td>
<td>-0.0800</td>
</tr>
<tr>
<td>Family type</td>
<td>-0.2946**</td>
<td>0.0794</td>
<td>0.0739</td>
<td>-0.0931</td>
<td>0.0582</td>
</tr>
<tr>
<td>Family income</td>
<td>-0.1223</td>
<td>-0.1884*</td>
<td>0.1069</td>
<td>0.0185</td>
<td>-0.0008</td>
</tr>
</tbody>
</table>

*Source:* *Significant (p<0.05), ** Significant (p<0.01)

*Note:* Only significant values are presented to avoid cluttering.

At T2, female caregivers considered the situation as a loss. With an
increase in age, the situation was not perceived as a threat; also better
the educational level of the caregiver, more was the situation perceived
as not controllable. With education does the caregiver develop an
awareness that the symptoms of the illness are beyond one’s control.
Widowers considered the situation as a loss as they were not certain
whether the illness symptoms would change for the better or not. The
caretaker’s family life stage was significantly related to the challenge
and controllability of the situation at the 5 per cent level of significance
indicating that as the family advanced in the family life cycle, the care-
giver’s perception of considering the situation as a challenge increased.
Nuclear families perceived the situation as a threat. Family income
was negatively correlated with loss, revealing the fact that higher the
income, lesser the perception of considering the situation as a loss.

Among the independent variables listed (Table 3), gender was signif-
ically and positively related to the caregiver’s appraisal of the situa-
tion as a threat) and with loss (at T1). It could be inferred that the
women did not perceive the situation as a threat or as a loss. Better the
occupational level of the sample, lesser was the perception of the situa-
tion as a threat. The ordinal position was negatively correlated with
challenge, that is, younger the patient, greater the caretaker’s percep-
tion of viewing the situation as a challenge.
The patient's relationship with the caregiver was positively and significantly related to the caregiver's appraisal of the situation, that is, when the patient was a spouse (husband), the caregiver considered the situation as challenge. In Indian culture, the wife plays a major role in attending to the needs of her family members and with her husband, her responsibilities are all the more focussed. The type of illness, duration of illness, frequency of hospitalisation and the present health condition of the patient was positively and significantly related to the caregiver's appraisal categories (at T1) at the 1 per cent level of significance: that is, more chronic the patient's illness symptoms, more was the situation appraised as a threat, loss and challenge by the caregivers. A similar trend was observed with regard to the caregiver's appraisal at T2 (Table 4).

**TABLE 3: Relationship between the Caregiver's Appraisal of the Situation and the Patient's Personal and Illness Characteristics (at T1)**

<table>
<thead>
<tr>
<th>Patient Variables</th>
<th>Appraisal Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Threat</td>
</tr>
<tr>
<td>Gender</td>
<td>0.2346**</td>
</tr>
<tr>
<td>Occupation</td>
<td>-0.3246**</td>
</tr>
<tr>
<td>Ordinal position</td>
<td>0.1172</td>
</tr>
<tr>
<td>Relationship with caretaker</td>
<td>-0.0692</td>
</tr>
<tr>
<td>Illness type</td>
<td>0.3087**</td>
</tr>
<tr>
<td>Illness duration</td>
<td>0.2917**</td>
</tr>
<tr>
<td>Hospital frequency</td>
<td>0.2032*</td>
</tr>
<tr>
<td>Present condition</td>
<td>0.1960*</td>
</tr>
</tbody>
</table>

Note: * Significant (p < 0.05), ** Significant (p < 0.01)

**TABLE 4: Relationship between Caregiver's Appraisal of the Situation and Patient's Personal and Illness Characteristics (at T2)**

<table>
<thead>
<tr>
<th>Patient Variables</th>
<th>Appraisal Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Threat</td>
</tr>
<tr>
<td>Gender</td>
<td>-0.0742</td>
</tr>
<tr>
<td>Occupation</td>
<td>-0.3182**</td>
</tr>
<tr>
<td>Ordinal position</td>
<td>0.2182*</td>
</tr>
<tr>
<td>Relationship with caretaker</td>
<td>-0.3735**</td>
</tr>
<tr>
<td>Working status</td>
<td>-0.0827</td>
</tr>
<tr>
<td>Illness type</td>
<td>-0.0143</td>
</tr>
<tr>
<td>Illness duration</td>
<td>0.0062</td>
</tr>
<tr>
<td>Hospital frequency</td>
<td>-0.0227</td>
</tr>
<tr>
<td>Present condition</td>
<td>-0.0688</td>
</tr>
</tbody>
</table>

Note: * Significant (p < 0.05), ** Significant (p < 0.01)

Tables 5 and 6 present the relationship between the caregiver's appraisal of the situation and the current level of psycho-social functioning of the patient. Based on the responses of the caregivers, it was found
that the illness severely impacted the overall functioning of the patient in relation to the pre-illness state, in all the five areas, that is, social, vocational, personal, familial and cognitive. These scores were positively and significantly related to the caregiver's appraisal of the situation at the 1 per cent level at T1 and T2. This indicates the fact that more severe the dysfunction of the patient, more was the situation perceived as a threat and loss, than as a challenge and controllable.

TABLE 5: Relationship between Caregiver’s Appraisal of the Situation and Dysfunctional Scores of the Patient (at T1)

<table>
<thead>
<tr>
<th>DAQ Variables</th>
<th>Appraisal Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Threat</td>
</tr>
<tr>
<td>Social</td>
<td>-0.2551*</td>
</tr>
<tr>
<td>Vocational</td>
<td>-0.1695</td>
</tr>
<tr>
<td>Personal</td>
<td>-0.2164*</td>
</tr>
<tr>
<td>Familial</td>
<td>-0.2360**</td>
</tr>
<tr>
<td>Cognitive</td>
<td>-0.2137*</td>
</tr>
<tr>
<td>Total</td>
<td>-0.6458*</td>
</tr>
</tbody>
</table>

Note: * Significant (p < 0.05), ** Significant (p < 0.01)

TABLE 6: Relationship between Caregiver’s Appraisal of the Situation and Dysfunctional Scores of the Patient (at T2)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Appraisal Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Threat</td>
</tr>
<tr>
<td>Social</td>
<td>-0.0394</td>
</tr>
<tr>
<td>Vocational</td>
<td>-0.1311</td>
</tr>
<tr>
<td>Personal</td>
<td>-0.0727</td>
</tr>
<tr>
<td>Familial</td>
<td>-0.0844</td>
</tr>
<tr>
<td>Cognitive</td>
<td>-0.0902</td>
</tr>
<tr>
<td>Overall Total</td>
<td>-0.0466</td>
</tr>
</tbody>
</table>

Note: * Significant (p < 0.05), ** Significant (p < 0.01)

Higher the burden experienced by the caregiver, higher the perception of the situation as a threat and loss, than as a challenge and controllable (at T2 only). Objective burden is related to the patient’s illness characteristics, that is, severity, duration of illness, associated behaviour problems and functional limitations, whereas subjective burden is related to the caregiver’s perception of stress as a direct result of providing care, which is reflected in role over load, role captivity and lack of time for social recreation (Bull, 1990).

It could be inferred from the results that objective burden refers to the reality demands of coping with mental illness and subjective burden to the caregiver's suffering as a result of caring for a sick person.
Results for the total sample revealed the fact that boldness, competition, leadership, maturity, mental health, morality, sensitivity, self-sufficiency and social warmth were negatively and significantly related to the overall appraisal of the caregiver at the 1 per cent level, indicating that higher the score values of these traits, lower the caregiver's appraisal scores, that is, they considered the situation as less of a threat and loss and more as a challenge, controllable and expected.

Guilt and imagination were positively correlated to the appraisal of the caregivers, that is, higher the scores for these traits, higher the caregiver's appraisal scores: that is, the situation was considered more as a threat, loss and less of a challenge, controllable and expected.
The above results present the relationship between the family environment and the caregiver's appraisal of the situation. The overall total scores only for the relationship dimension of family environment was negatively and significantly related to the caregiver's appraisal of the situation, that is, higher the cohesion, expressiveness and acceptance in the family, lower were the appraisal scores.

TABLE 9: Relationship between the Caregiver's Appraisal of the Situation and Family Environment

<table>
<thead>
<tr>
<th>Family Environment Variables</th>
<th>Appraisal Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Threat</td>
</tr>
<tr>
<td>Relationship Dimension</td>
<td></td>
</tr>
<tr>
<td>Cohesion</td>
<td>0.1097</td>
</tr>
<tr>
<td>Expressiveness</td>
<td>0.1097</td>
</tr>
<tr>
<td>Conflict</td>
<td>0.1607</td>
</tr>
<tr>
<td>Acceptance</td>
<td>0.1539</td>
</tr>
<tr>
<td>Personal Growth Dimension</td>
<td></td>
</tr>
<tr>
<td>Independence</td>
<td>0.0231</td>
</tr>
<tr>
<td>Recreation</td>
<td>0.0518</td>
</tr>
<tr>
<td>System Maintenance Dimension</td>
<td></td>
</tr>
<tr>
<td>Organisation</td>
<td>-0.0963</td>
</tr>
<tr>
<td>Control</td>
<td>-0.0534</td>
</tr>
</tbody>
</table>

Note: * Significant (p < 0.05), ** Significant (p < 0.01)

Table 10 presents a significant, negative relationship between the caregiver's appraisal of the situation and overall social support from kinship, in-laws and neighbours. Higher the scores from these sources, lower the caregiver's appraisal scores.

TABLE 10: Relationship between Caregiver's Appraisal and Social Support (T2)

<table>
<thead>
<tr>
<th>Family Environment Variables</th>
<th>Appraisal Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Threat</td>
</tr>
<tr>
<td>Spouse</td>
<td>0.1642</td>
</tr>
<tr>
<td>Kinship</td>
<td>0.2455**</td>
</tr>
<tr>
<td>In-laws/relations</td>
<td>-0.0495</td>
</tr>
<tr>
<td>Friends</td>
<td>0.0642</td>
</tr>
<tr>
<td>Neighbours</td>
<td>0.2341**</td>
</tr>
<tr>
<td>Co-families</td>
<td>-0.0312</td>
</tr>
<tr>
<td>Professionals</td>
<td>0.0445</td>
</tr>
</tbody>
</table>

Note: * Significant (p < 0.05), ** Significant (p < 0.01)
Determinants of the Caregiver's Appraisal of the Caregiving Experience

Step down regression analysis was issued to trace the determinants (independent variables) contributing to the caregiver's appraisal of the caregiving experience. The objective of this analysis was to make a prediction about the dependent variable (caregiver's appraisal) based on its covariance with all the related independent variables (Kothari, 1990). This technique was considered appropriate to use, when the investigator had a single outcome variable which was supposed to be the function of other explanatory variables (independent).

Tables 11 and 12 present the determinants of the caregiver's appraisal of the caregiving experience at T1 and T2. It was apparent that at T1, among the 48 variables studied, only four variables were found to be contributing towards the caregiver's appraisal of the situation (caregiving experience). Seventy-six per cent of variance was found to be sourced from four variables (which was significant, $F=10.69$, $p<0.01$). These variables were the caregiver's burden in the context of the caregiving experience, the number of dependent members (young children and old people) in the family, family income and illness type (schizophrenia or bipolar disorder). For every unit change in the caregiver's appraisal, six per cent of the change was contributed by the caregiver's burden in the context of the caregiving experience at the 1 per cent level of significance ($t=6.431$, $p<0.01$).

### TABLE 11: Determinants of Caregiver's Appraisal of the Situation through Step-down Regression (at T1)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Regression Coefficient ($B$)</th>
<th>Standard Error of $B$</th>
<th>$T$ Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness type</td>
<td>0.5614**</td>
<td>0.1087</td>
<td>-5.0500</td>
</tr>
<tr>
<td>Number of dependants</td>
<td>-0.1135**</td>
<td>0.0407</td>
<td>-2.7860</td>
</tr>
<tr>
<td>the family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family income</td>
<td>-0.1320**</td>
<td>0.0509</td>
<td>-2.5910</td>
</tr>
<tr>
<td>Caregiver's burden</td>
<td>-0.6514**</td>
<td>0.1012</td>
<td>-6.4310</td>
</tr>
</tbody>
</table>

Note: Multiple $R = 0.8724$, $R^2 = 0.7610$, $F = 10.6925**$
*Significant ($p<0.05$), **Significant ($p<0.01$)

The regression coefficient indicates ($t=5.05$, $p<0.01$) that when the nature of illness was more of a fluctuating type (bipolar disorder), the perception of the caregivers towards the situation changed drastically. The next contributing variable was the number of dependents in the family ($t=-2.786$, $p<0.01$), that is more the number of dependents in the family, the more it affected the perception of the caregiver towards the caregiving experience. The next contributing factor was family income ($t=-2.591$, $p<0.01$). The regression coefficient indicates that as the family income increased, the caregiver's perception of the situation as stressful decreased.
Table 12 presents the overall determinants of the caregiver's appraisal at T2. Out of the 48 variables studied, six independent variables namely type of illness, duration of illness, caregiver's relationship with the patient, caregiver's burden in the context of caregiving, psycho-social functioning of the patient's condition, and kinship support were found to be contributing to the caregiver's appraisal of the situation (58 per cent of the variance, which was significant: F=4.562, p<0.01).

The regression model indicates six per cent of contribution from the caregiver's burden (t=6.43, p<0.01), followed by type of illness (t= -5.24, p<0.01), duration of illness (t = -3.44, p<0.01), number of dependents in the family (t = -2.45, p<0.01), social support from kinship (t = 2.40, p<0.01), and psycho-social functioning of the patient (t = 2.30, p = <0.5). The model explains that the severity of the psycho-social functioning of the patient, the fluctuating nature of the illness (bipolar disorder), duration of the patient's illness (more than five years), caregiver's relationship with the patient (female caregiver attending to her husband), and the kinship support to be the determinants of the caregiver's appraisal in the context of their caregiving experience.

### Contribution of Independent Variables toward the Caregiver's Appraisal (Dependent Variable)

Path analysis was used to find out the relative direct and indirect effects caused by the independent variables on the dependent variables. The merit of path analysis is that it makes it possible to assess the relative influence/contribution of each independent variable on the consequence or outcome variable by first tracing the causal connections (direct effects) and then by elucidating the indirect effect of the independent variables (Kothari, 1990).

Among the 48 independent variables studied, 13 significant independent variables were identified through the correlation coefficient and regression analysis and subjected to path analysis. The 13 variables were type of illness, psycho-social functioning, kinship support,
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caregiver's burden, duration of illness, caregiver's relationship with the patient, family income, number of dependents in the family, support from in-laws/relations, frequency of hospitalisation of the patient in the last one year, caregiver's gender, caregiver's age, and family life stage. Figure 3 presents the direct and indirect effects of the independent variables on the caregiver's appraisal of the caregiving experience at T2. Out of the 13 independent variables, only five variables showing direct effect on the dependent variable (caregiver's appraisal), were identified — that is, type of illness, psycho-social functioning, caregiver's burden, kinship support, and duration of illness.

In terms of the magnitude of the effect on the caregiver's appraisal of the situation,

- 57 per cent of the impact was sourced from the caregiver's burden in the context of the caregiving experience,
- 55 per cent from the type of illness,
- 45 per cent from psycho-social functioning of the patient,
- 36 per cent from kinship support, and
- 30 per cent from duration of the patient's illness.

From the path analysis model, the caregiver's burden emerged as the most important variable contributing to the caregiver's appraisal of the caring experience, as it traces the indirect effects of 10 other independent variables through it. The caregiving experience does not typically involve nursing duties alone, but may indeed involve hours devoted to activities of daily living. Caring may also involve multiple expenditure of time and energy in seeking help from medical staff, which is not required in caring for a physically or developmentally disabled family member. The emotional stress involved in dealing with the behaviours of mentally ill patients, which may be disruptive, assaultive, self-destructive, socially constraining and above all incomprehensible, and the burden experienced by the caregiver was found to be further compounded by the lack of information and help from mental health professionals. Caregivers are thrown into a role for which they are neither trained nor prepared. Caring for mentally ill persons remained a family responsibility so long as its members could provide the basic necessities of life for the afflicted relatives.

CONCLUSION

The response of people varies tremendously as to how they respond to a given event/situation. These variations seem to grow out of the individual's personal resources, family support system and also from the stressor (patient's illness) characteristics. From the present study, it could be explained that several factors contribute to how individuals define the stressful situation (caregiving experience).

1. The caregiver experienced both objective and subjective burden. This could be further elaborated in the sense that the meaning of burden in the context of the caregiving experience goes beyond
FIGURE 3: Path Analysis Model Presenting the Direct and Indirect Impact of Independent Variables on the Caregiver's Appraisal T2

Indirect Effects

- Type of Illness
- DAQ
- Caregiver Burden
- Kinship Support
- Duration of Illness
- Caregiver's Relationship
- Family Income
- No. of Dependents
- Support from In-laws/Relatives
- Hospitalisation
- Caregiver's Gender
- Caregiver's Age
- Family Life Stage

Direct Effects

Caregiver's Appraisal

Note: * Significant (p < 0.05)  ** Significant (p < 0.01)
mere caregiving responsibilities. It includes: the mentally ill person's economic dependency and inability to fulfil the expected role functions; disruption of household routines; caregiver's investment of time and energy in seeking help from mental health professionals; confusing and, often, humiliating interactions with service providers; financial costs of the treatment of the illness; deprivation of personal needs and needs of other family members; curtailment of social activities; strained relationship with the ill person and also with the people outside the family; and the inability to find respite care or an alternative to hospitalisation of the patient or facilities for residential placement outside the home. In short, it can be said that economic strain, social stigma, isolation, burnout and the need for respite care were found to be the most significant aspects of caregiver's burden in the context of caregiving.

2. The nature of the precipitating event itself, that is, the patient's illness characteristics. The degree and intensity of the demands that mental illness creates and the uncertainty of the future condition of the illness was found to be one of the major contributing factors in the caregiver's appraisal of the caregiving experience.

3. Kinship support. Family support may intervene between the stressful event and a stress reaction by preventing a stressful appraisal response. In the present context, it means that the availability and adequacy of family support may help the caregiver to redefine the caregiving experience, by giving a positive connotation, that is, consider it more as a challenge than appraising the situation as highly stressful (Moos, 1991; Wilcox, 1981).

IMPLICATIONS

Implications for Social Work Practitioners

Surveys undertaken all over the world indicate that about one to two per cent of the population suffer from serious mental illnesses. In India, one out of 1,000 people (nine million) suffer from schizophrenia alone and the problem is compounded by the fact that there are very few mental health professionals available to care for such patients.

Based on the findings, it is suggested that social workers adopt the following steps to ensure that a proper support mechanism is established to assist the caregiving families in caring for their mentally ill relative:

- Promoting awareness of the symptoms of the illness, especially among the vulnerable families (low income groups).
- Identifying professionals from the mental health field to develop linkages with other professionals in the field to empower families to become more capable and competent in the management of the illness symptoms.
• Developing linkages with NGOs, who are willing to extend services for caregiving families.
• Helping the caregiving families in identifying their strengths and resources to capitalise on them.
• Interfacing between the medical professionals and the caregiver.
• Educating the caregiving families about the patient’s illness symptoms and its management and also about the importance of regular follow-up of medicines.
• Ensuring that families have adequate resources (time, energy, information, and so on), to attend to the needs of the patient.

implications for Medical Professionals

Statistics on mental health status reveal that nine million suffer from mental illness in India. There are only 42 mental hospitals in the country with 20,000 beds. Only 10 per cent receive active psychiatric assistance. It is important for mental health professionals to develop effective communication skills, while interacting with the caregivers to ensure that the caregivers understand the illness and its implications.

Mental health staff should establish outreach programmes that would provide mobile health services to the mentally ill, which would eliminate the cost involved in transportation of the patient to urban centres. Mental illness forms a significant public health problem in the community. Family members have multiple needs, while attending to a patient with mental illness. Hence, the needs should be examined to enhance the level of functioning of the patient as well as to decrease the emotional stress experienced by the caregiver. A multi-disciplinary team reaching out to the caregiving families of the mentally ill would be helpful in meeting the complex needs of the patient.

The most important component of the medical intervention should be teaching effective coping strategies that are at par with the family's beliefs and value system. The most important implication of the present study is the need for health professionals to play a major role in delivering health care services to the caregiving families.

Many physicians, nurses and other technicians have basic understanding of the needs of caregiving families. Hence, they can work effectively with them in different settings, providing education, support and counselling. There should be a close collaboration between medical professionals and family therapists to attend to the psycho-social problems of the caregiving families.

Majority of the relatives of patients with schizophrenia and bipolar affective disorder experience subjective distress in relation to the patient's symptoms, role dysfunction, and the adverse effects of the patient's illness. Hence, there is a greater need for planned services which are effective, integrated and comprehensive to meet the needs of the caregiving families attending on a mentally ill relative.
Implications for Family Intervention

There are two keys to successful family intervention: (i) describe the specific strengths and weaknesses of family response and design ways of bringing out more of the strengths, while supplementing the deficiencies; and (ii) resources — money, personnel, information and the services that the caregiving families require. Family intervention should focus mainly in:

- identifying and ventilating painful feelings;
- helping families with stress management and problem-solving strategies;
- educating families about the illness, the mental health system, and their role in rehabilitation;
- helping families develop realistic expectations of the illness outcome;
- teaching warning signs of impending relapse;
- encouraging family members to resume time and energy for their own activities and referring families to self-help organisations; and
- helping relatives to understand that many of the patient's problematic behaviours are the physical manifestations of illness symptoms rather than misbehaviour (Bernheim, 1994).

Towards a National Policy of Caregiving

It is acknowledged today that health is a multi-dimensional phenomenon. The levels and distribution of income, social and cultural practices and perceptions regarding health and illness, and the choice of technology, do influence the physical and mental health status of a society.

The health status of people in developing countries like India, needs to be understood according to the social conditions that include basic amenities like food, water, housing, education, employment, transport, communication, and so on. In addition, people's perception of illness is very much influenced not only by the social, economic and cultural factors, but also the role of the state in shaping the health services.

Another feature of developing countries that has been well-documented, is the critical gap between availability and accessibility of health services. This gap has been particularly instrumental in excluding a large proportion of the rural population in India.

Another serious lacuna of the mental health programmes in India is the inadequacy of medically trained psychiatrists with inadequate para-professionals such as psychotherapists, counsellors and psychiatric social workers. Based on the above emerging facts, there is a need for a coordinated national policy that provides adequate support services such as income support, respite care for the caregiver, transport facilities and counselling services to the caregiving families. There is
also a need to have a policy, which would shift its focus from individual patient care to tackling the problem from a family perspective.

The focus of counselling the families with mentally ill relatives should be on:

- developing a supportive climate for the family;
- providing necessary information for the family to understand the mentally ill person's conditions, its demands and its implications;
- helping the caregiver to overcome feelings of anxiety, guilt, low self-esteem, and so on;
- developing effective communication skills among the family members;
- enhancing the family's problem-solving strategies, coping skills and help-seeking behaviour;
- helping families in identifying their own resources and capitalising on them; and
- educating and guiding the caregiving families (especially low income groups) to adjust to the exigencies caused by mental illness.

Research Implications

There is a need for more empirical studies to help us to understand the family meanings, particularly with families of diverse cultural, ethnic, and racial backgrounds. Longitudinal studies are needed to understand the meaning attached to a given situation (diagnosis and illness characteristics) from a time perspective.

Families are complex social units that vary widely in their adaptive capacities. One of the most interesting questions still facing the social scientists is how some families develop positive, adaptive beliefs and meanings, and others do not. Hence, further studies are needed to understand the mechanism of constructing meanings in the context of a caregiving experience.

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